THE UNIVERSITY OF HULL

Caregiving Children in Malawi: Children's Work Within Families Affected by Illness and Disability

being a Thesis submitted for the Degree of Doctor of Philosophy in the University of Hull

by

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Abstract

Chronic illness and disability can result in children caring for sick parents, younger siblings or grandparents. This PhD thesis examines children's caring responsibilities in rural and urban areas in Malawi. It analyses the emotional aspects of care and examines the family as a whole system, whilst exploring the spatiality of care practices outside the home. This thesis weaves together children's and family geographies and emotional geographies to understand the experiences of young caregiving. The research adopts the 'new' social studies of childhood perspective, which recognises that children play an active role in the construction and determination of their lives, the lives of those around them and of their societies. A qualitative, participatory methodology was employed as most appropriate to gain in-depth understandings of their experiences. The findings suggest that the experiences of caregiving are not simply positive or negative, but rather are complex, fluid and shaped by circumstances including extended family support, lack of adequate support and poverty. The young caregivers in this study assumed a high level of responsibility which often impacted adversely on their educational, emotional and physical needs, but overall, they experienced caregiving in a positive way and felt proud of their role. Family relationships and the way participants experienced caregiving interconnected continuously influencing one another. Caregiving relationships were predominantly reciprocal and interdependent, tangled together with dependency, unequal power between adults and children and limited, if any, agency. Chronic poverty, the lack of a formal state care system, lack of awareness and corruption impacted detrimentally upon the caregiving children and their families. To support young caregivers, this thesis calls for improvement of health and social care services for people with disabilities and chronic illness, raising awareness, adopting a family approach and fair distribution of resources.

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Abbreviations/Acronyms

AIDS	Acquired Immune Deficiency Syndrome
DBS	Disclosure and Barring Service
DfID	Department for International Development (UK Government)
DoH	Department of Health (UK Government)
HIV	Human Immunodeficiency Viruses
NGO	Non-Governmental Organisation
NSO	National Statistical Office (Malawi Government)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNCRC	United Nations Convention of the Rights of the Child
UNICEF	United Nations International Children's Emergency Fund

Chapter 1. Introduction

1.1 Introduction

Caregiving children and young people[1] in Africa are not a new phenomenon, but the question of how young caregiving impacts on young Africans and their families has only recently come to be the subject of sustained academic research (Skovdal, 2011). This study is part of the growing research within the fields of childhood studies and the geographies of children, youth and families that acknowledges children as active participants in their lives who influence and are influenced by place and space (James et al., 1998). Childhood studies and children's geographies have significantly contributed to a growing number of debates and discussions about children's active involvement in shaping their own social worlds within the constraints that influence them (Evans & Becker, 2009; James et al., 1998). The research reported in this thesis furthers this contribution by adding new perspectives and debates to the field by incorporating consideration of children's emotional geographies and the geographies of care.

This chapter sets out an introduction to this PhD thesis. The first section (1.2) provides an overview of the study of children who are caregivers in Malawi and outlines the main debates that are considered later in this thesis. The following section (1.3) identifies the gaps in existing literature and research studies. The third section (1.4) presents the reasons I decided to conduct this study, my own

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[1] This thesis adopts the UN Convention on the Rights of the Child definition for children. According to article 1 of the UNCRC, a child 'means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier' (Unicef, 1989). When referring to young people or youth in this thesis they are young people 'between the ages of 15 and 24' as defined by the United Nations. However, it is essential to acknowledge that the term youth also describes the 'period of transition from the dependence of childhood to adulthood's independence' and thus, it is not easy to define this term only by age, as youth is considered more fluid. Interestingly, the African Youth Chapter of the African Union defines minors as 'young people aged 15 to 17 years subject to each country's laws' and the terms youth or young people refer to 'every person between the ages of 15 and 35 years' (African Union, 2006, p. 3). For the purposes of this research project, I use the terms children and young people while referring to individuals aged 0-15 as children and 15-24 years old as young people.

background as a researcher and position in relation to the project. The next section (1.5) gives an overview of the country of Malawi where fieldwork was undertaken and summarises some additional information relevant to the study. The chapter concludes with outlining the main aim and research questions of this study (1.6).

1.2 Context of the Research

This section offers an overview of the rationale behind this PhD thesis. In the Global South[2], the effects of HIV/AIDS in families has increasingly attracted the interest of researchers who have explored children and young people's caring roles (see for example Cluver et al., 2011; Evans, 2011; Robson et al., 2006; Skovdal & Daniel, 2012). To further extend this literature, this project draws on the theories of childhood studies, emotional geographies and geographies of care and families in order to investigate how children and young people understand and experience caregiving and offer them the opportunity to voice their needs.

Family caregiving is often identified as being a burden on the caregivers who are frequently described as being at risk of poor health and psychosocial distress (Kipp et al., 2007; Shifren, 2009). Most of the existing studies on informal care providers in Africa have focused on women (Kipp et al., 2007; Nkosi et al., 2006); nevertheless, some attention is being given to African children who provide care within families and the impact of caregiving (for example Evans, 2011; Robson et al., 2006; Skovdal, 2010). A number of studies have begun to challenge traditional notions of children's experiences and call for scholars to re-conceptualise prevailing ideas of childhood (e.g. Robson et al., 2006) in the light of evidence concerning the nature and extent of children's caregiving work.

During the last few decades, scholars and researchers have altered their attitudes towards children and young people. A growing number of studies have focused on

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[2] In the Oxford Dictionary of Human Geography, Castree et al. (2013) define both terms Global North and South as following: Global North refers to 'those countries found mainly, but not exclusively, in the northern hemisphere, characterized by high levels of economic development'. And the term Global South describes 'the countries of Africa, Asia, Latin America, and the Caribbean, often used in preference to alternative terms such as the developing world or Third World. There exists considerable social, economic, and political diversity within the Global South, which includes the majority of the world's countries'.

conducting research with young people all over the world (for example, Bauman et al., 2006; Cluver et al. 2009; Evans, 2012b; Katz, 2004; Panelli et al., 2007; Robson et al., 2006; Skovdal & Daniel, 2012). New theories have emerged exploring children's identities, agency and roles within society (James & James, 2004; 2012; James et al., 1998). A variety of disciplines including sociology, social work, psychology, geography, medicine and education have increasingly tackled issues relating to children and young people. And even though most research on children is being conducted by adults, slowly new research methods have been developed in order to empower children, hear their voices and acknowledge how the relations between adult researchers and children can affect research (Christensen & James, 2000). Following the debates about conducting research *with* children and not *on* children, this research project attempted to include and empower the participating children and young people throughout the fieldwork research (see Chapter 3).

In addition, this research, while exploring children's caregiving roles, is also focused on emotions. Studies in emotional geographies not only explore emotional experiences by embodied individuals and looking at specific environments, but also investigate the inter-relations of people and places. Undeniably, human beings are ethical, emotional and committed, as well as economic, political and cultural; there are sets of values that govern people's actions in everyday life that are central to how people live and define themselves (Sayer, 2005). Care and emotion intersect on many levels and their relationship is dynamic and fluid. Indeed, caring involves physical and emotional involvement of the carer and the person receiving care (Bowlby, 2012; Conradson, 2003). Care is a two-way process and it involves interdependency and reciprocity (Bowlby, 2012; Tronto, 1993), although individuals are often seen to occupy either the role of the 'cared for' or the role of the 'carer' (Bowlby, 2012). Studies looking at caregiving by children and young people also describe complex and fluid relationships which are characterised by notions of interdependency (Evans & Becker, 2009).

Consequently, the scope of this thesis is to examine the complex nature of children's caregiving through different perspectives. This is a project that sets out to connect geographical and sociological theories by adopting perspectives that draw from children's geographies and childhood studies, emotional geographies and geographies of care. This approach not only reveals important new insights and debates but also provides key understandings about children's and young people's lives and experiences in sub-Saharan Africa. Drawing these different theoretical frameworks together, the discussion below (section 1.3) pinpoints gaps in existing research and literature.

1.3 Identifying the Gaps

While caregiving children's responsibilities and experiences have received limited attention in both the Global North and South, the emerging dialogues and debates between childhood, caregiving, emotions and the impact on family lives need a greater and more focused engagement. This project sets out to represent children and families from the Global South, following Holloway's (2014) claim that despite a gradually growing stream of studies from different parts of the Global South, children and young people continue to be under-represented in children's geographies, much as research on the Global South is under-represented in human geography and childhoods studies as a whole.

Much of the existing literature conducted on young caregiving, so far have a tendency to present children as passive, vulnerable and at risk, undermining their agency and active participation in family life (Kipp et al., 2007). This thesis argues that concurrent to an emphasis on the negative impacts of caregiving should be a focus on children's active participation in coping with adversity. Children's active participation in decision-making is complex; there are different levels of participation in different contexts and different activities (Sinclair, 2004). As Sinclair (2004) argues 'if participation is to be more meaningful to children and effective in influencing change, it is necessary to move beyond one-off or isolated participation and consider how participation becomes embedded as an integral part of our relationship with children' (p. 106).

Henderson (2015) also states that when researchers discuss African children, they tend to focus too much on adults' narratives about childhood and the idea of 'absolute lack', such as lack of resources, lack of food, lack of money, lack of education, etc. Thus, Henderson calls for researchers to reconsider their approaches when exploring children’s experiences and to include children’s voices and experiences, while notwithstanding consideration of the economic and political context they are living into. This thesis responds to such a call.

Furthermore, until recently, children’s geographies and geographies of care have disregarded the body and emotions. Geographers studying the body and/or emotions have largely overlooked children as research participants. Hemming (2007) claims that children’s geographers need to give more consideration to the subject of emotions, as emotions have a central role in constructing children’s perceptions and experiences within everyday spaces. In response to this, my research project aims to identify a number of important connections between children’s geographies, emotional geographies and geographies of care and families. These are vital for answering the questions of how caring for family members ‘feels’, what care means to children and young people and in what ways their relationships with the family members they care for are influenced.

Although there is a growing body of research on young caregiving in sub-Saharan Africa, its focus remains mostly on children’s practical responsibilities, the day-to-day experiences of caring and coping mechanisms employed to face the hardships, rather than the emotional impact caring has on the family environment as a whole (for example see Cluver et al., 2011; Evans, 2011; Evans & Becker, 2009; Robson, 2000; Skovdal, 2010). Bondi and colleagues (2005) emphasise that emotions matter and thus, looking at the emotional geographies of children’s lives is essential as it shapes and transforms their lives and experiences. Studies about children providing care and undertaking domestic responsibilities associate these caregiving children with poor mental health without exploring this issue thoroughly (Bauman et al., 2006; Cluver et al., 2009; Martin, 2006; Zhang et al., 2009).

This project not only identifies and describes young caregivers’ feelings but also to explore their emotional involvement, to find out how they articulate and negotiate their complex emotional landscapes. Given that to date none of the limited number of papers have been published on children’s emotional geographies have examined the issue specifically from young caregivers’ perspective (for example, Bartos, 2013; Blazek & Windram-Geddes, 2013; de Besten, 2010; Hemming, 2007; Holt, 2007; Kraftl, 2013), this project contributes to the field of children's emotional geographies by exploring young caregiver's emotional experiences.

The high levels of HIV/AIDS infection in sub-Saharan Africa has led to many studies that focus mostly on the impact HIV/AIDS has on children and young people while excluding individuals and families affected by other chronic illnesses and disabilities[3] (see Evans & Becker, 2009). As a way of addressing this lacuna, this study examines not only families affected by HIV/AIDS, but also those impacted by other chronic illness and disability. With respect to the concept of care for chronically ill or disabled family members, there is no research to date which has looked specifically at children's approaches to understanding of caring and what care means and 'feels' to them. This study is an opportunity to interrogate the concept of 'care' from children's perspectives by exploring what care is for them, and their relationships with the people they care for.

In considering children's relations with adults, another matter to be addressed is the lack of studies that investigate family life as a whole and not only the parents/carers or the children and young people. In response to Seymour (2007; 2011), this project looks at the effect of young caregiving, not only from a child's perspective but also through the family life and relationships within the care-receiver. Moreover, as young caregiving and family life do not only exist in one place, such as only 'at home' (Seymour, 2007), this study explores the spatiality of care practices, observed, and recorded when and where it occurs and with whom it involves.

This PhD project also intends to empower the children and families who participated in this research while exploring their needs and identifying the best

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[3] The definition of chronic illness or diseases to be used in this thesis is 'long-term conditions that cannot be cured but can be controlled by medication and/or other therapies' (DoH, 2010). NSO report (2008) defines disability 'as having difficulties or problems in one or all of the following areas; seeing, hearing, speaking and walking/climbing' (p. 16). In addition, according to the Equality Act (2010) disability is 'a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities'.

ways to support them. This approach was adopted because of a desire to contribute to a project that has the capacity and potential to advocate for children and families' perceived wellbeing. Efforts were made to accomplish this by employing participatory techniques throughout the research process and supporting young people and families to decide on their own initiative what kinds of interventions are most useful and ways to disseminate the research results.

To sum up, the foregoing section explained the rationale behind the project by briefly looking at existing research and literature. The next section explores the reasons I decided to conduct this particular research project through consideration of my personal background and motivation. I believe it is important to briefly present and reflect upon my experiences and myself as they might shape this study both in relation to the topic and its approach.

1.4 Self-Reflections

The notion of care and well-being has always been of interest to me personally, academically and professionally. Being a young caregiver myself resulted in both negative and positive experiences. As a child, caring is not understood or experienced as it is for adults. In my experience, being a child caring for an adult meant increased and multiple responsibilities, loss of personal and social time with friends, and lack of educational support, but it was not experienced like that. Being a young caregiver 'felt' normal and the caring relationships were characterised by interdependency, I would provide and receive care at the same time. Also, care providing was not constant and even though, at times it was difficult, at other times it was rewarding. Having this role also meant that I developed many skills such as learning to be independent and interdependent, resilient, caring and empathetic, and finally adaptable and flexible, as I had to learn to adapt quickly to environments that did not always offer stability.

In many cases, young caregiving is considered only as a negative experience. In my adult life, during my first steps as a social worker, I worked with a number of 'invisible' young carers, who a decade ago, were seen as 'troubled' children from 'inadequate' family environments with 'poor' parenting. However, these attitudes never represented my beliefs and my experiences. I often used to find it difficult to challenge these more 'traditional' and stereotypical ideas of families and children.

Later, while studying for an MSc in Childhood Studies, along with a strong commitment to identify and promote children's and young people's agency, I explored my personal interest in young caregiving, only this time on a more academic and theoretical level. So, when the opportunity to conduct research with caregiving children in an African context arose, I felt that this was the chance to further my knowledge and contribute to the discipline by bringing together my personal, professional and academic experiences. I am interested in looking at children's holistic experiences of caregiving including their families, looking at them as a system, rather than just individuals. Care is a complex notion, underlined by ideas of interdependency and co-existence. From my experience, I believe that by addressing children's emotional difficulties and strengthening their positive attributes, children at any age find it easier to cope with the difficulties they are facing. They have the capabilities to find the solutions that are the most appropriate for themselves and their families. They become more confident and empowered. To accomplish better outcomes for children and young people, it is also vital to empower and strengthen their families as a whole, without of course ignoring the individuals' needs.

When I commenced this PhD research journey, my experiences had only been derived from the Global North and with this project, I explored further some of these notions in the Global South. As with most research, a researcher's personal background can have an impact on how they approach their projects. While I aimed to conduct this research and presented its outcomes in an unbiased way, I believe that objectivity is not easy to achieve. Chapter 3 addresses these issues of positionality and my attempts to balance this subjectivity further. The next section locates these issues in the Malawian setting and presents the cultural context in which this research project was conducted.

1.5 Cultural Context

The research for this PhD was conducted in the rural and urban districts of Blantyre in the Southern Region of Malawi, therefore, it is necessary to provide some, albeit brief, details of the cultural and geographical context within which the research took place. Malawi is a sub-Saharan African country in the southeast of Africa (Figure 1) which borders Tanzania and Zambia to the north and Mozambique to the south. According to the Department for International Development (DfID, 2018), Malawi is one of the poorest non-conflict countries in the world. The national poverty rate in 2016 was 51.5, which was increased from 50.7 in 2010 due to the 2015 and 2016 flooding and droughts (The National Bank, 2018). This indicates that a bit more than half of the population is poor and according to the Malawi National Statistical Office (NSO, 2017), 64% of the Malawian households reported that they had inadequate food for their household while 60% stated that they had inadequate housing. Even though there are no official statistics confirming how many children are caring for chronically ill or disabled family members, it is considered that especially in poor countries, such as Malawi, the number is extremely high (Evans, 2010). Thus, the project commenced with the expectation that are many cases of children and young people caring for family members in Malawi, in common with other sub-Saharan African nations.

Historically, Malawi was a British colony and was administered as the Nyasaland Protectorate from 1891 until 1964. In 1953, the Federation of Rhodesia and Nyasaland was formed and it was constituted by three countries, Northern Rhodesia (now Zambia), Southern Rhodesia (now Zimbabwe) and Nyasaland (now Malawi). In July 1964, Malawi became an independent state and gained republic status in 1966. Prior to the establishment of British colonial rule, the territory which is now Malawi experienced a history characterised by violent outbreaks and enormous changes due to Southern African populations (Ngoni Yao) migrating to Malawi and the development of the slave and ivory trades (McCracken, 2012).

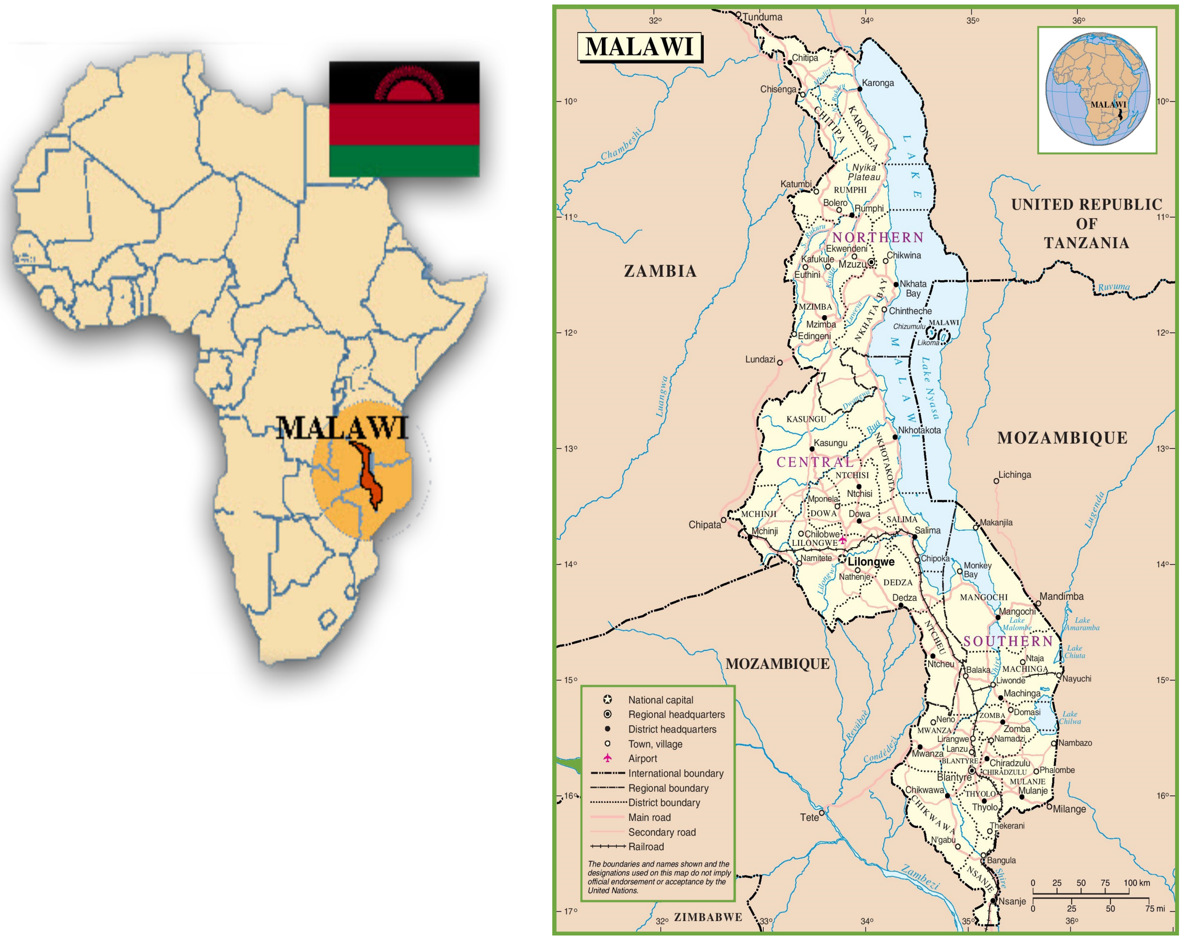

Figure 1: Location & Map of Malawi

In 2017, Malawi's total population was 16 million, with 19% living in urban areas and 81% living in rural areas (NSO, 2017). The main urban areas in Malawi are the four major cities of Blantyre, Lilongwe, Mzuzu and Zomba and other smaller urban areas, such as centres of district administration (NSO, 2017). Malawi's economy is based predominantly on agriculture and 82% of the households gain their income from rainy and dry season crops (78% and 8% respectively), tree crops (20%) and livestock (36%) (NSO, 2017). The majority of the country's exports are tobacco, sugar and tea and most of the population are rural subsistence farmers (NSO, 2017).

Malawi is divided into three main regions and 28 districts: the Northern (six districts), Central (nine districts), and Southern Regions (thirteen districts). The districts are divided into traditional authorities (TAs), supervised by chiefs (NSO, 2017). Each TA is comprised of villages that are the smallest administrative units, and the villages are presided over by village headmen or headwomen (NSO, 2017).

Due to the male dominance of rural to urban migration, there are more men than women in the four cities of Lilongwe, Blantyre, Mzuzu and Zomba, while in the rural areas of the country there are more women (NSO, 2017). The age distribution in Malawi indicates that the country has a youthful population with the median age being 17 years (NSO, 2017). In 2017, more than half (55.8%) of the total population was comprised of children aged 0-18 years old. NSO and ICF Macro (2011) state that the average household consists of 4.6 people and that approximately half (49%) of the individuals within the household are children under 15 years old.

In addition, this section outlines some key statistics of relevance to describing the key themes of this project, such as education, orphan children, disability and chronic illness. In regards to education, in 2017, self-reported literacy[4] was 73% per cent amongst young people 15 years old and above, with males reporting a much higher literacy (81%) than females (66%) and 14% of young people 15 or above reporting that they have never attended school. The 2017 Integrated Household Survey also gathered data on why children and young people have never attended school and the reasons included: lack of money, parents not allowing them, helping at home and school being too far from home (NSO, 2017, p. 25). The Survey also reports that 2% of children in primary and 10% of children in secondary dropout[5] and the main reasons are: they do not have money (51.4% for primary school children and 60.2% for secondary), they are not interested (26.6% for primary students and 4.2% for secondary school), they get married (9% for primary school children and 15.6% for secondary school students) (NSO, 2017).

Looking at orphan children, NSO (2017) defines an orphan as 'a person aged less than 18 years, who had lost at least one of the parents' (p. 16). Following this

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[4] Literacy is described as the ability to read and write in any language (NSO, 2017, p. 23).

[5] School dropout is defined as the percentage of pupils enrolled in a given grade or cycle or a level of education in a given school year who have left school either voluntarily or otherwise (NSO, 2017, p. 38).

definition, 1,600,000 (10.1%) of all children were orphans in Malawi in 2017, which means that approximately 1 child in every 10 was an orphan. Out of those children and young people, 63.1% had lost their father, 22.4% had lost their mother and 14.5% had lost both parents. Orphanhood was found to be almost the same in both urban (10.4%) and rural areas (10%) (NSO, 2017).

The total number of people with disabilities[6] in 2008 was 498,122, representing about 4% of the total population. Interestingly, there are major differences between urban and rural areas. Of all the individuals with disabilities, approximately 1 in 25 people (452,743) have a disability in rural areas, and 1 in 45 people (45,379) in urban areas. The 2017 Household Survey did not include information in regards to people with disabilities and there are no further reports published which present information about adults with disabilities in Malawi.

The 2017 Household Survey identified the overall occurrence of chronic illness in Malawi to be at 6.4% (NSO, 2017). Out of this population, the report shows that 20.8% suffer from asthma, 18.8% from HIV/AIDS, 5.2% from epilepsy, 5.5% from stomach disorder, 4% from mental health illness, 2.5% from chronic malaria, 3.3% from arthritis and the rest (38.8%) are classified as ‘other’ (NSO, 2017). UNAIDS (2017) report that declares that 9.6% of adults aged 15-49 suffer from HIV/AIDS. Notable is the way this reported chronic illness is diagnosed. Only 63% of the respondents stated that they were diagnosed by health professionals at a hospital and 21% by a professional at other healthcare facilities, while 8% indicated that they diagnosed themselves (NSO, 2017). In the Southern Region, the highest percentage of chronic illness diagnosed by a health professional was reported in Zomba City (97%), while Blantyre rural area reported having the lowest percentage (42%) (NSO, 2017). This reflects the lack of access to formal healthcare services for many of the population of Malawi.

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[6] The governmental census of 2008 identifies as people with disabilities only individuals with sight, hearing and speech problems and walking difficulties (NSO, 2008).

This demographic overview of the population of Malawi presents a brief sketch of some of the salient characteristics pertinent to the context within which the research of caregiving children and their families was undertaken.

1.6 Research Aim and Questions

The aim of this study is to re-conceptualise childhoods of sub-Saharan children and young people with caring responsibilities for family members with chronic illness and disability in Malawi. This is achieved by exploring how children and young people construct their childhood(s) in the context of caring and in particular, by investigating children's meaning of care, looking at the emotional aspects of care and care-practices by adopting a family approach.

In particular, the specific research questions addressed in this study at the levels of the individual, family and community are presented in Table 1 below:

Level of research focus	**Research Questions**
Individual (understanding and actions)	'Who/what is a child? How do children and young people understand and describe caregiving? Where is caretaking place? How/when do children become caregivers? What are children's caregiving roles? What are the ways through which children and young people show their agency?'
Individual (emotions)	What are children's and young people's emotional experiences and emotional geographies of caring for family members (parents, siblings, grandparents, other adult relatives) with chronic illness and/or disability?
Family environment & relations	How are family geographies constructed when children caring is involved? How are family relations affecting or are affected by young caregiving? What are children and young people different roles and how do these intersect?
Community & services	What is the role of formal (social services) and informal (peers, family, community) support? According to children and their families participating, which interventions are the most appropriate?

Table 1: Research Questions

1.7 Conclusion

The first chapter has introduced the rationale of this PhD study with firstly, a brief summary of the literature and the main debates that are discussed later in more depth in Chapter 2. It then highlighted the significant gaps in the existing theories and research studies. The following section looked at the personal background and the research's position in this study. The following section explored the cultural context and geography of Malawi as a country which is the setting for the research undertaken. Finally, the last section presented the overall research aim and questions. The subsequent second chapter provides the outline of the main debates in the existing literature in order to provide the conceptual framework that this study is based on.

Chapter 2. Literature Review

'Above all, their childhood is an opportunity.'
(Woodhead, 1996, p. 9)

2.1 Introduction

This chapter provides a review of the published research and current debates on childhood studies, children's geographies, emotional geographies and family geographies of care relevant to children and young people with caregiving responsibilities. It discusses assumptions on what childhood is considered to be within both the Global North and South. Constructions of childhood not only shape how adults treat children but also how research with children and young people is conducted, as well as influence policy and practice (Christensen & James, 2000; Christensen & Prout, 2002). Therefore, this chapter explores how children and young people with caring responsibilities are represented both in the Majority[7] and Minority world and evaluates current research.

Overall, the aim of this chapter is to study and evaluate the complexities of childhood from different perspectives and using geographical and sociological theories. A perspective that draws diversely from children's geographies and childhood studies, emotional geographies and geographies of care, not only reveals important new insights and debates but also provides key understandings about children's and young people's lives and experiences in sub-Saharan Africa. Drawing these different theoretical frameworks together, the discussion

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[7] The term Majority World is used to refer to Africa, Asia and Latin America where the majority of the world's population live compared to the Minority World of Europe, United States, Australia and New Zealand which has less population. Although the generic dichotomy of these is problematic, distinguishing between the two terms can be helpful to assist with discussing some of the dissimilar relations of these areas without referring to these locations by using more negative definitions such as Third or First World (Punch, 2003).

elaborates gaps in research, from which the research aim of the thesis has been generated.

The first section (2.2) offers an overview of the history of childhood and explores different approaches which consider childhood and children. It outlines the interdisciplinary nature of children's geographies and childhood studies. The second section (2.3) considers children across the globe and specifically in sub-Saharan Africa. The third section (2.4) summarises the contribution of contemporary research in emotional geographies. A spatially informed approach to the study of emotions can convey new understandings to geographical research (Bondi et al., 2005). The following section (2.5) discusses theories and debates on geographies of care and family relations. Caring and relationships of care are positioned in, formed by and form certain spaces and places that expand from the local to the global (Milligan & Wiles, 2010). Therefore, geographies of care can have a vital role in debates about care. Finally, the last section (2.6) of this chapter provides an overview of the existing research concerning children and young people with caring responsibilities in both the UK and sub-Saharan Africa.

2.2 Constructions of Childhood

2.2.1 Childhood Studies

Children and young people have become a significant focus for a variety of social science disciplines, including human geography. Childhood is a concept that has been historically and extensively used but has not always and everywhere been perceived in the same way (James et al., 1998). According to James and James (2004) childhood is considered to be a 'particular cultural phrasing of the early part of the life course, historically and politically contingent and subject to change' (p. 13). It is characterised by 'rapid physiological and psychological development and represents the beginning of the process of maturation to adulthood' (James & James, 2012, p. 14). Nonetheless, Woodhead (1996) states that this growth is related and interpreted in relation to different understandings of children's needs and welfare, which varies between cultures and across time.

Childhood thus cannot be characterised as a universal construction; instead, it is rather contextually specific due to its diverse cultural, historical and social interpretation (James et al, 1998; James & James, 2012; James & Prout, 1997; Wells, 2009). Aries (1962), a historian of childhood, is generally thought to be the first to claim that childhood is a historically specific notion and he believed that it was introduced in Europe in the seventeenth century. He argued that during the European Middle Ages children were thought to be little adults and once they showed any signs of reasoning and strength, they were then treated as adults (Aries, 1962). Even though Aries' approach has been criticised by other historians, it highlights the socially constructed nature of childhood (Heywood, 2001; James & James, 2012).

Following Aries's work and emphasising changes in the notion of childhood, Zelizer (1994) looked at Western childhood during the nineteenth and twentieth century. She explored the 'value' of children within the household and concluded that even though children had become economically 'worthless', they are emotionally 'priceless' (Zelizer, 1994, p. 96). Qvortrup (1994; 2009) identifies childhood as a structural form existing in all societies and emphases its 'permanent form of any generational structure' (Qvortrup, 2009, p. 23). Childhood is thus 'both constantly changing and a permanent structural form within which all children spend their personal childhood period' (Qvortrup, 2009, p. 26). This is important because it highlights that childhood is fluid and does not have fixed stages or guidelines, but it is 'a historically and culturally variable social construction' (Hutchby & Moran-Ellis, 1998, p. 6).

Subsequent to the acceptance that childhood is socially constructed and thus changes in the way childhood is recognised and perceived, a variety of disciplines, including human geography, psychology, anthropology, education and sociology have also contributed to the study of childhood (Prout, 2004). Developmental psychology was one of the most dominant paradigms in the study of children during the twentieth century (Woodhead, 2009). Based on Westernised ideas of childhood, developmental psychology presented a theoretical approach which claimed that children go through a variety of stages depending on their physical development and cognitive ability before they reach adulthood (Kehily, 2009).

However, it has been argued that psychology failed to give the appropriate consideration to the historical and social context of childhood and broadly labels childhood by using narrow measures and dichotomies like biology versus nature (Prout, 2004).

On the other hand, sociological approaches have focused more on matters related to socialisation and in particular on how children become members of society (Kehily, 2009). Sociological studies regard socialisation as a process during which children learn how to become fully adult beings and thus socialisation is considered an integral part of childhood (Holloway & Valentine, 2000a). While sociological approaches explored children within the cultural and social context, they neglected to look at children as individual human beings. Children were often viewed as future adults, as 'becoming' instead of 'being' (Qvortrup, 1994). Given the stark differences between the dominant approaches to childhood within psychology and sociology, it was not until after the 1970s when psychologists started exploring the effects of the social world on children's development and sociologists began to be interested in the individual characteristics of socialisation (Woodhead, 2009).

Discourses on the dichotomous opposition of culture (social) and nature (biology) were superseded by the introduction of the 'new' social studies or 'new' sociology of childhood (James et al, 1998; James & Prout, 1997; Prout, 2004)[8]. The 'new' sociology of childhood challenged dominant theories and debates of childhood which developed from various disciplines including sociology, anthropology and developmental psychology (James & Prout, 1997; Kehily, 2009; Prout, 2004). Significantly, the 'new' sociology of childhood recognised children as competent social actors, as agents and participants of their own lives. This area of childhood studies acknowledged the complex nature of childhood by focusing on dominant dualisms, such as 'being' and 'becoming'; 'agency' and 'structure' and so on (Prout,

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[8] Although, it is agreed that the 'new' sociology of childhood has greatly benefited the study of childhood and children, the term 'new' has recently been criticised by scholars who argue that it is not 'so new' anymore but it has undergone multiple changes, as new disciplines, from geography to education and law, have joined the sociology of childhood creating the discipline of childhood studies (Holloway, 2014; Tisdall & Punch, 2012).

2004). Indeed, instead of children and young people being seen either as active, autonomous and independent human beings, or as vulnerable, innocent, dependent and in need of care and protection, the sociology of childhood identifies that both agency and vulnerability interlink and can be a characteristic of children at the same time (James et al., 1998).

Without a doubt, a number of accounts have challenged this dichotomous aspect of childhood and stress the necessity of exploring children and young people in their own individual right (Holloway & Valentine, 2000a). Whilst the importance of the sociology of childhood conceptual approaches have been widely acknowledged (see Christensen & James, 2000; Kehily, 2009), criticisms have emerged and argue the necessity of reconsidering some of its positions and assumptions (Prout, 2004; Tisdall & Punch, 2012). Prout (2004) explains that while childhood is a social phenomenon, it cannot only be explained only within social studies; an interdisciplinary approach should be adopted and an open-minded process of enquiry (Prout, 2004). In fact, the new social studies of childhood has become gradually more and more interdisciplinary (see Tisdall, et al., 2009; Tisdall & Punch, 2012; Woodhead, 2009).

Finally, scholars of the ‘new’ social studies of childhood have been criticised for overemphasising their case to establish their contribution (Prout, 2004). Holloway (2014), however, stresses that this does not necessarily mean that these ‘new’ contributions have nothing to offer. On the contrary, they do and they become a valuable tool not just to childhood studies but also to the broader academic field of youth studies, including children’s geographies. Undeniably, children's geographies have been influenced by childhood studies adding a geographical approach which only enhances the interdisciplinary nature of the sociology of childhood (Matthews & Limb, 1999).

The start of this chapter has discussed the ‘new’ (but not so ‘new’) sociology of childhood and argued that children are competent and active agents of their lives and that childhood should be seen as a complex and nuanced social phenomenon which is constantly changed by physiological and psychological development and can be affected by the historical and cultural context. The next section considers how children's geographies contribute to the study of children and young people and the importance of space and place in social research.

2.2.2 Children's Geographies

Recent work in children's geographies has been informed by a variety of disciplinary approaches to research on children and young people both within and outside of geography. Several theories on constructions of childhood and children arising from sociology and developmental psychology inform contemporary discourse within children's geographies. Geographies of children are increasingly becoming multidisciplinary and interdisciplinary and this is especially evidenced by the diversity of papers published in the *Children's Geographies* journal established in 2003 (Robson et al., 2013a).

Children's geographers contribute to the discipline of childhood studies by exploring the spatiality of childhood and children's everyday spaces, such as school and other public spaces (Holloway et al., 2000; Holloway & Valentine, 2000a; Matthews et al., 2000a; 2000b). The concept of spatiality refers to 'the ways in which the social and spatial are inextricably realized in one another' (Keith & Pile, 1993, p. 6). Children's geographies examine the importance of place in differentiating children's livelihoods at a range of spatial ranges (Katz, 2004). Hackett and colleagues (2015) argue that exploring how space impacts and shapes children's everyday lives is central when trying to gain an in-depth understanding of children's experiences. Further developing research in this field, an extensive range of studies have investigated children's everyday lives and spaces across the world, including street children (Young & Barrett, 2001), gangs (Winton, 2005) and nursery schools (Gallacher, 2005). Space and place have been used in different ways by scholars, some write about children and young people in only one location, space or place, while others look at their connections (Hackett et al., 2015).

In addition, Aitken (1994), Bunge (1973) and James (1990) introduced discourses of children's geographies as being a vital and integral part of human geographical research. Bunge (1969) was the one who first gave a 'voice' to children and young people in geography and emphasised in the ways they are seen as 'victims' (Aitken, 2001; Holloway & Valentine, 2000a). Despite his pioneering work of bringing children to the attention of geographers, Bunge's methodological approaches have been critiqued for ignoring ethical values, although his research in urban landscapes pinpointed society's moral crisis and stressed the need for new policy measures (Aitken, 2001). Children's geographies began with researching children's spatial cognition and focusing mostly on the biological aspect of the child but later, with the introduction of the 'new' social studies of childhood, the focus of geographical research with children shifted the nature/culture dualism (Holloway, 2014).

Children's and young people's agentic notions inform much of the contemporary work within children's geographies. Geographic research focused on children and young people has increased in recent decades (see for example Aitken, 2001; Holloway, 2014; Holloway & Valentine, 2000a; Matthews & Limb, 1999; Robson & Ansell, 2000) and has emphasised that exploring children's understandings, experiences and representations is vital for understanding socio-spatial structures and relationships. The expansion of research focusing on the experiences of children and young people indicates that children's geographies alongside the social studies of childhood actively try to incorporate the experiences and voices of children while promoting their agency and empowering them (Holt, 2011). Children's geographies, following the conceptual approaches of social studies of childhood, recognise children as social actors and as agents of their own lives. Seymour (2015) further calls for scholars to address the distinction between the terms 'social actor' and 'agent'. Children who participate in social life are social actors, while children whose participation has an actual impact on social life are agents (James, 2009). Seymour (2015) emphasises that this distinction can be particularly useful when exploring children and space, and looks at some children as social actors who are involved in changing spatialities and exhibit some level of resistance to adult power and control, and other children as 'spatial innovators' and agents who can construct their own spatialities.

Contributing further to the new sociology of childhood, geographies of children focus on the importance of place and space in children's experiences and lives (Holloway & Valentine, 2000a). Even though both the cultural and historical context in childhood play a significant role when studying children, it is argued that initially social studies of childhood had focused mostly in the historical rather than the cultural or spatial (Holloway & Valentine, 2000a; 2000b). However, more recently, children's geographers' work on the diversity and variety of childhoods across different spaces, places, countries and regions have made a key contribution in the discipline of childhood studies (Matthews et al., 2000a; Philo, 2000). As children are not either completely autonomous nor under complete adult control (Aitken, 2001), using space and the notion of spatiality through different scales, such as domestic, local and global can help scholars comprehend children's worlds in a much better way (Seymour, 2015).

Critics argue that children's geographies have been overwhelmingly qualitative (Philo, 2000), local (Ansell, 2009), and lack rigorous debate, particularly around matters of competency and agency (Vanderbeck, 2008). Others claim that the term 'children's geographies' might exclude teenage and youth's views and also fails to recognise how undertaking research with children differs from conducting research with young people and teenagers, not only in respect to ethical considerations but in terms of the perceived competencies of the children neglecting the lives of adolescents and young people (Skelton, 2001). In addition, Ansell (2009) states that children's geographies research emphasises micro-scale research which restricts the power of children's geographers to be involved with policy issues and wider geographic discussions. In spite of this, Holloway (2014) argues that it is essential to mention that geographers' commitment to notions around spatiality has helped the discipline to avoid 'the dualist split between either global (social structural/minority group) or local (socially constructed/tribal child) modes of thinking' (p. 381).

Children's geographies and childhood studies have been further criticised from those within the sub-discipline for focusing too much on empirical discourses of children and young people's everyday experiences but not being critical enough on a theoretical level (Holloway & Pimlott-Wilson, 2011; Holt, 2011; Horton et al., 2008; Horton & Kraftl, 2006; Tisdall & Punch, 2012). Nonetheless, Tisdall and Punch (2012) argue that 'theoretical suggestions and conceptual discussions may become lost among the sheer volume as well as the detail of empirical accounts' (p. 251).

Moving forward from the critics, children's geographies have investigated the integral part gender plays in childhood (Philo, 2000; Reay & Lucey, 2000). Research done on the experiences of children over the use of space provides detailed accounts of how gendered childhood spaces are, showing how children's geographies take account of gender (Smith & Barker, 2000; Tucker & Matthews, 2001). Such accounts, for example, express that boys are often observed to have greater levels of autonomous spatial mobility than girls (Matthews et al., 2000b; Valentine, 1996,), although later research in the Global North stated there are no noteworthy gendered differences in children's spatial mobility, as both girls and boys are gradually accompanied until transitioning to secondary school (Thomson & Philo, 2004).

Furthermore, Gutierrez and Hopkins (2014) identify the connections between young people's geographies and feminist geographies having a number of common interests. Both perspectives of human geography share their interest in criticising and challenging issues of power relations and inequality and at the same time focusing on conducting ethically nuanced and rigorous research (Gutierrez & Hopkins, 2014). This was also acknowledged by Evans (2008), who states that

> 'as with debates around the definition of feminist geographies (Women and Geography Study Group 1997), children's geographies are often defined in relation to a shared political agenda to centre children and young people in geographical research, to challenge negative stereotypes of children and young people, to empower children and young people, and to challenge barriers to children and young people's participation in policy decisions' (p. 1660).

Spatialities, gender discourses and feminist geography research are all vital frameworks for this research project and provide an irreplaceable platform for further critical thinking and knowledge production and that is why they are explored in this chapter. This chapter so far has provided an overview of childhood studies and children's geographies and the current debates in these fields. As this research project not only includes children and young people but also takes place in Malawi, a country within sub-Saharan Africa, the next section will investigate current discussions and issues of literature around children and young people in the Global South.

2.3 Children and Young People in the Global South

The previous section provided an overview of the theories of childhood and identified that conceptualisations of childhood differ across culture, space and time (James & Prout, 1997; Wells, 2009). Contemporary research with children's geographies and theories of the sociology of childhood argue that understandings of what childhood is differ from one context to another and across time. As childhood varies in different ways in different times and spaces, so too children's and young people's experiences are diverse (Ansell, 2005; Montgomery, 2003). There is, however, less known, compared to the West, of the construction of childhood and children's experiences in the history of Africa (Wells, 2009).

Western concepts of childhood often have a romantic view of children and young people (Montgomery, 2003). Western perspectives construct childhood as a carefree time characterised by play and innocence. Critics argue though that such western ideas have been transferred to children globally (Boyden, 1997; Katz, 2004). In the nineteenth century, western ideas of childhood became globalised through migration, colonialism and missionary activity (Ansell, 2005). Later, the influence of international NGOs and other supranational organisations spread across areas such as Africa, Latin America and Asia (Ansell, 2005). This contributed to the creation of a global idea of childhood that fails to accurately encapsulate children's and young people's experiences in poorer countries (Ansell, 2005). Therefore, it is essential for childhood studies and children's geographies to adopt a more globally nuanced approach.

Aitken (2013) argues that, as globalisation is not new, attention to how global developments impact on children's lives is essential. Living in a global world results in high levels of technological changes, mobility and transnational families (Punch & Tisdall, 2012). Although the effects of globalisation can be both positive and negative, they can often produce greater inequalities between the Global North and Global South (Kaufman & Rizzini, 2002; Punch & Tisdall, 2002). Montgomery (2003) argues that globalisation has penalised poorer countries by increasing power differences and stigmatising them by comparing them to richer nations. Having considered this, Lund (2007) states that globalisation has resulted in making children and young people more vulnerable.

In order to effectively capture the diverse and complex nature of children's lives, which is constantly changing, children need to be portrayed with reference to the kind of society in which they live, the cultural values they adopt and the position they occupy within that society (Matthews & Limb, 1999). Adults around the world appreciate children's competencies in ways that appear to be culturally appropriate at a particular historical moment (Hutchby & Moran-Ellis, 1998). For instance, studies in rural Tanzania (Porter, 1996) and in urban Madagascar (Sharp, 1996) revealed that children, often as young as five years old, have roles and responsibilities for essential everyday domestic chores, such as cooking, cleaning and fetching water.

Furthermore, in Tanzania, children with caregiving responsibilities for others infected with HIV clash with dominant Western ideas of childhood that see children as vulnerable and in need of protection (Evans & Becker, 2009). It is highlighted that dominant western notions consider childhood to be a protected period when children and young people should have the time and be allowed to socialise, go to schools and spend time with their friends without being concerned with responsibilities related to 'adulthood' (Evans & Becker, 2009).

In contrast, Woodhead (1996) argues that children are more often seen as immature and vulnerable than as active participants in social and economic reproduction. Recent global discourses of children's rights emphasise their autonomy and competence but do not address active forms of social participation (Burr & Montgomery, 2003; Kjørholt, 2007). A pertinent issue is whether or not there are potential tensions and conflicts amongst rights' discourses and concepts of active participation that are argued to be global, and more traditional notions of childhood which differ across cultural, local and national frameworks (Kjørholt, 2007). Indubitably, as Katz (2004) states, global changes have had disruptive results on societies and their children in the Global South and the Global North.

From another perspective, Kjørholt (2007) considers children to be social contributors in the societies they live and that children impact on cultural life in many respects. For instance, she claims that children can be seen variously as consumers, soldiers and/or labourers and that they 'reproduce and produce culture in everyday lives in different localities on a par with adults' (Kjørholt, 2007, p. 30). Notably, children and young people are seen as co-constructors of their own livelihoods and active agents in creating and governing relationships with other children and adults (Kjørholt, 2007; Matthews & Limb, 1999). From this standpoint, children are caring beings and embodied entities who impact on their own and others' lives and welfare by emotionally contributing to them (Kjørholt, 2007).

Panelli and colleagues' (2007) work acknowledges differences and similarities between rural young people in both the Minority and Majority worlds. Predominantly, they recognise that despite the socio-economic, political and cultural differences, children in the Minority and Majority worlds have many in common. Indeed, they argue that the Majority and Minority worlds have much more similarities than acknowledged and that young people's lives are often shaped by common basic processes and dimensions (Panelli, 2002; Panelli et al., 2007). For example, research related to young people's agency identifies similarities in the limitations youth face through a variety of restrictive forces in urban areas in both the Majority and Minority world, including the limited access to transportation and thus lack of mobility in rural areas, the inadequate opportunities in rural areas and the common experiences of belonging and place (Robson et al., 2007b). However, critics emphasise the importance of acknowledging the diversity of children and young people's experiences living within both worlds (Robson et al., 2007b). A study of child domestic workers in Tanzania offers an overview of rural young people's various levels of agency (Klocker, 2007). Klocker (2007) highlights the impact that the economic and socio-cultural context has on young people's lives and agency, and in particular, on whether they will or will not become child domestic workers.

With reference to this research project, there is not much known about how childhood is constructed and perceived in Africa broadly and specifically in Malawi. Serpell (1996) offers a very good account of children in West Africa. He suggests that childhood within West African culture is connected with 'cultivation'. He states that while Western ideas of childhood promote the agency and autonomy of children, African societies are more preoccupied with 'the cultivation of social responsibility and nurturance' (Serpell, 1996, p. 133). This is aptly epitomised by the Chewa[9] proverb 'Ku-ongola m'tengo mpoyamba' (A tree is straightened when it is young) (Serpell, 1996, p. 131). Milimo (1972 as cited in Serpell, 1996) says that this proverb illustrates the idea that people cannot change during adulthood and that 'all the corrections are to be made, they must be done when one is young and supple' (p. 15, as cited in Serpell, 1996, p. 131). Within this context, the child is seen as a 'growing organism' and the parent as a 'cultivator' who passes on their knowledge through social interaction and efforts to shape the younger generation (Serpell, 1996, p. 134).

Many accounts of African childhoods emphasise the amount of work children perform on a daily basis (Hollos, 2002). Often, children from five years old onwards learn to help in the house and farm and carry out tasks such as carrying water, herding cattle, care for babies, going to the market, etc. (Oppong, 1973). When children are still very young, there is not always a sexual division of labour with regard to the allocation of chores and the help they provide, but, from about eight or nine years old, girls will be more likely to do 'women's work' such as washing, caring for younger siblings or cooking and the boys will carry out tasks such as getting water or working on the land (Hollos, 2002). Hollos' (2002) study in northern Tanzania also observed that girls' work increases with age, while boys' work starts to decrease as they reach adolescence. She also highlights the importance of understanding that the work which children carry out is not considered as 'helping' the adults, rather it is something everybody does to ensure household survival (Hollos, 2002). Hollos' (2002) findings highlight that children

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[9] Chewa (also known as Chichewa) is a language widely spoken across much of Malawi, Zambia, Zimbabwe and Mozambique.

living in traditional, large families have to work considerably more hours than their peers living in 'modern' nuclear families and identified the converse for play time, with children within nuclear families having more time to play than their peers in large households.

While work is a key element in African childhoods, Twum-Danso Imoh (2016) suggests that the majority of research into African childhoods focuses on what children in Africa lack and what is problematic within their lives. Twum-Danso Imoh et al. (2019) recognise how significant this kind of research is, but also explain that by focusing on the challenging aspects of African children's lives a negative and narrow view of the notion of their childhood is created which encourages false dichotomies between children in the Global South and North. There is also a need for greater recognition of children and young people's agency, especially in the context of young caregivers, who carefully construct and maintain important networks of support within and beyond family, kinship and household settings and to the fact that they are agents of support rather than simply recipients of support or 'beneficiaries' (Payne, 2012).

Twum-Danso Imoh (2016) recommends that children's work could be used to understand better differentiation between different social groups in contemporary sub-Saharan Africa and thus opening up the space to explore those childhoods which are not necessarily characterised by work. Abebe and Ofosu-Kusi (2016) expand this argument and state that African childhoods are often characterised as 'crisis childhoods' lacking the technological, political and economic circumstances of the 'developed' world. Aiming to bridge the existing dichotomies, the authors argue for the intersection of different childhoods and emphasise that even those African childhoods that correspond with global notions of what childhoods should be are tightly rooted within social norms that affect and regulate relationships and parenting styles (Twum-Danso Imoh, 2016; Twum-Danso Imoh et al., 2019). They add that a relational perspective could offer researchers the opportunity to explore children's lives beyond the dichotomy of the Global South and North thus focusing on the dynamics and variety of forces that shape childhoods and highlight the diversity of childhoods not just globally, but within communities as well (Twum-Danso Imoh et al., 2019).

Focusing on research with children and families in the Global South, Evans (2019) emphasises the challenges when attempting to theorise family meanings and practices in sub-Saharan societies without imposing Minority world framings and perspectives. Evans (2019) argues that working in cross-cultural settings can create particular challenges such as issues with use of language and data interpretation. This is the reason the author calls for researchers from the Global North working in the Global South to be reflective at all the research stages, including research formulation, analysis and writing up, to acknowledge and, recognise ethnocentrism and implicit understandings when theorising children's lives (Evans, 2019).

Taking this further, Phillips (2018) looks at youth and calls attention to the emerging debate within youth studies about how to develop a more globally oriented perspective on youth. Phillips (2018) focuses on two main concerns, first being the question of "conceptual validity across different social and geographical contexts and the problem of institutional barriers between academic disciplines in the study of different parts of the world" (p. 11). The second concern is ways to overcome the academic division between sociology for the 'modern' world versus anthropology and area studies for the 'developing' world. He highlights that the different youth study areas draw upon different bodies of literature thus failing to produce a holistic and insightful understanding of young people's lives (Phillips, 2018).

Twum-Danso Imoh (2019) underlines that scholarly understandings of the diversity of perspectives, attitudes and lived realities of African children and young people are under-researched. She continues to explain that much of the current literature views African childhood through global ideals and often disregards the local (Twum-Danso Imoh, 2019). Youth, like childhood, is differently constituted and constructed in different places and times (Christiansen et al., 2006). Young people endlessly cross the boundary between childhood and adulthood (De Boeck & Honwana, 2005). Youth is inseparably connected to issues of power, authority and gender and there are a variety of different perspectives which reflect ways youth is lived (Christiansen et al., 2006).

Despite the difficulties they face, young people in Africa are active participants in economic, social and political developments while they are constructing their own identities (De Boeck & Honwana, 2005). Often young people actions are steered by dominant social expectations and cultural ideals of what a desirable and respectable future involves as well as by the actual space of possibility in the space they move through (Langevang, 2008). Achieving respectable adulthoods though is a complicated and convoluted journey involving the careful management of social relationships (Langevang, 2008). Young people are regularly regarded as both destructive and creative forces that shape and transform their social world constantly (De Boeck & Honwana, 2005). Many studies view African young people as a 'lost generation' or in 'crisis' but De Boeck and Honwana (2005) emphasise the variety of ways young people have demonstrated remarkable creativity in making a living for themselves within adverse conditions and social instability.

For young people in Africa, transitioning to adulthood can constitute a challenge. Transition can be impacted by unpredictable events in young people's lives, such as bereavement or parental illness, and can change or shape their transition to adulthood (Bowlby et al. 2010). Transition to adulthood is not characterised by developmental stages and it is not a linear process (Day, 2016). Instead, transitions are influenced by a number of social, cultural, familial, and individual processes that dictate what transitions young people go through and when (Day, 2016). Day (2016) explains that young people in Zambia are under increasing pressure to achieve a good education and employment to support their families and make "successful" transitions to "adulthood" while, in the context of caregiving, they are having to cope with the loss of parents and care for relatives with little external support. While young caregiving results in developing useful skills and competencies, it can have a negative impact on transitioning to adulthood, such as generating difficulties with attending and completing school, finding skilled employment, and having the resources to marry and start a family of their own (Day, 2016). As a result, young people can be caught in a "liminal position" between youth and adulthood as they are unable to make the socially accepted transitions related to their age and stage (Evans, 2012b). This often means that although completing education and securing employment are the expected "pathways to adulthood", the impact increased responsibility to care for sick or disabled relatives has on young people as they try to achieve independent adulthood, is enormous (Day, 2016).

In addition, rates of unemployment and underemployment are especially high for young people in sub-Saharan Africa, which present challenges not only for the youth themselves but also for their families and society in general (Gough et al., 2013). There are increasing concerns that young people are being marginalised and excluded from employment and subsequently from the status of adulthood (Gough et al., 2013). This is why the transition to adulthood for African youth is becoming increasingly difficult to achieve and can result in inactivity and frustration among young people, which in turn can result in risky behaviour and involvement in crime, organised violence and protests (Day, 2016; Gough et al., 2013). The issue of youth unemployment remains one of the major challenges for governments and is a key issue of concern for many development partners (Gough et al., 2013). There is thus a need to generate a better understanding of how young people are managing to find or create employment, the opportunities and constraints that they face, and how they can best be supported (Gough et al., 2013).

This section attempted to conceptualise the lives of children and young people in the Global South. There are a number of studies that highlight both the similarities and differences between the Global South and North, as well as nuances within the Global South. This provides a valuable base for what follows in this thesis which explores children's experiences in Malawi. The next section investigates another theoretical framework that this study explores in relation to the emotional geographies of young caregivers.

2.4 Emotional Geographies

Human geography for a long time has disregarded people's emotional experiences and understandings despite their apparent effect on all aspects of life (Bondi et al., 2005; Frijda, 2009; Wood & Smith, 2004). Robson and colleagues (2007b) acknowledge that emotional issues are frequently disregarded by scholars within childhood and youth studies and highlight that the relationships young people from within their society and their sense of place play a much more significant role than the place itself. Exploring emotions is critical for gaining an in-depth understanding of how human interactions work (Wood & Smith, 2004).

Emotion can take a variety of forms; it can be heart-breaking, joyful, distressing or a myriad of other feelings. Emotions are complex phenomena, not easy to articulate or define (Bondi et al., 2005). The absence of a definition of emotion leads to hesitation in terms of its role, nature and how to use it in research (Cabanac, 2002). As Cabanac (2002) states 'emotion is any mental experience with high intensity and high hedonic content (pleasure/displeasure)' (p. 69). Individuals' sense of who they are is continuously (re)shaped by the way they feel (Davidson & Milligan, 2004).

From a psychological perspective, emotional language and feelings are the means to describe the moment when a person realises what he/she feels and thus, is essential in the communication of emotional experiences (Bradley & Lang, 2000). When researching emotion, looking at and investigating the emotional experience is central. Lambie and Marcel (2002) suggest a two-level model of emotional awareness, within which phenomenology (non-reflective consciousness) and awareness (reflective consciousness) are two different notions. This allows researchers to distinguish and more accurately interpret cases of 'unconscious' feelings, during which there is a lack of phenomenology or awareness (Lambie & Marcel, 2002).

Because of the plastic and complex nature of emotional experience, people often find it difficult to articulate a precise description of what they feel (Izard, 2009; Lambie & Marcel, 2002). Emotions can become apparent and experienced after an event has occurred (Reisenzein & Doring, 2009). Emotional awareness might be achieved through reflection and self-interpretation as well as during the process of a self-report or even an interview (Eatough & Smith, 2006; Lambie & Marcel, 2002; Reisenzein & Doring, 2009). Indeed, emotional language is not always clearly conveyed, but it is frequently embedded within people's narratives (Goldie, 2009). Subsequently, apprehending and considering such emotional understandings can be problematic as they cannot be reduced to only narratives or just bodily experiences (Eatough & Smith, 2006).

Despite the difficulties that academic disciplines, including geography, face to capture emotions, a growing body of research and publication acknowledge the existence and impact of emotions (Bondi et al., 2005). This 'emotional turn' plays a significant role in continuing geography's critical frame (Anderson & Smith, 2001; Bondi et al., 2005). Many different academic disciplines and theoretical frameworks have turned their interest to emotion creating a "theoretical diversity to the point of fragmentation and contradiction" often without having the capacity to form a "unique, distinctive framework" (Blazek, 2015, p. 99). What Blazek (2015) highlights though is that despite the differences between the many approaches looking at emotion, they all have a common idea; that emotion matters and that is shaped and shapes geographical environments, mobilities and places.

Emotional geographies do not only aspire to describe feelings but also their scope is to express what seems to be indescribable through looking at the emotional involvement of people and places and their relational dimensions between the space and the social, rather than the emotional disengagement from them (Blazek, 2015; Bondi et al., 2005). As Bondi and colleagues (2005) state "an emotional geography attempts to understand emotion - experientially and conceptually - in terms of its socio-spatial mediation and articulation rather than as entirely interiorized subjective mental states' (p. 3). What is important to take into consideration though is that emotion is messy and often elusive and it is not always easy to represent and articulate, particularly when exploring children's emotional experiences (Blazek, 2015). This does not mean that emotion should not be investigated, but rather that researchers should consider and challenge methodologies and limitations in research (Blazek, 2015). A number of studies have been conducted attempting to capture the intangible nature of emotions.

Critical geographies of chronic illness and disability have explicitly acknowledged and represented the emotions of those they do research with (Bondi et al., 2005; Dyck, 1999; Moss, 1999). Several scholars concerned with mental health problems have also recognised the importance of emotional experiences. For example, studies on agoraphobia (Davidson, 2003) and other phobias (Davinson & Smith, 2003) associate emotion with patients' symptoms and others examine the impact deinstitutionalisation has on the emotional experiences of the mentally ill (Parr, 2000). Feminist geographers present detailed accounts of how women feel, for example, women's emotional experiences of being pregnant and being treated as being 'too' emotional (Longhurst, 1997).

Feelings exist in both bodies and places (Bondi et al., 2005). Geographies of embodiment explore how the body is continuously emotionalised and how feelings are represented through a variety of bodily performances, such as eating, exercising, etc. (Bondi et al., 2005). The interconnections of emotions in between people's bodies and places are explored in a variety of studies, for example, Morris and Thomas's (2005) work on the impact place has upon people who are dying and the powerful and painful connections of emotions, body and space. Also, Collis (2005) offers an analysis which explores women's experiences of hysterectomy and concludes that emotional reactions to hysterectomies vary depending on elements such as age and employment. Another study that presents how emotions are located in the constitution of particular places has been conducted by Urry (2005). This study focuses on touristic environments and shows how touristic places are inundated often with relaxing and pleasing feelings and other times by frightening and wild ones (Urry, 2005).

Studies in emotional geographies not only explore emotional experiences by embodied individuals and looking at specific environments, but also investigate the inter-relations of people and places. A study of the relation of the external environment and interior spaces with the emotional experiences of individuals of a respite care centre suggests that particular types of the landscape could have therapeutic results (Conradson, 2005). A different way to explore individuals' feelings is by looking at the representations of emotions. Jones's autobiography aims to investigate memory (conscious and unconscious) looking at his past, and, finally, suggests that although emotions are recorded in individuals at the moment of their experience when they are re-encountered, they are experienced in various ways (Jones, 2005).

The way people experience, understand and express their emotions varies across different cultures and occupations (Hargreaves, 2001). Hargreaves' (2001) work on teachers' emotional geographies mapped the significance of friendships in the workplace. He discovered the benefits these relationships have upon not only the work of teachers but also on their individual emotional status, as for example, strong enough friendships withstand disputes and reduce levels of anxiety and fear that a disagreement could result in breaking off their friendship bonds.

The literature on children's emotional geographies that has emerged, although limited, is insightful and offers a good description of the significance of the emotion when researching children and young people (Blazek & Windram-Geddes, 2013). A number of studies have presented children's emotions within a wide and diverse context. In these studies, children's emotional geographies are explored through different social, cultural, economic and political views of childhood (for example, Bartos, 2013; Blazek, 2013; Holt, 2007; Kraftl, 2012; Wood, 2013). The complexity of the methods through which children's and young people's emotions emerge are channelled and come to the surface within everyday actions and interactions (Blazek & Windram-Geddes, 2013).

Emotions and bodily senses can be a powerful tool when studying experiences of place in childhood. A study with children in New Zealand explored the interconnections between the place, the body and the self across time when the sense of place starts to be shaped in childhood (Bartos, 2013). Bartos (2013) explored children's experiences by untangling all their five senses and sense of movement and found both positive emotions (such as pleasure, joy and comfort) and negative emotions (such as sadness, pain and discomfort) are all emotional responses to place that presents children's complex and problematised nature.

Nevertheless, some scholars have suggested that places can often be determined by adult values looking at children's best interest (Olwig & Gulloy, 2003). Murray and Mand (2013) studied the emotional traits of children's mobilities and their experiences of travelling in relation to adult hierarchies of power. The results of this study showed that children's emotional responses to travelling, short and longer journeys, are contested and complex. Remarkably, it was emphasised that even though decision-making about journeys children made was within the control of adults and other institutions, children's emotional responses to travel seemed to be agentic (Murray & Mand, 2013).

Furthermore, children's agency over their own emotional responses and constructions has been addressed by other studies. Hemming's (2007) work on children's experiences of sport in primary school showed their capability to adjust and reconstruct expansive physical routines via their own agency. The results of this study emphasised the way children's agency effectively works within institutions such as school and showed that children not only challenge specific regimes through using their own bodily practices but also through the application of emotional discourses (Hemming, 2007).

Wood (2013) also explored young people's emotional geographies of citizenship within a different context. She looked at young people's narratives about citizenship in New Zealand and observed how emotions produced a significant part of their citizenship understandings and participation (Wood, 2013). Looking beyond traditional dualisms, Kraftl (2013) explores the 'more-than-social' emotional relations, looking at theories of attachment, neuroscience and alternative education. He develops a hybrid concept of childhood that goes beyond biosocial dichotomies and urges for critical thinking in children's emotional geographies beyond voice/agent dualisms (Kraftl, 2013).

While most of the research on children and emotions focuses on the individual child, some also explore the collective aspect of emotions. Holt and colleagues (2013) examine the sentimental spaces of peer relationships and friendships in schools. Dickens and Lonie (2013) investigate a community music project in the UK and highlight that young people are able to creatively articulate and express their emotions through lyrics and acknowledge them as creative and expressive individuals and thus, as capable citizens who are fully able to actively participate in the formation of their own communities.

To summarise, emotion matters when researching lived experiences and the growing body of research around emotional geographies can be especially useful for the study set out in this thesis. When researching caregiving roles in families it is vital to look at emotion. Furthermore, as care is a relational experience, the next section explores the existing literature on geographies of care and family relations.

2.5 Geographies of Care and Family Relations

The section above discussed the emerging sub-discipline of emotional geographies, presented how emotion impacts on people's experiences and outlined the main discourses within this field. It is, indeed, vital to consider emotions, especially when investigating notions of care. Caring is not only practical; it is also an emotional practice. Caring can be a source of pleasure and even a labour of love (Conradson, 2003). Over the last fifteen years, research on geographies of care has significantly grown (Bowlby, 2012). This section offers an overview of the existing debates and research on geographies of care.

2.5.1 Theorising meanings of Care

> 'Most of us need care, feel care, are cared for, or encounter care, in one way or another. Care is omnipresent, even through the effects of its absence. (…) To care can feel good; it can also feel awful. It can do good; it can oppress. What is care? Is it an affection? A moral obligation? Work? A burden? A joy? Something we learn or practice? Something we just do? Care means all these things and different things to different people, in different situations. So, while ways of caring can be identified, researched, and understood concretely and empirically, care remains ambivalent in significance and ontology' (Puig de la Bellacasa, 2017, p. 1)

Defining care, and particularly caring, is not easy due to its dynamic and perpetual nature that adopts and is shaped by different meanings depending on the context, location, culture and thus constantly changes over time. Joan Tronto's and Bernice Fischer's definition of care is one of the most prevalent, according to which care is understood as 'a species of activity that includes everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment' (Tronto, 1993, p. 103). Tronto (1993) indicates that there are four stages that generate different dimensions of care. Those begin from ‘caring about’ and ‘taking care of’ which articulate a sense of affect and ethical responsibility to worry about someone and take responsibility for their well-being, to the material and active aspects of care expressed through the actual activity of ‘care-giving’ and ‘care-receiving’ (Tronto, 1993). These different stages of care should not be regarded as separate elements but rather as one mechanism that determines that care involves both an ethical and emotive aspect while it requires hands-on and practical consequences (Puig de la Bellacasa, 2017). Care needs both the affective aspect of it and the actual practice, as only practising care does not ‘make’ care and without including hands-on care, just the affective care remains on a moral level to ‘care about’ without setting the work to ‘care for’ (Puig de la Bellacasa, 2017; Tronto, 1993).

Caring involves the physical and emotional involvement of the carer and the person receiving the care (Bowlby, 2012; Conradson, 2003). Care is a two-way process and it involves interdependency and reciprocity (Bowlby, 2012; Tronto, 1993). Individuals are often seen to have either the role of the ‘cared for’ or the role of ‘carer’ (Bowlby, 2012). It has been argued that this too simplistic a dichotomy and that caring human relationships are characterised by notions of interdependency (Bowlby, 2012), i.e. being both carer and cared for, which some of the young people who participated in this study are.

Nevertheless, despite the reciprocity of care relationships, offering and receiving care often includes inequalities of power (Bowlby, 2012). These inequalities vary and can be characterised as complex as the caring relationship can include subtle or more brutal power relationships (Bowlby, 2012). Indeed, when discussing relations of care, power has become a central notion (Matthews & Limb, 1999). Power is spread irregularly within families and generations, constructing complex forms of authority and resistance (Goldson, 1999; Punch, 2000). When it comes to children and young people, adults often use their control and power to regulate and restrict children, even though the level of this authority varies depending on social variables (Holloway & Valentine, 2000b). Studies show that adults (ill or not) are the ones who often make family decisions, such as deciding children should drop out of school or provide care to ill relatives (Foster & Williamson, 2000; Robson, 2000).

There are many levels of care and people with caring responsibilities may occupy a variety of care roles, such as unpaid and paid, private and public, informal and formal, unregulated and regulated (McEwan & Goodman, 2010; Tronto, 1993). Whereas governments are not able to always provide care, families have to take responsibility and respond to their own care needs (McEwan & Goodman, 2010). This, however, does not only have an impact on the individuals and families but also has global implications, especially for poorer societies (Ehrenreich & Hochschild, 2003).

Moreover, feminist geographies have investigated the complex nature of care, looking at the gendered spatialities of caring (McEwan & Goodman, 2010). 'Care ethics' has been a central concern for feminist geographers, looking at care as a way of relating to others rather than care as just an activity (Held, 2006; Popke, 2006; Smith, 2005). Ideas of care, welfare and emotions are criticised by feminist geographers as being limited to the notion of private and specifically reserved for women (McEwan & Goodman, 2010). Indeed, caring for family members is often considered to be a feminine responsibility that occurs within the household in an informal way (Bowlby, 2012). It is important to highlight that within contemporary research on care there is a growing interest in men as carers and investigations of aspects of masculine care (see Hanlon, 2012 & Lazaro, 2018).

Critical examinations of conceptualisations of care, however, are not limited to gender issues, but also expands to other dimensions. For example, in cases when children are stigmatised, discriminated or labelled due to their race, gender or disability, adversities can be a social construction (Woodhead et al., 2003). To handle those issues, the concept of intersectionality draws from different theoretical perspectives[10] and rejects the notion that human beings can be reduced to isolated categories like age, gender or class (Hankivsky, 2014). According to Davis (2008) ''intersectionality' refers to the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional

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[10] For example, critical race theories, biological theories, socialisation theories and feminist post structural theories.

arrangements, and cultural ideologies and the outcomes of these interactions in terms of power' (p. 68).

Intersectionality understands power and people's experiences from looking at what is created at 'the intersections of axes of oppression' (Davis, 2008, p. 255). Social identities do not just operate separately from each other, but they complement each other and are interconnected (Hankivsky, 2014). Hankivsky (2014) suggests an intersectional approach to care in order to understand oppression and power within social contexts in an attempt to end the dichotomy of power versus powerlessness. As a result, this rejects the dualised notion of caregiver versus care-receiver to see them either as privileged or as oppressed (Hankivsky, 2014). Similarly, Evans and Thomas (2009) state the significance of exploring the interactions of age, gender, poverty and stigma when looking at caring relationships.

The social model of disability also rejects portrayal of individuals or groups of people with disabilities as passive victims and emphasises the impacts social and environmental structures have on individuals' daily lives (Morris, 1991; Oliver & Barnes, 2012). This model highlights that the misused concepts of 'care', 'caregiving' and 'dependency' falsify not only the needs of the ill and/or disabled individual but also their relationship with their 'carer(s)' (Evans & Becker, 2009; Morris, 1991; Oliver & Barnes, 2012). In the cases of families where children have caring responsibilities for other family members, the social model of disability rejects and discards the term 'young carer', as it underpins stigmatising approaches that present disabled people as insufficient parents (Evans & Becker, 2009; Keith & Morris, 1995). Additionally, Robson and Ansell (2000) have criticised the term 'young carer'. They question the use of this term in the Global South and ask whether it is useful to describe African children's and young people's experiences and understandings of caring with the term 'young carers' (Robson & Ansell, 2000). In particular, they explain, 'to impose on these Zimbabwean students the definition of 'young carer' is perhaps to pathologise the activities in which they engage' (Robson & Ansell, 2000, p. 191).

When a chronic illness or a disability is present in the family, the whole family is affected. It is thus argued that researchers and practitioners should employ interventions that seek to support the whole family as a system instead of offering support only to the children or to the parents (Aldridge & Becker, 2003). Considering the complexity of caregiving and care receiving within a family, research suggests that parents with HIV/AIDS both in the Global North and South continue to maintain their parental roles and authorities (Evans, 2005; Tisdall et al., 2004). As research shows, retaining these parental roles signify the development of protective factors for children to become more resilient through having extra responsibilities that are not usually expected at their age (Evans & Becker, 2009; Woodhead et al., 2003). Evans and Becker (2009) state that 'reciprocity and intergenerational interdependence are common features of families where children are 'caring' for parents with HIV/AIDS in the UK and Tanzania, and that meanings and experiences of care 'giving' and care 'receiving' are complex and blurred, sometimes embraced and sometimes contested' (p. 14).

In addition, the notion of 'caringspaces' can be useful when exploring time-space practices of informal care (Bowlby, 2012). This includes practical tasks of caring as well as the emotions and individual positions of different people involved in caring across a variety of temporal and spatial contexts (Bowlby, 2012; Evans, 2012b). In particular, a 'caringscapes' perspective aims to examine the complex 'actualities and possibilities of the social patterning of time–space trajectories through a range of locales significant to caring' (McKie et al., 2002, p. 914). Evans (2012b) explores siblings' caringspaces to evaluate young people's daily practices and caring pathways across time and space. Bringing together emotional geographies and geographies of care, Evans' study investigated how young people discuss emotional geographies and tempo-realities of caring. She concluded that the 'competing rhythms of bodies, schooling, work and seasonal agricultural production can result in 'arrhythmia' and time scarcity, which has detrimental effects on young people's health, education, future employment prospects and mobility' (Evans, 2012b, p. 824).

Finally, Bowlby (2012) uses the term 'carescape' to signify 'the resource and service context shaping the 'caringscape terrain''; therefore, to discuss the 'carescape' of a local government area, a nation-state, or a particular organisation' (p. 2112). For example, a recent study in the UK elaborates on the concept of carescape by displaying the ways the 'organisation carescape', the care practices and policies of organisations, impact on the caringscapes of employees both within and outside the place of work (McKie et al, 2009, as cited in Bowlby, 2012). Bowlby (2012) concludes that exploring the origins and impacts of different carescapes could have the capacity to offer new understandings in regards to variations in care relations in societies and be a useful tool to create more critical evaluations of care in individuals' social engagements.

Geographies of care and family relations are complex and fluid. Scholars from different disciplines have for a long time been looking at care and only recently focused on the spatiality of care and family relations. The next section offers a more detailed account of children and young people's experience of caring roles in the UK and sub-Saharan Africa, locating young caregiving in both the Global North and South.

2.6 Children and Young People with Caring Responsibilities in UK and Africa

The earlier section presented the dominant notions of childhood and children's geographies. This section outlines how children and young people caring for family members in the UK and African setting are represented in the existing literature.

2.6.1 Exploring Young Caregiving in the UK

The term 'young carers' is used to describe children with caring responsibilities within the UK. The Department of Health offers the following definition for young carers:

> 'a child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person which would usually be taken by an adult. The term refers to children or young people under 18 years caring for adults (usually their parents) or occasionally siblings' (Walker, 1996).

In addition, Becker (2000), a leading scholar in this field, defines young carers as:

> '. . . children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.' (p. 378).

When considering caregiving children in the UK, the work of Aldridge and Becker (1993; 1997; 2003) relating to young people with caregiving responsibilities has had a significant influence on the Department of Health, social services and other third sector bodies in the UK. There is a range of publications and research projects for young carers in the UK focusing on exploring the effects caring has on children and young people (see Aldridge & Becker, 1993; 1997; 2003; Evans & Becker, 2009).

It has been argued that research about children with caring responsibilities in the UK has focused on discussing the negative aspect of caring (Olsen 1996). Some of these aspects include problems with their education (Dearden & Becker, 1998; Underdown, 2002), problems with their physical health (Becker et al., 1998; Doran, et al., 2003), poor mental health (Cree, 2003), restricted social life and emotional difficulties (Dearden & Becker, 1998). Analogous results have been recorded in the United States of America where there are about 1.4 million children with caring responsibilities (Shifren, 2009). This emphasis on the adverse impacts of young caregiving on young people might be the result of the fact that in western societies children are not expected or even encouraged to take on extensive or systematic caring responsibilities (Evans, 2014).

Conversely, a few reports in the UK (Becker, 2000) and USA (Gates & Lackey, 1998) have also identified positive outcomes of caregiving, such as increased self-worth, a sense of responsibility and maturity. It is claimed that the attention only to the negative results of young caregiving, has to an extent to do with the victimisation of this population of children (Aldridge & Becker, 2003; Skovdal et al., 2013).

According to the disability rights movement, the majority of studies on young caregiving position caregiving children as vulnerable victims and directly or indirectly criticise the adult for whom they care for and devalue their childrearing ability (Olsen, 1996). While the disability movement affirms that it is vital to underline young carers' rights and the negative circumstances of this role, they consider that just categorising young carers as a 'welfare category' will not eradicate caregiving by young people over what might be expected as acceptable (Morris, 1997; Olsen, 1996). It also disregards other aspects that impact on child welfare such as unemployment, poverty and social class (Morris, 1997; Olsen, 1996). They state that it is parents who first need to have their needs and rights met, and then they could help them acknowledge which of the tasks and responsibilities given to their children are inappropriate (Morris, 1997; Olsen, 1996). Keith and Morris's (1995) work with disabled mothers has also argued against the concept of 'young carers'. The parents interviewed stated that they do not acknowledge their children as 'carers' or as their 'parents'[11] and they blame the media for drawing unnecessary attention to their families and creating unhelpful stereotypes (Keith & Morris, 1995).

Considering such ideas, Olsen (1996), on behalf of the disability movement, challenges the assumed 'facts' about 'young carers', and the way those children and families are represented in research and the media. Olsen (1996) stresses that there are diverse experiences of caregiving, discussing that few of the children care for a parent while some are taking care of other family members, such as siblings or grandparents with a variety of caring responsibilities. Olsen (1996) finally questions what is a 'normal childhood' and argues about who has the role of the 'cared for' and the 'carer'. It has been claimed that care is usually reciprocal and mutual and that children and young people, as well as adult family members, can be both carers and ones cared for (Horwitz et al., 1996) (also see section 2.5 of this thesis).

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[11] This could also refer to the idea of 'parentification'. Broszormenyi-Nagy and Spark (1973, as cited in Earley & Cushway, 2002) define 'parentification' as the expectation from a child to adopt a parental role within the family which could include caregiving task, as well as 'gratification of parental figure's sexual, aggressive or dependent needs' (p. 165).

Furthermore, Evans (2011) in her research in Uganda and Tanzania uses the term ‘young people with caring responsibilities’ to refer to her participants, instead of the term ‘young carers’, as she claims that only a small number of young people see themselves as ‘carers’. Also, the term ‘carers’ was found to further stigmatise both children and adults with HIV. Additionally, Evans (2011) highlights that the term ‘young carers’ does not describe ‘the reciprocal, interdependent nature of caring relationships between young people and parents’ and thus ‘could potentially undermine the support needs of disabled parents’ (p. 356). Therefore, the term ‘young carers’ is not used in this thesis. This thesis agrees that this definition offers useful ways to conceptualise young caregiving but it is also closely related to Western notions of young caregiving.

Looking critically at the term ‘young carers’ and its applicability beyond the UK, Robson and colleagues (2006) state that

> ‘the validity of such a definition internationally and cross-culturally may be questionable but nonetheless it is used here in the belief that such a definition of young carers (not least in the absence of other culturally specific definitions) has at least some usefulness’ (p. 108).

Noticeably, the Malawi Government defines the presence of ‘children involved in household chores above the age-specific thresholds’ as child labour (NSO, 2014, p. 20). Nevertheless, this report does not offer any other details or examples of what the ‘age-specific thresholds’ are. The Department of Labour in the Republic of South Africa has disseminated a leaflet that provides guidelines for acceptable household chores by children. This leaflet indicates that it is common in many countries for children to help at home but when they spend extensive time on the household chores or carry too much responsibility for their age, then this help can become problematic. The leaflet then goes on by giving very specific examples on what it is considered appropriate and what not, for example, acceptable chores: cleaning the household, appropriate age: 7-11 years old (with supervision) and amount of time spent per week: 3 hours.

2.6.2 Exploring Young Caregiving in Sub-Saharan Africa

A number of academics have published remarkable work on young caregivers in sub-Saharan Africa. Foster and Williamson (2000) looked at the impact of HIV/AIDS on children and young people in sub-Saharan Africa and highlighted that research should investigate both positive and negative effects caring has on caregiving children as well as the ways in which schooling disruptions can be minimized. There is indeed limited literature on caregiving children and young people in Africa but existing work provides a clear account of the range of both negative and positive outcomes (see Bauman et al., 2006; Cluver, 2011; Evans & Becker, 2009; Martin, 2006; Robson, 2000; Robson & Ansell, 2000; Robson et al., 2006; Skovdal & Ogutu, 2012).

Pioneering work on young caregivers in Africa, Robson's research on young caregiving and the livelihood impacts of AIDS on youth in Zimbabwe, Tanzania, Lesotho and Malawi outlined young people’s circumstances, including negative and positive aspects of caring. Her work also provides an overview of what kind of tasks caregiving involves, how children become carers through investigating factors such as age, gender, stage of education, looking at decision- making within the family, sense of obligation, poverty and lack of support services (see Robson, 2000; 2002; 2004a; Robson & Ansell, 2000; Robson et al., 2006).

Robson’s (2000) research in Zimbabwe suggests that the caring responsibilities of children in developing countries are mostly invisible, and they have no institutional recognition or support. Young people with caregiving responsibilities might face disruption of education, isolation and loss of networks, difficulties with looking after ill family members and being responsible for the household, as well as experience trauma as a consequence of their caregiving roles, of loss and bereavement (Robson et al., 2006). Positive aspects of caregiving are also mentioned, for example, developing new skills, creating affectionate relations with the family members they take care of and becoming responsible and mature people (Robson, 2000; Robson et al., 2006). Notable, the emphasis is on the significance of the privilege young people feel for caring someone they love (Robson et al., 2006).

Looking at the geopolitical factors of caregiving, Robson (2004a) argues that children with caring responsibilities should be seen as child workers and their responsibilities should be recognised as forms of labour. Studies show that caregiving responsibilities can vary from farm work and domestic tasks to personal care such as feeding, toileting and bathing (Robson & Ansell, 2000). Even though there are cases of male caregiving, most frequently the burden of care for HIV/AIDS family members falls on the female relatives who in sub-Saharan Africa customarily are thought to be the principal caregivers (Kipp et al., 2007; Olenja, 1999). Kipp and colleagues (2007) looked at family caregiving in rural Uganda and focused on the female role in care and the negative aspect of caregiving as well as emphasising that children drop out school to bring income, and highlighted limitations of services and local authorities (Kipp et al., 2007).

Walker also provides extensive work on the socio-cultural context of AIDS in South Africa, the stigmatised nature of AIDS and the impact of the epidemic (and more latterly the provision of anti-retroviral therapy) on families and communities (see Gilbert & Walker, 2009; 2010; Walker et al., 2004; Walker, 2007). Skovdal (2010) focused on the coping mechanisms and peer support systems young carers in Kenya employ in order to deal with difficulties. Skovdal found that young people receive a lot of support from their friends while stating that empathy and understanding is the most important support they can get; and observed that that most of the young carers he spoke with have become very resilient (see Andreouli et al., 2013; Skovdal, 2010; 2011; Skovdal et al., 2009; 2013).

Evans has extensively researched young caregiving in Africa and in particular the situations of children caring for parents/relatives with HIV and for siblings in youth-headed households in Tanzania and Uganda (see Evans, 2005; 2010; 2011; 2012a; Evans & Becker, 2009; Evans & Thomas, 2009). Additionally, Evans and Becker (2009) researched the experiences of children and young people caring for parents with HIV/AIDS in both the UK and Tanzania. They looked at children's and young people's resilience and provided a useful framework on risk factors and problems children face (Evans & Becker, 2009). Issues of poverty, stigma, social isolation and poor emotional and physical health have been associated with caregiving by children and young people, but the significance of supportive social environments, strong friendships and understanding school settings are also highlighted (Evans & Becker, 2009).

Bauman and colleagues (2006) explored children caring for their ill parents with HIV/AIDS in Zimbabwe and New York and looked at the different roles and responsibilities children adopt. They were in particular interested in young people's psychological status (Bauman et al., 2006). The results presented the devastating effects of caring, focusing only on the negative aspects and as criticised reflected on mostly the western ideas of suffering (Skovdal & Daniel, 2012). A very interesting finding was that they discovered that 63% of Mutare children had high levels of depression but this was not correlated with the actual responsibilities and tasks children had (Bauman et al., 2006). Importantly, they also stated that the bond between parent and children could be an accurate predictor of children's mental wellbeing and that, children might, in fact, benefit emotionally from caring for their parent (Bauman et al., 2006).

Similarly, Martin's (2006) work in Zimbabwe highlights children's need for psychological and emotional support while stating that caring can have 'unbearable' effects on children and young people. The link between psychosocial distress and caregiving also takes precedence in the only study of children caring for parents with AIDS in China (Zhang et al., 2009). Furthermore, Mmari's (2011) findings suggest that young people with caregiving responsibilities in Tanzania experience 'extreme sadness and the lack of love and support in their lives' (p. 305).

Cluver's work on children affected by AIDS in South Africa concurs the foregoing and further reports the potentially negative effects of young caregiving (see Boyes & Cluver, 2013; Cluver et al., 2012). Cluver and colleagues conducted a four-year longitudinal study and the research findings indicated that both children who were caring for adults with AIDS and children who were AIDS-orphaned experience high levels of anxiety, depression and symptoms of posttraumatic stress (Cluver et al., 2012). A study with adolescents in high-poverty areas of urban and rural South Africa looking at the educational impact of AIDS-affected households distinguished three key themes; (i) low school attendance; (ii) frequent hunger when at school;

and (iii) concertation difficulties as they were worried about the sick person left at home (Cluver et al., 2011).

In African countries, it is common for orphans and vulnerable children to be taken care of by extended family (Foster & Williamson, 2000; Mmari, 2011). This nevertheless, it largely depends on relatives' economic situations and motivation (Mmari, 2011). Foster and Williamson (2000) state that 'extended families involve a large network of connections among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations' (p. 277). Further examining the social support offered to vulnerable children and to stress the agentic abilities of children, Skovdal and Ogutu (2012) explore how children and young people cope with adversity through peer social capital. Robson (2004b) also emphasises that 'it is important to remember in these processes and outcomes that children and young people are agents, not just victims' (p. 233).

To conclude, research to date offers valuable contributions to documenting children and young people's caring responsibilities and roles in parts of both the Global North and South. Scholars from different fields provide detailed accounts of those children's experiences, emotions and coping mechanisms. The research project reported in this thesis sets out to further enrich the knowledge of young caregiving in Africa by drawing together the theories discussed in this chapter and by offering children the opportunity to voice their emotional and caring experiences.

2.7 Conclusion

This chapter recognises that children and young people should be investigated 'in their own right', rather than as poor reproductions of the adult world (Holloway & Valentine, 2000a). This entails conceptualising children as human beings instead of human becomings (James et al., 1998). Such an approach embraced by the 'new' social studies of childhood sees children as 'socially constructed' and acknowledges the diversity and variety of children's experiences and childhoods (Holloway & Valentine, 2000a). Indeed, childhoods are not homogenous, and so they can only be fully understood through the consideration of variables such as gender, social class, culture, ethnicity, time and space (James & Prout, 1997).

Children's geographers have played a vital part in studying the meaning of place in childhood. Section 2.2 explored the contribution of children's geographies to childhood studies and highlighted its interdisciplinary nature. It highlighted contemporary research and existing debates in the field. Particular examination is presented of children's geographies' research focus initially on children's spatial cognition and later, the turn to more culturally constructed understandings of childhood.

The third section of this chapter (2.3) looked at global childhood and how children's experiences and lives are investigated by current studies. Research has shown that children experience life in different ways across different cultures and times. It is argued, however, that despite the differences between the Majority and Minority world, there are significant similarities that should be acknowledged. Globalisation has played an important role in interconnecting those two worlds.

The subsequent section (2.4) outlined the main discourses and focus of studies in emotional geographies. It investigates how examining individuals' emotions and relation to place are important in order to further understand children and young people's caring experiences. Geographies of care and family relations also are an integral part of the empirical focus of this research and therefore, the fifth section of this chapter (2.5) dealt with the existing theories and debates of this field.

Lastly, the final section (2.6) reviewed of contemporary research on children's and young people's experiences as carers in both the UK and sub-Saharan Africa. It can be concluded that despite the detailed and significant work conducted to date with children and young people who carry caring responsibilities, there is scope for further in-depth research to gather further information on how children with caring responsibilities in sub-Saharan Africa experience care and emotions in their everyday lives and how they construct their own lives and identities. This study is situated in the context of this complex and varied literature, specifically within the place of emotional geographies in caring relationships between children with caregiving roles and the relatives who are disabled or living with chronic illness.

Chapter 3. Methodology

'Children need allies.
For these allies, there remains to be solved the contradiction between the world from a child's viewpoint and the world they experience as adults'
(Matthews & Limb, 1999, p. 83)

3.1 Introduction

In this chapter is described the research design and methodology of this project. The preceding chapter discussed the theoretical approaches adopted, this chapter demonstrates how the suggested methodology allows the research aim and questions to be addressed fully and ethically, and also in a way that mirrors my theoretical positions. In line with theoretical approaches which highlight the agency of children, this study used child-focused methodologies, while encompassing children and young people of different age groups, gender, backgrounds and ethnicities. A qualitative multi-methods approach was employed as the most appropriate way to address the research questions concerning the construction of childhood for young caregivers in Malawi (as set out in Chapter 1, section 1.6).

Rather than using only one method, a combination of research methods provided greater empirical depth and allowed more angles into meanings of care and children to be investigated (Bryman, 2008). Contemporary research with children and young people often employs a variety of methods, in an attempt to capture the complexity and fluid nature of children and childhoods (Skovdal, 2011). Representing children and young people in sub-Saharan Africa can be very challenging and thus using a plethora of methods could more effectively capture children's complex dimensions (Henderson, 2015). Aspects and techniques of the following four methods were incorporated in the research undertaken for this thesis: (i) ethnographic observations, (ii) semi-structured and unstructured interviews, (iii) innovative visual methods and (iv) a focus group discussion to provide feedback and involve participants in dissemination.

The first section (3.2) of this chapter begins by describing the ontological and epistemological perspectives that have influenced the research position adopted. The succeeding section (3.3) pays special attention to the debates around conducting research with children and young people and argues the importance of active participation and listening to children. The following section presents an overview of all methods and existing debates (section 3.4). Next, the synopsis of the study design and data collection follows, alongside the summary of my fieldwork research in urban, semi-urban and rural areas within the districts of Blantyre in Malawi, which was conducted between 4th of September 2015 and 24th of April 2016 (section 3.5). This chapter also elucidates the ethical considerations encountered in conducting research with children and young people and the significance of the researcher's positionality and reflexivity (section 3.6). Finally, this chapter ends by examining the data analysis methods (section 3.7) and dissemination of the results (section 3.8).

3.2 Ontological[12] and Epistemological[13] Perspectives

Researchers who study the social world need to have a perspective from which they shape their analysis and its interpretation (Greig et al., 2013). This research study follows three distinctive ontological and epistemological approaches:

i) First, it is located within the interpretivist framework, which is based on the premise that there is no absolute and single reality and knowledge is produced based on people's perceptions and understandings of the social world. Hence, researchers should not only research what children are doing, but also explore the intentions and meanings of the activities they are performing (Greig & Taylor, 1999; Greig et al., 2013);

ii) Secondly, this research study is guided by constructivist ideologies, which acknowledge that 'the social world is constantly 'in the making' and therefore the emphasis is on understanding the production of that social world' (Elliott, 2005, p. 18) and thus, knowledge is 'symbolically and socially constructed' (Craig et al., 2013, p. 77). Adopting a

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[12] Ontology refers to 'a set of assumptions that underpin a theory or system of ideas – that which can be known' (Hoggart et al., 2002, p. 310).

[13] Epistemology is 'a conception of what constitutes valid knowledge (or a particular kind of knowledge, such as scientific knowledge)' (Hoggart et al., 2002, p. 308).

constructivist ideology implies that children are seen as social actors who construct their social identities and ways of living within their families and communities (Craig et al., 2013); and

iii) Thirdly, this study is influenced by feminist and critical geographies that challenge 'conventional' ways of producing knowledge by conducting research within 'white, Western, male, middle-class' values (Hoggart, et al., 2002, p. 4). This research adopts a critical approach in its aims to reflect the voices of a group of people that are highly underrepresented and do not often have the opportunity to raise their voices and express their needs. Furthermore, it is feminist research because it responds to the noticeable gap in contemporary research of children and young people in sub-Saharan Africa, specifically in relation to girls and their everyday lives (Henderson, 2015). The aim of this research is however to not only consider female voices (as a basic tenet of feminist research) but to also take into consideration boys' and young men's voices, particularly in relation to notions of care and caregiving responsibilities. In this way, my research aims to foster an analysis of interactive gender relations, acknowledging the centrality of masculinities within gendered power relations.

3.3 Researching with Children and Young People

Traditionally, children have been excluded from the research process, as adults were thought to be adequate key informants about children's lives, and hence, adults were approached by researchers to speak on behalf of children (Christensen & James, 2000). This approach was later questioned by perspectives which perceived children as 'possessing distinctive cognitive and social developmental characteristics with which researchers, must consider in their research design' (Christensen & James, 2000, p. 2). The introduction of the 'new' social studies of childhood perspective challenged dominant and traditional understandings of children as vulnerable, incompetent and 'becoming' who are inferior to adults (James et al, 1998). Indeed, there has been a noteworthy change in attitudes towards children that see them as the subjects and not as the objects of research (Christensen & James, 2000; Tisdall et al., 2009). Scholars are now focusing much more strongly on conducting research with and for children rather than about and on children (Clark & Moss, 2011; Tisdall et al., 2009).

Both sociology of childhood and human geography acknowledge children as active and competent beings in their own right (Christensen, 2004; Holloway & Valentine, 2000b; Matthews et al., 1998; Tisdall et al., 2009). Emphasis has increasingly been given to the socially constructed notion of childhood and particularly, to individual childhoods (Gallacher & Gallagher, 2008). It has been agreed that it is essential to recognise that childhoods are constructed in different ways, within different societies (Christensen & James, 2000). This is important to acknowledge because the way childhood is conceptualised influences the way researchers conduct research with children and young people (Thomson, 2007).

Researchers have adopted a variety of methods when conducting research with children (Punch, 2002a; Thomson, 2007). Children's age and development are often criteria upon which scholars design their research methods and techniques (Christensen & James, 2000). Others approach children as equally competent as adults and use the same techniques with children, as they would use with adults (Punch, 2002a). However, criticisms highlight that this approach neglects the power differences between children and adult researchers (Alderson & Morrow, 2011). In response to this, Punch (2002a) suggests that a multi-method approach (photography, drawing, diaries, etc.) not only challenges the limitations of adult-centred techniques, but also increases the chances to include children from different age groups and backgrounds in the research process.

To increase children's participation, O'Kane (2000) argues that participatory techniques are central when conducting research with children because children communicate their understandings and experience of the world in different ways to that of adults. It is suggested that participatory methods, in contrast to ethnographic methods, are less time consuming, 'less invasive and more transparent' (O'Kane, 2000, p. 130). She highlights that when developing participatory techniques, researchers need to pay attention to the setting, culture, language, children's ethnicity, ability and other considerations (O'Kane, 2000). A number of scholars suggest that participatory methods enable children to articulate their views and perspectives, rather than emphasising adult/researchers' perspectives about children's lives (Gallacher & Gallagher, 2008; Hadju et al., 2011; O'Kane, 2000).

A range of participatory research techniques have been used with children, including child-led photography (Evans & Becker, 2009), drawings (Punch, 2002b), mapping exercises, child-led tours, role play exercises and storytelling (Bartos, 2013; Clark & Moss, 2011), the use of visual prompts like dolls, puppets, photographs, pictures and others (Greene & Hill, 2005), responding to scenarios and vignettes (see Barter & Renold, 2000), diaries, worksheets, spider diagrams (Punch, 2002a) and others (see Bartos, 2013; Clark et al., 2003 for an overview). All of these participatory research techniques can be seen as engaging with the 'hundred languages of childhood' (Edwards et al., 2012).

A participatory approach, adopted in this research, is manifested through interactive techniques but is also characterised by an emancipatory epistemology and reflexive methodology. According to De Lissovoy (2015), "a genuinely emancipatory epistemology challenges the limits of power, which includes a confrontation with the limits of power's definition of knowledge itself" (p.136). And while issues of power and reflective approaches are discussed later in this chapter, multi-method techniques can enable children and young people to communicate their thoughts and experiences in a more effective way and that is the reason many researchers adopt more than one technique during data collection (Bartos, 2013; Greig & Taylor, 1999; Longhurst, 2003; O'Kane, 2000; Valentine, 2005). Looking specifically at research in the Global South, this kind of methodology has been popular in research with young carers in Nicaragua (Dahlblom et al., 2009), Kenya (Skovdal, 2011), Lesotho, Tanzania and Zimbabwe (Robson et al., 2006), South Africa (Cluver et al., 2011) and as well as Tanzania and the UK (Evans & Becker, 2009). Participatory methods not only offer a way to work with children using engaging and fun tools, but employing some of these techniques has also proven to be a way to empower the young participants (Mizen & Ofusu-Kusi, 2007; Rifkin & Pridmore, 2001; Wang et al., 1998).

3.4 Multi-Methods Approach

This research project employed a combination of the following methods: ethnography (including participant observation, innovative visual methods, fieldnotes and diaries); semi-structured and unstructured interviews; and a focus group discussion for dissemination purposes.

3.4.1 Ethnography

Ethnographic research is a qualitative research approach and has been widely adopted in social research, especially in anthropology (Hammersley & Atkinson, 2007). Ethnography encompasses a variety of meanings, and thus, there is not one single definition (Hammersley & Atkinson, 2007). A succinct description of the ethnographic processes is provided by Hammersley and Atkinson (2007) who state that: 'Ethnography usually involves the researcher participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts- in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry' (p. 4).

Studies of children and childhoods have been increasingly using ethnography, within a variety of sociocultural settings, underlining in this way the multidimensional nature of childhood (Anders, 2012; Clark et al., 2003; James, 2001; Jenks, 2000; Katz, 2004; Konstantoni, 2012; Yelland & Saltmarsh, 2013). Furthermore, as Yelland and Saltmarsh (2013) suggest: 'ethnographic studies generally culminate in rich detailed accounts that are the result of sustained time being spent with participants, learning what happens in their lives, asking questions and listening to what is said' (p. 5). Ethnographic research that is 'concerned with broadly defined cultures' is also known as 'macroethnography' (Polit & Beck, 2017, p. 468). Yet, it is not always possible or suitable to use traditional ethnographic approaches in social research. In this case, 'focused ethnography' or 'microethnography' has been developed as an alternative approach for conducting ethnography (Cruz & Higginbottom, 2013).

Focused ethnography explores ‘a distinct issue or shared experience in cultures or sub-cultures in specific settings’ in order to achieve a better insight of the experiences of specific aspects of communities and individuals (Cruz & Higginbottom, 2013, p. 36). Although it was not possible to conduct traditional, in-depth ethnography, I adopted a focused ethnographic approach and employed some ethnographic techniques. This way, I was able to investigate the nuances of the meanings of young caregiving and the emotional effects of caring for children and their families, as well as to explore the multiple layers of practices and meanings shaped by, and in turn shaping, their everyday lives.

3.4.2 Participant Observation

I used participant observation to record information relating to everyday young caregiving in urban and rural areas in Malawi. This data was obtained by recording children and young people’s caregiving practices and observations in researcher-completed diaries in relation to observing caregiving practices, where care was taking place; by recording children’s and family’s emotional responses to young caregiving; the family relations and dynamics within households with chronic illness and/or disability; and finally, by documenting formal and informal support offered to the families.

Observations, and especially participant observation along with informal conversations, are important methods of ethnographic research. Participant observation ‘involves spending time being, living or working with people or communities in order to understand them’ (Laurier, 2003, p. 133). Indeed, a number of researchers have effectively used participant observation and have generated fascinating accounts of children’s everyday lives (Woods, 2013). Particularly when researching emotional geographies, Hargreaves (2001) emphasises the importance of thoroughly examining the emotional traits and relations with others, especially through observations, when emotions are genuinely exhibited, and not purely reflected on, as in an interview discussion.

Laurier (2003) states that the best way to conduct participant observation is to be actively involved and be a part of what is happening. Varying degrees of participation can take place such as participant observation, semi-participant observation, non-participant observation and so on (Emond, 2005; James, 2001). Indeed, during my fieldwork, I did not only observe children and young people and their families but also talked to them and asked them to participate in a variety of child-led activities.

Interviews in ethnography most often take the 'form of naturalistic conversations', rather than 'highly structured interview schedules' (Mukherji & Albon, 2010, p. 74). During my visits at the houses of young caregivers to observe their everyday lives, on many occasions unplanned and natural conversations took place with all the adults and children in the families providing a number of unexpected but significant findings for the research data. Valentine (2005) argues, when conducting research within a household it is important to talk to all the members of the family at the same time. Interviewing families together provides richer, more spontaneous and detailed accounts than those obtained from talking to family members individually and, hence, is an effective way to obtain a clearer understanding of the collective household life (Valentine, 2005).

3.4.3 Innovative Visual Methods

Observations are often accompanied by other methods like interviews, participatory activities and documents. Especially when working with vulnerable people, like children with caring responsibilities, participatory, 'hands-on' activities 'enable people to generate information and share knowledge on their own terms using their own symbols, language or art forms' (Kindon et al., 2010, p. 17). James (2001) argues that such techniques, particularly emphasising 'task-centred activities', are particularly important under the light of reflexivity. Such techniques are considered 'to draw children in as research participants, thereby furthering the research dialogue' and also, they can 'encourage childhood researchers to be reflexive about the data and how they will reproduce it' (James, 2001, p. 253).

In the research described in this thesis photography, mapping, drawings, diaries, essays and games were used as innovative visual methods to investigate children's experiences of caring and their emotional worlds. Child-led and visual activities have been effectively used by many childhood researchers, to obtain rich and varied data (Christensen & James, 2000; Konstantoni, 2012). These techniques, such as drawing care maps, offer children alternative ways of expressing and articulating their experiences and understandings of the social world (Christensen & James, 2000; Evans & Becker, 2009).

Mapping and drawing exercises offer the opportunity for children to explore and communicate their sense of home and place. These activities welcome children of different age groups and literacy levels to participate and have a say (Evans & Becker, 2009). Drawing activities are widely used in research with children (Punch, 2002a). Drawing is seen as a creative method for children to express their understandings and in most cases, children explain the meaning of their drawings or make stories (Christensen & James, 2000; James et al, 1998). I used age-appropriate activities and when necessary, further adapted those activities by taking into consideration children's literacy backgrounds. To build up relationships and actively interact with the children, on many occasions, I asked the children to teach me how to play their favourite games, which I then used to engage them further in the research.

Emotional and physical understandings of home and space are experienced differently by children and young people. The ways children draw and map their own understanding of space offer an awareness of how they sense it. There is a long history of geographers and others using mapping activities in research with children, in various ways. In a recent example, Christou and Spyrou (2012) used mapping in ways that illustrated how children are able to construct their own sense of place. Thus, during a mapping exercise, one of the boys showed how he created a sense of place by adding his own experiences and images on his map instead of presenting a typical schoolbooks map (Christou & Spyrou, 2012). In the research for this thesis mapping activities were a rich opportunity to walk around with the children and young people, and I was able to see part of their worlds from their perspective.

Another technique employed was life stories activities which I obtained through verbal and/or visual methods or through written accounts (diaries) from those young people able and/or interested to do so. Life stories are stories constructed subjectively and often flooded by emotions and feelings that illuminate specific angles of human experience by producing and re-producing them and reflection (Christou, 2011). As Riessman (2000) advocates storytelling 'is a relational activity that gathers others to listen and empathize' (p. 2). The author adds that storytelling 'is a collaborative practice, and assumes tellers and listeners/questioners interact in particular cultural milieu-historical contexts essential to interpretation' (p. 2-3).

Furthermore, to support children to articulate and express their thoughts and feelings, I used photography. A number of studies have used photography as a tool to elicit sensitive and in-depth data. For example, Thomas' (2007) research indicates that living with chronic and stigmatised illness has an impact on shaping people's identities and well-being. She argues that when employed in combination with other qualitative methods, photo diaries and solicited text can produce thorough and sensitive information on people's emotional experiences of HIV/AIDS (Thomas, 2007). Within the context of young caregiving for parents with mental health illness, Aldridge and Sharpe (2007) found that visual data offered them a deep insight in children's responsibilities, relationships and resilience. They also noticed that children not only enjoyed being involved in the study, but also revealed 'a high level of competency in understanding, directing and collecting the visual data' (Aldridge & Sharpe, 2007, p. 5).

I offered one disposal camera to each of the children and young people who participated in the research asking them to record in photographs their daily routines. I specifically asked participants to capture things that make them happy, what they would like to change and how they take care of their family member who has a chronic illness or disability. I also explained that they could use the camera to take photographs of other situations and/or people and that there would be no consequences if they would not to follow the instructions given above. I then developed the films and printed off two copies of all photographs taken by the participants. I gave the participants one of the copy to keep and after obtaining their consent, I used the second copies for my project.

This section outlined the innovative visual methods employed during this research project and explained the reasons these methods were chosen. The next section explores the use of fieldnotes and research diaries as another method to collect data and which also helps to reflect on it.

3.4.4 Fieldnotes and Research Diaries

Both my research assistant and I kept fieldnotes and diaries throughout my fieldwork. We used one notebook for each family on which we wrote fieldnotes and observations during our visits to the families. When returning home, my research assistant and I used the same notebooks as a reflective diary. During fieldwork, my female research assistant, who could understand and speak Chichewa, was also able to record informal conversations or observations that I was not able to understand due to language constraints. Laurier (2003) describes fieldnotes as being 'badly written, dull and cryptic', which no one should or could read (p. 138). However, fieldnotes are written accounts of the researcher's observations and thoughts that will be most useful after the fieldwork in order to recall what has been observed (Laurier, 2003). Brockington and Sullivan (2003) state that 'being a good diarist is not easy' (p. 58). The note taking needs to be rigorous and to continuously examine ideas and impressions (Brockington & Sullivan, 2003). Holmes (1998) suggests that researchers should include emotional, personal and social factors that might affect any stage of the fieldwork in their written accounts.

Fieldnotes and diaries can be written in such a way that would help the researcher to relive the moments and feelings experienced. This is the reason both the researcher and the research assistant also kept a reflexive diary for each family which was written after leaving the field. As suggested by Connolly (2008), there is a need to be critical and reflexive. Connolly, drawing on Bourdieu (1990, as cited in Connolly 2008), advised that it is important for researchers to take 'two steps back' from the research process'; primarily the traditional process, which is adopted by researchers who aim to meritoriously understand what is transpiring, and secondly, step 'back from themselves in order to understand how they are as much a part of and contribute to the unfolding social milieu as everyone else' (p. 174). Indeed, the fieldnotes and diaries were an important source of information to use not only data collection, but also for reflections during fieldwork and later, during data analysis.

This section briefly looked at the important role fieldnotes and diaries had during different stages of the research project. The following section investigates semi-structured and unstructured interviews as another research method employed for this study.

3.4.5 Semi-structured and Unstructured Interviews

It has been argued that interviews are central to social scientists and human geographers (Arksey & Knight, 1999; Winchester, 2005). To adequately answer my research questions, I used unstructured and semi-structured interviews with children and young people, family members and professionals who engage with caregiving children and their families. Interviews offer the opportunity to create rapport, allowing discussions on sensitive topics as the interviewee is able to talk about their thoughts and experiences in their own words (Valentine, 2005). Complex matters can consequently emerge and be explored within deeper levels of meaning and understanding (Bryman, 2008; Hoggart et al., 2002). Unlike surveys and questionnaires, interviews are not meant to be representative but aim to in-depth understand people's experiences and attitudes and emphasise the meanings individuals attribute to their social lives (Dunn, 2005; Valentine, 2005).

With regard to the degree of structuring interviews, there are three types of interviews: unstructured, semi-structured and structured interviews (Fontana & Frey, 2005). Longhurst (2003) explains that during semi-structured interviews 'although the interviewer prepares a list of predetermined questions, semi-structured interviews unfold in a conversational manner offering participants the chance to explore issues they feel are important' (p. 117). Semi-structured interviews are considered a sensitive method as they allow the interviewees to articulate their own detailed accounts in their own words (Dunn, 2005). This results in a two-way process of reflection and learning rather than a simple data extraction exercise (Dunn, 2005). The data obtained through these conversations is detailed, multi-layered and rich as the participants can answer the questions thoroughly and explain complex and contradictory issues (Hoggart et al., 2002; Valentine, 2005).

Zhang and Wildemuth (2009) explain that during an unstructured interview the researcher does not have a specific hypothesis or questionnaire, but rather aims to generate a discussion directed by the interviewee's narration. They further clarify that 'the intention of an unstructured interview is to expose the researcher to unanticipated themes and to help him or her to develop a better understanding of the interviewees' social reality from the interviewees' perspectives' (p. 696). For this reason, during my fieldwork, I decided to use unstructured interviews to discuss the children's photograph activities and diaries. My main aim during those interviews was to understand children's experiences of young caregiving and give the participants the opportunity to lead the conversation to what they considered important.

When conducting interviews, it is important to pay attention to subjectivity and power relations. As Hoggart and colleagues (2002) claim, 'interviews are not neutral procedures; they are social interactions replete with power relations' (p. 212). Researchers need to recognise their positionality and be constantly reflective when conducting interviews since their own identity and conduct will shape interactions and subsequent interview data (Valentine, 2005). Those who do not value qualitative methods often argue that interviews are not able to offer an objective view of the issues explored due to the interviewers' bias (Valentine, 2005). Others in opposition to such argument, however, state that when it comes to social research there is no such a thing as 'objectivity' (Valentine, 2005). More issues on positionality and subjectivity are discussed in the next section considering ethical considerations of the research.

3.5 Ethical Considerations

Undertaking social research means that society will be influenced by participating in it (Dowling, 2005). By having to answer questions and be part of research activities, people's everyday lives are altered (Brockington & Sullivan, 2003; Dowling, 2005). Especially, when researching with children and young people in different cultural contexts, it is vital to consider the various and often complex ethical issues that might arise and be able to negotiate ethical interactions in the field (Valentine, 2005). This is why considering and discussing ethics, issues of positionality and power relationships are unquestionably essential before conducting research; as well as during fieldwork and after the research completed.

3.5.1 Ethics of Research with Children and Young People

When conducting research with children and young people, there are a number of ethical matters that the researcher should consider before embarking to carry out his/her fieldwork research (Alderson & Morrow, 2011). The first matter researchers need to address is to consider the harm their research project could produce and additionally think about how the research can benefit the children (Alderson, 2004; Alderson & Morrow, 2011; Gallagher, 2009).

Although the research I conducted did not cause or constitute any risk of harm, throughout my fieldwork I was careful not cause any kind of emotional discomfort or any kind of stress to the participants. This is because while conducting interviews a subject or a question could instigate distress and upset the participant (Alderson & Morrow, 2011; Hennessy & Heary, 2005). For example, while conducting interviews with young people in Zimbabwe, Robson (2001) found that some of her participants became very distressed as they were recently bereaved. As a result, most of them were unable to continue with the interview and asked to stop, highlighting that in time of distress young people are able to demonstrate agency and withdraw their consent (Robson, 2001). Learning from these experiences, I deliberately did not work with bereaved children who had lost a close relative in the previous 6 months. To accomplish this, I discretely asked the advice of the stakeholders I was working with to recruit participants.

Nevertheless, it is not always possible 'to avoid tears' and distress when researching with children and young people (Robson, 2001). In the case where participants would become distressed, as a qualified social worker, I am trained to support the participants if they wished to talk about any issues that come up during our conversations but this did not occur. Participants were also clearly informed that if they felt uncomfortable, they only needed to let me know and we would stop the discussion immediately. Moreover, participants' recruitment was voluntary and all participants were told and continuously reminded that they could withdraw from the research at any stage, without any repercussions or negative consequences.

3.5.2 Power, Positionality and Reflexivity

Conducting qualitative research involves social interactions between the researcher and one or more participants which are influenced by societal norms, structures of power and individuals' expectations (Dowling, 2005). Feminist social science perspectives regard researchers as active participants throughout the whole research process (Hertz, 1997). Especially when conducting research in different cultural contexts and, in particular, in less developed countries, a heightened sensitivity to the complex power relations and to the local codes of behaviour is required (Howard, 1997; Valentine, 2005). Power relations in the research process need to be taken into account especially when conducting research with children and young people (Robinson & Kellett, 2004). Power in the research process can be described as a person's ability to oppress or influence another individual through communication (Robinson & Kellett, 2004). In order to balance this power usually vested heavily in adult researchers who are older and frequently have authority over children, a researcher should address children and young people as social actors and actively include them in the process (Robinson & Kellett, 2004).

There are a few ways that power can interfere with the conduct of research, including processes to obtain people's stories and interpret them (Dowling, 2005). When researching with children and young people, an adult researcher is in a position of more power than the participants (Skelton, 2001). Dowling (2005) identifies two ways to deal with power issues. The first one is to employ participatory methods and involve participants in the research process as much as possible and secondly, to continuously critically reflect on the means used to obtain data throughout the research (Dowling, 2005). Hertz (1997) suggests that through reflexivity, researchers can identify how their own experiences and interests can affect their research at all stages; 'from the questions they ask to those they ignore, from who they study to whom they ignore, from problem formation to analysis, representation and writing, in order to produce less distorted accounts of the social world' (p. viii). On the other hand, Brockington and Sullivan (2003) prompt researchers to be careful of 'extreme' reflexivity to avoid turning fieldwork in 'individual psychoanalysis'.

Many authors highlight the marginal role that children have in society in relation to adults, suggesting that adult researchers in many cases will have control over children, or that children are used to having adults control their lives in various spheres (Mayall, 2000; Punch, 2002a). The child may thus do or say things just because of the presence of an adult, neglecting his/her own feelings (Mayall, 2000). However, other authors claim that power relations are fluid and more complex. Christensen (2004) argues that 'in the process of research, power moves between different actors and different social positions, it is produced and negotiated in the social interactions of child to adult, child to child and adult to adult in the local setting of the research' (p. 175).

Connolly (2008) states that in this sense, children are active in 'resisting and challenging the relationships created between themselves and the (adult) researcher' (p. 175). But also, that power is 'played out around the subject positions created through wider discourses on race, gender and childhood' (Connolly, 2008, p. 175). Research with young children can thus be described as dynamic, context specific and contested (Connolly, 2008). Conversation and expressing views, listening and respecting are often useful ways to respond to power relations and conflicts.

Moving beyond power issues, when using qualitative methods, it is necessary for researchers to draw on their own subjectivity and even bias by outlining their personal backgrounds, their relationship to the research and its anticipated audience (Winchester, 2005). Valentine (2005) suggests that when planning to conduct interviews and thinking who to talk to and what to say, researchers should first think about who they are and how their own identity might shape their interactions. Critical reflexivity can deal with issues of positionality and subjectivity (Dowling, 2005). Even though researchers cannot be completely independent of their project, being aware of the nature of their involvement and the impact this might have on the social relations is useful to identify the ways this might impact on the research and the participants (Dowling, 2005).

3.5.3 Informed Consent

One of the main issues in research ethics is the participants' consent. Alderson and Morrow (2011) highlight that 'respect for people's consent or refusal helps to prevent harm and abuse' (p. 101). Participants need to be clearly informed and the researcher should ensure that participants comprehend the aim and description of the research project, before they can give their consent (Gallagher, 2009). It is generally agreed that when conducting social research that involves people, informed consent should be obtained during the first stages of the research (Frankfort-Nachmias & Nachmias, 2008). Informed consent includes informing participants about the research project and obtaining their consent to be a part of it, but also includes information of all risks involved and their rights (Frankfort-Nachmias & Nachmias, 2008). It should derive from both legal and ethical considerations and cultural values (Frankfort-Nachmias & Nachmias, 2008).

Considering power issues further, Howard (1997) suggests that 'white Anglophones' are considered to be more powerful and superior, and as a result, individuals feel that they have to cooperate. It was, therefore, important to be clear from the early stages that people were not obliged to participate and if they did not want to and that they can change their mind at any point of the research process (Valentine, 2005). To accomplish this, I ensured to obtain ongoing consent from all participants, especially by children and young people at the beginning of every visit and activity. I did this by asking them to verbally review their written consent at the beginning of each home visit. I also used prompts with the children and young people who participated, as explained in the next paragraph.

When research involves minors, permission should be obtained from parents or legal guardians or any of their legally authorised representatives. I requested all children, their parents or guardians, adults and professionals involved in the study to sign a consent form written in both English and Chichewa (see Appendices 1-13) and I ensured to the best of my ability that the participants comprehended the aim of my research, what would happen and how and the role of the consent forms ensuring that they knew that these were not legal documents and they could change their mind at any stage. While I consider children to be sufficiently competent to provide their own consent, obtaining consent from parents or guardians for participants below the age of 18 is commonly considered to be good practice. All children and young people involved in the research project were offered an information sheet and asked to sign a consent form (suitable according to their age) that explained the purpose of the study and their role if choosing to participate in the project (Appendices 1-5). This consent form specifically for children complemented the information sheet and consent form addressed to their parents or guardians (Appendices 6-9). A third consent form addressed to the children and young people who agreed to take part in the photography activity was given in order to inform their understanding of the ethical implications of the activity and asking them to give me the right to use their photographs (Appendices 10 & 11). Also, an information sheet and consent form were given to professionals who agreed to participate in the study (Appendices 12 & 13). I provided participants with cards with my contact details, in case they had any questions to ask or if they would change their minds about participating (Appendix 14). Finally, in order to support ongoing consent procedures, signs of happy and sad faces, a stop card and a question mark were created and used with the children and young people during fieldwork observations, interviews and activities (Appendix 15) so they could easily indicate if they wanted to pause or stop the activity.

3.5.4 Anonymity and Confidentiality

It is considered fundamental that researchers inform and ensure the participants that the information obtained is kept confidential. Anonymity and confidentiality are important because they can protect participants and their communities from harm or potential negative associations that might arise by disseminating the research data and results (Banks & Scheyvens, 2014). Nonetheless, confidentiality and privacy might be a concern and quite challenging to ensure (Alderson, 2004; Alderson & Morrow, 2011; Banks & Scheyvens, 2014). During fieldwork, I explained to all the participants that they should only disclose information with which they felt comfortable and that what they would share is confidential. Nevertheless, I also clarified that there are circumstances in which the researchers might have to break confidentiality, such as if there is concern of harm or abuse. It was important to inform the participants about the reasons I would break confidentiality from the early stages of the research (Alderson, 2004; Alderson & Morrow, 2011).

I took all precautionary measures to make sure that sensitive and personal data would not be accidentally disclosed in any way and that information was gathered in a manner that did not invade the participants' privacy. I ensured confidentiality by using pseudonyms (all participants were given the choice to select their own pseudonym) to protect the identity of the communities and the participants. Researchers ensure anonymity by separating people's names and individual features from the data they provide and camouflaging identifying characteristics, such as locations and this is also why the exact locations of the participants' homes are not given on this thesis (Dowling, 2005; Frankfort-Nachmias & Nachmias, 2008).

Another way that confidentiality could be breached was during the photography activity. The public nature of photographs means that it can be a challenge to completely disguise the identity of the participants or the setting (Fang & Ellwein, 1990). I thus explained to all children, young people and their families that all faces on the photographs used in this thesis, presentations and other outputs would be blurred to ensure their right to privacy. I also discussed with the children and young people that when using the camera, before taking photographs of other people, to try and ask their permission. Most of the participants were happy to participate in this activity, except for one mother who thought I was going to use those photographs in the UK to make people give me money. To address this, I had to clearly explain how I was going to use the photographs for research purposes and also to build trusting relationships.

Finally, in line with the theoretical background and approaches of this project, it was ensured that all research assistants and I addressed all the children and young people who participated in this study as competent. This way was an effort to ensure that some of the power inequality was circumvented and that I used some of my power in a positive way by representing children and young people as active agents (Skovdal, 2009).

3.5.5 Validity and Generalisability

The concepts of reliability (whether the results of a study are repeatable) and validity ('a concern with the integrity of the conclusions that are generated from a piece of research') (Bryman, 2008, p. 545) have been questioned in qualitative research, as both concepts are mainly concerned with measurement. Some have expressed the need to replace the above with terms such as trustworthiness and authenticity, when used in qualitative research (see Bryman, 2008, p. 272-278).

In terms of reliability, a clear and descriptive account of the research process is provided in this thesis. In relation to validity, these chapters make clear the research process and are explicit about my theoretical background and value system. In this thesis, the use of various forms of evidence, (which include inter alia, quotations from interviews, children's artwork, photographs and field diary note); as well as being transparent about the processes of data analysis in these chapters provide validation and confirmation for the both the authenticity and legitimacy of the research and its findings. Indeed, a key element for the standards of evidence and quality in qualitative inquiry is the systematic and careful documentation of all procedures which provides a record for a researcher's ongoing contemplation as well as for peer review (Freeman et al., 2007). This documentation of procedure is essential especially for research projects using innovative methodologies and is essential to validate their work convincingly (Freeman et al., 2007).

Also, triangulation, defined as, 'the use of more than one method or source of data in the study of a social phenomenon so that findings may be cross-checked' (Bryman, 2008, p. 545), has been applied through the adoption of a multi-method approach (Greene & Hill, 2005). However, this should not imply that there is 'a reality to which one can come closer by combining multiple perspectives' (Greene & Hill, 2005, p. 16). Triangulation has also received its share of criticism, as it implies that there is some kind of 'truth'. Some also argue that these techniques are not really a form of validating data, but means that allow for greater reflexive moments (Davis, 2000).

Connolly (2008) claims that there is:

> 'no unitary, authentic account of children's lives to be found, only a diverse range of accounts and that children as competent social actors —will approach and respond to particular social settings in differing ways …(and) it is… meaningless to attempt to identify which of these represents that child's 'true' and 'authentic' voice. In a sense, they are all equally authentic' (p. 184).

Being 'truthful' and providing different voices at the same time is an important aspect of providing 'valid' representations (Davis, 2000).

In addition, another limitation of qualitative research methods is in relation to generalising the results to other contexts and populations (Stewart-Withers et al., 2014). Because of the context-specific research design and the usually smaller numbers of participants, it is often difficult to generalise the results of qualitative studies such as the research recounted in this thesis or draw general conclusions (Stewart-Withers et al., 2014). Nevertheless, Flyvbjerg (2001) argues that producing context-free and generalised research findings should not always be the main aim, but that researchers should follow their 'judgment' to determine whether the results of a specific project could be applied to a different situation and thus be generalised. This approach depends on the researcher's experience and interpretative skills and relies on the belief that by producing a thorough understanding of a specific social phenomenon, a social scientist can develop the expertise and skills to deal with another similar phenomenon in a different context (Flyvbjerg, 2001). Qualitative research is not generalisable but it is reflective of other minority contexts and thus, transferable.

Section 3.5 discussed the ethical considerations this study encountered and how these were addressed. The next section outlines the study design and data collection of the research project presented in this thesis.

3.6 Study Design and Data Collection

3.6.1 Fieldwork Summary

When conducting research in a developing country, already made plans might need to change, thus researchers need to be flexible (Evans, et al., 1997). It is advisable, however, to start planning the fieldwork early and start corresponding with local authorities and institutions as communications might be slow and at other times, difficult (Evans, et al., 1997). I began my fieldwork preparation in December 2014 by getting in contact with stakeholders and relevant authorities. I acquired an academic affiliation with the Catholic University of Malawi at the end of April 2015 (Appendix 16) and then obtained ethical approval from the Department of Geography, Environment and Earth Sciences of the University of Hull (Appendix 17). I then applied for research clearance at the National Commission for Science and Technology in Malawi which I gained in July 2015 (Appendix 18). I, lastly, completed my risk assessment forms and other paperwork (travel insurance, vaccinations, visa, DBS check, etc.) required from the department and attended a first aid training course.

Fieldwork in Malawi was undertaken for seven months, from September 2015 to March 2016. The data collection in Malawi was carried out in both urban and rural areas of Blantyre. Blantyre is the second largest city of Malawi, which provides a sample of both rural and urban areas of the country. When I first arrived, I worked part-time as an intern at Joshua Orphan and Community Care Malawi[14], an NGO that supports vulnerable and orphan children in Blantyre. My role was mostly administrative and I also drafted a child protection policy for the organisation. Joshua helped me with advice on how to best approach recruitment of research participants and on cultural processes, for example, it was recommended to inform the Chiefs[15] of the area I would be working at. Permission was sought from appropriate local leaders (e.g. traditional authority and village heads) before

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[14] Joshua is an organisation that runs programmes of education, health, feeding, water and income generating projects to support HIV/AIDS orphans, vulnerable children and their families in rural areas in Blantyre, Malawi (http://joshuainmalawi.org.uk)

[15] Chiefs are local traditional leaders and usually people of power who are involved in decision-making that affect their areas. How one becomes Chief depends on the local traditions but most commonly the 'title' stays within a family.

starting working with the families. Before commencing with data collection, I employed and trained my research assistant on my research project, aim and methods. We also visited the local Police and government Social Welfare Office in order to introduce ourselves as researchers in Blantyre district working with vulnerable children and families.

3.6.2 Accessing and Recruiting Participants

The intention was to recruit children and young people who were carrying out significant caring tasks and assuming a level of responsibility which would usually be taken by an adult for one or more family members with chronic illness and/or disability. Responding to McNamee and Seymour's (2012) claim that 'there is a prevalence of 10–12 year olds in research on childhood' (p. 1), I intended to include (i) children and young people aged 0-18 years with caring responsibilities for family members with chronic illness or disability who had more caring responsibilities than expected of children their age or responsibilities that would normally be expected to be undertaken by adults; (ii) family members with chronic illness or adults significantly involved in the children's lives; (iii) professionals and key community members who engage with caregiving children. I was planning to use snowball or chain sampling to recruit participants by using a local NGO as my main gatekeeper. Snowball or chain sampling 'identifies cases of interest from people who know other people with relevant cases' (Bradshaw & Stratford, 2005, p. 72).

The plan was that the local organisation would assist me in identifying families to recruit. However, finding and recruiting participants proved to be a challenging task mainly due to my cultural expectations. There were two main problems in identifying families to recruit. First of all, stakeholders and professionals were confused with what exact kind of families were being sought and it took a while for them to understand and moreover, for me to figure out how much information and what kind of information I should give them regarding my research to help them understand. Furthermore, for most people I talked to, a child was considered anyone who was not married and lived with their parents at her/his family house, even if he/she was 25 years old. After clarifying that I was looking for children up to 18 years old, I was directed at first to families with children with disabilities.

The second main issue was that Malawi does not generally have official records of people, people may not have formal identity documents showing their age and there are few official records of any kind. Also, there are often no street names, house numbers or maps for someone to find their way around villages and communities. This makes it very difficult to identify people, especially when looking for people living under very specific circumstances. It was through word of mouth, through meeting a lot of strangers, often without knowing their names or connection to the organisations I was working with that suitable participants were found.

Qualitative research is different from quantitative in terms of sample size and numbers. When conducting quantitative research, it is important to have a representative number of participants, but things are different when it comes to qualitative research (Bradshaw & Stratford, 2005). With social research, researchers focus on people's experiences and meanings in specific contexts, so numbers, in this case, will not be much of a help (Bradshaw & Stratford, 2005). It is, therefore, up to the researcher to justify how many participants could provide in-depth information to answer their research questions (Bradshaw & Stratford, 2005). Taking into consideration the timeframe, research methods employed and budgeting, it was decided to work with 10 families in which there were children with caregiving roles from Blantyre urban and rural districts.

All the families were recruited by three different local NGOs which work with vulnerable children and families. In total research was conducted with 12 children and young people with caring responsibilities because two of the families had two children with caregiving responsibilities each (see Table 2 & Appendix 19 for participants' details)[16]. There were nine female and three male participants with caregiving responsibilities - the youngest participant being 10 years old and the oldest 19 years old. Two out of the three male participants cared for female relatives and one of those two was responsible for the care of two female family members living with disability and illness. The two younger female participants

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[16] All names presented in this report are pseudonyms.

cared for one older female relative. Three of the participants cared for their mother, six for a grandparent, one for her sister and one for her aunt. Furthermore, three participants cared for family members with HIV/AIDS, two participants cared for relatives with other chronic illness, five participants took care of relatives with disabilities and one participant takes care of a relative with mental health problems. In total, ten households participated in this research project. Four households consisted of nuclear families, which means young caregivers lived with their mother, father and siblings. Three households consisted of children and young people with caregiving responsibilities, siblings and grandparents. And lastly, three young participants lived in different households to where the care-receiver lived but were close enough so they could provide care as needed.

	Name	Age	Gender	Attending school[1]	Education Level[2]	Location	Caring For	Age	Relationship	Disability/Illness	No of Visits
Participants (children and young people)	1.Hannah	19	F	Dropped out	Standard 7	Rural	Memory	35	Mother	HIV	11
	2.Louise	12	F	F/T	Standard 5	Semi-urban	Rute	63	Grandmother	Blindness	13
	3.Eveline	11	F	F/T	Standard 5						
	4.George	17	M	Dropped out	Standard 8	Rural	Esnat	41	Mother	HIV	9
	5.Rejoice	17	F	P/T	Form 2	Rural	Christina	52	Mother	Chronic Skin Condition	10
	6.Andrew	19	M	P/T	College (Business Management)	Urban	Nessie Aisha	90 105	Grandmother Grandmother	Mobility problems Heart problem	10
	7.Chimwemwe	17	F	Dropped out	Form 2	Rural	Helen	95	Grandmother	Heart problem	11
	8.Chifunilo	10	F	F/T	Standard 4						
	9.Matias	16	M	P/T	Form 2	Semi-urban	Masamba	82	Grandfather	Mobility problems	8
	10.Samantha	17	F	Dropped out	Form 2	Urban	Clara	85	Grandmother	Mobility problems	8
	11.Rosemary	18	F	Dropped out	Form 3	Urban	Mary	35	Sister	Mental Health Problems	10
	12. Daisy	13	F	F/T	Standard 7	Semi-	Elesi	51	Maternal Aunt	HIV	7

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[1] School attendance depends on various reasons, such as ability to pay school fees, caring responsibilities, pregnancy, etc.

[2] In Malawi primary school education lasts eight years and is referred to as Standard 1 to Standard 8. Secondary school education lasts four years and is referred to as Form 1 to Form 2.

Table 2: List of participants

Furthermore, ten professionals were interviewed from organisations and services which support vulnerable and/or orphan children and families (see Appendix 20 for professionals' details)[17]. Accessing professional participants was much easier. Some were encountered while recruiting families. I contacted them by going to their organisation, introducing myself and asking to speak to someone about my research. Table 3 below presents the list of the organisations and services at which the participants of this study worked when they were interviewed. In order to ensure the participants' anonymity and confidentiality, their pseudonyms will not be linked to this list.

Organisation/Service
Social Welfare Office - Governmental Service
Malawi Council for the Handicapped (MACOHA) – Government Service
One Stop Centre (for abused children and adults) - Government Service
Federation of Disability Organisation in Malawi (FEDOMA)[18]
Nancholi Youth Organisation (NGO)[19]
The Samaritan Trust (for street children) (NGO)[20]
My Girl Project (NGO)
Malawian Girls (children's home) (NGO)
Joshua Orphan and Community Care (NGO)
Step Kids Awareness (organisation for street children) - (STEKA) (NGO)

Table 3: List of NGOs & services participated in this study

Finally, one focus group discussion was conducted towards the end of fieldwork with the young people from the participating families. The aim of the focus group discussion was to give the young people feedback on what was learnt from them and also to ask them ideas on how to disseminate the information gathered.

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17 Pseudonyms are used for all professionals participating and their organisations are not named to ensure confidentiality and anonymity.

18 http://www.fedomamalawi.org

19 https://nayoinmalawi.wordpress.com/home/

20 http://www.samaritantrust.org

3.6.3 Working with Families & Professionals

As detailed above, this research was undertaken with 10 families, 12 children and young people with caregiving responsibilities and 11 adults with disability and/or chronic illness.

In total 97 research visits to the families were undertaken. The first visit was usually short with the aim of introducing the researcher, research assistant and the research. During the first visit, information was gathered about the family and questions answered, if any. Table 4 sets out the aims and planned programme of all the visits.

Visit	Aim
1	Introductions
2	Consent forms and observations
3	Observations and preparation for interviews
4	Semi-structured interview with child or young person and observations
5	Semi-structured interview with family member with disability or illness and observations
6	Introducing camera and diary/essay activities and observations
7	Collecting camera and diary and observations
8	In-depth unstructured interview with child or young person and observations
9	Pre-last visit, invite for focus group discussion and observations
10	Last visit – ending

Table 4: Structure of family visits

Not surprisingly, things did not always happen as planned. For example, sometimes the adult had to be interviewed first and then the young person or I had to wait for two weeks before collecting the camera or go back within less than a week to collect it. Overall, however, the visits largely followed the structure above.

Finally, as mentioned previously, semi-structured interviews were conducted with 10 professionals who, at the time of fieldwork, worked with vulnerable and/or orphan children and families in NGOs or governmental services. This offered valuable information in addition to what I obtained from the families.

3.6.4 Data Collection

In total 32 semi-structured interviews were conducted; 12 with the young people, 10 with the adults with the disability or chronic illness and 10 with professionals working with vulnerable children and families (Appendices 21-23, questionnaires). During the semi-structured interviews with the children and young people, a care map activity (Appendix 24, examples of care map activities) was employed to visually investigate how participants gave and received care. For the care map activity, I asked the children participants to write their name at the centre, then add family members or friends around their name placing those names closer to their own name depending on how close their relationship is and finally, to use arrows to indicate the direction of caregiving.

In addition, a number of other visual activities were conducted with the children and young people with caring responsibilities. First, was the camera activity in which children were invited to take photographs to show how they are taking care of their family member with disability/illness, what makes them happy and what they would like to change in their life (Appendix 25, example of photography activity). Alongside the camera, they received a diary (Appendix 26, example of diary activity) to record their emotions and anything else they thought was important.

Some of the young people also wrote essays (Appendix 27, example of essay activity) in the diary answering the three questions given above as instructions for the camera activities. The essay was something that happened without having it planned when one young person did it on her own, as another way to listen to the voices of children and young people, I suggested it to more young people who were also happy to do so.

Later, 11 unstructured interviews were conducted with the same young people who had taken part in the earlier semi-structured interviews. During the unstructured interviews the photographs, diaries and essays were used to develop in-depth conversations led by the young people. At the beginning of these unstructured interviews, I asked them to do an activity – to place each photo in one of three categories: how I take care my family member with disability/illness, what makes me happy and what I would like to change (Appendix 28, examples of unstructured interview activities).

Furthermore, in order to assist the young people to express themselves using alternative ways to writing (as few of them did not know how to read or write), I explained that they could draw instead of writing essays, writing in the diary or taking photographs. One young person who was very talented decided to only draw and not do the diary activity at all (Appendix 29, example of drawing activity) one young person also refused to do either the camera or the diary activity (she did not explain why). All participants were constantly reminded before every activity that their participation has completely voluntarily and they did not have to do any of the activities and they decide to do so, they could change their mind at any time. In total, the data I gathered in these activities comprised 10 diaries, 10 films from camera activity, 12 essays (from 4 young people) and lots of drawings, including 1 drawing book. Additionally, as explained earlier in this chapter, during all visits both my research assistant and I kept fieldnotes on our diaries from our observations and later also included reflections after the visits (Appendix 30, example of fieldnotes).

Finally, I conducted one focus group discussion with the young people I had been working with, with the aim of giving them feedback on the findings of the research and asking for ways to disseminate the information gathered. The group discussion was conducted at the end of February at a community location (Feeding Centre) provided by a local NGO. At the group discussion 8 young people out of the 10 invited came (unable to come were the two young sisters who were taking care of their grandmother who died during the fieldwork so they had moved back to their parents' house in another district far from Blantyre). The outcome of the focus group discussion included two posters and two letters, all made by the young people (Appendix 31, focus group posters and letters).

3.6.5 Family Profiles

This section provides a brief profile of each of the families who participated in the research.

First family (rural): Hannah (female) is 19 years old (even though her mother says she's 17)[21]. Hannah is caring for her mother Memory who is HIV positive, her sister Gillian, 10 years old, who has learning disabilities and the rest of her family (i.e. Salif, brother, 15 years old; Fay, sister, 5 years old; John, son, 2 years old). Hannah dropped out of school when she started taking care of her mother. Hannah is both the 'mother' and 'father' of the family, as her mother has claimed. Hannah is the one who provides money (by doing piecework) and food, cleans, cooks, fetches water, does all other house chores, baths the children, makes most of the family's decisions and takes care of her mother when she is ill. According to Hannah, it was her decision to become her family's caregiver after her mother became ill and weak. Hannah's relationship with her mother is a strong one and even though it seems that Hannah is the one making everyday decisions at the house, her mother makes the important decisions. For example, Memory was the one who decided that Hannah should not marry John's father and have her own family because she would not take care of her (Memory) and the rest of the family. Hannah does not have a good relationship with her 15-year-old brother Salif. Even though he has dropped out of school, he does not help the family in any way. There have been issues of domestic abuse from Salif towards his mother and his siblings. The government Social Welfare Office and a local NGO were informed and stated that they would deal with it. During visits, it was observed that Hannah almost never rests or stops with chores/work. Although she has a lot of responsibility, of course, I feel that sometimes she would rather keep herself occupied so that she will not have time to think. Hannah was very defensive at the last interview about her emotions; her answer to almost all the questions was 'I do not know'. I think Hannah is a strong and very resilient young woman who is happy to care for others and make them happy, but I do not think she is happy in herself. Hannah does not think her future can be a good one unless she gets to go back to school.

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[21] It is common in Malawi for people not to know their exact age.

Second family (semi-urban): Louise (female) is 12 years old and she takes care of her blind grandmother Rute (Rute is actually Louise's great aunt as she is Louise's grandmother's sister). There is a second carer, her name is Eveline (female) and she is 11 years old. Eveline used to be Rute's main carer. Eveline's father is Rute's son, so Eveline cares for her grandmother. Eveline's parents separated and Eveline started staying with her mother so Rute had no one to care for her. That is when Louise became Rute's main carer. This is a very complex family. It was difficult to understand who is who and their relationships and dynamics. Rute and her sister Old Louise are strong older female adults and are the 'family heads'. All decisions/money etc. go through them. Those two 'appear to have authority over 20 children and adults within the extended family. Caring in this family is a family matter. Louise's and Eveline's roles vary – they do chores as every child in Malawi does, and they are also 'responsible' for guiding blind Rute to places and being their grandmother's 'eyes'. And they do whatever Rute or Old Louise say, as they've stated. They both go to school, have lots of friends and have time to play in the afternoon with their friends.

Third family (rural): George (male) is 17 years old and he cares for his mother, Esnat who is HIV positive. His two sisters (12 and 8 years old) and one brother (10 years old) stay in the house as well. George does not like talking much but he expresses himself through drawing. He was always very quiet during our visits. But he was always there and always welcomed us. He felt 'heavy' sometimes like he's carrying the entire world on his shoulders. When Esnat became ill (3-4 years ago), George dropped out of school and took over everything at the house. Chores, piecework, providing food and caring for his mother and siblings. After his mother became a bit stronger George started focusing on mostly doing piecework and bringing money and food. The rest of his day he spends with friends, drawing or going to TV shops to watch TV. George thinks that unless his mother becomes completely well and can go back to work, he cannot go back to school. And if he does not go back to school he does not think his future will be a good one. He wants to be an artist.

Fourth family (rural): Rejoice (female) is 18 years old and takes care of her mother, Christina, who has a chronic skin condition. Christina cannot work if exposed to the sun because her skin feels like it is burning and it is sore. Rejoice lives with her mother Christina, her father and two nieces (10 and 2 years old who are orphaned). According to Christina, Rejoice's father does not do anything to help except making straw mats for sale. Rejoice does piecework to support the family financially, as well as house chores. During the interview, Christina stated that Rejoice is a child and she is treating her as a child because if Christina ever says that Rejoice is an adult, Rejoice will want to leave her and make her own family. And then nobody would take care of her (Christina, the mother who is sick).

Fifth family (urban): Andrew (male) is 19 years old and is a part-time carer for his two grandmothers, Nessie who is around 90 years old and Aisha who is around 105 years old. Andrew stays at the same village as his grandmothers but sleeps at a friend's house. They all used to stay at the same house - Andrew, Nessie, Aisha and Andrew's uncle (Nessie's son), but rains destroyed the house so they had to find alternative accommodation. Andrew is going to college where he studies Business Management. His English is very good – we only spoke in English during our fieldwork. He usually spends Mondays at his grandmothers' house doing chores. The rest of the weekdays when he is at college, he wakes up early, goes at his grandmothers' house and cleans and cooks before going to classes. His care work involves cleaning, cooking, chatting with elderly grandmothers, as well as personal care. The older grandmother, Aisha, does not leave her bed often and she does all her needs there. So, Andrew has to clean her up after toileting. Andrew is proud of helping them, but he found it difficult with some of the things he has had to do. He became their carer when he was 14 years and it was very difficult at the beginning he said. But he states that now he is used to it. Andrew believes that if he is able to finish college his future will be good.

Sixth family (rural): Chimwemwe (female - 17 years old) and Chifunilo (female - 10 years old) are sisters and used to take care of their grandmother, Helen, who was over 90 years old at the time of fieldwork and had a heart condition. Helen passed away in January 2016. The woman who introduced us to the family called me the night of her death, so my research assistant and I attended the funeral. The girls left soon after to live with their parents in another district and we were unable to keep in touch. Chimwemwe stated that it was her own decision to move to Helen’s house and care for her grandmother. Helen used to have a daughter (Chimwemwe’s aunt) who cared for her but she died 2-3 years ago. When Chimwemwe heard this, she said to her mother that she wanted to be the one taking care of Helen. And so, she did but things were not as easy as she thought it would be. So, she felt she needed help and asked her mother to send Chifunilo as well. Chimwemwe did not go to school because they did not have money for the school fees and she was Helen’s full-time carer. Chimwemwe was acting as the head of the family. When visiting the family, the grandmother Helen was very ill and apart from her heart problems, she couldn’t hear well and possibly also had dementia. We were not able to understand her when she talked and on a couple of occasions she would say hello when we would get there and after a while, she would get upset because there were visitors at her house that she did not know about. Chifunilo was usually very quiet and did not talk much. She liked to play with her friends a lot and sometimes missed school to do that. They had lots and lots of friends and most of the time no adult supervision (unless an aunt or neighbour would visit them). Due to Helen’s severe health problems, she would spend most of her time in her room resting, something that gave the opportunity to the girls to play out all day. When playing with their friends, they both looked very happy.

Seventh family (semi-urban): Matias (male) 16 years old takes care of his grandfather Masamba, 82 years old who has mobility issues. Matias does not live at his grandfather’s house but he lives in the adjacent house. Matias’s responsibilities are mostly personal care. Masamba cannot walk very well. His legs are getting worse and worse with the years and he uses crutches for any movement. Sometimes he loses control of his legs and falls down. Masamba does not want to go to see a doctor because he thinks the cause of his disability is witchcraft and the doctor cannot help him. Matias helps his grandfather with walking around, going to and getting up from his bed, bathing and he is the one who helps him to get up when Masamba falls. Matias also cleans up after Masamba in the morning, as during night-time Masamba cannot go to the toilet on his own. In these cases, Matias helps his grandfather have a bath and then cleans his clothes and bedding. Matias goes to secondary school unless they do not have money for school fees or Masamba is not feeling well that day. Matias loves football and according to his family, he is very good at it. Matias has a very good family support system around him and he looks like a happy young man. Responsibilities are shared within the whole family, for example, Matias's mother and uncle provide the money, his sisters and cousins do the house chores, so Matias can focus just on supporting Masamba.

Eight family (urban): Samantha (female) 17 years old takes care of her grandmother Clara, 85 years old, who has mobility issues and pain in her legs. Samantha does not live with her grandmother but lives with her husband in the same town. Samantha got married a year ago and after she got pregnant, she dropped out of school. At the time of our visits, Samantha was 6 months pregnant. She works at a hair salon and she gives some of her income to her elderly grandmother Clara. Before getting married, Samantha used to live with Clara. Before getting pregnant, Samantha used to go to Clara's house on a daily basis and help her with chores, cooking and shopping. Since she got pregnant however Clara gets tired after work so she cannot go to her grandmother's house. Instead, she usually pays someone to do some shopping for her and help a little bit at home. Clara is happy for Samantha, but she feels she does not get the help she needs and she misses Samantha because she can't see her every day. They do not have any other family members living nearby so there is no help coming from any other relatives.

Ninth family (urban): Rosemary (female), 18 years old takes care of her sister Mary who is 35 years old. Rosemary's mother, Rosemary's younger sister (17 years old) and her son (8 months old), as well as Rosemary's nephew (7 years old) all live at the same house. When introduced to the family, we were told that Mary has a heart condition and when we met her the first time, she looked weak and her breathing appeared irregular. However, during the interview with Mary, she mentioned that her 'illness' started when she was working in South Africa and found out that her brother had died. After hearing the news, she became 'ill' as she said, not being able to work, leave the house, sleep or do anything else. And soon she became more and more stressed and thoughts started taking over her mind (possibly a response to bereavement, accompanied by panic attacks or an anxiety disorder). Mary wanted to come back to Malawi but she had no money, as she could not work. After a long time, her friends managed to help her and bought her a ticket. Since she returned home, her younger sister Rosemary has been taking care of her. When asked about the medication she receives, she said that the doctor gives her tablets to stop her thoughts taking over and help her sleep at night. Rosemary is trying hard to start her own business (sell clothes and bread) but she does not always have the money to buy the clothes or the ingredients. After Mary came back from South Africa, Rosemary dropped out of school. Rosemary does not want to go back to school because she says she would not be able to focus if she knows Mary is home not feeling well. But with no education, Rosemary does not think her future will be a good one.

Tenth family (semi-urban): Daisy (female) 13 years old takes care of her maternal aunt Elesi, 51 years old who is HIV positive. Daisy lives in both her mother's house and her aunts' house, depending on how much help Elesi needs. Elesi is very weak and looks very ill and needs lots of support with house chores, as well as personal care. Daisy is going to upper primary school and during school hours her mother is the one caring for Elesi. Elesi has also two sons, one who lives with Daisy's mother (his aunt) and one who was 'kicked out' of the house because he was always allegedly taking drugs and was verbally abusive towards his mother Elesi. Elesi's sister and Daisy's mother is a local Chief and this offers the family some financial security and access to things such as a car if Elesi needs to go to the hospital. Daisy participated in the first interview, but declined to do the camera and diary activity, and also the second interview. Unfortunately, despite my efforts to discuss this and understand why I do not know why Daisy did not want to do the research activities.

3.7 Data Management and Data Analysis

3.7.1 Data Management

As already mentioned, my research assistant and I used notebooks to keep hand-written notes of our ethnographic observations during visits to the ten families described above. We had a different notebook for each family and we only carried that one notebook with us to each family visit. The notebooks not in use were locked in a safe place. A voice-recorder was used to accurately record the interviews and the focus group discussion. Observations and recordings all were transcribed into electronic format for data storage and analysis. I employed four interpreters, some of them transcribed interviews in Chichewa and others translated them into English. To ensure the translations' validity, I used different interpreters for different roles, asked some to translate same Chichewa interviews. Towards the end of my research, I asked my research assistant to check all translations before leaving fieldwork (see Appendix 32, example of interview transcription). I transcribed all the interviews conducted in English, i.e. with Andrew and the professionals.

3.7.2 Data Analysis and Interpretation

By using a multi-methods approach, the data obtained greatly vary. The data gathered include fieldnotes, diaries, photographs, drawings and other materials gathered from activities with the children, voice recordings from the interviews and the focus group discussion. With regard to proper data management, the data was stored in a safe place to guarantee confidentiality, and only myself, the research assistant and interpreters had access to it.

After transcribing and translating all the data, it was organised by themes, coded and analysed in Nvivo and manually using thematic analysis (Attride-Stirling, 2001). Data that could not be coded through Nvivo, such as photographs, was coded manually. Thematic analysis examines data for themes that arise as being significant to the description of the phenomenon (Fereday & Muir-Cochrane, 2008). The process includes the detection of themes through 'careful reading and re-reading of the data' (Rice & Ezzy, 1999, p. 258). It is a procedure of recognising patterns within the data, where emerging themes develop categories for analysis (Fereday & Muir-Cochrane, 2008). Rigorous techniques were used to summarise and interpret the information (Ezzy, 2002). A number of themed categories were created which were used to organise and describe the participants' perspectives. The data were processed according to the themes throughout the analysis and writing stages in order to produce an accurate representation of the information gathered.

In order to accommodate and adequately attempt to describe the multiple, fluid and complex nature of children and young people's emotional experiences and family relations, the notion of case studies is employed. In depth case studies can be used to explore and describe complex social issues (Flyvbjerg, 2006). Case studies are important in social research because they can provide 'a nuanced view of reality, including the view that human behaviour cannot be meaningfully understood as simply the rule-governed acts found at the lowest levels of the learning process and in much theory' (Flyvbjerg, 2006, p. 223). Similarly, Yin (2003) states that a case study can provide answers to 'why' and 'how' questions and allows the researcher to observe and not to manipulate participants' behaviours and attitudes in any way. It is important to highlight that case studies are not used as a methodological approach in this study but rather the analysis adopts the notion behind case studies in order to present in-depth the children's and young people's caregiving experiences.

This section presented the data management and data analysis techniques this study assumed. The following section explores dissemination with children and young people through focus group discussion.

3.8 Dissemination with and for Children and Families: Focus Group Discussion

I agree with the view that research with children and families should not be conducted and reported for 'its own sake', but 'should lead to outcomes which encourage empowerment, participation and self-determination consistent with levels of competence' (Matthews & Limb, 1999, p. 61). As Matthews and Limb (1999) argue, adult decision-making might be focused on the 'best interest' of the child, but evidence suggests that children's involvement is not more than tokenism. Indeed, the debates on how real and meaningful children's participation is in decision-making are numerous. Although there are many debates concerning children's meaningful participation, they claim that it is still important to attempt to understand children's experiences, even partially, rather than not trying at all (Matthews & Limb, 1999). Following this rationale by conducting a focus group discussion at the end of the fieldwork period, I intended to include the participants in the dissemination process. The caregiving children and young people who had participated in the months of research had the chance to say how the results should be disseminated (considering always time and other practical factors) to conclude this research project.

3.8.1 Focus Group Discussion

Thus, I conducted one focus group discussion with the help of two research assistants (the female research assistant who accompanied throughout the fieldwork and a male research assistant employed only for the focus group discussion) with the aim of sharing the preliminary results of the research, gathering their responses to the findings and discussing how the young participants wanted to disseminate those results.

Langford and McDonagh (2003) explain that a focus group discussion is 'a carefully planned discussion, designed to obtain the perceptions of the group members on a defined area of interest' (p. 2). Focus group discussions involve 'a small group of people discussing a topic or issues defined by the researcher' (Cameron, 2005, p. 116). The key characteristic of this method and what differentiates it from interviews is the interactions between the participants (Cameron, 2005). The interactive feature of focus groups offers the opportunity for participants to examine a variety of opinions and views and thus, formulate and reassess their own thoughts and understandings (Cameron, 2005). A focus group discussion can offer the opportunity to participants to communicate and actively interact with each other and share views and experiences (Bruseberg & McDonagh, 2003; Morgan, 1997).

Focus group discussions can present researchers with a number of challenges and that is why I tried to prepare for most of them. For example, studies have shown that the dynamics of the group might influence the conversation. Some of the participants might be influenced by others participating and thus, they might stop themselves from expressing their own thoughts and views (Hennessy & Heary, 2005; Morgan, 1997). Other factors such as gender, age, self-confidence and other personal qualities might similarly play a significant role in how the conversation evolves (Hennessy & Heary, 2005; Mauthner, 1997). In order to overcome some of the challenges that focus group discussions pose, it was essential not only to be well prepared and train my research assistants carefully, but I also employed a variety of activities, including icebreaker games, age and literacy appropriate fun activities for young people to obtain data and in order to facilitate conversation flow.

At the early stages of my research design, I was planning to conduct a number of focus group discussions as another way to collect data. This however proved to be difficult for a number of practical reasons, such as participants' lack of finance to use transport to attend a central venue, difficulties in identifying appropriate venues, time constraints due to the level of organising etc. Towards the end of my fieldwork it became important to have some kind of agreement with all participants on how to end this project and disseminate preliminary results. So, the plans were revised to conduct one focus group discussion with the aim of feedback and deciding ways of dissemination.

Active dissemination can be used as a way to facilitate discussions which include the participants and give them the opportunity to have a level of say with regard to the outcomes of a research project (van Blerk & Ansell, 2007). Van Blerk and Ansell (2007) state that although active dissemination does not always bring change, it can act as a 'potential agent of social change' (p. 313). From the first stages of organising this group, I continuously discussed with the participants what the outcomes could be and that this might not have any direct and immediate impact for their families. Evans (2016) discusses the ethical implications of involving participants in the research process and observed that through participatory dissemination, participants invest emotionally in the project to a greater level which has both positive and negative implications. The participants of this research study highlighted the positive aspect of this, such as sharing their thoughts and feelings within a group with similar experiences. They did not share any negative thoughts, although I observed that the focus group discussion, as well as the whole process of this research project, increased their expectations and developed hopeful feelings for support and intervention from services which I do not know if they have received.

3.8.2 Ending Fieldwork

As mentioned before, the outcome of the focus group discussion was two letters and two posters (Appendix 31) and the agreement that these would be disseminated to key organisations in Blantyre. This was carried out immediately after the group discussion, by visiting all the relevant organisations and services I had been in contact with in Blantyre. All the non-governmental organisations and government services were happy to see me again and accepted the posters and letters.

Following this, all the families were visited for a final time to inform them about how the dissemination went and to finish up. All of the families were really positive and expressed satisfaction with the research project. They said they enjoyed having us at their homes and they liked talking to us and they will miss us. All the young people said the best part was the focus group because they '*met friends*' as they stated, and they were able to express themselves with the letters/posters. Two of the families said that they are grateful I was doing this research because it encouraged them to go on with their caring responsibilities. Families said there were no problems encountered and at my question if they would like to change anything if we would do it again, they said they did not have anything they wanted to change.

The problem that came up was the access to government services mostly due to corruption. According to the families and professionals participated in this study, all government services, like MACOHA and social welfare office, are accessible through the Chiefs. The procedure is that the family should go to the Chief and tell them what they need, the chief should know who the child protection officer working for social welfare office is or the officer working for MACOHA and refer them onwards. Afterwards, the officers will make an assessment, report to their managers and decide what happens next. All the families I talked to (except the one where the mother of the young person is the Chief), said that they do not want to or cannot go to the Chief for help for three main reasons: Firstly, Chiefs are viewed as corrupt and using the resources they have for their own relations; secondly, in many villages to see the Chief they have to pay and families cannot afford it; and thirdly, two of the families were not born at their villages where they live now so they are considered foreigners and not eligible for help, even if they lived there for over 20 years. The families asked me to intervene and provide them with a letter to go on their own to social welfare or bring the child protection to them or help them access the social welfare in other ways. I did not give them a letter, as even if I would have, the letter[22] from myself as a student and outside researcher would not have the authority they were expecting it to have.

To follow up on what I had discussed with the families, I contacted the social welfare office to discuss the issue further. The social worker I talked to admitted that the problems the families highlighted are real and that they indeed have ongoing issues with corruption. We agreed that I would give him all the names, locations and phone numbers for the families and he will ask the child protection officers to contact them and make their assessments. So, I gave him the list and for a while, I kept in contact with him to make sure he follows our agreement. Since my return in the UK, we spoke a couple of times and he stated due to unforeseen circumstances, he had not managed to see the families but that once things would get more settled, he was still planning to do so.

3.9 Fieldwork Reflections

When conducting social research, especially when researching emotional experiences, it is significant for the researcher also to self-reflect on their own emotions and background. A growing literature is investigating the role of emotion in social research and its impact on producing knowledge and understanding how the social world works (Bondi, 2008; Evans et al., 2017; Hubbard, et al., 2001; Widdowfield, 2000). The ways researchers are positioned by their gender, age, experiences and identities can impact on the research field and production of knowledge (Evans et al., 2017). Reflexivity thus is significant in order for the researcher to understand their position in the field and the ways they can influence and be influenced by it (Pillow, 2003). Pillow (2003) suggests that one of the most common uses of reflexivity 'is increased attention to researcher subjectivity in the research process' and asks whether this self-reflexivity can

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[22] Letters like the one they asked me to give them are usually referral letters provided by the Child Protection Officers who are government employees. Those letters refer the people to the appropriate service with some information of their case.

produce better research or not (p. 176). Pillow (2003) highlights the ways this can be problematic as this kind of reflexivity depends on the ability of the researcher to be subjective and make it accessible to the reader. This can cause a number of issues but can be especially beneficial if 'better reflexivity' can produce 'better knowledge' (Pillow, 2003). Despite the dilemmas and questions reflexivity can trigger, Pillow (2003) argues that researchers should not refrain from looking at their positionality, but that they can use reflexivity as a tool to gain better understandings of the social world and not 'as a confessional act, a cure for what ails us, or a practice that renders familiarity' (p. 177).

3.9.1 Personal Background

The earlier section 3.5 of this chapter examined the ethical implications this study encountered. Positioning myself in this project is therefore imperative before reflecting on fieldwork and analysis. Some initial thoughts with regards to my positionality are already discussed in Chapter 1. As a social worker, I have been working with children with caregiving roles for about ten years before commencing this project. I have worked with children and families affected by chronic illness and disability in both Greece and Scotland. While working with young carers, as called in Western societies, I found a lot of commonalities and soon realised that I had been a carer as a child as well. What struck me the most then was the perception by colleagues and myself that young caregiving was not a good thing, because caregiving was 'stealing' children's childhoods and made them victims. Looking at my role as a young carer though, I realised that although having the role of a carer in a young age is challenging, it actually helped me develop skills and qualities that my peers did not possess. In addition to being a carer, a few months before commencing my PhD studies, I was diagnosed with a chronic illness which has also played a significant part in this project.

Entering the field was both very exciting and very intimidating at the same time. It was the first time I had ever travelled to a sub-Saharan African country and although I had read and prepared a lot, actually going and experiencing it was very different. I thankfully had a place to stay initially and I had made contacts prior to my arrival. The most challenging of all was adapting to a culturally different environment, which although expected, I had underestimated. I was in a new place where I was not sure how things worked and as I had a very specific timetable, I had to quickly learn as much as I could for my new environment and adapt in order to commence my research. Additional challenges I faced were issues in relation to transport and personal security. At first, I was hoping to use mini-buses and taxis to travel but soon realised that these methods of travel significantly limited the places I could go to, so I then hired a car for the rest of my fieldwork. Personal safety was a major aspect both during fieldwork and when I was at home in Blantyre. During fieldwork, I was thankfully always with my research assistant but even being together, we were unable to travel if it was after dark or when the weather was really bad during the rainy season. Also, I lived in a house with three housemates and security guards but we had three break-ins during my stay in Malawi which was very frightening.

3.9.2 Being an 'Insider' and an 'Outsider'

My experience of young caregiving and chronic illness was useful to create links and up to a degree understand some of the issues facing the participants, children and adults, are facing. Being a social worker and having worked with young carers and families affected by illness and disability before also helped, but at the same time, I had to be careful not to presume anything because of my job experience. These commonalities, alongside my gender and on some occasions my age, placed me in an 'insider's' role.

Being an 'insider' or an 'outsider' matters when conducting research. According to Dowling (2005), an insider is someone 'who is similar to their informants in many respects' and an outsider is someone 'who differs substantially from their informants' (p. 26). So, I also, and mostly, had the role of an outsider in the research, as a European Caucasian female researcher conducting research with Malawian children and families. Being an outsider has both negative and positive aspects. Not being a member of their community meant that I needed time to create rapport with the children and the families to establish trusting relationships with them and thus, obtain in-depth information (Dowling, 2005). Being an outsider could also have an effect when interpreting data (Dowling, 2005). A benefit of being an outsider could be that because I am coming from a very different country, people would make an effort to communicate and articulate their attitudes, experiences and feelings (Dowling, 2005). Due to being an outsider, however, I was not able to conduct ethnography in the way I initially hoped, i.e. developing relationships with the families so I would become more and more invisible and then 'follow' participants observing their everyday routines. As an outsider, it was very difficult not to be the centre of the attention, not just for the families but also for many other people at the villages which meant they would not 'forget' I was there. What made me so visible was not only that as a European female researcher I was an outsider, but it was also that the families were so welcoming and hospitable, they wanted to ensure I was offered everything they could give.

Nevertheless, it is useful to acknowledge that I was not explicitly an outsider, but at times had an insider's view. Gender, age, childhood experiences are to some degree similar to those of the participants and in these situations, I could be considered as an insider. Researchers' and participants' characteristics, identities and social roles often overlap and being aware of both the discrepancies and commonalities is not only useful for the research but also can be one of the pleasures and surprises of social research (Dowling, 2005). Spending so much time with the families I worked with and being able to particularly empathise with some due to my personal circumstances and life experiences, I found myself adopting a caregiving role which I had to reflect on continuously and balance those feelings throughout my fieldwork. My role was predominantly one of a researcher but through reflections, I attempted to hold the balance of being a researcher while embracing my human nature and my training as a social worker.

3.9.3 Working with Research Assistants

As I have explained, during my fieldwork project I employed in total six people to assist me with the research. One of them, a female research assistant, accompanied me throughout the fieldwork and also had the role of cultural advisor and interpreter. Another male research assistant joined us for the focus group discussion only and the other four were translators who transcribed and translated the interview recordings. All of these people were an enormous and incredible asset to the project who helped me navigate through the fieldwork and I would not have been able to do it without them. There are a number of issues associated with working with research assistants that also require consideration. When working with a research assistant, it is important to reflect on their expectations, positionality and how they could affect the data collection (McLennan et al., 2014). My female research assistant, for example, is a wealthy, educated, Malawian woman who although was a 'local', due to her educational and economic background had a very different position in comparison to the less privileged families we worked with.

This was especially obvious in some instances. For example, despite undergoing some training about my research project, aim and methods, my research assistant had her own ideas of what a child is and their place in the family. At the first visit, and although I thought I had explained to her clearly the way I was looking to work, we arrived at Hannah's house where we were welcomed by Memory, Hannah's mother, and all of her siblings. We did all the necessary introductions and then I started explaining all the information regarding my project. I observed that when my research assistant was translating what I was saying, she only addressed Memory, the mother and only adult of the family. When it was time to ask for consent, I specifically asked my research assistant to address Hannah but it seemed that she found that strange and difficult. My research assistant explained that she could not speak over Memory, Hannah's mother, as Memory could be offended. We discussed this further and decided to ask permission from Memory to talk to Hannah directly, which worked well and which we did with all the families. After that, I was more careful to ensure that my research assistant understood how my research was looking to approach children directly and to empower them which overall helped – although there were still some occasions, but not many, when although I would be very clear that my question was to be addressed to the child, my research assistant would ask it to the adult sitting with us.

3.9.4 Working with Poverty and Corruption

One of the most difficult parts of fieldwork was to witness the level of poverty the families I worked with faced and the level of corruption within the government, authorities and local services. Working with people and families that struggle to meet their basic needs made me a number of occasions consider supporting them by providing material things. And although at the very end of fieldwork, as a sign of gratitude and thank you for their time, I offered a small gift to all the families, I felt that giving more material assistance was inappropriate due to many ethical considerations but in many ways, I felt powerless.

For instance, one of the mothers participating in the research, half-way through the data collection, asked me when I would give her the money for her daughter's school fees. Following an extensive conversation, my research assistant and I realised that the NGO who introduced us to the family had told them that I would give them money if they participated in my research. Having explained many times and reminded all the participants that there would be no financial gain from participating in this study, we were surprised the mother believed that we were going to pay her daughter's school fees. The mother said that she thought we were lying and that she was hoping to get the money from me. I explained again the reasons for conducting my research, what it means taking part and clearly stated that I would not be able to give money to any of the participants. It was a very difficult thing to say and do, which I acknowledged at the time with the family and I also said that we can stop and that I would not use any of the data gathered by working with them for my research. The mother said she felt disappointed but she wanted me there, she had been enjoying our company and conversations and she felt we were helping her just by being there. I asked for permission to discuss this matter with the NGO involved, but the mother said that she did not wish that to happen as she did not want them to blame her about anything. A few days later, another family who had been introduced to me by the same NGO, also mentioned that I was saying to them different things to what they were at first promised by the NGO.

This family also wanted to continue being part of the research project and did not give me permission to discuss this with the NGO. I respected the participants' wishes and did not say anything at the time. Following these experiences, I started asking for renewed consent from all the participants at the beginning of every visit and explained that I would not be able to give them any financial support if they were to decide they wanted to remain in the study. In addition, at the end of my fieldwork, when disseminating the preliminary results to the professionals, I had a meeting with that NGO and used the opportunity to discuss what conducting social research means and that I would not be able to provide any of the participants with financial support.

Looking at power relations between researchers and (child and adult) participants, Brockington and Sullivan (2003) specify that ‘economic and other inequalities are frequently implicit in relationships between researcher and researched’ (p. 66). Having considered this, especially when researching in a developing world context, researchers should question ‘the legitimacy of fieldwork in Third World contexts, and, of course, of the notion of ‘the Third World’ itself’ (Brockington & Sullivan, 2003, p. 66). Indeed, Evans and Becker (2009) state that the most challenging aspect of Evans’ fieldwork was that she was seen as ‘a potential source of financial support’ and that even the professionals she worked with were asking how she was planning to help the families (p. 79). It is suggested that ‘participatory, collaborative approaches and research conducted alongside interventions’ might be the most suitable way to respond to these concerns (Evans & Becker, 2009, p. 80).

Subsequently, what I tried to do was to link in with the organisations that acted as gatekeepers during the recruitment stage and discuss with them the participants’ practical needs. I also disseminated posters and letters which were created at the focus group discussion and tried to raise awareness to practitioners about young caregiving. At the end of my fieldwork, as already mentioned, I also worked with the government Social Work office in Blantyre and gave them the list of all the families I worked with and of course of those who had given me consent to do so, so the Social Work office, alongside the NGOs, could hopefully offer them support.

3.10 Conclusion

The aim of this chapter was to explain and justify the methods I used for my research project. The first section of this chapter (3.2) outlined the ontological and epistemological perspectives that underpinned this study. Section 3.3 discussed the theoretical approached encountered when conducting research with children and young people. In section 3.4, I argued that multi-methods qualitative approach was the most appropriate way to answer the research questions as it offered an in-depth understanding of the complex nature of young caregiving. Section 3.5 concentrated on the ethical considerations of conducting research with children and young people in a sub-Saharan African context. Sections 3.6 and 3.7 explored the study design, data collection, data management and data analysis this study implemented. I investigated ways to address those issues, such as obtaining informed consent and ensuring confidentiality and anonymity.

In section 3.8, dissemination was discussed through the focus group discussion which took place before fieldwork ended with the aim to include children and young people at as many stages of the research project as possible. Finally, section 3.9 examined of the researcher's positionality and how power relations might influence participants, alongside issues encountered, for instance, when working with research assistants. The next chapter is the first of the four analysis chapters. It presents notions of children and childhood in Malawi and nature of young caregiving as portrayed by the participants.

Chapter 4. Children, Childhood and Care

'While their lives were harsh and far from the ideal childhood, …, their responses revealed a degree of agency that shows the inadequacy of perceiving them simply as vulnerable victims.'

(Bourdillon & Musvosvi, 2013, p. 105)

4.1 Introduction

Children and childhood are two concepts widely used but not always understood in the same way. The issues and debates of defining and understanding childhood were discussed in Chapter 2, concluding that the meaning of childhood is constructed in different ways with respect to different historical, social and cultural contexts. This chapter outlines the research participants' diverse interpretations and experiences of children's everyday lives by looking at both Malawian children's everyday lifeworld and focusing further on the particular lives of children with caregiving responsibilities. The notion of childhood and comprehending how it is experienced is complex and nuanced, so to understand the participants' experiences a range of data sources from different individuals and groups of adult and child participants is closely interrogated. By looking at everyday lives and not only caregiving responsibilities, this chapter also aims to develop a holistic and broader view of the experience of children as caregivers instead of isolating children's experience of caregiving only.

This chapter attempts to answer the first research questions stated in Chapter 1 (Table 1): 'Who/what is a child? How do children and young people understand and describe caregiving? Where is caretaking place? How/when do children become caregivers? What are children's caregiving roles? What are the ways through which children and young people show their agency?'. The first section of this chapter discusses ideas in relation to who is a child in Malawi. It considers age to be one of the indicators, however, not the most popular one among the views of the research participants in Malawi. In many sub-Saharan African societies, childhood and adulthood are measured against beliefs and events, such as rituals, rather than biological years (Alanamu et al. 2018; Clemensen, 2016). Indeed, Abebe and Ofosu-Kusi (2016) highlight that in many cases African children identify themselves and are considered as adults long before they legally reach adulthood while others are still considered children long after legal age of majority, for example, they have not been married, become parents, etc. The distinction between children and adults reflects a variety of physiological, psychological and social development stages. Maturity, intelligence and capacity are some of the significant factors mentioned by the participants who took part in the research presented in this thesis. These factors were widely used by the research participants to identify in their view and lived experience who is an adult or a child exemplifying the fluid and subjective nature of childhood.

This chapter then looks at the circumstances of young caregiving which are very complex. In attempting to explore part of what care and caregiving responsibilities are, this chapter hopes to demonstrate the tension between contemporary understandings of childhood and traditional notions. This, however, does not mean that concepts of childhood are binary (traditional vs contemporary, indigenous vs western), but the aim is to demonstrate the fluid and complex nature of local constructions of childhood, and how these concepts are influenced by poverty, western ideas, illness and disability (Skovdal, 2009).

It is important to understand these aspects which influence conceptions of childhood because, as the participants state, they take account of several factors when making decisions as to who becomes a caregiver and why. Consequently, the following sections of this chapter investigate what care means for the participants, how they became young caregivers and what their caregiving roles are. According to the participants, 'care' can be found in many aspects of life. Care extends from practical and personal care to providing emotional and spiritual care. The participants in this research understand those multiple meanings of care as normal, everyday practices within a family. Sometimes, when a family member is in need of more intensive care because they might be affected by illness or disability, it is acknowledged that the family will identify someone to provide that care. It is usually the parents of the child or an adult in a higher position and authority within the family that makes the decision to allocate a specific child as caregiver to the family member in need, or it could be that the young person themselves makes that decision. On some occasions, it is also simply circumstances that place the child in a caregiver's role as there might be no one else to do it. The last section of the chapter explores children's caregiving responsibilities and offers different accounts provided by the participants in regards to their roles and responsibilities.

4.2 Children and Childhood in Malawi

Considering 'childhood is a contested concept' which changes through time and culture (Kraftl, 2006, p. 488), this section explores the different ways in which children and childhood in Malawi are viewed and conceptualised. It is widely argued in the literature that western ideas of conceptualisations of childhood should not be applied globally (Twum-Danso Imoh & Ame, 2012). For this reason, as already discussed (see Chapter 1), this thesis aims to explore who is a child and how childhood is understood in Malawi.

In order to work within a conceptual framework, this study takes into consideration the UN Convention on the Rights of the Child's definition of children, according to which, a child 'means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier' (UNICEF, 1989). However, this research project recognises that there is multiplicity in the ways children are viewed by the research participants and hence it is worthwhile exploring those views before looking at young caregiving further. Indeed, Twum-Danso Imoh (2012) suggests that even though the Convention has played an important role in thinking and focusing on children, it is based on Western historical developments of childhood and therefore, is unsuitable for other contexts. Evans and Skovdal (2016) add that in the Global South the distinction between childhood and adulthood is not as simple as the marker of biological age. They instead state that the transition from childhood to adulthood is exhibited by a number of social expectations the young person should go through, such as becoming 'responsible' and 'independent' for example by completing their education or getting married and having their own family (Evans & Skovdal, 2016). The following section looks at the different ways the participants of this study understand and describe what it means to be a child in Malawi.

4.2.1 Understanding Who is a Child in Malawi

Conversations with the research participants indicate that there are different ways of understanding childhood in Malawi. A child is described not only by their biological age, but also in terms of a variety of cultural, social and economic dimensions. This is important to take into consideration because in line with the social study of childhood (see Chapter 2), many of those viewpoints move away from rigid ideas of definitions of children and childhood that are based solely on age-related stages of development and that view children as passive receivers of socialisation (see James & Prout, 1997; McNamee, 2016).

To start with, similar to Western ideas of childhood[23], a small number of the participants (both adults and children from the families) identified a child by considering their age. For example, Rosemary (18, F)[24] states that a child is someone "*who is below 18 years of age*". Christine (52, F) further adds, "*From birth to 18 years we know that this person is a child. When they reach 19 years going up, that person is an adult.*" Interestingly, all the professionals interviewed identified a child being someone below 18 years, as legislation dictates, indicating that their formal education and affiliation with international organisations could have influenced their opinions. Professionals, however, also acknowledge that many people in Malawi, especially those from 'traditional' backgrounds, often identify children in different ways and not according to their biological age. For instance, Kondwani (32, M, social worker) states, "*So most of the tribes define children within their own context. Yes, because of the initiation ceremonies. So, one who wouldn't have gone through the initiation ceremony would be regarded as a child to them.*"

Indeed, Evans and Skovdal (2016) state that adulthood comes after a number of gradual phases such as initiation ceremonies, marriage, having a child, etc., and

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[23] As explained in Chapter 2, when discussing 'Western ideas of childhood', this thesis refers to particular concepts of childhood developed in Western Europe which consider a child to be anyone below 18 years old and which view the child as innocent, passive and often in need of protection (see Aries, 1962; James & Prout, 1997; Twum-Danso Imoh & Ame, 2012)

[24] The parentheses following the participants' pseudonyms include a number and the letter F or M. The number refers to their age and the letter indicates whether the participant is female (F) or male (M).

argue that not only does this mean that transition to adulthood is fluid and depends on individual circumstances but that firm age-based definitions of children and youth might be problematic. The reason is that this could mean that only children up to the age of 18 need support and that those over 18 years old are not as vulnerable, but what research shows is that young adults are often as vulnerable as young children are and that they are often involved in more hours of care work than younger children with caregiving responsibilities (Evans & Becker, 2009; Evans & Skovdal, 2016).

Certainly, in Malawian society age appears from the responses of the participants in the research not to be the most important factor in defining a child, as it would be in a Western society. A common way encountered in describing a child is by defining their level of maturity[25]. Chifunilo (10, F) says that a child is someone who "*is small*" and explains further "*a baby who does not know anything*". Clara (85, F) comments on behaviour when asked who is a child and states, "*S/he*[26] *does childish things. Being childish*" which supports Memory's (35, F) opinion that a child is "*one whose doings portray immaturity*". Andrew (19, M) elaborates this further:

> *"In my opinion, a child is a younger person who is supposed to live with parents, a boy or girl. In other ways, he should be helping their parents in domestic chores. And other things like go to school. They are a younger person in terms of age, thinking capacity."*

It is worth noting that the children and young people who participated in this study used maturity as an indicator to define someone as a child or an adult. However, maturity is not a rigid rule for describing a child, as the notion of maturity is fluid, and it depends on a number of factors and thus, cannot be easily and objectively measured. Here, Samantha (17, F) states that a child is someone who is not yet mature and explains when asked how she sees herself:

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[25] The participants of this study generally used the term 'maturity' to describe both physical and emotional maturity.

[26] In Chichewa language, there is no differentiation between female and male personal pronouns. This is why there is no way of knowing whether the participants mean 'he' or 'she', unless specifically clarified. Thus, most quotations state 's/he' instead of just 'he' or 'she'.

> Research assistant: *Would you say you are a child or an adult?*
>
> Samantha: (laughs) *I am a child.*
>
> Research assistant: *Do you think you are not mature enough?*
>
> Samantha: *I am a mature person. I know some things but I also do not know some other things* (laughs).

Samantha articulates who a child is in her own way. She indicates that physical and emotional maturity are not the only factors to consider and that knowledge and life experience are equally important for someone to enter adulthood.

Intelligence and capacity are two more criteria that became apparent in the research participants' efforts to distinguish if someone is a child or not. For example, Esnat (41, F) expresses that a child "*is young. It means s/he cannot do the things/ chores that we adults do. S/he just can't do it*". Adding to this idea that a child is someone whose capacity to do things is limited, George (17, M) adds the notion that a child is someone who depends on others for meeting his/her needs. He states that a child is "*someone who does not know anything. A child depends on someone else to support him/her".* Additionally, Samantha (17, F) elaborates on children's capacity to follow rules and instructions:

> "*On intelligence, I can say that when you tell a child something s/he tends to not know what exactly s/he is doing. When you tell him/her that you have to stop what you are doing, s/he cannot stop. Because s/he may think as if what s/he is doing is right but in reality, it is never right*".

Finally, although mostly the views of children and adult participants of who is a child did not differ remarkably, there was one different notion in some of the adult accounts. Some of the adult research participants describe what a child in terms of 'ownership' and 'belonging'. For instance, Rute (63, F) explains, "*I take that person as my child*". Similarly, identifying her role as a mother and grandmother, Nessie (90, F) states, "*S/he is my child, s/he is mine*". This idea of a child belonging to an adult, especially a parent or a grandparent, is not only defined by the biological relationships, but it follows ideas of extended family constructions that will be further discussed in Chapter 6.

This section recounted at the different ways the research participants understand what a child is according to age, maturity, intelligence, competency and even ideas of ‘belonging’ and ‘ownership’. According to those accounts, an absolute definition of children would not be possible as the data gathered suggest that the notion of what a child is, is much more complex and varied than defining a child simply according to biological age for example. This is important because it helps to gain a better understanding of what childhood means for the research participants. The next section explores those Malawian children’s everyday childhoods.

4.2.2 Constructing Childhoods

As explored in Chapter 2, childhood is viewed by sociologists and other social scientists as a social phenomenon which is socially and culturally constructed (James & James, 2004). It is significant to not only look at children as contributors to society but also to explore the ways society influences childhood (Mayall, 2013). Considering childhood is historically, socially and culturally constructed (McNamee, 2016), this project aims to explore the various ways childhood is constructed in the Malawian context by examining children’s everyday lives.

In order to investigate further the way children’s and young people’s constructions of everyday childhoods are conceptualised, this project looks at childhoods and children in three main ways. There were many themes which emerged from the data analysis but three main themes occurred which described some of the aspects of children’s everyday lives in Malawi according to the views of the Malawian research participants. It is vital to highlight that the data presented below only offer a small glance into the complex and nuanced characteristics of Malawian childhood. Firstly, children are viewed as a family ‘asset’, for both the present and future depending on their competencies, education, potential future marriages, etc. Indeed, children in sub-Saharan African cultures are required from their early years to start making contributions at different levels to the household by helping with household chores and/or economic life (Evans & Becker, 2009; Evans & Skovdal, 2016; Laird, 2012). Secondly, childhood is seen as a period of ‘innocence’ and an opportunity for guidance and support, following both discourses of children having a carefree and romanticised life and being ‘blank slates’ that need work (McNamee, 2016). And thirdly, children are viewed as ‘social agents’ who actively and constantly interact reciprocally with society. Children and young people experience these constructions in a dynamic way along a continuum.

Starting with the concept of childhood that regards a child as an 'asset', it is important to highlight that this construction is the one that differs the most in comparison to Western versions of a 'real' or 'proper' childhood (McNamee, 2016). Many studies have observed that to ensure and maintain a household both in relation to production and reproduction, all children and adults need to actively participate to meet everyday life needs for life and survival especially in poor societies (Evans & Becker, 2009; Phiri & Abebe, 2016; Robson, 2004a; Skovdal, 2009). In Malawi, as in most sub-Saharan African societies, children are an important part of household survival and livelihood strategies. Saur and colleagues' (2005) study of gender-based violence in Malawi mentions that violence perpetrated by children towards parents includes children refusing to do household chores, either because they are tired or too hungry (p. 58). This illustrates the significant cultural responsibilities of children with regard to performing work within the home in a Malawian context.

Day-to-day routines are a way to present children's everyday life. The following two accounts offer a summary of children's everyday lives from children's perspectives:

> "*If s/he has a grandparent or parent, s/he* (the child) *should take care of him/her* (the parent or grandparent) *like washing for him/her, doing every work for him/ her which s/he may want to be done. The child is supposed to go to school and when s/he is back if s/he will find food already cooked s/he should eat, after eating he/she should wash plates. After s/he has eaten s/he is supposed to wash plates, after washing plates if they have anything to give her, maybe s/he has to go the market, to draw water s/he is supposed to go and do that."* (Louise, 12, F)

Samantha (17, F) adds further, "*Then s/he goes to play or washes dishes. When it's evening, we prepare the evening's meal and then go to sleep. When s/he is back from school s/he can have food to eat if there is any. Then s/he finds time to play. When s/he has played, s/he comes home to study. Yeah, that's it".*

Both Louise and Samantha describe children in Malawi as having a very busy and structured daily routine, predominantly of household work, alongside time for school and play. Evelin (11, F) explains further that a child is supposed to follow this kind of routine because this is his/her role: "*a child is the one who takes care of parents. ….. like cleaning dishes, washing for them, sweeping the house for them and cooking for them*". This idea that children are the ones who take care of their parents is very common in Malawian society and this is highly connected to ideals of respect and age and gender hierarchies (see section 4.2.3). It is considered that older people 'know better', so "*a child is supposed to listen to his/her parents. For instance, when parents tell him/her that this is bad, s/he has to listen and abide to*" (Samantha, 17, F).

Subsequent to the belief that views children as an 'asset', ideas of romantic and carefree notions of childhood are common mostly amongst adult participants. "*A child loves to play, s/he cooks with friends 'masanje'*[27]*, but also singing and dancing".* During the time of play and socialising, children are perceived as carefree who are "*expected to be happy in his/her daily life. I can say for a child to be happy, s/he needs to be fed with the right food, cleaned, and clothed properly, then the child is happy*" (Esnat, 41, F).

Additionally, to a 'carefree' childhood, almost all of the adult participants claim that children need to be taught values and constantly be advised, as they do not know what is right or wrong. Children are seen both as 'biologically vulnerable beings in need of protection and nurturing' and concurrently as a social construction, which influences certain social functions and relationships (Boakye-Boaten, 2010, p. 108). Masamba (82, M) here explains, "*We then teach her/him our tradition. We teach children what is good and bad. We direct them to do what is right and obstructing them doing what is wrong. We do that until the child becomes adult.*" Advising and guiding children are adult responsibilities identified by all adult participants in this study reflecting notions of children as 'becoming'. Indeed, Phiri and Abebe (2016) state that 'a child ought to be trained, socialised and

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[27] *Masanje* is a role-playing game where children, mostly girls who are still learning to cook, pretend to cook different things in small amounts using small utensils.

inculcated into the values and norms that lead to successful adulthood' (p. 389). Nevertheless, moving beyond the narratives from the participants, agency plays a vital role in the construction of childhood and children construct their childhood by being social agents in their everyday lives.

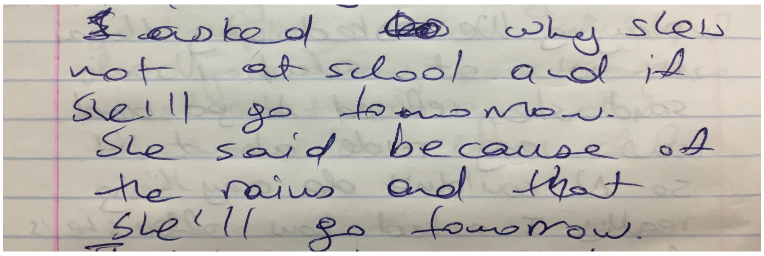
Even though children's agency is not always clearly stated, it is observable and noted by children and young people, as well as by their families in different ways. For instance, Seymour (2005) observed that children working in the family business would exercise their agency by either performing the minimum required labour or would turn the work to personal gain. Children and young people are considered as agents of their own lives, who actively make decisions and influence their environment (see Chapter 2). The children and young people, who took part in this research, even though due to their particular caregiving roles they have increased responsibilities in comparison to other children and young people of similar age in their communities, display their agency in different levels, ways and occasions. For example, during observations it was noticeable that children actively make decisions or negotiate everyday life activities and important decisions, such as when they would go to the market, when they would play and who with, when they would do household chores and whether they would go to school or stay home with their ailing relative.

Robson and colleagues (2007a) argue that agency 'is dynamic' and consider that children and young people demonstrate different degrees of agency, over different periods of time (p. 144). Specifically, they identify the following degrees of agency: 'no agency' (children need to act in a way against their will); 'little agency' (children have little choice/ they act out of necessity); 'secret agency' (children exhibit some resistance to adults); and 'public agency' (children demonstrate agency openly) (Robson et al., 2007a, p. 144).

Considering these degrees of agency, there were a few instances demonstrating complete lack of agency in the children's lives. For example, when Chimwemwe (17, F) and Chifunilo's (10, F) grandmother (Helen, 95, F) passed away, Chimwemwe (17, F) told me on the day of the funeral that she wanted to stay in the village instead of returning to the distant city of Lilongwe where her parents and family live, in order to wait for Chifunilo (10, F) finish her schooling. A day later, I received a phone call from a neighbour informing me that the girls' father had decided to take them back to Lilongwe the next day.

Following this event, Chimwemwe (17, F) having only 'little agency' responded by finding a way to call me and say goodbye: "*My phone rang and surprised me because it was late evening. It was Mina (Chimwemwe's neighbour) who told me that the girls are leaving tomorrow for Lilongwe until further notice. Now Mina gave Chimwemwe the phone and she started talking to me in Chichewa, I think she was trying to say goodbye*" (Fieldnotes, 13/02/2016).

Although the girls were not included to the decision making in relation to where they were going to live following their grandmother's death, it was observed that the girls were able in some instances throughout their everyday lives to make decisions and act in their own way even if that was limited. The following example could indicate 'secret agency' and resistance to 'adult' control. One day, I arrived at Chifunilo's (10, F) house to find her there when she should have been at school.



I asked why she's
not at school and if
she'll go tomorrow.
She said because of
the rains and that
she'll go tomorrow.

Figure 2: Extract from fieldnotes (27/01/2016)

Chimwemwe (17, F), who acted in a parental role as her younger sister's guardian, was not happy with Chifunilo (10, F) and thought she was just using rain as an excuse as she explained that this has happened other times when there was no rain.

Despite the occasional resistance Chifunilo (10, F) exhibited, Chimwemwe (17, F) was the one making almost all the decisions in their household, from important decisions about finances to everyday decisions, such as whether Chifunilo (10, F) should go to school, thereby demonstrating 'public agency'. Their grandmother was very ill and not able to be part of any kind of decision-making, so her parents had sent Chimwemwe (17, F) to this village outside the city of Blantyre to take care of her grandmother and the household. Chimwemwe (17, F) was responsible for renting out an extra room they had in the house and dealing with the finance, including how much they need to keep and spend and how much to send to her parents in Lilongwe.

Involvement in decision-making and control is not the only way to explore agency. By taking a situation into their hands, children and young people can feel empowered (Bessell, 2009; Phiri, 2016). By getting involved in their families' economic and social lives, they become responsible and capable individuals. In his research about children's work in Zambia, Phiri (2016) states that 'children in this research are aware that their parents are often not in a position to meet all their needs; hence, they take personal initiatives to meet them' (p. 693) showing children's agency and active roles in their own lives.

This is exhibited also through the relationship that developed between the children and young people with myself, my research assistant and the project. "*So, that was a first – first time a participant said 'yes, I want to stop' during an interview*" (author's fieldnotes, 15/12/2015, first visit). When I asked Eveline (11, F) if she is happy to continue with our interview or not, despite her age and situation, she replied that she wanted to stop which was unusual and surprising but did not explain why. Eveline was not the only one who stated her mind during a situation where many would not choose to do so. As discussed in Chapter 3, Daisy (13, F) also declined to do the camera and diary activity despite her aunt's (Elesi, 51, F) persistent advice to do otherwise.

Overall, this section has attempted to show a little of how dynamic, fluid and complex children's childhoods in Malawi are. It also looked at children's agency which in many ways is limited but it was observed that children constantly attempted to have an active role in their everyday lives. This is important to take into consideration when next considering children's roles and experiences of young caregiving. The following section considers how age and gender hierarchies add to the construction of Malawian childhoods.

4.2.3 Age and Gender Hierarchies

Gender and age are both dominant notions structuring Malawian societies. Despite some similarities, ideals of femininity and masculinity are not always the same in Malawi as in Western societies. When considering gender influences, there are varied dominant ideas of femininities and masculinities among the research participants, including examples that present girls and boys in different ways.

Figure 3: Drawing collage by George (17, M) (drawing A) & Eveline (11, F) (drawing B)[28]

The drawings above (Figure 3), made by two different young research participants, display their ideals of how young boys and girls "should" look and, as the young participants indicate, these are influenced from South Africa and Western societies. When asked to talk about what they had drawn, both George and Eveline stated that the drawings represent how children should look and more specifically

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[28] These two drawings were not part of any of the activities I asked the participants to do. During home visits, I always took paper and coloured pens and all the participants were told they were free to use those and draw whatever they want. So, these drawings were made within this context.

what they should own, such as modern clothing, electronic devices, like MP3 players, satellite TV, watches, two-storey houses with swimming pool and playground. Both George and Eveline reported that these are ideas taken from television and magazines and are very popular amongst their peers. During our conversations stimulated by the drawings, they stated that they do not want to look like them though, as they know they cannot have the money to do so. Conversely, however, when later asked how they envision themselves in the future, many of the participants claim that they would like to earn money to have big and expensive houses and described a very similar life to the one they previously said they cannot have.

Moving further from gender influences and stereotypes, age and gender hierarchies are very common in rural and urban households in Africa, with women and girls usually deferring to men and children to adults (Laird, 2012). Among children in families, older siblings are also often the ones who have more caring roles and responsibilities than their younger siblings (Evans & Skovdal, 2016). Data gathered for this thesis showed clearly that issues of hierarchy in terms of age and gender were salient in the research participants' everyday lives. Age and gender constructions were mostly expressed through the lens of what individuals' responsibility and rights are. For instance, it is common that younger girls are the ones responsible for even younger siblings and household chores (Laird, 2012). It is observed, however, that as the survival of the household is the paramount aim, children of both sexes are involved and contribute accordingly depending on the needs of the family, both inside and outside the house. Correspondingly, Punch's (2001) findings from her study in Bolivia suggest that birth order and age can be more influential factors than gender when allocating household responsibilities amongst children. Indeed, findings from research in Kenya (Skovdal et al., 2009) and Tanzania (Evans & Becker, 2009) also concluded that although it is usually girls those who assume caregiving responsibilities, many boys also undertake these kinds of roles when there is no female relative available.

The following conversation with Samantha (17, F) highlights that even though there are traditional gender expectations when required anyone will do the same things for the household regardless of their age or sex.

> Research assistant: *Who is supposed to cook for lunch in the family?*
>
> Samantha: (laughs) *a mother.*
>
> Research assistant: *Is a mother supposed to prepare supper for the family as well?*
>
> Samantha: *If there is no girl child in that family she can cook then as well, it is our tradition here in Malawi. She can cook in the afternoon and she can cook in the evening. But if there are some girls in that family, they can help each other cooking.*
>
> Research assistant: *What kind of other help can a young girl offer to her mother?*
>
> Samantha: *Washing dishes, mopping in the house, giving father and her mother water to bath, then taking tea, thereafter sit back and relax.*
>
> Research assistant: *You mean helping her with all household chores?*
>
> Samantha: *Yes.*
>
> Research assistant: *Are those chores done by girls only and not boys?*
>
> Samantha: *Aaah! No!* (laughs) *Boys can also work. For instance, they can sweep outside on the ground or mopping in the house. They can do all that without any problem.*

Thus, Samantha explains that there are conventions and expectations about divisions of labour based on gender and age, but they are flexible divisions according to circumstances.

Skovdal (2009) observed that chronic disease and poverty have de-gendered expectations of children and many cultural practices. He explains that 'although the socialisation of children tends to be gendered, what happens in practice within some households is an adaptation to poverty and disease, further highlighting the fluidity of childhood' (Skovdal, 2009, p. 124). Fieldwork observations and informal conversations confirm that household chores and other related responsibilities of reproduction are performed by all household members, with young girls being first candidates, then adult women or young boys and lastly adult men, although this is not the case when it comes to production (e.g. farming) and income generating activities. Income generating activities are usually men's responsibilities, however, women, young girls and boys are also required to economically contribute to their families.

The following collage of drawings (Figure 4) by the research participants shows how one important daily task essential for household reproduction, carrying water, is performed by both girls/women and boys/men, but in different ways. Water carrying is a very common everyday activity, which is usually young girls' responsibility, although young boys often carry water as well, which when very heavy loads are carried can be detrimental to the health of children and young people (Robson et al., 2013b). It is considered to be a feminine way of carrying water (and other loads) for girls and women to place the bucket on their head, while boys (and rarely men) carry water by their side. Unless the object they carry is extremely heavy, head loading is not generally the preferred carrying method for men and young boys.

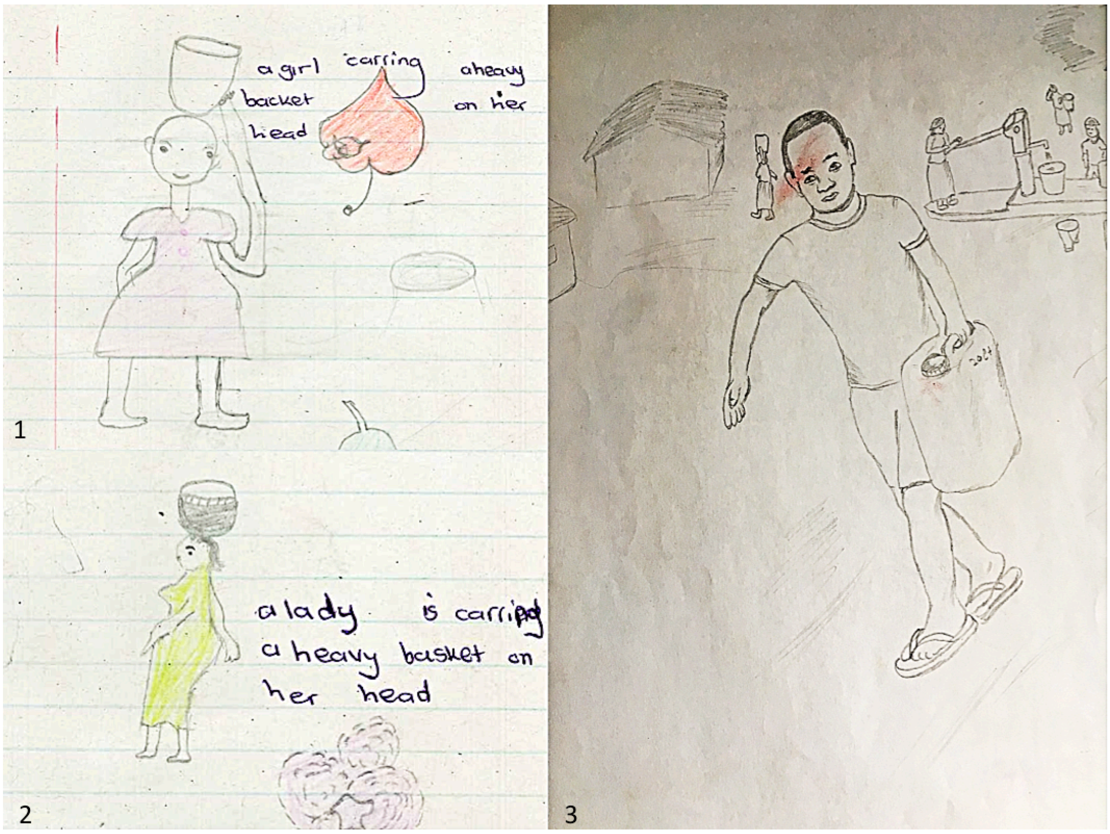

Figure 4: Drawing collage by Rejoice (17, F) (drawings 1 & 2) & George (17, M) (drawing 3)

Furthermore, highlighting age and gender hierarchies, in this account Christina (52, F) offers a list of a child's duties and concludes with an example that highlights the age hierarchies dominating children's lives: "*Then he/she puts the water on fire* *so that the father should bath, and the mother should also bath. Then the child will be the last one to take a bath. Not that the child should take a bath before the father and the mother*". It is indeed considered very important within Malawian households that these age hierarchies are followed and respected, and sometimes age hierarchies are prioritised over gender. These are reverse of Western values where parents often are expected to put their children's needs before their own.

Gender differences do not only exist when household chores or other activities are allocated to people. Gender is also important when matching a carer to the person needing the care. Most of the families in this study match in terms of the gender of the caregiver and care receiver, but as Robson and Ansell (2000) state this is not always possible, so for example, Andrew (19, M) is caring for his two very ill grandmothers, Nessie (90, F) and Aisha (105, F). This, however, has not been an easy task for Andrew who explains that because of the gender differences, he had to face a number of additional challenges especially when he had to undertake personal care for his elderly grandmothers (see Chapter 5).

Exploring discourses of caregiving and masculinities further, Andrew (19, M) and George (17, M) both take care of female relatives often leading to uncomfortable feelings for them, especially when carrying out personal care tasks. Examples of these feelings and participants' narratives are explored later in chapters 5 and 6, but what is significant to highlight here is that the notion of hegemonic masculinity is complex and contested in the Malawian context. It is challenged and unsettled by carrying out caregiving tasks, including the personal care for female relatives, which male participants undertook (Connell, 2005). Some participants did not feel 'masculine enough' in comparison to their male peers and had to re-negotiate their identities in relation to their understandings of their caregiving roles. On the other hand, Matias (16, M) was chosen to be his grandfather's caregiver precisely because of his masculine features, as due to his grandfather's disability and mobility limitations, being strong enough to lift and carry his grandfather is necessary for assuming this role. When Matias discusses this, he clearly states that he feels very proud and is happy to continue undertaking his caregiving role.

4.2.4 Summary

Overall, this section explored who is a child in Malawi, how children construct their everyday childhoods and how they display agency, as well as a few of the roles, including gender and age norms, play in children's everyday lives, and in decision-making within families and their societies. The summary of the findings of this section is that children and childhood in Malawi, as in many countries in sub-Saharan Africa, are not and should not be described primarily with reference to Western ideas of childhood norms. As Robson (2004b) states 'there needs to be less emphasis on northern myths of childhood as a time of play and innocence and more attention on defending children's rights to work as well as to be supported in their work under appropriate circumstances' (p. 227). Although scholars have started to address these kind of issues, there needs to be a better understanding and recognition of the diversity and multiplicity of global childhoods which are geographically and historically specific (Evans & Skovdal, 2016). What is also noteworthy though, is not to represent those children and young people as passive and victims and label them as 'African children who have a 'dark' childhood' (Ntarangwi, 2015). It is vital though to look at the complexity and diversity of African childhoods while considering and understanding the extremely challenging realities those children face due to the social, economic and political circumstances they are living into (Ntarangwi, 2015).

What the accounts of this study present are that participants consider children as individuals who are under 18 years old, who are not mature enough to be adults, who do not have the thinking capacity or intelligence to be independent individuals and those who still 'belong' to their family. Children are seen as 'family-assets' who actively contribute to their household and who when they grow up to be adults they will continue contributing through providing financial or other material help. Narratives from this study also describe children as innocent, who need guidance and support, who need education and their friends. In addition, according to the participants of this study, children are seen as the ones who continue with keeping Malawian traditions alive for the next generation. Children and young people of this study also exhibit variable levels of agency depending on the household situation and their age. Age and age hierarchies also play a significant role when it comes to allocating responsibilities and decision-making in the household.

In regards to gender and caregiving, although girls and women are usually the ones assuming caregiving roles, boys can also undertake caregiving responsibilities for both male and female relatives. Although it is important to acknowledge the gendered nature of caregiving, when considering children and young people with caregiving responsibilities, boys and young males should not be excluded from this group. Therefore, caregiving should not only be associated with girls and women, but male caregivers of all ages should be considered as well. Understanding the nuances and plurality of children and childhoods in Malawi, where this study took place, provides a suitable basis before exploring in the next section, the meanings of care, becoming a caregiver and young caregivers' roles.

4.3 Meanings of Care[29]

This study is concerned with children's and young people's experiences of caring at individual, family, social and policy levels. This chapter so far has attempted to investigate understandings of everyday childhoods in Malawi. Subsequently, it will explore care and its meanings within a Malawian context before moving on to discuss children's and young people's caregiving roles.

There are multiple meanings of care shaped by age, sex, gender, social status, role, health and spirituality. Those meanings reflect how someone experiences care which is further influenced by their values and beliefs about relationships, families and communities (Bowlby, et al. 2010). This is why it is very important to discuss the different meanings of care at an individual and socio-economic level. Care is about responsibility, reciprocity and shared understanding. Caring relationships

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[29] According to the Oxford English Dictionary care (verb) is defined as 1. "Feel concern or interest; Attach importance to something; Feel affection or liking" which has an emotional tone and 2. "'Care for' look after and provide for the needs of" which gives a more practical tone. In Chichewa, 'taking care of' and 'caring for' means the same thing and is translated as 'kusamalira'.

are characterised by interdependency and reciprocity (Bowlby, 2012; Bowlby, et al. 2010; Evans & Becker, 2009; Tronto, 1993) (see Chapters 2 & 6).

4.3.1 Care as Material and Practical Support

'Care is the provision of practical or emotional support' (Milligan & Wiles, 2010, p. 737). Undeniably, participants express the meanings of care in a variety of ways. The most common 'definition' among both children and adults focuses on the practicalities of caring tasks or work, according to which care means giving "*a person what s/he wants at the right time, things like food or bath*'' (Elesi, 51, F). Samantha (17, F) explains further that care is also related to household chores:

> Samantha: *Mmmh! Taking care of someone means doing everything you can manage to somebody. Like doing everything at home if you say that you are taking care of somebody.*
>
> Research assistant*: Can you give us an example?*
>
> Samantha*: Taking care of somebody like washing his/her clothes, cooking for him/her, washing his/her dishes, mopping his/her house, and everything.*

4.3.2 Sharing as a Form of Caring

Care is not only synonymous with providing material care, but sharing is also important; *"I should just say sharing things is one way of taking care of someone"* (Matias, 16, M). Louise (12, F) states that her little cousin Stefan (8, M) takes care of her in the following way:

> Louise*: Maybe when I am at school and my friends have food but I do not, he (*Stefan*) will give me money, he takes it from Fiona* (his mother)*. If my parents have not given me money, he comes to me and says, 'I have money K20 take this K10 use it for food and I will remain with K10'*.

Here, Louise describes how common it is in Malawian settings that the younger take care of the older, even among children, and at the same time, children (while still young) take care of parents and grandparents, highlighting the distinct difference to Western norms.

Viewing sharing as caring portrays the strong sense of community within Malawian societies. Care is not limited to only one person or a family, but extends to a whole community. For example, during a home visit, we were discussing funerals and the family explained that in events like this the whole village would help by giving food, nsima or money. I wrote in my fieldnotes '*when a funeral takes place, it is customary for the family to feed everyone attending. Most families do not have money and so the whole village share what they have*' (Fieldnotes, 12/01/2016). It is considered important that especially in the case of unpredictable yet culturally important events like funerals the family has everything they need and this often means that the Chief and the whole village need to offer any kind of resources available. This was the case with Chimwemwe (17, F) and her sister Chifunilo (10, F) when their grandmother, the person they were taking care passed away (see Section 4.2.2) they received money and food from their village. This kind of caring support offered by the community does not always occur, for example, Hannah's (19, F) required support due to her mother's ill health but the Chief would not agree to provide any. The reason for that according to Hannah and her mother was because a local NGO had already given them a house and thus it was considered that they had received more than enough help and maybe there was also the expectation that the local NGO would (or should) continue to help them in other ways.

4.3.3 Adult Care vs Child Care

According to Elesi (51, F) there is a clear distinction between care provided by adults and care provided by children. She claims that adults/parents take care of children "*by sending them to school, giving them enough food, bathing them and giving them time to play*", while "*children take care of parents by helping them to clean dishes, drawing water, washing clothes or even sweeping the house*". Similarly, Louise (12, F) states that parents take care of children by "*telling them to go to school and also that when they go to school they will learn good things. Then what they tell them is not to engage themselves in boy and girl relationships whilst they are still young*", and continues saying that children "*take care of others by respecting them*".

In addition, some of the adults interviewed presented one meaning of care as an obligation to teach children what is morally right and wrong.

> "*Taking care, meaning that people are taking care of someone, because caring is in two ways. There is care where someone is drawing you water, and then there is care for those that are children, like giving them advice, tell them about manners if they are rude to you*" (Rute, 63, F).

Thus, is expressed the view that not chastising or correcting the poor behaviour of children would be uncaring.

4.3.4 Care as Emotional Support

Children and young people who were interviewed during my research, overwhelmingly acknowledge that care is not limited to providing material support or doing household chores. Care could be also described as an emotional response to those in need. For instance, Andrew (19, M) mentions that "*it (*care*) is like looking after someone else. Maybe if he or she is disabled or not able to work or too old, is like you take care of her, be with her*". He describes emotional support as being there, being present as he then explains that his grandmothers might feel lonely as one of them cannot walk and is bedridden and the second one has significant mobility issues, so they constantly stay at the house and they can feel quite isolated. George (17, M) also explains that care means being there for the other person to support emotionally when the other person feels sad and explains "*it* (care) *means helping someone with those things which they cannot do on their own because they feel sad*".

Emotional care is also described by the family members receiving the care. For example, Rute (63, F) talks about the different ways her granddaughters are caring for her and says that one way of caring for her is loving her. Rute further explains that this feels to her "*sweet like sugar that I am loved"* and continues by explaining how this makes her forget her disability and ill health and makes her feel happy. Mary (35, F) also discusses how difficult it was when her brother died and she started experiencing mental health problems which were triggered by the sudden loss. Mary describes that she was in South Africa then and that it took a very long time until she got money to return to Malawi and that when she was home she could not do anything, she could not sleep and she had many thoughts in her mind that made her heart beat very fast. Mary then explained that her Rosemary (18, F) supported her by showing her love, by being there near her and telling her that it will be ok and that "*she* (Rosemary) *just chats with me, she tells me stories that maybe I should forget some of the things*".

4.3.5 Care as Respect, Understanding and Duty

Care in the view of the research participants is also related to agency and decision-making, as well as respect and understanding. Here Eveline (11, F) explains how a child is told by their parent what they need to do but also that the child knows their responsibilities to prepare food for the household and does it unasked:

> "*In the morning, even if the parent*[30] *does not see me before going to school, I know I have to make porridge and give her* (her blind grandmother) *the porridge in the hands with a spoon. Then I can ask them* (the adult who is around and makes the decisions) *if I can go to school and then the parent says yes. When I am back home from school and I will find my grandmother just sitting down, I will cook for her and the others around."*

Then Eveline (11, F) continues with explaining that sometimes the food they have is not enough and that although the adults will offer all there is available to the children, the children will share their food anyway.

> *"Sometimes when we have relish and I cook it, but we realise that the relish is not enough, the parent tells me and the other children to eat it and they* (the adults) *will just have nsima and that it is enough for them. But we* (the children) *tell them 'no, let's eat together'*".

This quotation from Eveline (11, F) makes an important point that was observed in most of the families I worked with. From the perspective of children, care for children means accepting what their parents can provide for them, and if this is not enough, usually due to poverty, children regard as care sharing what they have with their parents, even if the parents are prepared to forgo food in order that their children eat a full meal.

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[30] When Louise says "the parent" here, she does not refer to her biological parents but she means the adult who is around at the time and who is making the decisions.

Furthermore, Chifunilo (10, F) states that a person is taking care of someone by "*doing what they ask you to do*", while Louise (12, F) clarifies "*if asked to work for them* (parents/adults), *they* (children*) should really work for them*". Andrew (19, M) also states that when a child takes care of someone older it is important that "*if she asks you 'do this', you do this for her or him*". Rejoice (17, F) adds that children take care of adults by "*listening to elders, respecting them and assisting them with chores they cannot manage*". This suggests that from the children's perspective, caring can be presented as a duty of fully complying with adults' authority, and doing what they are asked, especially helping the older generation.

4.3.6 Care and Love

Love, gendered roles and care are connected in different ways. Here Elesi (51, F) talks about mothers and women being the ones who usually take care of people. When asked why do mothers and women usually do that, she replies "*a mother is someone who gives birth with love and so, she loves to stay at home most of the times. Whilst a husband usually goes to search for food for people to eat at home*". Rute (63, F) looks at care, love and God and explains:

> *"my interpretation is, someone who is giving care to me is merciful, and s/he is loving me because there has to be love. Like the way you are, you have The Holy Spirit of God. When you sit here with us, your heart is touched like how our heart is touched as well. That is the love of God because Jesus Christ was taking care of even the lepers".*

Rute (63, F) here refers to spiritual love and explains that through knowing how God loves everyone, she feels the same love in her heart. As explained in section 4.3.4 about emotional support, Mary (35, F) also states that her sister's love was one of the things that helped her overcome the difficulties she was facing when she returned from South Africa to Malawi.

The idea that love and other emotional drives are an important motivation factor to care for others even under very difficult circumstances was noticeable amongst all research participants. Chimwemwe (17, F) says that care is "*helping those who cannot do anything, doing what they cannot do for them because you love them*", while Chifunilo (10, F) states that care means "*helping those who cannot do anything, doing what they cannot do for them, so you do things for them to make* *them happy and healthy*". Matias (16, M) also explains that caring for someone is about wanting to help someone out of love to feel better. He specifies that "*caring means looking after someone who lacks something and is not feeling happy and s/he needs help*".

Loving someone and taking care of them meant for the participants that they help someone to be happy and healthy. Esnat (41, F) here summarises this idea "*care means taking care of someone so that s/he has a healthy and happy life*". There was a common idea that when a person, child or adult, loves someone and cares for them, they want them to be healthy, happy and successful.

4.3.7 Care as Economic Value

The economic value of care that children can provide is highlighted by Masamba (82, M) who states:

> "*Aaah! A child can help* (care for) *the elders provided s/he is educated. Some elder women are poor. So, a child can help her in many ways. S/he can help her by buying clothes, by sending her sugar, soap and many more. Even by visiting them. Yes, there are a lot of ways that people can make money; for helping elders. Yeah*".

The emphasis from this elderly respondent is on a child gaining an education so they can earn enough money to be able to buy things needed by poor older relatives and provide material care from a distance by sending help in cash or kind and also caring by visiting them and wanting to know how they are doing.

As discussed in Chapter 2, care does not passively occur between caregiver and care-receiver, but it is a complex network of actions and actors that involves a wide range of connections (Tronto, 1993). The nature of care provided and decisions about who will provide care depend on a range of factors, including family relationships, people's availability, traditions and norms, access and opportunity, etc. Therefore, in order to understand care further, a systematic examination of those factors is needed while taking into consideration not only the relationship between caregiver and care-receiver, but also including all the people involved (Milligan & Wiles, 2010). The following sections examine the factors which determine how children became caregivers and what kind of responsibilities they have. The nature of relationships within families where young caregiving occurs is discussed later in Chapter 6.

4.4 Caregiving Children

4.4.1 Children Taking Caregiver Roles

Research suggests that children and young people get involved in care work for a wide range of reasons and factors, such as love and attachment, gender, age, family norms and traditions, family structure, financial situation, needs, etc. (Becker, 2007; Evans & Becker, 2009; Robson & Ansell, 2000). These factors can be push or pull factors; they can contribute towards the decision for a child to become someone's carer or not to. Moreover, children and young people may take on the role of the caregiver either because they were asked to do so because they wanted to, because '*there was nobody else to do it*' (Hannah, 19, F) or a combination of any of those factors and more.

In some cases, the decision was made in a straightforward way by a family member. For example, considering age as a factor, in Andrew's (19, M) case it was his mother who decided to send him when he was 12 years old to take care of his two grandmothers, as he was the only one of his siblings considered to be old enough to take on this responsibility.

> Kalia*: Whose decision, was it? To start taking care of them?*
> Andrew: *Mostly my mother's.*

Something that his grandmother, Nessie (90, F) confirms:

> Nessie: *It* (the decision) *was made by Andrew's mother alone to say 'you will be helping grandparents'.*

Family expectations and pressure are also factors that contributed in this case. Andrew (19, M) states that it was very hard for him to become his grandmothers' carer (for more details in regards to this, see Chapter 5).

In addition, taking into account factors like age and sibling order, the following example shows that in some cases more than one adult family member makes the decision. In Matias's (16, M) case his mother was the one who decided that he was going to take care of his grandfather, Masamba (82, M). Initially, his older brother was the carer, but as Matias explains, things had to change:

> Research assistant: *Who made the decision that you should be taking care of your grandfather?*
>
> Matias: *My mother. I have an older brother who used to love to take care of him* (grandfather) *but he also loved to walk around and not stay home, so I was the one who would stay home most of the times. Then my older brother got married, so I am the older one who is here at home and then there is my younger brother. So, I am the one who takes care of him* (grandfather).

Later, based on the child's maturity and level of competency, Matias's grandfather, Masamba (82, M) clarifies that Matias became his carer when he was *'intelligent'* enough, showing that 'appropriate' care is valued:

> Masamba: *Matias started helping me at the time he started to show some intelligence. Yeah, thus, then I took him to start helping me.*
>
> Research assistant: *When you say that he started to show some intelligence, can you explain what do you mean?*
>
> Masamba: *For instance, when I gave him a brush to wash my back, I found him doing it properly. So, it is when I saw he is becoming intelligent.*

Thus, Matias (16, M) became a young caregiver when it was thought by his family that he was competent at practical caring tasks, as well as personal care, such as bathing.

A similar situation was Eveline's (11, F) and Louise's (12, F) case who are both taking care of their blind grandmother, Rute (63, F). Eveline (11, F) was the first caregiver of her grandmother Rute (63, F) but when her parents got divorced and her mother moved to another village, a second caregiver was necessary. That is when Lina (72, F, Rute's sister) alongside the girls' parents decided that Louise (12, F) was going to help when Eveline would be away at her mother's house and gradually Louise became the main caregiver.

> Research assistant: *So, should we say that you are the one who helps Eveline or is she the one who helps you take care of her (Rute*)?

> Louise: *She helps me sometimes when she is in the mood, and sometimes she goes at* (name of village) *at her mother's place.*

Moreover, exhibiting agency, Samantha (17, F) claims that she decided to become her grandmother's (Clara, 85, F) caregiver on her own after Clara's sister who used to be her main caregiver passed away five years ago.

> Samantha: *It happened that I used to come and stay with my grandmother. Then after my other grandma died and my mother moved to Lilongwe, I refused to go with her. I told her that I would stay with granny here. So that time I was in standard 8. Thus, the same time I started taking care for her.*

Another case of displaying agency and decision-making by the young person is Rosemary (18, F) who decided on her own to become her older adult sister's (Mary, 35, F) caregiver four years ago, as there was no one to help, which suggests no choice.

> Rosemary: *Myself, I decided myself after seeing that mom is old, Mary came back (*from South Africa*) sick* (with depression and panic attacks)*. She* (Mary) *is the one that failed to take care of us, so I, myself, just saw that there is no one who can help and I should just take courage and help her so that she should get better.*

In the same way, Chimwemwe (17, F) was 13 when she decided to take care of her grandmother. Her grandmother (Helen, 95, F) became very ill due to heart problems and Chimwemwe who used to visit her often, took the decision to stay with her permanently. With a sense of commitment, Chimwemwe explains "*I felt good because I was feeling sad that she was living all alone without anyone to take care of her. So that's when I thought of moving from where I was staying to come here*". A couple of years after she moved in with her grandmother though, Chimwemwe realized it was difficult to take care of her grandmother on her own, so she asked her mother to send her some help. So, it was decided that her younger sister, Chifunilo (10, F) was going to be an additional second caregiver *"so that I should be helping her with other things".*

Finally, motivated by caring and loving relationships with their kin, in some cases the young people saw their relatives becoming ill and no one there to help, so they took over the responsibility. George (17, M) started taking care of his mother when she became very ill and was diagnosed with HIV/AIDS. His siblings were much younger at the time and as the older child he felt he was the only one able to do this. Likewise, Hannah (19, F) testifies that:

> *"Nobody advised me to do this only that I was forced by the circumstances. When I saw that my mother is ill, I got forced to drop off school, look for piecework and take on the responsibility of taking care of the whole family*."

Her mother, Memory (35, F) further adds "*this decision was made by God but through Hannah*", attaching a more spiritual feature involved in the decision-making. This is similar to Robson and Ansell (2000) findings that suggest that many of the participants claim to be motivated to be carers from Christian values.

This section has explored the reasons and factors which lead children and young people to become a caregiver impelled by the circumstances, by choice and responsibility and/or by obligation and expectations. The next section investigates what kind of responsibilities they assume.

4.4.2 Caregiving Responsibilities

Following the complex nature of becoming a young caregiver, this section examines what kind of responsibilities the children and young people with caring responsibilities assume. Without having access to any kind of local or government services (see Chapter 7), families affected by disability or illness are often forced to place children and young people in the role of care-provider (Evans and Becker, 2009).

It has been observed that children and young people with caregiving responsibilities, both in the Global South and North, undertake a level of responsibility that is usually associated with adults (Aldridge & Becker, 1999). Research suggests that these caregiving responsibilities of young people vary from domestic tasks and farm work to more personal care (Aldridge & Becker, 1999). It is however 'the intimate care (giving the care recipient medication, bathing, massaging and dressing them) that most clearly distinguishes the labour of young caregivers from the usual work young people do in Africa with respect to household chores' (Robson et al., 2006, p. 100).

Evans and Becker (2009) investigate children's work within families affected by HIV & AIDS in the UK and Tanzania and identify a list of categories that outline a summary of children's duties. The following table (Table 5) is an adaption from Evans and Becker's (2009, p. 130) summary and additionally includes findings from Robson and Ansell's (2000) study with young carers in Zimbabwe, Skovdal's (2009) results from his research with young caregivers in Kenya and finally, an outline of the findings of this study.

Tasks	**Robson & Ansell (2000)**	**Evans & Becker (2009)**	**Skovdal (2009)**	**This study**
Household chores	Domestic work, cooking, washing clothes, fetching water, heating water, sweeping, shopping, gardening	Cooking, cleaning, washing dishes, laundry, shopping, fetching water, tending livestock, crops and vegetables	Cooking, cleaning	Cooking, cleaning, fetching water and firewood, washing clothes/dishes, shopping, harvesting crops and vegetables
Healthcare	Hospital-related care, taking care-receivers to the hospital, staying with them, giving medication	Collecting/giving medication, accompany to doctor/hospital, providing nutritional food, assisting with mobility	Administering medication	Finding and providing medication, accompanying to doctor/hospital appointments, assisting with mobility
Personal Care	Feeding, bathing, toileting sleeping in with care recipient	Washing, bathing, assisting to eat, dress and use toilet	Bathing and applying creams, feeding and personal care	Washing, bathing, assisting them with eating, dressing and using toilet, emptying morning bucket
Childcare		Helping with schoolwork, supervising siblings, bathing siblings		Supervising children, helping with schoolwork, comforting, supporting, personal care
Income-generating activities	Agricultural work such as harvesting crops, feeding and herding animals	Begging, farm work, selling produce, domestic work, working in shop	Contributing significantly to the household economy	Piecework, e.g. domestic work, farm work, building/construction, painting,

				etc., begging, selling products
Emotional and practical support	Giving comfort and encouragement, providing reassurance	Talking, comforting, reminding about appointment, bills, etc.	Emotional support, encouragement, sharing happy stories, being present and caring	Talking, comforting, supporting, encouraging, being present, sharing happy feelings Maintaining and repairing house, looking for alternative safe accommodation
Spiritual care				Praying with the care-recipients and for them, going to church together or escorting them, reading the Bible to them

Table 5: Children's & young people's caregiving responsibilities

All the participants of this study reported that they are taking or had taken on the above responsibilities either during the time of the fieldwork or at some point in the past. Indeed, from Table 5 above, it is evident that the findings of the research studies from Zimbabwe, Kenya, Tanzania and Malawi are similar with only a few differences in the caregiving responsibilities of children. The results from this study additionally demonstrate that young people identify within their responsibilities spiritual care, such as praying, reading the Bible and going to church with the care receiver. Below are examples of each of the categories of caregiving responsibilities as stated by the participants of this research project.

Staring with household chores, Chifunilo (10, F) states that her sister (Chilwemwe, 17, F) *"asks me to sweep the house, fetch her water to help with bathing. She tells me to wash her* (grandmother's) *clothes, she tells me to wash the dishes*". Nessie (90, F) describes how Andrew (19, M) takes care of herself and her sister in law,

> “*Mmmh, Andrew takes care of us, he cooks for us. He draws water and puts it inside this house, sometimes he goes to the market to buy relish or maybe draw water from the tap and brings it here*”

The level of responsibility changes over time depending on the circumstances and needs of the family. For example, while chatting about household chores, Daisy (13, F), who is taking care of her aunt Elesi (51, F) with HIV, stated that:

> “*At first when my aunt used to stay at her home, I would first cook for her at her house because she would go to bed early and then would go to my mother’s house and cook there as well. But since she* (her aunt) *started staying here* (mother’s house)*, I just cook once and we all eat together.”*

Figure 5: Drawing collage by George (17, M)

(drawings showing: 1. Washing clothes, 2. Doing income generating activity (piecework), painting advert, 3. Giving money and shopping to his mother, 4. Cooking, 5. Working in the fields, 6. Repairing his mother’s house, 7. Doing income generating activity (piecework), carrying bricks)

The collage (Figure 5) with drawings made by George (17, M) illustrate the wide variety of responsibilities young caregivers have. Indeed, apart from household chores, healthcare and personal care are both responsibilities that the children and young people undertake within their families. Andrew (19, M) shows his grandmother's photograph (Figure 6) to explain that he has to be involved in personal care as well: "*I have to empty her bucket*[31] *every morning and make sure her bedding is clean and dry*".

Figure 6: Photograph taken by Andrew (19, M)

Esnat (41, F) explains that her son George (17, M) had to quit school to take care of her and that he used to provide personal care especially during the time when she was very ill:

> "*Yes. He did not know how to take care of me, and he thought that maybe he should just quit school so that he takes care of his mother. So, he was cooking for me, sweeping and doing other household chores because my whole body was swollen and I used to wear adult nappies when I wasn't well. He even had to carry me to the roadside to get to the car to take me to Queens* (hospital)."

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[31] Andrew's grandmother uses the bucket in her room as a toilet during the night.

While talking with Christina (52, F) about how her daughter Rejoice (17, F) takes care of her, she states that her daughter takes her to the hospital and sometimes even carrying her there if they cannot afford to get a mini-bus or a taxi.

> "*Rejoice takes good care of this home and me. I really depend on her that even when I get sick, she is the one that tells me to go to the hospital and carries me from here to there. When I go to the hospital with this skin disease, I go with Rejoice. She would be absent from school to help me".*

For most young caregivers, childcare duties are also included in their responsibilities. Here, Memory (35, F) explains how she had to be left alone in the hospital so that her daughter Hannah (19, F) would stay with the rest of the family at home, as there was nobody else to help them and the consequences this event had.

> "*When I fall ill, she* (Hannah) *takes me to the hospital instantly. Once I had a tumour, right here... It grew bigger so that I was taken to the theatre at Queen Elizabeth Hospital. Before getting operated on, the doctor told me that the operations cannot be done unless a certain drug is given to me which will make me sleep and feel no pain. The doctor demanded the presence of at least a relative, however, I told him that my husband died long ago, therefore I have only my daughter, Hannah left. I told the doctor that Hannah is at home taking care of children, but you can go ahead with the operations here. The doctor and listened probably understood what I said and then I went under anaesthesia"*.

Figure 7: Photograph of Matias (16, M) & Masamba (82, M)

In the photo above (Figure 7), Matias (16, M) is helping his grandfather Masamba (82, M) to get up after falling down and explains that "*taking care of my grandfather means I have to help him get up when he falls*". Some of Matias's responsibilities are to be with his grandfather all the time so when Masamba falls and loses control of his legs, Matias becomes his help. Matias morning routine starts with going to Masamba's room, helping him get up, undressing him and helping him get dressed in clean clothes, emptying his bucket used as a rudimentary commode and then cleaning up everything. Then, if his grandfather feels well and strong Matias will help his grandfather to sit outside and then go to school, but if not, he will stay at home. During our interview, displaying the implication caring responsibilities can have for young caregivers' education and the unpredictable nature of his caring role (see also Chapter 7), Matias narrates the following story:

> "*That day I got prepared to go to school. Then, my grandmother who was still alive called me. My grandfather's legs were not functioning well that day. As I was getting ready to go to school, my grandfather called me and asked me to*

> *take him to the bathroom. So as I waited for him to come out from the bathroom, I waited until it was past the time of going to school. So I just stayed and did not go to school, I was just here and helped them with different things*".

A very important role that most of the children and young people take on is income generating activities most often in the form of casual labour, most commonly known as piecework (*ganyu*). Hannah (19, F) states "*I sometimes do piecework, for instance, I will go to the maize corn grinding mill where they pay me with maize flour, which then I use it to prepare nsima to feed the family*". However, Samantha (17, F) who has her own more formal job in a hair salon, states "*I give her* (grandmother) *money when I receive my monthly salary at the end of the month*". Income generating activities can be time consuming and create a lot of stress and worries for young caregivers, as they are often the only or main source of financial income within their household (see Chapter 7).

Subsequently, Rosemary (18, F) illustrates all the different ways she is taking care of her sister including but not limited to emotional support.

> "*Like I cook, clean, mop the house.. Eh.. In the house, I take care of Mary* (sister, 35), *mother, sometimes wash their clothes. And Paul* (her nephew, 7, M) *as well. I make sure he goes to school. Sometimes when he is hungry, he denies, so I escort him to school. That is what I do. Then the next thing I do is to make sure that I am taking care of my sister, when I wake her up in the morning I am supposed to heat water for her to bath, so she may gain some strength. Thereafter, if there is maize flour, I cook porridge and give her to eat. After that, she needs to take her medicine, so I also follow the time, so if she takes the porridge around 6, it means at around 7 I have to give her the medicine. Sometimes it is difficult because the sick person refuses to eat the food whilst a person who is alright can eat anything. Because she is not alright, and she is also not alright inside her body so you need to help her*".

Lastly, when times can be difficult for the person with the disability or illness, but not limited to that, their caregivers seek to help and support them through their spiritual beliefs. Rosemary (18, F) explains "*when I have some time I take the Bible* *and I study it with Mary* (sister, 35, F). *So, this makes us feel happy because it is like this reminds us of something and we do not forget it. It reminds that other people face hardships as well*". It is widely accepted that spirituality is a fundamental component of sub-Saharan African culture (Greeff & Loubser, 2008). Spirituality is not only used to help people cope with adversities, but it is also an integral part of their present and after lives. Informal conversations with participants revealed that they believe that praying and studying the Bible can benefit their physical and mental health. Nessie (90, F) also described a time when she had to go to the hospital and that more important than having food or other resources, she needed her grandson Andrew (19, M) to pray for her: "*So, the help I needed was of someone to be praying for me, not that he should bring food but that he should tell me the word of God. To say 'you will be fine do not worry' and that way one is happy in their whole life*". In addition, on several occasions, Hannah (19, F) claimed that she prays for her mother and the rest of her family so they can be healthy and well. In addition, Memory (35, F) states that her daughter Hannah (19, F) has always her mother in her mind especially when it is time to pray: "*At night, she* (Hannah) *comes to me to remind me to say the night prayer. She* (Hannah) *says to me: 'Mother, you have gone to sleep too early and you have forgotten to say a night prayer'*". All of the participants mentioned the value of religion and spirituality in their personal lives as well as being a part of their caregiving roles.

What this level of unpaid caregiving duties highlight is that the children and young people undertake a high level of responsibilities for relatives with chronic illness or disability in comparison to their peers who only have everyday domestic responsibilities as part of their household. Robson (2004b) highlights that this level of young caregiving is often invisible and calls for scholars who engage with global discourses on children's and youth geographies in sub-Saharan Africa, and also elsewhere, to consider children's unpaid and hidden care work in the household and the economy. Many scholars and policy makers have described these caring responsibilities as 'familial responsibilities' instead of child labour (Evans & Skovdal, 2016). This is a particularly problematic categorisation as this excludes young caregivers from legislation and policies in regards to child labour which has a detriment effect on their development, education and health (Evans & Skovdal, 2016). This study has found that there is also lack of awareness among government and local services of the roles and responsibilities caregiving children assume which means greater lack of services and support (see also Chapter 7). It is therefore important to re-consider and challenge global myths and stereotypes of romanticised and innocent childhoods claimed by the Global North, whilst considering and supporting children's right to work including caregiving work under appropriate conditions (Robson, 2004b).

4.5 Conclusion

This chapter explored the different ways of understanding who a child is, as well as exploring some of the meanings of childhood in Malawi. This chapter attempted to answer the first of the research questions which concern the individual, meaning of care and agency, i.e. "Who/what is a child? How do children and young people understand and describe caregiving? Where is care taking place? How/when do children become caregivers? What are children's caregiving roles? What are the ways through which children and young people show their agency?". The first part of the chapter looked at the multiple definitions of children and childhood which are not just understood in reference to biological years, but extend to reflections of social, emotional and physiological development. This chapter presented only some of those views without of course being able to capture the whole extent of the nuanced and complex nature of childhood. It was important however to look at the understandings of children and childhood amongst the participants as this way a baseline has been established which can help to understand the roles of the research participants as young caregivers in depth. What the data from this study has shown is that children in sub-Saharan Africa are not seen as vulnerable, innocents who need adult protection from harm, but children in Malawi are expected to actively contribute to the household from their early years.

Secondly, this chapter considered what the meaning of care is amongst the young research participants. Participants described care in general and specifically caregiving by children and young people in many ways. Most of the caregiving responsibilities the research participants undertake are similar to other studies and compromise household chores, healthcare, personal care, childcare, income-generating activities, emotional and practical support, and a unique and original finding of the important component of spiritual care. The research participants also acknowledged that due to their family circumstances they have and sometimes want to provide more care to some relatives than their peers would have to do. What is noteworthy though is that none of the children and young people really identified with the western idea of ‘young carers’. Although their role as caregivers adds responsibilities which other children do not have, the participants looked at their caregiving roles as part of being a member of the family. An active family member, who cares and looks after their family as a whole system without seeing themselves as doing anything more than what is expected of them in the circumstances.

Chapter 5. Emotional Geographies of Caregiving

'Care circulates in all its ambivalence.'
(Puig de la Bellacasa, 2017, p. 220)

5.1 Introduction

As discussed in Chapter 2, emotional geography aims to understand emotion in terms of its socio-spatial formulation instead of looking at emotion as a separate individual mental condition (Bondi et al., 2005). This chapter endeavours to investigate children's lives with caregiving responsibilities while taking into account their everyday sensory and emotional experiences (Mackley et al. 2015). It will address the second research question (see Chapter 1) which is the following: 'What are children's and young people's emotional experiences and emotional geographies of caring for family members (parents, siblings, grandparents, other adult relatives) with chronic illness and/or disability?'. This chapter focuses on the emotional geographies which are played out in their everyday lives and which are related, but not limited, to their caregiving roles. Looking further than children's emotional experiences of caregiving, this chapter builds on the idea that children's emotions and emotional experiences are entangled and cultivated with other aspects of their lives, which puts 'emotions and emotional experiences on view as simultaneously constitutive and constituted' (Blazek & Windram-Geddes 2013, p. 1) (see Chapter 3).

This chapter aims to discuss further some of the points made in Chapter 4. Caregiving interactions are infused with emotion (Giesbrecht et al., 2017). Caregiving is steered by powerful emotions that produce strong emotional impact, and caregivers' work is as much social and emotional as it is physical (Wiles, 2003). Caregivers' diverse and dynamic emotional experiences indicate not merely the caregiving experience but also the significance of the impact on and from other relationships with family, friends and social life (Wiles, 2003). Considering emotion as central to all interactions and relationships (Davidson & Milligan, 2004), this chapter is closely related to Chapter 6 which looks at family relations and how relationships can potentially support or obstruct young caregivers.

Exploring how children 'feel' helps to understand how they see the world and how they sense time and space (Davidson & Milligan, 2004). As the previous chapter illustrated, caregiving roles and responsibilities can be a difficult and challenging task in children's and young people's everyday lives. Concerning its emotional impact, research data show that the young caregivers experience a wide range of emotions and attitudes regarding caregiving which are not either solely negative nor positive (Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009). The emotional experience of caregiving varies greatly from young person to young person and to exemplify the nuances of the emotional experiences this chapter will look at the main common themes underlined by the participants with the caregiving responsibilities in this research and subsequently will present three case studies for in-depth analysis.

This chapter explores children's lives by looking at the multiple and complex emotional experiences of young caregiving. The first section (5.2) explores both the positive and negative emotional experiences of caregiving. The themes mentioned in this section are then connected and presented in sections 5.3, 5.4 and 5.5 in detail through three case studies. Firstly, this chapter explores the case of Louise (12, F) who experiences her caregiving role mostly in a positive way due to the strong family support she receives. Louise also addresses the negative emotional aspects of the caregiving and how these impact on her everyday life. Secondly, this chapter looks at Rosemary (18, F) who experiences caregiving in both positive and negative ways at the same time. Rosemary loves and cares about her family very much and states that she likes her role but, as the case study investigates, there are a number of aspects that means this experience is also associated with negative feelings for her. Thirdly, Andrew's (19, M) case study offers a male perspective to young caregiving. The case study explores how Andrew was very young when he started caring for his grandmothers and caring for his elderly female relatives at such an early age impacted on his experience of caregiving in both positive and negative ways.

This chapter concludes with section 5.6 which reflects further on how caregiving evokes a range of both positive and negative emotions such as love, happiness, pride, satisfaction, acceptance, devotion, alongside guilt, frustration, loneliness, hopelessness, disempowerment and anxiety. Similar to Giesbrecht et al.'s (2017) study, the participants of this project negotiated these emotional experiences 'in a manner reflective of geographical notions of distance and proximity' (p. 10). Participants also used the concepts of space and place to create places of safety and hope in the present, as well as in the future.

The main themes portrayed in regards to young caregivers' emotional experiences were formed in relation to their own selves and situation; in relation to their family and other people; and finally, in relation to the community and organisations. In relation to themselves, the children and young people interviewed mentioned positive experiences such as feeling happy and proud having caregiving roles, and feeling more mature in comparison to their peers. The participants also discussed negative emotional experiences of caregiving such as difficulty assuming their responsibilities, especially for those who were very young when they started, and that the high level of responsibilities make them feel tired and exhausted.

In relation to their families and others, the participants mentioned both positive and negative emotional experiences as well. They feel that they develop particularly loving relationships especially with the people they are caring for, as well as feeling they have a significant role within the family, which results in feeling proud and happy as mentioned above. The participants also cited feelings of guilt and anxiety due to the high levels of responsibilities. These are the outcomes of situations like not being able to find or do piecework because there are no work opportunities or because they are too tired to go. This means they cannot provide their family with the money and the food they need which makes them feel guilty. Many young people also stated that they feel responsible for the whole family's welfare and not just the family member with the disability or chronic illness they care for. As a result, a third theme which was common amongst the participants was feeling worried and unable to leave their families for long periods. This could result in the children dropping out of school and being unwilling to go back or limit their socialising time or even move forward with their lives, such as getting married. Otherwise, if they would attend school or spend time outside the family home playing, they would feel remorseful and guilty for leaving their care-recipient.

In relation to their community and organisations, the participants state that, with only few exceptions, their emotional experiences are mostly negative. All of the participants feel that due to poverty, lack of resources and government services, they are left to deal with their hardships on their own. This has a significant impact on how they experience caregiving as it adds more responsibilities and greater burden without receiving any kind of support. This affects not only their emotional wellbeing, but also their education and future. Only few accounts, however, mention that at times charitable organisations have assisted them and their families, and many mention church and religion as the most consistent place from which they receive support.

5.2 A Landscape of Emotional Experiences

This project attempts to explore and understand the complex emotional relations between children's everyday lives and caregiving to demonstrate the significance of ensuring that both daily and caregiving practices of everyday life are understood in relation to the (re)constructions of their multifaceted childhoods.

Although the data showed that children and young people in this study experience young caregiving in different ways, some common themes emerged from the analysis. This section presents examples of both the positive and negative emotional experiences of young caregiving as recorded from children and young people's narratives and everyday lives.

5.2.1 Positive Aspects of Young Caregiving

The most common emotion was feeling proud and happy about being their relative's caregiver. There are a number of reasons that explain why young people feel happy and proud of their role. Here Daisy (13, F) explains that she feels "*good when I take care of her* (aunt)*. Because when a person falls sick, I feel so sorry and I want to help*". Samantha (17, F) further states that taking care of her grandmother makes her "*very happy*" because "*I know that I get blessings when I take care of her*" addressing a more spiritual aspect of her motivation. Evans and Becker (2009) also reported that young people in Tanzania are happy to assume caring responsibilities as they felt it was important to help their relatives remain happy and healthy. Skovdal's (2009) study in Kenya also identified that even though caregiving is associated with a variety of emotions and meanings that are influenced by individual circumstances and social environment, almost all of his young study participants identified their role as a positive occurrence.

In addition, Matias (16, M) articulates how his caregiving role has changed him and made him a more mature and responsible person:

> "*What happens here at home is what caused me to grow up and become mature in my mind*. (For example) *it is hard to find money for school fees, so I have realised that it is better to just work hard in school and I should put some of these things* (bad behaviours) *behind."*

Many studies with young caregivers postulate that their role results in enhanced personal development, growth and maturity (Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009). The data analysed here indeed indicates that although it is not always recognised by the young people themselves, as Matias does earlier, the children and young people of this study have developed a greater sense of responsibility, social skills and competencies as a result of caregiving. Seymour (2005) explored children's emotional labour within their family's workplace and identified that the outcome of children's labour often resulted in developing social and communicational skills as well as developing their ability to exercise resistance to adult power and control. In addition, the quotation from Matias above also indicates that other factors, such as poverty contribute to becoming a mature individual. For Matias and other young people who participated in this project, poverty and lack of resources make young people take responsibility and act as an adult would be expected to thus result in them becoming mature faster than their peers.

5.2.2 Negative Aspects of Young Caregiving

On a different note, embarking on their caregiving roles was a challenge for many. Hannah (19, F) says that when she started taking care of her mother she felt "*so hurt*" but as time passed she "*got used to. Because I have accepted the situation I am in. I began taking care of my mother and the rest of the family a long time ago and I* *am now used to it*". Caregiving is not only assuming responsibilities that young people did not have before, but it is also a new state of life, a new 'identity'. The construction of this new identity is not always easy for children and young people, especially when they begin at a very young age. So, this might be the reason why Hannah felt 'hurt' because the level of responsibility was so great that she had to drop out of school and put her personal happiness aside. It was a 'new' reality she had to accept and deal with. Most of the young people encountered during fieldwork in Malawi, who were caregivers for a significant amount of time, recognised that at first the role was a challenging one but they are now used to it and accept things as they are.

As other studies of young caregivers in sub-Saharan Africa with similar findings indicate (for example, Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009), poverty and lack of basic needs are probably the greatest challenges young caregivers face. Poverty often leads to poor living conditions and housing, lack of food and malnutrition, lack of basic needs, lack of money to support education and many other challenging impacts. Most of the young caregivers feel that it is their responsibility to make sure the relative they are responsible for and the rest of the family have their basic needs met, such as food, water, shelter, clothes, and soap. Not being able to provide those needs for their family makes them feel responsible for the family's living in poor conditions and as a result, guilty. George (17, M) states that he feels '*bad*' when thinking of his caregiving responsibilities and describes how difficult it is to lack basic necessities. He uses the two photographs (Figure 8) he took during the photo activity to explain that:

> "*The space in this house is not enough. The beddings are not enough either. They have to squeeze themselves to fit under this cover. And the roof is leaking when it rains. And you see here they all* (his mother and siblings) *eat from two plates only, there is not enough food. I want to change all these but I can't.*"

The photographs (Figure 8) show a house made by mud and a poor grass thatched roof, George's mother and his five siblings. The first photograph on the left is taken from inside his house and shows the place they sleep. They all usually sleep on the floor next to each other having a sheet to put on the floor and one as a cover. The second photograph on the right shows George's mother and siblings sitting outside his house, near the entrance. George and his mother on many occasions mentioned how unsafe they feel in the house and their concerns that the inadequate grass roof might fall on them during the rains. George explains that he feels responsibility and guilt for his family living under these circumstances as he is the one who has the responsibility for providing for his mother and siblings. George is finding it very difficult though to find income-generating jobs to be able to buy materials and properly repair the house or even build a new one and so he uses resources available around him to temporarily fix some of the problems their house has.

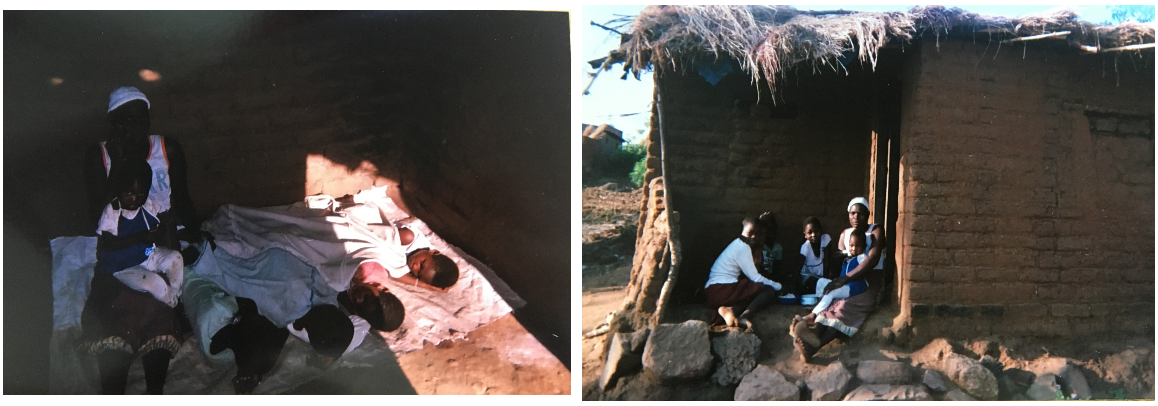


Figure 8: Photographs taken by George (17, M)

As in George's case, this often leads to young people dropping out of school either to seek income generating activities or because they do not have the money to support their education. The data of this study show that this brings additional anxiety and uncertainty, especially in regards to their future, as they are aware that without education they will not be able to find good jobs and earn a steady income in the future.

Moreover, many children and young people find caregiving challenging due to the high level of household chores and manual labour (piecework) they are required to do which exhausts them and makes them feel very tired. Daisy (13, F) explains that when "*I work for a long period of time I feel very tired*". This can create issues not only because of the impact tiredness has on their mental and physical state. In some cases, the young people are unable to do piecework or go for shopping due to the exhaustion, and as a result, their family lacks food and money, which leads to them feeling responsible and guilty. Rejoice (17, F) further advises that "*I feel pain* *when I do not manage to go for piecework because people here at home look up to me if there is nothing*".

Being away from home is another challenge reported by young people. Matias (16, F) explains that when he is away playing football with his friends his grandfather stays alone at home. This creates a number of issues, for instance:

> "*When I am away to play football, a lot of things happen here* (at home). *For example, yesterday I went to play football at school and when I came back I was shouted at that I had left my grandfather alone and he fell because I was not around to help him. It hurts me a lot to leave him okay and when I come back, I find out that he* (grandfather) *has fallen down and that makes me think to say, why did I leave? Most of the times when I am going out, I think about this home*."

This brings immense feelings of guilt, responsibility and anxiety affecting Matias's overall wellbeing. In many cases, the young people report that they had to drop out of school to be with their relative or even in Hannah's (19, F) case not to marry the father of her 2-year-old son because she needed to remain at home and take care of her own mother.

This section explored the general themes emerging from this study linked to emotional geographies of caregiving. Children and young people with caregiving responsibilities experience a number of positive and negative emotions, which sometimes can be conflicting, such as love, pride and happiness in combination with guilt, tiredness, anxiety and worry. The next section presents three individual case studies to further explore the complex nature of caregiving-related emotional experiences.

5.3 Case Study: Louise

Background

Louise (12, F) is her grandmother Rute's (63, F) primary caregiver alongside her cousin Eveline (11, F). Rute is blind and needs someone to help her with basic needs and activities throughout the day. The initial plan made by the family was that Eveline was going to be Rute's caregiver but after her parents separated

Eveline was not able to remain a fulltime caregiver. Her mother moved to another town and as a result, Eveline started spending her time shared between both her mother's and father's houses. Considering the intensive level of support Rute needed, it was decided by older members of the family that Louise would become her main support.

Happiness and Love

When I first met Louise my initial impression was that she *"looks like a happy and carefree young girl. I always see her smile, her eyes look happy*" (author's fieldnotes, 19/10/15). It was apparent from our observations, informal conversations and interviews that despite the numerous difficulties she faces, Louise seems to live a happy life and feels very proud of her caregiving role. During our first visit, a lot of people were around the house, both adults and children, who tried to greet us and talk to us. At first, I was not sure who they were and assumed they were people from the community who were just curious about who my research assistant and I were and why we were there. But I soon realised that they all belong to the same household. This household consists of a large number of extended family members and has a very good support system in place for all of its members. I soon observed that for this household caring is a family matter and not only one person's job. Responsibilities are thoroughly and carefully allocated to all adults and children and usually decided by the oldest members of the family.

Having this support from immediate and extended family means that as well as caring for her grandmother Louise can attend school and have a social life without feeling burdened. In her diary Louise ticked only the 'happy' face section (see Figure 9) and when asked why she states that she loves her family and friends and that is the reason she feels happy all the time. Her grandmother Rute reflects on Louise's loving nature towards her and explains that she believes this is the case because Louise had her parents as role models.

> Rute: *Care is really there, it starts with the parents. If the parents had mistreated me, then the children would not have loved me. Even this child's parents, Louise's mother, when she sees that I am sick, she comes to see me. When I am sick, Louise's mother comes and puts water on the fire and then leaves it in the bathroom. Then she holds my hand and takes me in the*

> *bathroom and she goes out, or she tells me 'today, put a wrap around your waist I should bath you'. And she bathes me very well and afterwards she leaves the bathroom and I can finish up myself as a woman.*

This quotation demonstrates the power that family and communal care have in shaping children's experiences and lifeworld. Louise's mother undertakes caregiving responsibilities and, according to Rute, this means that Louise can learn by example not only the practical aspect of caregiving, how to do it, but also how to care for her and be attentive.

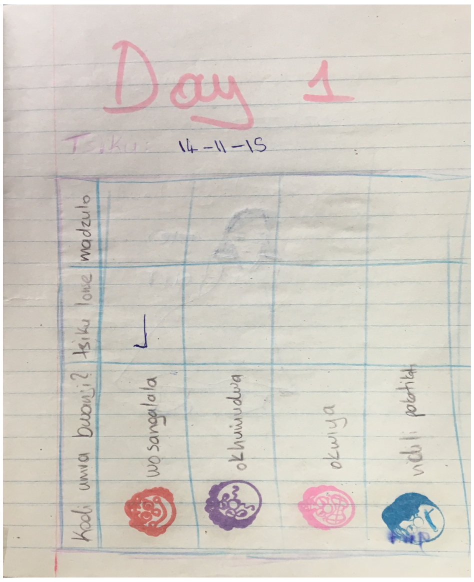


Figure 9: Extract from Louise's diary

Family and social life are also very important for Louise. When it comes to socialising Louise is almost always surrounded by a large group of friends comprised of school mates and relatives. She actively and happily interacts with them and participates in games and activities. During the third visit to her household, I had the chance to spend lots of playtime with Louise and some of her friends. We played two different ball games and despite the heat, we all had a really good time. Louise states that she loves playing, chatting, singing and dancing with her friends. She shows us the photographs (Figure 10) she took with her friends and explains how friends are an important part of her life. The photographs (Figure 10) show Louise with her friends playing near her house and when she talks about them she seems to be very happy.

Figure 10: Photographs of Louise with friends

When considering her caregiving role during the photo activity (see Chapter 3), Louise choose to place a photograph of herself under the category of 'how I take care of my grandmother' (Figure 11). When asked why she chose a photograph of herself, she replied:

> Louise: *I want to take care of my grandmother forever.*
>
> Research Assistant: *Can you explain what you mean by that?*
>
> Louise: *Some people say I should not be walking with her, that I should be walking alone, but I tell people that I can't leave her to walk on her own, she is my grandmother.*

Louise here expresses her love towards her grandmother and also a sense of duty which is a common socio-cultural concept in sub-Saharan Africa. Similarly, in other studies exploring caregiving, those caring for family members with chronic illness regarded their roles and care work as being 'part of their love, moral duty and reciprocal responsibilities towards their family' (Evans & Thomas, 2009, p. 114).

Figure 11: Self-portrait of Louise

This means for Louise that she experiences caregiving as a positive thing. Following cultural norms that respect and consider elders as the top of the hierarchy of family, Louise shows how appreciative and happy she feels that she is the one to be her grandmother's caregiver:

> Louise: *I feel happy in my heart.*
>
> Research Assistant: *Can you explain more, why do you feel happy?*
>
> Louise: *I know some people who do not have grandparents because they passed away a long time ago. Those people are worried because they do not have an elder in their family and they advise us to be careful, that we might lose our grandparents. So they say you are supposed to take care of your grandparents because it's difficult not to have an elder person amongst them.*

This extract describes Louise's appreciation towards elderly people as well as offering an idea of the role and place of older people in the wider family and community.

But it is not just appreciation that makes Louise experience caregiving in a positive way. Louise loves and feels loved by her grandmother, her immediate and extended family and her community. She feels safe and relaxed at home, in her village, at school, with her family and her friends. Her grandmother Rute further explains:

> "*That child* (Louise) *shows a lot of love. She comes and helps me to walk, she knows I can get hurt if she is not there. That is what those children* (Louise and Eveline) *do, I do not walk alone, when they see me going to church, even if they are playing, they stop and say 'let me go with you and leave you at the church'. And she holds my hand, guides me and leaves me at CCAP* (The Church of Central Africa Presbyterian) *before she returns to her friends*."

This quotation highlights the mutual emotional support, appreciation and reciprocal nature of Rute's and Louise's relationship. In many studies about young caregiving in sub-Saharan Africa, the reciprocal relationships are evidenced (Evans & Becker, 2009; Evans & Thomas, 2009; Robson et al., 2006; Skovdal et al., 2009). This offers both sides of carer and cared for with a sense of comfort, hopefulness, reassurance and the sense of 'being there' which all play a vital role in developing strong and loving relationships (Evans & Thomas, 2009) (for more on family relations, see Chapter 6).

Transferable skills

Developing a loving relationship with family members through caregiving roles is not the only benefit of caregiving Louise identified. While discussing things that make her feel happy, Louise states that she loves taking care of her young niece when her older sister is busy with other things (Figure 12). During a conversation as part of the research, Louise explains that she enjoys looking after her young niece, preparing and giving food to her and entertaining her. She particularly enjoys playing games with her niece and making her 'happy'. During home visits, my research assistant and I observe Louise taking care of younger children around and looking confident and happy while doing so.

Figure 12: Photograph of Louise with her niece

What could be notable here is how Louise transfers her caregiving skills from looking after her grandmother to her niece and is able to also adjust them to the child's needs and age. Skovdal's (2009) research found that a number of young people understood caregiving as an opportunity of self-growth that can benefit their future. Louise does not articulate her ability to transfer her caregiving skills in this way, but it could be that the skills she has acquired make her feel confident and happy to take care of other individuals as well. As already discussed in Chapter 2, what is important to consider though is that it is a common socio-cultural practice that girls (and to a lesser extent boys) care for young children in sub-Saharan African countries and is considered a normal part of childhood. What was different with Louise comparing her with other girls around during our observations was that Louise's noticeable confidence in dealing with the younger children and that while visiting she would be the first to comfort a crying baby or give food to a toddler which could perhaps indicate that her particularly caring responses were due to her skills developed from her caring role in looking after her grandmother.

Stigma and Responsibility

Although family and community have played a significant role in making caregiving experiences positive for Louise, not everyone has always been supportive and understanding. Louise explains that

> "*A lot of people come here to chat with her* (grandmother)*, so people tell me to leave her to chat with the visitors. After the visitors leave this place though, she* (grandmother) *remains quiet here and alone. Those people tell me to leave her by herself but I say 'no I will stay with her because I do not want her to be alone, someone can come and attack her'*."

Louise feels her grandmother is vulnerable due to her blindness and does not want to leave her alone. Her eagerness to protect her from harm is also evident from observations during our research encounters. For instance, while we were interviewing her grandmother Rute, Louise came into the room we were sitting in with food, as it was lunchtime. Louise mentioned that she knew the interview was not going to finish on time for her grandmother to eat lunch with the rest of the family, so Louise did not want her grandmother to get hungry. Of course, there is no way to know if bringing the food was her own initiative, but when she arrived Louise seemed genuinely interested in her grandmother's wellbeing.

In addition to protecting her from strangers, Louise also tries to protect her grandmother from the stigma of disability. Focusing on the issues that stigma brings, she says:

> "*I would want my grandmother to be able to see again, because a lot of people talk about her in bad ways and say she can't see, call her blind. So, I tell them to be blind is not a problem, it is how God made her. A lot of people talk about her in a bad way and I do not like it, I feel bad*."

As mentioned earlier, on some occasions Louise has also been told '*not to walk with her*' grandmother. Louise describes feelings of frustration and disquiet towards those people who do not agree with her being her grandmother's caregiver. She cannot understand why people would think that it is wrong to be alongside her grandmother and take care of her. For Louise, Rute is someone she loves deeply and wants to help and support and not a blind individual she should be avoiding.

Another negative aspect of caregiving is tiredness. Although Louise herself did not refer to this during our conversations, her grandmother Rute describes how tiredness sometimes causes Louise's unwillingness to help:

> "*Now, her unwillingness is to say that comes from tiredness. It is like you are asking her to do too much. So, when she feels tired such and I want to send her to the market, she will say 'grandmother, I am tired'*."

Rute understands that Louise can be tired at times and that is when Eveline, Louise's cousin, can help if she is around. Rute further believes that Louise used to be more 'unwilling' to help her before I began visiting the family. She explains that with my coming, Louise realised how important her role as a caregiver is. The impact this has on the research was explored earlier in Chapter 3. Louise's ability to decline her grandmother's request to send her to the market also shows Louise's resistance and agency and ability to express her tiredness and temporary unwillingness to help.

This further highlights both the positive and difficult impacts her caregiving role brings Louise, as well as how she manages to deal with them. Louise is able to use her support system (family and friends) adequately and feels supported and valued. Robson's (2000) research about caregiving children in Zimbabwe also identified that 'families form the greatest means of support' highlighting the importance of having a caring and extensive family (p. 65). The outcome of having this support from extended family is that Louise is able to express both positive and negative feelings and search for coping mechanisms and solutions. As Skovdal (2009, p. 198) identified in his study, this positive experience of young caregiving is the result of 'a complex interrelationship' between children's ability to positively rationalise their experiences, as well as the quality of their social support systems available. Next, a different case study presents an example of a young woman whose experience is not as overwhelmingly positive as Louise's.

5.4 Case Study: Rosemary

Background

Rosemary's (18, F) story as caregiver for her older sister Mary begins when "*Mary* (sister, 35) *was in South Africa she called me and said 'Rosemary I am not feeling alright'. I told her to come back here, to the original home, which is Malawi. But when she came back to Malawi, to me, I realised we were facing a big problem, Mary returned sick. The thing was that she was in South Africa to work, so she could send money for me to pay school fees and feed the family. So, I got very worried when she came back sick because I realised that the plan had failed*." Rosemary's sister Mary had to return to Malawi when their older brother suddenly died from an infection. Mary found out he had passed away while she was in South Africa for work. The news made her really upset and as Mary states, she soon fell ill with heart problems.

> Mary: *I had a brother who suddenly passed away. One day I received a call that my brother has passed away. I then started to think about what would happen now? Because he acted like a father, he would take care of the children and everyone else in the family. Then it became difficult because sometimes when I would think… When my friends were away at work, and I was alone, I would start thinking and crying. I started living from other people's contribution because I couldn't work. And when all people have gone to work and I was alone, I would start thinking and my heart would then start beating fast and wouldn't stop, and that's when my friends took me to the hospital.*

Mary's narrative offers a description of the events that took place when she first fell ill. This information, alongside other data collected by interviews and conversations, could indicate that her heart problems could be physical symptoms of mental health issues, such as depression, anxiety and panic attacks. This is important to highlight and take into consideration when analysing Rosemary's story because caring for someone with mental health issues can be a very different experience in comparison to caring for someone with disability or chronic illness (Aldridge & Becker, 2003). Aldridge and Becker (2003) looked at literature in regards to children with caregiving responsibilities in the UK and concluded that most of the studies available focus on children who care for relatives with physical disabilities rather than for family members with mental health problems. They explained that the few studies exploring young caregiving for adults with mental illness give emphases on the medical and child protection concerns which report that in most cases those children have higher risk of harm and neglect (Aldridge & Becker, 2003). The authors, however, conclude that this is not always true and that children's experience of caregiving for adults with mental illness varies and thus, needs careful examination (Aldridge & Becker, 2003). The few other studies that exist suggest that the children caring for adults with mental health problems are more likely to provide emotional support rather than intimate care or other nursing tasks (Dearden & Becker, 1999). Also, Elliott (1992, as cited in Aldridge & Becker, 2003) found that children caring for parents with mental illness deal frequently with confusion in regards to their parents' unusual behaviours and the stigma these behaviours may bring.

Responsibilities and struggles

Their brother's passing and Mary's subsequent illness and inability to work meant that Rosemary's family unexpectedly and abruptly lost two income sources. Suddenly the responsibility for income-generating activities fell to Rosemary who had to leave school and start working. And when her sister found the money to return from South Africa, Rosemary had to take care of her as well. On her return, Mary was very weak and most days could not leave her bed. She quickly started taking medication for her sleep and to "stop the thoughts" that would upset her and keep her awake at nights. Rosemary found it very challenging from the beginning to assume both the caregiving and providing roles. She feels that the responsibility, of making sure her sister and her family are well and fed, is a challenge and she faces a number of difficulties.

Rosemary’s immediate family consists of her mother, her older sister Mary, her younger sister Naomi and her infant son, and her nephew (son of her deceased brother) Mike. They all live in an urban area where there are amenities like electricity and transportation, but Rosemary finds it difficult because they are not near her extended family and village community.

> Rosemary: *Because everything is hard in this town; for example, you need to buy firewood. If you cannot afford it you go to that hill, and it seems as though it is near but to get there, it is very far. In the village, we would have our own space to grow things, we would have family and neighbours who can help us. But here to find a place to farm it means you need to borrow land. Whilst at the village, there is plenty of land. A place just stays uncultivated and a person can farm without using fertilizer and still get maize. Whereas here, we have to buy everything.*

Here Rosemary offers the economic and social reasons she finds living in a town difficult and what the benefits of living in a village would be. When asked why they are not planning on moving back to their family village, however, Rosemary indicates that the reasons they stay in town are availability of electricity, access to hospital and more opportunities for piecework.

It was evident from a number of encounters and accounts gathered during the fieldwork that Rosemary struggles with her caregiving role not just because they are living in a town. She does not struggle because she does not want to take care of her sister and family, but due to poverty and arduous circumstances, it is very hard to successfully meet her own and her family’s basic needs. This affects her everyday life significantly. For instance, on day 7 in her diary, she marks the angry face and explains:

> *This day I was sad because some of my customers* (Rosemary buys clothes from the markets and sells them door to door) *did not give me money. So, when I realised that we do not have anything at home and I suppose to buy food using the money I did not get, I felt very sad. I thought of the kids who would be hungry. I feel sorry for these kids because they will starve.* (Rosemary’s diary, Day 7)

This is only one diary entry example of many showing the effect this situation has on Rosemary. Regardless of the adversities she faces, she is “*a brave young lady.*

She always puts her responsibilities for her family first" (Research assistant's diary – 23/11/15). During the time, we worked together with her family, it was evident that even though Rosemary had very difficult days, she would not abandon hope but would courageously fight through.

Sleep difficulties and preoccupying thoughts

Rosemary's feelings of responsibility, guilt and burden impact on her night sleep and other situations. Here Rosemary describes that sometimes when it is time to go to sleep, agonising thoughts regarding her family's circumstances take over and she cannot sleep.

> Rosemary: *Sometimes it would happen that I am done with all my work but then when it is time to sleep… You know to be the head of the family means I have to think what I'm going to do tomorrow. So sometimes sleep won't come.*

Rosemary continues by explaining that she is worried about the lack of money, not meeting her responsibilities and the impact all these have on her sister and the rest of the family. She is preoccupied with thoughts about her sister's wellbeing and illness and feels helpless, as she cannot help her. Rosemary declares that even if she had the money, she would not be able to go back to school, as her mind would be preoccupied with the needs of her sister and family.

> Rosemary: *But I also cannot say that I will go to school when there is nothing at home, I cannot leave these people who have nothing and who are not feeling so well. That would mean that I could not learn properly at school, I would be having thoughts.*

Despite the emotional attachment and loving relationships with their care-receivers and this meant they would not abandon their caregiving roles, many young people struggled with conflicting feelings that were particularly difficult to deal with (Evans & Thomas, 2009). This complex and often contradictory nature of young caregiving is something that characterises Rosemary and her experience of her caregiving role.

Except for the high level of anxiety and sadness that living under poverty generates, Rosemary reflects on her circumstances and compares herself with other people's lives which make her feel even more distressed. During a conversation about her friends and other young people her age, Rosemary explains how she sees herself differently.

> Rosemary: *The reason* (I feel different) *is because others are born in rich families they can find what they may want for themselves whilst for you to find that thing I… I… I am supposed to work hard to get what I want and help my relatives. The other thing is…. People like those ones are able to go to school... Others are working. I feel so painful, I feel bad.*

This was a frequently demonstrated notion amongst most of the young caregivers who participated in this research study. Most of the participants compared themselves with other children and young people their age and identified a number of differences which were usually impacting themselves in a negative way.

"Just females" – Unsafe Spaces

In addition to the hurdles of Rosemary's everyday life, living in a household consisting of only women and children, generated further problems. Her sister Mary describes an incident that happened recently.

> Mary: *We are just females living here and that is not good. A home composed of just females is never respected, people take it for granted. But when there is a man, people will afraid of him. Yes, it is a hard thing because sometimes thieves come to disturb us. One time they came through the window here. The windows do not have a lock so they just open it. So, they broke in and we screamed 'thieves'! And then they ran away. But they came again that night when we slept. We heard them trying to open the door this time. We thought they were gone but they came again. So, then we screamed again and they ran away and we did not sleep again till morning.*

Evans (2015) explored the impact gender has in increasing vulnerability, risk and as a result poverty amongst widows and caregiving children affected by HIV in Tanzania and Uganda. Evans (2015) demonstrated that issues such as gender discrimination and stigmatisation resulted negatively for inheritance practices. Certainly, in Rosemary's case, they had already lost assets and access to land after her father passed away and they moved to an urban area and in addition to this, they continue to face recurring problems and increased vulnerability due to their gender and the fact there is no adult male in the household. This has led the family to chronic poverty, food insecurity and poor health, in addition to cumulative feelings of insecurity and anxiety, making the whole family very vulnerable. This could also mean that their house is not considered to be a safe place to live and it is not easy to relax and unwind.

Positive feelings and Spirituality

Fortunately, though, Rosemary has a safe space where she goes, physically and mentally, and gets to relax and feel happy. Church, Bible and spiritual life are important parts of Rosemary's everyday life. For example, in her diary, Rosemary describes how happy she had been because of nurturing her spiritual life.

> *My day was fabulous because I was chatting with my siblings. We were talking about many things and encouraging each other spiritually. When I was studying I learnt stress is not good and can lead to high blood pressure which is not good. As a result, I make sure that I should have happy moments during my day.* (Rosemary diary - Day 4)
>
> *My day was very good because I went to the church to gather with my friends so that my spiritual life should grow as well.* (Rosemary diary – Day 6)

Rosemary mentions frequently how her faith has helped her during the difficult times. Church and reading the Bible has been her support system, not only for herself but for her family as well. Rosemary picked the photo below (Figure 13) to show that when things go wrong, she reads the Bible because it gives her "strength" and makes her "happy".

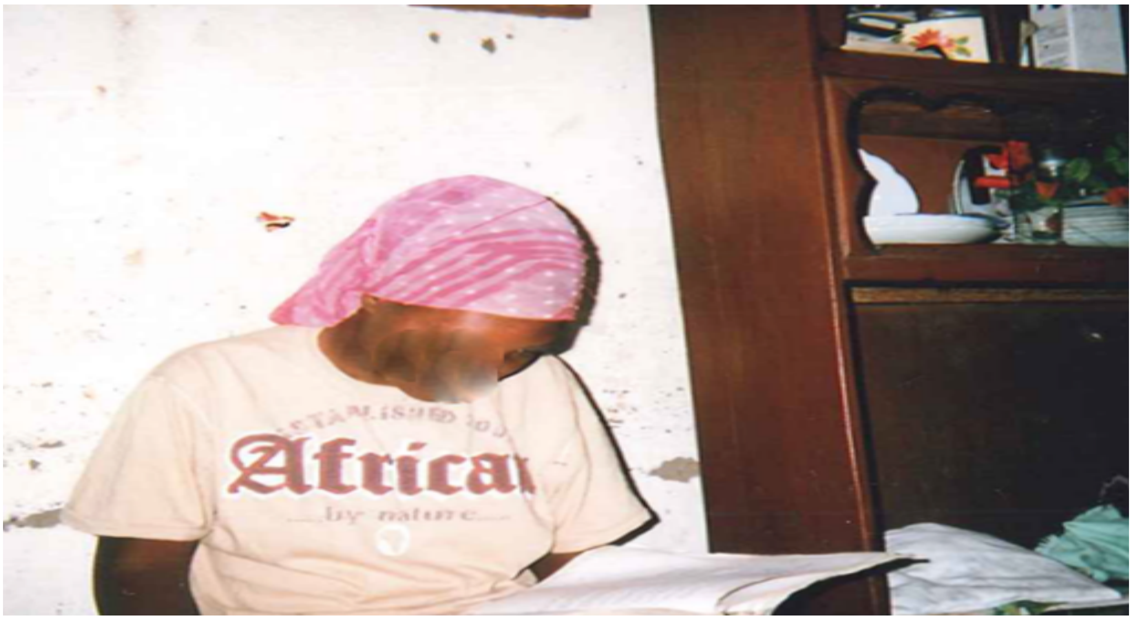


Figure 13: Photograph of Rosemary - 'Reading the Bible gives me strength and makes me happy'

In addition, during one of our interviews, Rosemary says:

> Rosemary: *Sometimes I read my Bible. Because in the Bible there are stories that I can read and feel encouraged. Find out what happened to other people. So, if I take it* (the Bible) *and read then I feel better. I say 'ah', I say myself that if I work hard or if I find support somewhere, it means I would continue with school and maybe do a certain course.*

Rosemary explains further how her faith helps her cope with adversity and also indicates her hopes for the future, like finding support and going back to school. What is interesting is that this contradicted her earlier statement that she cannot attend school due to being concerned about her family and specifically about her sister Mary. When I discussed this with her, Rosemary said that she would only go to school if she was certain her sister Mary and the rest of her family had all the things and support they needed first.

Future and Hope

Thinking of the future and going back to school, Rosemary states that she finds hope in the future. She talks about how she would like to find the money to start her own business of selling clothes at Limbe market in town. At the moment, she buys clothes from the market on her own or takes orders of what clothes people want and sells them directly to them by visiting their houses. But Rosemary would like to be able to have a stall at the market, as this would generate more money. This way she could support her family with basic needs and she would hopefully be able to go back to school.

> Rosemary: *In the future if maybe… if I had a good capital for my business. My business, which I want to continue, is selling clothes. Because now I go to Limbe* (market), *find clothes and sell them to other people, but the money is not enough. So, I think the best way is if I could have enough money to open.. have my own clothes in the market. Thereafter I could maybe go back to school.*

When Rosemary talks about her future she feels hopeful that something will happen or someone will help and things will get better. She hopes that her sister will recover her health and will be able to go to work and that she will find the money to go back to school.

Despite all the hardships, Rosemary is a brave young woman who even though her life changed dramatically, very quickly, she is doing her best to deal with all the difficulties. Rosemary's story presents the complex and often contradictory nature of young caregiving. Not having an extended family as Louise has seems to make things even more difficult to cope with on an everyday basis. What is crucial to highlight though is the importance of spiritual consolation for Rosemary and her family as this is a key finding in this research. Next, Andrew's case will present a young man whose caregiving responsibilities, emotional experiences and everyday life are displayed in different ways.

5.5 Case Study: Andrew

Background

Andrew (19, M) started caring for his grandmothers when he was very young. His grandmother Nessie (90, F) and grandmother Aisha (105, F) are both very old with a number of health and mobility problems. At the age of 12, Andrew's mother decided that he was going to become his grandmother's caregiver as Andrew was the oldest of the children at the time and he was additionally already living with them. He is studying Business Management at a local college. During the night, Andrew stays at a friend's house but during the day he is either at school or with his grandmothers. There used to be a house where Andrew, his grandmothers and his uncle used to live together but it was destroyed by heavy rains so they had to find alternative accommodation.

Happy and Proud

Andrew is very proud and happy of his role to take care of his grandmothers. He talks about feelings of love and a sense of appreciation.

> Andrew: *It is like, Nessie and Aisha, they love me too much. To be where I am right now is* (because of) *them. And I love them too much. Yes. This is what I can say. If they did not exist I couldn't have been here. But with the love which they gave me, that's why I am here and living and talking to you. Yes.. I feel very grateful for what they did for me, to be where I am. Cooking for my grandmothers, that's what makes me happy.*

In studies exploring children and young people caregiving responsibilities, it is considered that many children stated that they were feeling proud of their roles as a way to help them deal with anxieties and worries in regards to their parents' illness and mortality (Evans & Thomas, 2009). There is no way to know if Andrew is using his sense of pride and appreciation as a way to cope with his concerns, but Andrew takes care of two elderly female relatives who have had a mother's role in his life and from his narratives and other observations it is apparent that he cares deeply for his grandmothers and that he was very concerned of losing them because of their illnesses and age. So, in this case, even if coping with their feelings is one of the reasons this takes place, Andrew genuinely feels proud of his role and appreciative towards the care he has so far received from his grandmothers.

Andrew considers feeling happy as a positive thing that can bring a healthy life. The caregiving role is not the only thing that makes him happy. Andrew further explains that:

> Andrew: *Going to school makes me happy. Going to church. Chatting with my friends. Helping other people makes me happy. Where I am living makes me happy. People like you makes me happy.*

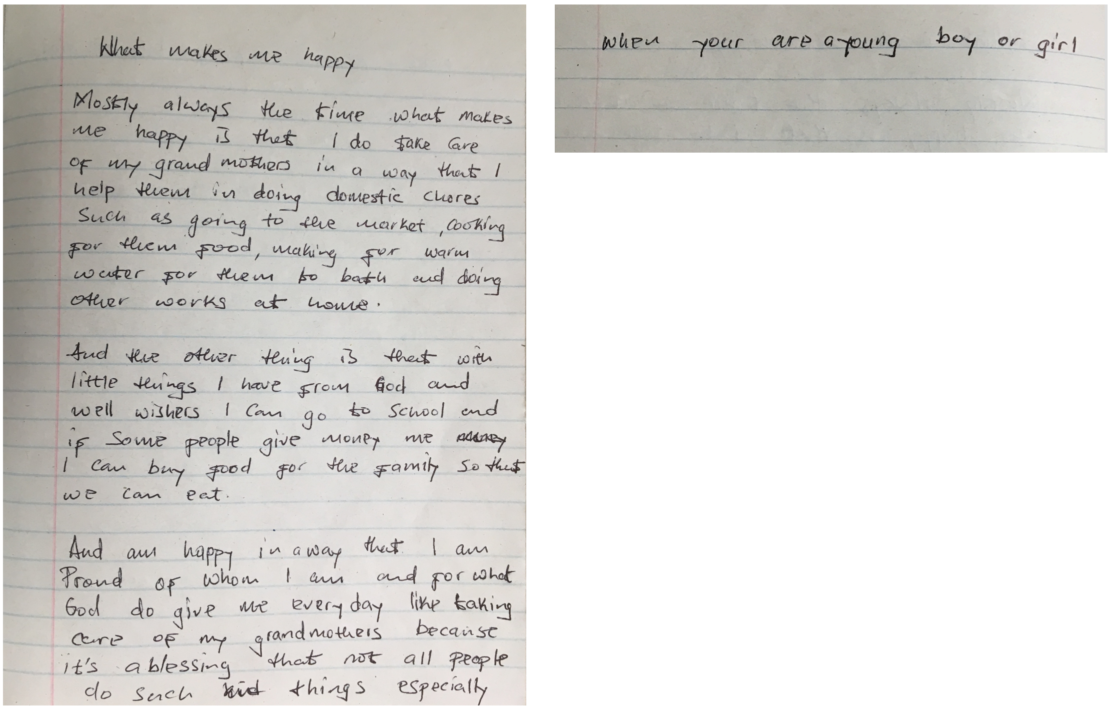
He continues reflecting on these feelings and he states that although he tries, he understands that he is not able to be happy all the time, "*sometimes you are happy and sometimes you are not. It depends on the situation you are going through. Your mood. So many things*."

Elaborating further on things that make him happy, he writes in his essay (Figure 14):

> *Mostly always the time what makes me happy is that I do take care of my grandmothers in a way that I help them in doing domestic chores such as going to the market, cooking for them food, making for warm water for them to bath and doing other works at home.*
>
> *And the other thing is that with little things I have from God and well-wishers I can go to school and if some people give money me I can buy food for the family so that we can eat.*

> *And am happy in a way that I am proud of whom I am and for what God do give me every day like taking care of my grandmothers because it's a blessing that not all people do such things especially when your are a young boy or girl.* (extract from Andrew's essay – Figure 14)

This essay adds to the understanding that Andrew experiences caregiving in a very positive way and acknowledges how much his religious faith has contributed to this positive experience. And even though there are, of course, negative feelings, which are discussed later, he expresses his overall experience of caring as a positive one.



What makes me happy

Mostly always the time what makes
me happy is that I do take Care
of my grand mothers in a way that I
help them in doing domestic chores
Such as going to the market, cooking
for them food, making for warm
water for them to bath and doing
other works at home.

And the other thing is that with
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I can buy food for the family so that
we can eat.

And am happy in a way that I am
Proud of whom I am and for what
God do give me every day like taking
care of my grandmothers because
it's a blessing that not all people
do such ~~kid~~ things especially

when your are a young boy or girl

Figure 14: Andrew's essay (what makes me happy)

Places of Happiness

Andrew has moved around a lot in previous years and although he seems to feel happy and safe with where he is, many of his family live in different villages and towns and this means he does not see them as often as he might like. Considering his mother's village and a reservoir near it, during an informal conversation, Andrew shows me the photographs below (Figure 15), taken as part of the research, and explains that those were taken near a reservoir by his mother's village. These are open, outdoor places Andrew visits with his friends or on his own to relax and unwind. Those are emotionally significant spaces as they offer him a break from the everyday hardships and bring him close to his family and mother who loves very much. He also refers to things that happened there when he was young indicating that nostalgia and positive memories are also senses attached to those places.

Figure 15: Photo collage by Andrew "places of relaxation"

Becoming a young caregiver

Despite the positive experiences caregiving has for Andrew, there are a number of negative aspects of his role that he has identified. When he started his caregiving responsibilities seven years previously at the age of 12, Andrew found it very hard. During an informal conversation, he told me he used to run away all the time because he did not want to do what he was asked. His biggest challenge was that as a young boy he had to take care of two elderly females, one of whom has needed a high level of personal care. He could not understand why he had to do that and he described how it was mentally and physically hard as he was very young. Many of the tasks he had to do he said required a lot of physical strength that he did not have at the time. Andrew also says that taking care of female elderly relatives has been hard as *"there are so many things that make you not feel comfortable"* and continues to explain that sometimes his older grandmother refuses to leave her bed to go to the toilet and so Andrew has then to clean her and her bedding. Andrew further explains that this was a very hard thing to get used to, but with time and his grandmothers' love, he did and he is happy to help them in any way now.

Existing research shows that usually the gender of the caregiver and care receiver matches, but there are cases when due to circumstances that cannot be controlled this is not what happens (Evans & Thomas, 2009). When the caregiver is not the same gender as the ailing person, then usually the caregiver will not undertake personal care due to cultural notions of gender roles, bodily intimacy and sexuality (Evans & Thomas, 2009). Andrew's case is a very unusual example and perhaps that is why Andrew struggled so much when he first assumed his caring responsibilities. Andrew gradually came in terms with his role and accepted his responsibilities. Looking after his female elderly relatives though is not the only challenge Andrew faces.

Tiredness and School

Andrew explains that he often feels too exhausted to do anything, because, for example, the distance he has to cover to walk to his college is very long, especially when he is not with his friends or has not eaten.

> Andrew: *Yes, I get very tired because the school is very far away, so I have to walk so if I have to go to school I feel tired. Sometimes you are going there without eating. With no friends or food. So, life is a bit hard.*

Andrew wakes up early in the morning to go to his grandmothers' house to make sure that everything is clean and there is food for them. He then goes to college but by that time he might be very tired especially if he has nothing to eat. He lives in a big town that has easy access to mini-bus transport but he cannot afford it so he has to walk. As a result, this has an impact on his college attendance and educational quality, as he is not always able to focus and study productively.

Poverty

Andrew is very concerned about his studies and his educational future, but he is equally worried about his grandmothers' health and wellbeing. Although they get financial support mostly from his uncle and other extended family members, there are times when things are not going well, they do not get money and as a result, they do not have food and other necessities. During those times, he is very worried and stressed about his grandmothers as they are very old and sick.

> Andrew: *Sometimes in the morning to find out there is no food so I think that at least I am strong enough, but to them is like they need to eat, usually, most of the times. So, it is like I come here and I find there is no food so I get a bit stressed with that okay, they (grandmothers) haven't taken anything, so what will happen in the next few hours? Yes....*

Andrew is further thinking about all the hardships he and his family are facing and wonders why this is happening to them. Receiving strength and support from his faith, Andrew accepts what life has for him and he is dealing with anything that comes across.

> Andrew: *For me it was sometimes stressful. I wonder why are we living this life? That with what God provided for us, it is like this is how it's supposed to be. So, I just take it as it is. This is what I should be doing now and then.*

As mentioned earlier, in the Happy and Proud section of Andrew's case study, in order to deal with stressful and difficult situations, many children and young people use feelings of pride and other positive emotions as a way to cope. Here, Andrew also indicates that faith is seen as a tool of accepting his role of being a young caregiver and gives him purpose and strength.

Future and Places of Hope

For Andrew, as for almost all of the young people involved in this study, the future for him is a hopeful space that not only strengthens, but also empowers. Andrew believes that if he could find help to cover basic needs, such as food and money, he could complete his education, find a good job and give back to his family. This, alongside his faith and love of his grandmothers, motivates him to continue despite the challenges.

Andrew writes in his diary the following essay (Figure 16) about things he would like to change in his future and remaining optimistic, he explains further how his own and his family's future can change in a positive way:

Firstly, I can say that there are so many things to change in my life but I cannot get them all. I can only thank God for what he has gave me that day.

I need school fees to go to school so that I can fulfil my dreams that my grandmothers can live a better life someday through the money which I will get when I start work and the other thing is that I can be able to support my family financially so that they can not have troubles.

Since I am a young boy I need a lot of things to take care of my grandmothers and the only way to get help is from well-wishers.

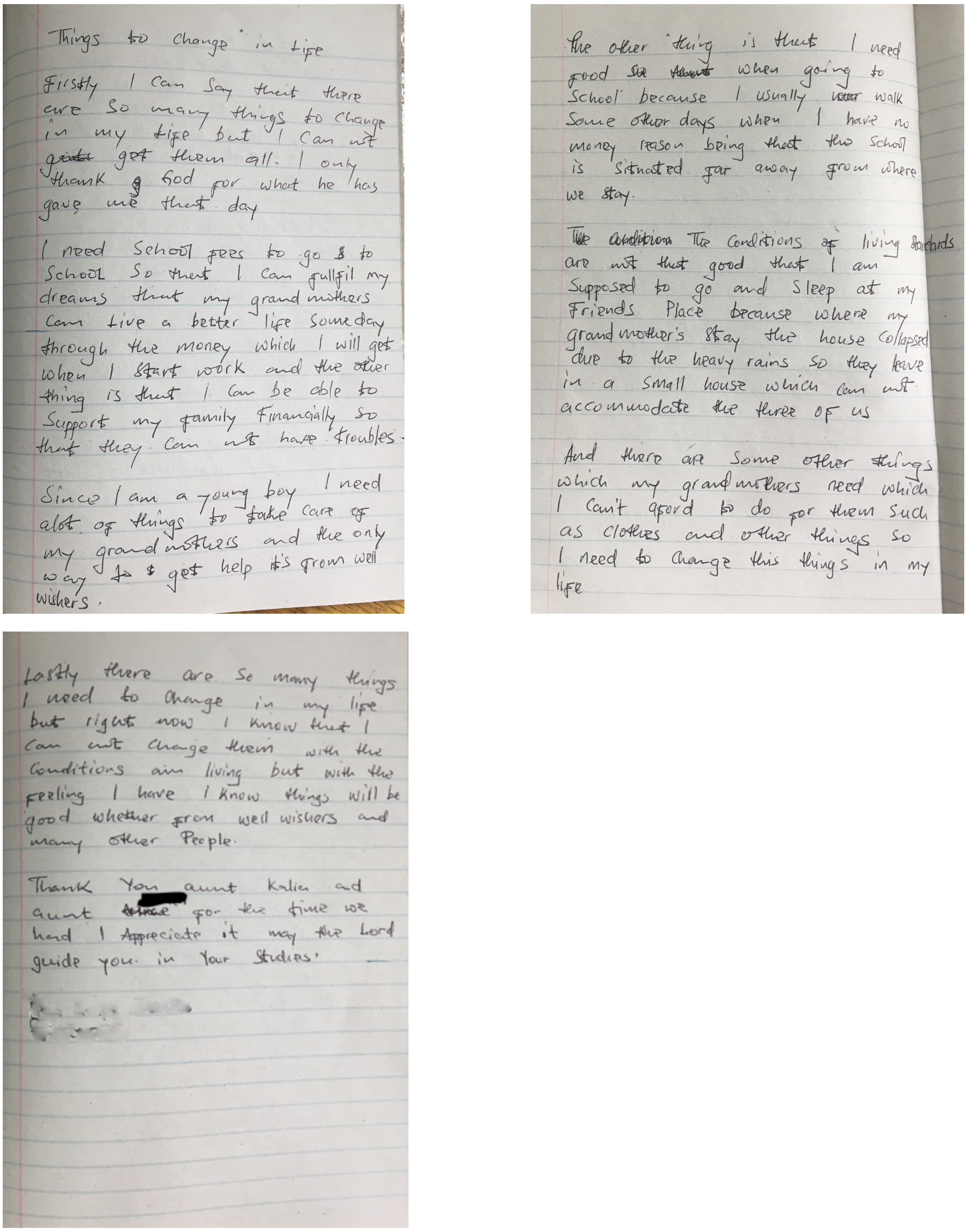
The other thing is that I need food when going to school because I usually walk some other days when I have no money reason being that the school is situated far away from where we stay.

The conditions of living standards are not that good and that I am supposed to go and sleep at my friends place because where my grandmothers stay the house collapsed due to the heavy rains so they leave in a small house which can not accommodate the three of us.

And there are some other things that my grandmothers need which I can't afford to do for them such as clothes and other things so I need to change these things in my life.

Lastly, there are so many things I need to change in my life but right now I know that I can not change them with the conditions am living but with the feeling I have I know things will be good whether from well wishers and many other people.

Thank you aunt Kalia and aunt (name of research assistant) for the time we had I appreciate it may the Lord guide you in your studies.



Things to change in life

Firstly I can say that there are so many things to change in my life but I can not ~~[illegible]~~ get them all. I only thank g God for what he has gave me that day

I need school fees to go & to school so that I can fullfil my dreams that my grand mothers can live a better life someday through the money which I will get when I start work and the other thing is that i can be able to support my family financially so that they can not have troubles.

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The other thing is that I need food ~~[illegible]~~ ~~[illegible]~~ when going to school because I usually ~~wear~~ walk some other days when I have no money reason being that the school is situated far away from where we stay.

~~The~~ ~~condition~~ The Conditions of living Standards are not that good that I am supposed to go and sleep at my Friends Place because where my grand mother's stay the house collapsed due to the heavy rains so they leave in a small house which can not accommodate the three of us

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Lastly there are so many things I need to change in my life but right now I know that I can not change them with the conditions aim living but with the feeling I have I know things will be good whether from well wishers and many other People.

Thank You aunt Kalie and aunt [redacted] for the time we had I Appreciate it may the Lord guide you in Your Studies'

[redacted]

Figure 16: Andrew Essay (things to change in the future)

In his essay, Andrew talks about the hardships he and his grandmother face, such as lack of food, lack of safe and appropriate accommodation and lack of money. Andrew hopes that in the future things will be better and that he will be able to financially support his grandmothers to live a better life. Andrew also mentions how the lack of money for food and transport affect his education and that he has to depend on well-wishers and other people to help him financially and with material support. The future for Andrew is a collective one and he sees positive change in himself and his grandmothers. And in combination with his faith, he can cope in the present and regard his role as an overall positive role accompanied by adversities that can be fixed if they get help.

All three case studies show three different stories and experiences of young caregiving. All three case studies though have some common themes, such as the nuanced and complex nature of caregiving, displaying both positive and negative feelings and understandings that can be experienced simultaneously. What else seems to be overwhelmingly common and dominant is the impact poverty and circumstances have in shaping the children's and young people's caregiving experiences. Geography and time matter and impact on shaping people's experiences and that is why the next section looks specifically at children's and young people's emotional experiences of care and how this further affects their caregiving as lived experiences.

5.6 Children's Emotional Geographies of Care

Children's and young people's emotional experiences of young caregiving present two main conflicts. On the one hand, children regard their roles in a positive way, feel happy and proud of their role and enjoy the strong and loving relationships they have with the care-receivers. On the other hand, they face a number of difficulties due to poverty and other issues, such as caring for someone of the opposite gender, developing dependent relations or being concerned and stressed about not being able to provide what the ailing individuals need. The findings also highlight that children and young people manifested their ability to hope by using their faith, positive relationships and support received from others.

Emotions shape people's experiences and affect their sense of space and time while at the same time, the environment and geography can also alter individuals' experiences of everyday lives (Davidson & Milligan, 2004). As already seen through the three case studies presented earlier, as Bondi (2008) explains, emotion plays a vital role in determining experiences of care. Exploring the effect geography has on these experiences will help gain a better understanding of individuals' lived experiences.

5.6.1 Emotional Geographies of Proximity and Distance

The participants in this study experienced a variety of emotions, such as happiness, pride, love, devotion, fear, anxiety, frustration and loneliness. These emotions, although conflicting, are also interconnected and in a way, demonstrate geographic notions of proximity and distance. Giesbrecht and colleagues (2017) conducted a study exploring the emotional geographies of men who care for family members with multiple chronic conditions. They observed that the participants interviewed frequently articulated their emotional experiences through the geographical concepts of proximity (such as feeling connected) and distance (feeling alone and isolated) (Giesbrecht et al., 2017). Analogous to these findings, this study also discovered similar results as all three case studies above exemplify.

Sense of self

Exploring participants' sense of self, a few young people stated that when they assumed their caregiving roles they experienced feelings of frustration and anger and found their responsibilities challenging. Andrew's (19, M) case study above highlights that it was extremely hard for Andrew to assume and accept his role at first, but that later this changed with time and he was able to accept his new identity. Andrew says that he does not "*feel like that anymore, now I want to do it (take care of his grandmothers), now I am used to it*". Andrew, like the other participants in this study, who had to distance themselves from their 'old selves' who could not cope with feelings caused by their caregiving roles and they say that this 'new self' has accepted the situation and thus experience more positive feelings. Time and age seem to play an important role in this change and in the way emotional experiences are formed (Giesbrecht et al., 2017). On the other hand, George (17, M) states that he feels the most relaxed and feelings of happiness and hope when he is on his own by the river where he draws to relax and feels connected with himself (see also section 5.6.2). This indicates how a sense of proximity with himself shapes his and changes his emotional experiences from feeling stressed due to his caregiving roles to feeling relaxed and happy.

Relationships with others

A sense of distance in relation to others is also apparent amongst the participants with feelings of loneliness and isolation. Hannah (19, F) states that she sometimes feels like taking a step away from her mother and family because of how tired and angry she feels. Some of the problems she has to deal with within the household are due to the challenging behaviours of her brother Salif (15, M) and the fact that her mother is too weak from her illness to deal with him. Hannah (19, F) says that "*I need to go away and walk, sometimes where we draw the water and I stay there for a while, because I cannot deal with him* (Salif) *anymore. He makes me feels angry and I need to go*". Although Hannah does not explicitly state, this indicates that by distancing herself from her house and her family, she manages to take a break and then feels much better.

Samantha (17, F) explains how her caregiving role has brought her closer to her grandmother and made their relationship even stronger. She states that she feels "*very lucky to be the one caring for my grandmother because I have come to know her very well and we can chat and I can tell her everything. She is the first one I told I was pregnant*". Samantha, commonly with most participants' cases, demonstrates how her caregiving role has developed a sense of proximity and deepened their relationship into a trusting and loving one. This kind of relational proximity helps to construct a positive experience of young caregiving and as described in different sections in this thesis, it is echoed by all the participants in different ways.

Position of self within the community

As described in the case study above, Louise (12, F) distances herself and her grandmother Rute (63, F) from the rest of the community when she feels angry with people who discriminate against her grandmother because she is blind. By distancing the others away, she feels like she is protecting herself and her grandmother from stigma and from "*feeling bad*". Many of the participants feel isolated from their communities because of the lack of support and services and feel stressed and alone in dealing with the high level of responsibilities their caregiving role requires. Memory (35, F), for instance, describes how isolated and detached she feels from the other people of her village because the Chief will not provide anything to her family due to the fact that four years ago a local NGO gave them a house. This has as an outcome of experiencing caregiving in a negative and stressful way and also feeling different in comparison to others.

However, by contrast, in Daisy’s (13, F) case her wider community feels very close to her because her mother is the Chief in her village and due to her family’s status, Daisy receives a lot of help from her community. For example, she explains that when her aunt Elesi (51, F) does not feel well, the local youth centre provides them with a car so her aunt can go to the hospital. Daisy states that she feels worried when her aunt is unwell, but that this support helps her feel much better and less anxious and helps her feel closer to her community and the services around her. Also, most of the participants stated that they received a lot of support and comfort from their churches which helped to make the experience of young caregiving due to illness or disability a much more manageable one. This gives the participants a sense of belonging and that their community ‘cares’ for them and prays for them. As a result, the participants who receive this kind of support express their gratitude and describe feelings of hope and acceptance of their situation.

This section described how the experiences that occur between and within spaces contribute to the emotional experiences of young caregivers. This was important to explore as it offers a better understanding of children’s and young people’s emotional experiences in relation to feelings of proximity and distance and the relationships developed with themselves, their family members and their community. The next section explores how the power of space, real or imaginary, can also shape participants’ emotional geographies of caregiving.

5.6.2 The Power of Places and Spaces

Moving forward from the sense of distance and proximity but still exploring the sense of place and emotional spatiality, this section looks at how some spaces, both real and imaginary, can help children and young people to cope with adversity. As many other studies have shown, children and young people with caregiving responsibilities develop coping mechanisms using support systems such as extended family, friends, and members of their community to deal with the hardships (Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009). What this research has also discovered is the construction of safe spaces and places usually located away from home. On numerous occasions, the participants of this study claimed that they would go to church, by the river, the reservoir or some other place away from home to escape and relax by themselves, or with friends or family.

For instance, the photo (Figure 17) below shows George (17, M) standing by the river where he often goes by himself or with friends to draw and relax. These safe spaces are an integral part of their everyday lives and help them energise and feel more empowered to manage the challenges they are facing. These are places actively constructed by the young people in this study and which can differ depending on their needs. Skovdal (2009) in his research identified that often young people create safe social spaces alongside peers from whom they feel that they gain support and solidarity. Indeed, it is evident that positive relations with friends and family facilitate coping and creating positive experiences (further discussed in Chapter 6).

Figure 17: Photograph of George (17, M) at the river where he goes to draw and relax

Except for relational safe places, there was also evidence of ‘hopeful places’; of spiritual and future places that helped young people during their everyday lives. Many of the participants stated during informal conversations that praying and reading the Bible were important to help them overcome the challenges that they face. Religion, faith and spiritual beliefs play a significant role to make them feel empowered enough to deal with challenges and also learn from what their religion teaches. In addition, hope and aspirations for a better future were also significant for them to hold on to and to look forward to a better future for themselves and their families. As Skovdal (2009) indicates, this is a significant finding that presents how young people can use emotional strategies and tools from within themselves as an antidote to the challenges they are facing.

5.7 Conclusion

This chapter discussed the emotional geographies young caregivers experience. It addressed the second part of the research questions (see Chapter 1): 'What are children's and young people's emotional experiences and emotional geographies of caring for family members (parents, siblings, grandparents, other adult relatives) with chronic illness and/or disability?'. Participants experience a range of positive and negative feelings that are portrayed in different ways and connected with a range of internal and external factors. Although there are a number of emotional experiences related to caregiving, specific feelings are not always clearly separated from other factors and influences of everyday life. That is why three somehow contrasting case studies were presented in order to illustrate further some of the nuances of participants' everyday lives.

The most common theme presented amongst the participants was feeling proud and happy to take care of their family members. They talk about loving them and being loved and the importance of having this kind of positive emotional relationships with the person(s) they care for. Their role results in them becoming mature and responsible people and contributes to their personal development. For many to start with their role was difficult but as time passed they accepted it and got used to it. But for almost all of them, poverty and lack of basic needs are those factors that impose the greatest challenges and that result in dropping out of school, to look for work and ways to support their loved ones.

Louise has a very good support system that helps her to cope with her caregiving responsibilities, attend school and have a 'normal' social life, while she struggles with the stigma against her grandmother's disability. Rosemary, on the other hand, is struggling much more with coping on an everyday basis due to lack of income and basic needs. Spiritual life and peers are a great source of empowerment for her and other young caregivers in this study, but lacking in extended family support and living in a city means she has to deal with a number of challenges other caregivers do not have. Also, Rosemary’s sister suffering from mental health problems and the recent loss of her brother resulting in bereavement and leaving a household of only women and children to pose even more difficulties. It would be interesting to be able to identify whether a mental health problem might be more difficult to deal with in a family, especially when there is a lack of both practical and emotional support. Andrew experiences caregiving in a very different way, as he is a young man taking care of his two grandmothers. Andrew has a good support system but due to the fact that his family lives in different places, he does not have the everyday support as Louise has and additionally also suffers from the effects of poverty.

Despite the range of emotional geographies and experiences recounted by the young caregivers who took part in this study, there are some common themes emerging from analysing the data. Education is a common theme that will be further be discussed in Chapter 7. It is, however, important to acknowledge the connection of education to feelings of stress and anxiety when it is not accessible and feelings of hope when it is. Future, hope and aspiration are also themes that empower young people and give them the motivation to continue to deal with their hardships. And of course, relations, family relationships, friendships, community and social life play very significant roles in how young people experience caregiving.

As emotional experiences are closely connected with relations and social interaction, the following chapter 6 will explore young people’s family relationships, especially with the person they are caring for.

Chapter 6. Family Relations

“Caring requires no measurable outcomes”

(Maclntyre 1996, p. 150)

6.1 Introduction

Chapter 5 investigated children’s and young people’s emotional experience of caregiving and how this affects everyday life. It illustrated that children and young people experience caregiving in multiple ways depending on a number of factors without describing this experience as purely negative or positive. The accounts offered by the participants showed that emotional experiences of young caregiving are characterised by complexity and fluidity, and like the experience of being a child in Malawi (presented in Chapter 4), it can be shaped by and shape everyday lives, relationships with the self, family and wider community. Looking at these nuances is important in order to gain a deepened understanding of young caregivers’ experiences and needs. These diverse experiences and perspectives can impact on the nature and level of resources, interventions and support that young caregivers might need.

To investigate further, this chapter is concerned with family relations developed within caring contexts and explores family geographies of care while investigating how these impact on children’s and young people’s overall experience as caregivers. This chapter attempts to answer the third set of research questions in regards to family environment and relationships: ‘How are family geographies constructed when children caring is involved? How are family relations affecting or are affected by young caregiving? What are children and young people different roles and how do these intersect?’. This chapter is presented in two parts, the first explores family relations through the caregiver’s view and investigates if and how relations affect or are affected by young caregiving (sections 6.2, 6.3 & 6.4); while the second part looks at the community and care by exploring family geographies of care (section 6.5). It examines care in terms of children’s mobilities and time-space dimensions of care.

Young caregivers and their family members affected by illness and disability develop reciprocal caring relationships that are complex and dynamic. Often, at the same time, both sides adopt the role of caregiver and care-receiver and thus it is not always easy to define when someone's role changes. Evidence from research undertaken in sub-Saharan Africa and the UK indicates that caring relationships are characterised by mutual emotional support and a sense of reciprocity, as both caregivers and care-receivers provide and receive guidance, advice and emotional support (Evans & Thomas, 2009). While many caring relationships are characterised by reciprocity and interdependence, often due to the lack of resources and support, care becomes a burden leading to relations of dependence (Evans & Thomas, 2009). As seen in the preceding chapter, this can be associated with feelings of anxiety and sometimes guilt, when the young caregiver cannot provide for his/her ailing relative. This situation places young caregivers in a particularly vulnerable situation and can impact on the caregiver's relationship with the care-recipient, affect their education outcomes, well-being and social life (Evans & Becker, 2009; Skovdal et al., 2009).

As with other studies, analysis of the data gathered in this research demonstrated that the nature of family relations can affect how children and young people experience their caregiving roles. It is however much more complicated than just saying that a good relationship leads to a positive caregiving experience or a bad relationship between the caregiver and care-receiver means a negative experience. For example, although love and emotional closeness are developed within caring relationships, there is also evidence that long-term and intimate caregiving can result in difficulties and strains within caring relationships (Evans & Thomas, 2009; Robson et al., 2006). In order to demonstrate the complexity of caring relations within a family and the impact on the children, one case study will be presented showing the fluidity and interconnections of different aspects of family relations and how other factors impact on those.

In addition, research studies about young caregiving in sub-Saharan Africa (include this research project) demonstrate that due to lack of government support and poverty, families need to strategically allocate children and young people to those family members who need support (Evans, 2014). The frequency and planning of this allocation depend on various factors, but especially the needs of the family members who are the most vulnerable and the availability of various forms of support if any. This results in complex relationships that constantly change, and although this does not seem to provide secure environments for children, none of the children and young people who participated in this study pinpointed this as a negative aspect of their experience. The results of this research project support the findings of several other studies in sub-Saharan African that increased movement and household fluidity characterise families affected by illness and disability (Evans & Becker, 2009). Finally, the last section of the second part of this chapter looks at the spatial temporality of young caregiving and concludes that caring happens constantly, even when the caregiver and care-receiver are not in the same space or when they are away from home, the place where caregiving activities usually take place.

6.2 Caring Relationships in Families Affected by Chronic Illness and Disability

Data from this research study illustrate that all families participating exhibit strong bonding, and loving and caring relationships in different ways. For example, Rute (63, F), who is blind, has her two granddaughters Louise (12, F) and Eveline (11, F) to take care of her.

> Rute: *I feel sweet like sugar that I am loved, and yesterday they washed for me. I feel sweet that these are really my children now. You look at the breast you breastfed with and you feel happy that these children are really working for me. Our relationship is good because these children do whatever I tell them to. Like, I tell them 'you need to go to draw water and also to wash the clothes'. Then they share the duties and say 'I will go and draw water and you should go and start washing'. Whatever I tell them they do, they do not refuse.*

Rute describes how happy and loved she feels because her granddaughters listen to what she says and do as they are asked. Her statement presents notions of how love and discipline interrelate within a relationship. This is a family within which relations are characterised by feelings of love and respect for each other which are expressed through the notion of discipline and obedience. And although this is generally the case, what is noteworthy to highlight is that this is not always what actually happens. Both Louise and Eveline, as well as Rute, at different points of this project's fieldwork, discuss how sometimes the two girls feel too tired to do household chores or they just want to play with their friends and are not willing to listen to their grandmother. Despite those moments of resistance, this family have a strong and effective support system, and despite the adversities they face, they are able to enjoy a happy and healthy life developing strong loving attachments and relations.

Matias (16, M), who takes care of his grandfather with mobility problems, explains that he loves his grandfather very much and that he enjoys spending time with him.

> Matias: *When I return from playing football, if he can't make it because it's far, he calls me to ask me what happened with the game. He also tells me what I need to be careful about so bad things won't happen. I love it when he tells me stories. He loves to teach me how to do pottery because he loves pottery. But I also love to stay close to him when he is doing his work such as fixing umbrellas and shoe repairing. I do this in order to learn his work.*

For Matias and his grandfather, the caregiving relationship has brought them closer together. In addition to the evidence of their loving relationship, Matias here also provides insight into their reciprocal relationship and how his grandfather takes care of him. What Matias says shows the sense of respect and appreciation they have for each other. It highlights that despite the challenges Matias often has to deal with due to his caring responsibilities, his relationship with his grandfather has grown stronger. The quotation also reveals information about how their close relationship results in the grandfather teaching Matias life skills, as well as skills for income-generation activities and livelihoods. Robson and colleagues (2006) also discovered that children and young people with caregiving responsibilities in Zimbabwe enjoyed a number of positive outcomes that emerged from their caring roles such as strong relationships with the care-recipient, learning new skills and becoming an emotionally mature individual. Furthermore, Maclntyre (1996), a professional nurse who had to take care of two loved ones with AIDS, explains that having an established loving relationship with the person being cared for creates new insights within the relationship and new knowledge.

On a different note, Memory (35, F) reflects on her loving relationship with her daughter while acknowledging all the hard work, Hannah (19, F), her daughter does.

> Memory: *Our relationship it's bounded by love. I appreciate her love when she does the following: she prepares food and warm water for bathing for all family members. Each and every day, particularly after having meals, she brings the water to the bathroom and asks me to wash my body. After taking a bath she asks me to put out dirty clothes and keep them separate, then advises me to wear clean garments. She makes me so proud. She is a child who loves. During the day, she does not go out of my sight. She kindly advises me that I should avoid getting too many worries. She says, 'this will help you to live a relaxed life'.*

What Memory describes here is a very close, intimate and warm relationship with her daughter, Hannah. This family is one of the most isolated in this study and with the least extended family to provide support for their household, which means they only have each other. This results in building loving relations and strong bonding, which brings positive experiences of young caregiving. This does not mean though that Hannah only experiences positive outcomes because of her close relationship with her mother but the picture is a complex one.

Despite the loving nature of their relationship, there is a sense of loneliness amongst some of the young people with caring responsibilities. Young people reflect on their lives and caring responsibilities and realise that their lives are very different from the lives of their peers. Although they experience loving, caring relationships with their families but due to additional circumstances like poverty, they feel isolated and lonely, as if they are the only ones who experience this life. Hannah (19, F) states that she loves her mother Memory (35, F) very much and she is happy to be taking care of her, however, due to her mother's illness and lack of extended family, Hannah feels alone when she gets unwell and when comparing herself to young people of her age. Hannah explains:

> Hannah: *My fellow peers are provided for by their parents while, in my case, I do not. I have my mother but I take care of her and my family and provide all necessities myself. But when I fall sick I can't do any piece work and hence I sleep without food as there is nobody to help and bring money and food for us.*

This, however, does not mean that Hannah does not have a loving relationship with her mother. It is evident from their narratives and from observation of their interactions that they love each other very much. Hannah is so committed to her mother that she was also willing not to marry her son's father in order to remain at home with her mother and take care of her. Yet, her mother is ill and very weak and unable to bring income to the household. This in combination with the fact that there are four more children all under 16 years old living with Hannah and Memory means that the responsibility for everyone in the household falls on Hannah only.

Due to their circumstances, some of the caregiving children and young people in this study are vulnerable to the dangers of abuse and neglect. For instance, Daisy (13, F) who takes care of her maternal aunt Elesi (51, F) who has been diagnosed with AIDS, has lived on and off at her aunt's house to provide intense personal care when her aunt is not feeling well. Her aunt Elesi usually lives on her own as her children are all grown-up and live in their own houses. All except one, Elesi's youngest son, Mike, who according to Elesi has drinking and gambling problems and goes to Elesi's house asking for money but when he does not get any help he becomes violent. Although he has never hurt Daisy, she has witnessed a number of his outbursts and has sometimes taken the role of mediator. Elesi explains that she has a good relationship with Daisy because she takes cares of her even when her son is around and "*is causing trouble*". Elesi elaborates further with an example:

> Elesi: *One day when Mike was being a trouble, Daisy came and sat right there with me. She tried to make him leave but couldn't and so she started crying. She was feeling sorry for me, as she was thinking that I am having problems with my legs and there is nothing I can do. And also that I am not working but he is still troubling me that I should give him money. And after a while, he left and Daisy stopped crying.*

Here Elesi describes the very challenging circumstances both she and Daisy have to deal with. Daisy, who is only thirteen, has to manage and negotiate her cousin's, Mike, aggressive behaviour and protect her aunt who is unable to do that for herself. This exposes Daisy to situations where both physical and emotional harm is a high risk and could result in severe abuse. Other studies have also highlighted that although the majority of caregiving children described loving and caring relationships with their families, there were a few cases where young people were treated in uncaring ways and were at risk of abuse and neglect (Evans & Becker, 2009).

Samantha's (17, F) case, on the other hand, is a bit different from Daisy's and Hannah's. Samantha takes care of her grandmother Clara (85, F) who has mobility problems due to her old age. Samantha explains during an informal conversation that her grandmother Clara is the one who has raised her and that is why when Clara felt ill, Samantha decided to become her caregiver indicating an existing strong bond between grandmother and granddaughter. This indicates a sense of appreciation and reciprocity, but also as other studies suggest as well, it illustrates a correlation between the pre-existing relationship of the care-receiver and caregiver and the decision to become carer (Brown and Stetz, 1999).

Furthermore, it could be that because of their very good relationship that Samantha was able to create her own family, get married and move to her own house. It seems that their relationship is characterised by a sense of reciprocity and interdependence. Both Clara and Samantha have the role of the caregiver and contrary to others, they have managed to develop a relationship that allows both to also live independently. When she left her grandmother's home, Samantha made sure to find a house close to her grandmother in order to be able to continue looking after her. Both Samantha and Clara are happy with the new arrangements, but Samantha highlights that "*I am more worried now because I'm not with her the whole time. And now that I'm pregnant I can't go there as often as I used to. But because both I and my husband have a job, we pay a girl to check on her every day and do shopping or fetch water if necessary*." This indicates the fluidity of caregiving relationships and although the loving and strong bond remains, the circumstances and the way care occurs can be modified. There is a shift from providing care directly and in person to managing care provided by someone else who is a paid caregiver (and the only paid caregiver in this study).

Samantha's quotation above also describes feelings of uncertainty and worry about the future and about her grandmother's health. Evans and Becker (2009), who worked with families affected by AIDS and HIV, observed that many of the children expressed stress and worry about their parents' future and wellbeing. Due to the nature of the illness, in their study both the young caregivers and adult care-receivers thought it was important to spend as much time as they could together and learn from their parents and that this was an opportunity to bring them closer together (Evans & Becker, 2009). Stress and worry about the ailing individuals' health and future were also present amongst the children and young people who participated in this research project. What was interesting was the absence of discussions around death. None of the families affected by severe illnesses and old age, expressed particular thoughts or feelings of concern of loss of their family, which could be due to stigma and cultural beliefs around conversations about death. Hosking and colleagues (2000) explored cultural attitudes towards death in South Africa and found that terminal illness and death were not discussed with the children in half (50%) of the families participated in their study. They also stated that children who were not informed of the diagnosis of the terminal illness were most likely to develop increased anxiety and psychological problems (Hosking et al., 2000).

6.3 Reciprocity of Care

The preceding section (6.2) offered some of the general key findings that describe the different types of relationships between the young caregivers and adult care-recipients encountered in this study. This section looks at the reciprocal nature of care relationships. Care is not a one-way process; it is reciprocal, dynamic and its intensity changes over time. As discussed in Chapter 2, caring relationships are characterised by interdependence and reciprocity (Evans & Becker, 2009). In examples where children care for their ill parents, it is often observed that their relationships are described as reciprocal and characterised by mutual care and support (Evans & Thomas, 2009). For instance, Evans and Thomas (2009) explain that it was found that both parents and children received and provided emotional support, guidance and advice. During the research conducted in Malawi with young caregivers and their families, the reciprocal nature of care was obvious during observations of everyday life. Observations confirm that caring is a two-way process and it is exhibited in diverse ways and levels. Data from the care map activities (see Chapter 3) showed that only two participants identified reciprocal care with a family member (Louise, 12, F & Daisy, 13, F), while two others

(Rosemary, 18, F & Rejoice, 18, F) stated that even though they have the role of caregiver no one is taking care of them. All the other seven participants illustrated that they are caregivers and care-receivers at the same time, but it is not the people they are looking after, who are taking care of them.

Louise (12, F) drew her care map (Figure 18) which illustrates that in addition to taking care of her grandmother, she is also caring for her three cousins and friends. She highlights that her mother, cousins and friends take care of her while specifying the reciprocal relationship with one of her cousins.

> Louise: *When I am playing and people want to beat me, she (my cousin) tells them to say 'aah, do not beat her just play'. Or when I am at school and maybe I have fallen sick, they ask me, have you any relatives, yes, my cousin, and they say, in what standard are they? One is in standard 6, and then I tell them her name so they should come and take me home.*

What is interesting here is that Louise identifies different types and levels of care and regards herself as both a caregiver and a care-receiver.

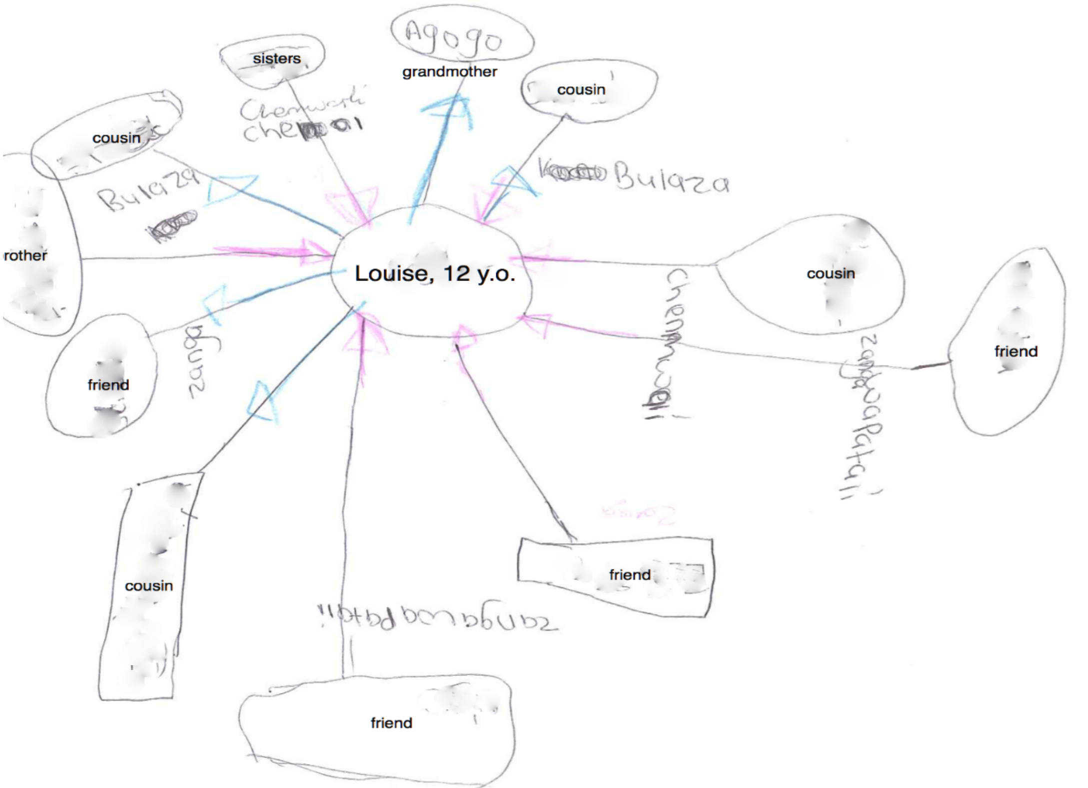

Figure 18: Louise's Care Map

Samantha (17, F) takes care of her grandmother and although she was also raised by her grandmother (like Andrew (19, M), see case study in Chapter 5), she states that it is her mother, father and husband who take care of her.

> Samantha: *Ok. My mother takes care of me in a way that if she happens to have money she sends me some so that I can share it with granny. So, do my father. My husband also buys me clothes, he gives me money to buy water that I use for bathing and other things. Another thing is that he feeds me. In fact, he provides for everything that we may need at this home.*

Similarly, but under different circumstances, Matias (17, M) who takes care of his grandfather, states that his mother, father and sister take care of him.

> Matias: *My mother takes care of me by bringing food here at home and also money for school fees. My father takes care of me by giving me the advice on how the world is. As for Rita (sister), she takes care of me when I am sick because she is the one who stays very close to me.*

Rosemary (18, F) on the other hand states that she has no one to take care of her. On the contrary, Rosemary explains that she has to take care of her family but has no support herself. The outcome is that she struggles to cope with the high levels of responsibility (see Chapter 5).

Although caring roles and responsibilities differ and change over time, care is constantly happening even if it is not always acknowledged as such. For instance, my research assistant writes in her fieldnotes "*Andrew (*19, M) *is cooking for the family while his grandmother is giving him advice on school matters*" (Research assistant fieldnotes, third visit) indicating that while Andrew is taking care of his grandmother by cooking for them, his grandmother is emotionally supporting him and guiding him. Yet, when he was asked who is taking care of him, he replied "*my mother will pay my school fees when she has money. My uncles will give me clothes. Some other times shoes*". In this example, Andrew displays a practical view of caring as provision of material basic needs and does not acknowledge his grandmother's emotional caring work. As mentioned in Chapter 5, Andrew, who was raised by his grandmothers, loves and values them immensely explaining this emotional relationship as his motivation to be their caregiver. This could perhaps be due to living in poverty which makes him focus on the practical and material side of care rather than the emotional. It is, of course, a priority to meet essential basic needs and everyday necessities for survival, placing emotional care a second priority.

6.4 Family Case Study - Rejoice and Christina

Background

Rejoice (17, F) and with her family live in a rural area outside Blantyre. Rejoice lives with her mother Christina (52, F), father Mike (61, M) and nieces Enifa (13), Anna (10) and Eileen (2). Christina and Mike had six children, but two of them passed away so the children of the family are now Rejoice and her three siblings. All of her siblings are married with children and live in the same village. As is shown on the genogram (Figure 19), the family's older child, Asha (F), who passed away, had two children (Eileen, 2 and Anna, 10) who now live with Rejoice and their grandparents. Enifa (13) is one of Emma's daughters and also lives with Rejoice and the rest of the family. In terms of extended family, Christina has only a sister left who lives in Lilongwe but does not see often. There is no extended family reported from Mike's side.

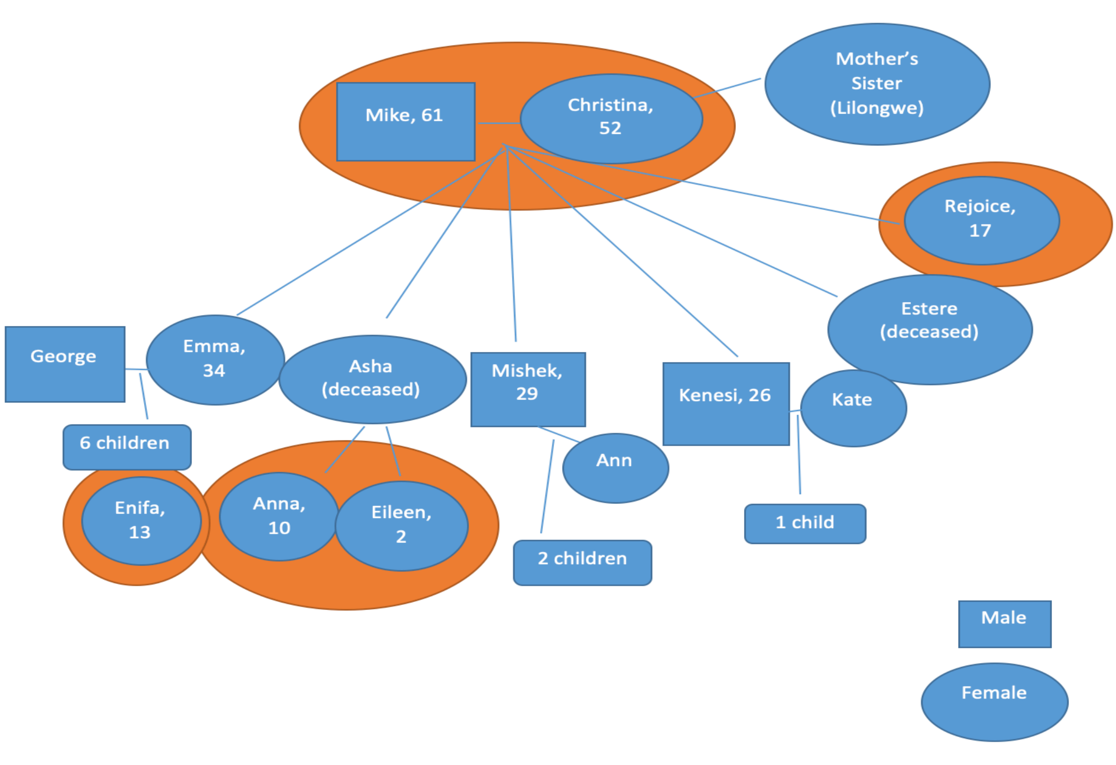

Figure 19: Christina's family tree (the orange ovals indicate the household Rejoice belongs to)

Rejoice is taking care of her mother Christina who has a chronic skin condition which does not allow her to stay exposed to the sun for a long time as it can become itchy and painful. This makes undertaking everyday activities difficult as it is naturally often sunny in Malawi and much rural life activities take place outdoors. Rejoice states that she takes care of "*mother and her grandchildren*" referring to her three nieces Enifa, Anna and Eileen. When reflecting on her role, Rejoice indicates that she was not sure when exactly she became her mother's caregiver; she remembers however noticing that her mother could not cope with everyday life and was not able to work, so she felt that she had to step in and help. Rejoice has managed to reach Form 2 of secondary school, but had to drop out of school due to her high level of caring responsibilities. As education is imperative for the whole family, Rejoice has at numerous times attempted to return to school, but was unsuccessful.

It was always busy during our visits to Rejoice's family with the observation of more children than adults being around. At the first visit, during the first introductions, I recorded in my fieldnotes mother's and Rejoice's name and age, as well as the names of the ten more children hanging around, all under 15 years old. I wrote that "*I am very confused, who are all these children? I count fourteen of them. Are they all family*?" (author's fieldnotes, 4/11/2015, first visit). We soon found out that most of the children are related to Rejoice's family and they live in houses nearby. During the day, when their parents, Rejoice's siblings, are away at work, they stay with their grandmother Christina.

Although very welcoming, this family seemed very quiet and lethargic during our visits. Children often sat near us, but would not engage with us or with each other. The research assistant mentions in her diary "*the family members are not active. Every time we are there people just sit with us. I have never seen the children play and there are always so many children around*" (diary, 12/11/2015, second visit). This is a family with more children than adults, i.e. a high dependency ratio, and although most of the adults' work, the income they provide is not enough. They are living under arduous circumstances and the lack of necessities, like food and clothes, contributes to the family's 'stillness' observed during visits.

Appreciation and Trust

Due to this high level of need, Rejoice has taken on a high level of responsibility to take care not only of her mother, but also of other family members. This family has a lot of young children who need caring for. Christina is the one who as their grandmother is responsible for them. But considering that Christina can only do a limited number of things due to her illness, Rejoice shares her mother's responsibilities and takes care of the grandchildren. Describing a time when Christina was admitted to the hospital, Christina explains how Rejoice would visit her and bring her food, but then she would go back to take care of the children left at the house.

> Christina: *Even during the time I was at the hospital with her, Rejoice was the one bringing food. She was the one who would walk from here to Queens*[32] *without any money for transport. She would just cook the food and bring it to me to the hospital and go back home.*

This indicates that caregiving responsibilities can extend further than just towards the person with the chronic illness or disability. And although, it is culturally common that older children take care for younger siblings in an African context, what it is important to highlight here is that Rejoice has in addition the role of taking care of her mother and the rest of the household.

Christina recognises and appreciates the work Rejoice is doing for her and the rest of her family. She speaks openly to us about how thankful she is that Rejoice is helping out the whole family:

> Christine: *Rejoice takes good care of this home, and I really depend on her that even when I get sick, she is the one that carries me from here and she takes me to the hospital. She is the guardian (of the grandchildren) when the older ones (family members) are with their families. Sometimes they (family members) also hear that I am sick when she has already taken me to the hospital. Like the time I used to go to the hospital with this skin disease, I used*

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[32] 'Queens' is how the Queen Elizabeth Central Hospital in Blantyre is referred to locally. It is usual in government hospitals in sub-Saharan Africa that relatives bring food to patients who are admitted.

> *to go with Rejoice. She would be absent from school so she can help me. She was like 'if a mother is not well and gets admitted, what will happen?'*

From observations, the strong bond between mother and daughter is evident. Rejoice seems to be aware of her mother's appreciation and trust and this seems to help her to carry the burden of her responsibilities. During visits, when Christina tells us how proud she is of Rejoice, I observed Rejoice's reactions and wrote in my fieldnotes diary '*Rejoice smiles, her face looks so happy. Is this related to what her mother is saying about her*?' (author's fieldnotes, 27/11/2015, third visit). Christina goes on and talks about me and how happy she feels that she met me because I am now a role model for her daughter Rejoice. She emphasises that by providing Rejoice with necessities, such as money for school fees, Rejoice could become like me. Christina believes that she could go to university, travel and meet many people and experience other cultures. Rejoice is smiling throughout the whole conversation indicating perhaps that she agrees with what her mother says. Despite the challenging ethical and methodological considerations this generates as it seemed to be a hint for me to help Rejoice with school costs, it is also a very interesting observation of their relationship. Although Christina needs Rejoice to be at home resulting in her dropping out of school, Christina considers it important to try to communicate with her daughter that she hopes she will have a happy and promising future. This highlights the very contradictory nature of this relationship which will be explored further in the section below.

It is noteworthy that during the same visit an interesting conversation took place between Christina and Rejoice. My research assistant describes in her fieldnote diary the following:

> "*While Enifa, Anna and Eileen were eating, Christina asked Rejoice if tomorrow she can wash her clothes, but Rejoice said 'no'. Then Christina said that then Enifa would wash her clothes. I do not think the relationship between Christina and Rejoice is that bad, but it may be that Rejoice has something else to do tomorrow. I think Rejoice loves her mother and even respects her*" (research assistant fieldnotes, 27/11/2015, third visit).

This quotation from my research assistant's diary is interesting as it discusses a couple of important points. Firstly, it describes a moment between mother and daughter where the mother, Christina, asks Rejoice to help with household chores to which Rejoice says no. Then, Christina tells Rejoice that she would then do something else. This demonstrates that, at that moment at least, decision-making is not a one-way process, but more like a negotiation. It is Christina the one who begins with the request, but it is Rejoice's display of resistance that makes this a negotiation and finally, another task is agreed to be taken. A second interesting point from this quote is that, in the research assistant's opinion and observations, due to the relationship mother and daughter have, Rejoice can say 'no' to her mother and still show her love and respect for her mother, contrary to the common notion throughout the fieldwork that children should respect and listen to adults, and do as they are told.

Love and Devotion

It is true that Rejoice is happy to take on her caring responsibilities motivated by her love and devotion to her mother and the rest of her family. Rejoice confirms how much she loves her mother and how loved she also feels, as illustrated during our first interview:

> Research assistant: *How would you describe the relationship between yourself and your mother?*
>
> Rejoice: *We love each other very much.*
>
> Research assistant: *And when you are together what is it that you usually do?*
>
> Rejoice: *Chatting and she counsels me, she gives me advice.*

As discussed in Chapter 4, amongst other things, both counsel and advice strongly emerged as care responsibilities that adults had towards children and an imperative part of parenthood. Amongst other things, this also means that Rejoice feels loved and cared from her mother who listens to her, chat with and gives her advice. Evans and Thomas (2009) also found in families affected by HIV and AIDS that most of the parents, although when they had the role of care-receiver, parents continued to advise and give guidance to their children.

Indeed, counsel is a significant positive aspect of their relationship between Rejoice and her mother something that both acknowledge and Christina further explains that what makes her feel even closer to her daughter is that she follows her advice. During our interview with Christina, we were talking about Rejoice's social life when she stated that:

> Christina: *She has many of them* (friends)*. But one thing that makes me happy is that she kind of isolates herself. Because her friends wear skirts of this style* (short), *but she does not do that. You will hear her say 'mother, I was born in a village, I am not from a town; I am living in a village so to wear such kind of skirts, I would not manage'. I know that my child does not possess this kind of behaviour which is there these days and she also… maybe she will start later when she is older. But I see that she has no part in such kind of behaviours.*

Long skirts are socially acceptable dress for women, especially in rural Malawi where communities tend to be relatively conservative and associate short skirts worn by girls with poor morals and disrespectful urban fashions. Christina clarifies further that she advises all the girls in her household to dress appropriately and according to cultural norms and feels very proud of Rejoice that she is now doing this of her own will.

Rejoice holds her mother's interest in her life close to her heart, resulting in their bond and positive relationship. She continues by explaining "*she* (her mother) *encourages me to work hard in school, encourages me to pray and choosing the right friends, people with good manners and behaviours*". Although Rejoice and Christina are very close, Rejoice is also close to the rest of her family and enjoys spending time with her father, siblings, nephews and nieces. She chooses the photograph below (Figure 20) as something that makes her feel happy. Describing the photograph, she explains that "*this is my mother carrying my little sister on her back and that's the grandchildren. That's my father weaving a mat, and that's me sitting behind*" and elaborates further that she was feeling happy when this photo was taken "*because I was chatting with parents and I like that very much*", underlining further her reciprocal relationship with her parents.

Figure 20: Photograph of Rejoice sitting with her family

Despite Rejoice's positive relationship with her mother and her family, it is obvious that mother and daughter have a much stronger attachment compared to the rest of the family. There is no way to know exactly the reason she is closer to her mother than the rest of her family. It could be because of the role Rejoice has as her mother's caregiver, but there is no way to know this for sure. Christina reflects further on her relationship with her daughter and highlights that Rejoice compared to others from her extended family is faithful to her mother and immediate family, and that is why their relationship is good.

> Christina: *The relationship, I can explain is that, if I say that I have a child with good manners, then it is Rejoice. I also know and think that if she was a boy, I would know that she will place me somewhere and leave me alone. Because even that boy (Eileen's father) you saw there earlier, he went to school, up to form 4, but there is nothing he does to help us. Rejoice has reached form 2 but she does not say 'I should do this and that', no. And to say the truth, I know that in the future, if she goes further with her education, I see that I will get a lot of help from Rejoice.*

Christina here is referring to gendered ideas of caring and to the link between having children and receiving financial help. Other participants from this study also stated that it is usual for girls and women to assume caregiving roles within the household and that boys and men usually partake in income-generating activities. As this study and other research projects demonstrate though, this is not always the case and often boys also undertake a high level of caregiving responsibilities, including for opposite sex relatives (see Chapter 3 and 4). It is also common in Malawian society that when the children of a family become adults and get a job they give money to their parents and help them with necessities. So, Christina believes that when Rejoice finishes her education and finds a job, she will not 'forget' them as others have done, but she will be there for them and help them, although as the next section explains, this is not as straightforward in Rejoice's case as she has been unable to regularly attend school.

Dependency and Control

Care and domestic work can lead to strong family relationships and resilience, but it also has the potential to result in negative outcomes depending on the level of responsibility, available supports and resources (Evans & Skovdal, 2016). Despite all the positive aspects of Christina's and Rejoice's relationship, similar to many other relationships, there are some negative aspects as well. Christina's dependency on Rejoice is noticeable as although she says she would like Rejoice to finish her education and move on with her life, Christina does not think that Rejoice is yet ready to do so. She explains that she sees Rejoice as a child and not an adult because if she would accept Rejoice as an adult, it could mean that her daughter would leave her:

> Christina: *To me, I see that she is still a child. She hasn't reached the adult stage. But also, if I tell her that you are an adult, she will start misbehaving, she will say 'I am an adult and I can do whatever I want', and that will not be good. Because of how things are with her generation, she might think she can go and have her own family.*

Christina contradicts herself as previously (see preceding section), she states that firstly she is proud that Rejoice is making the right choices according to their cultural norms and Rejoice chooses not to wear short skirt, and secondly, Christina emphasises the importance of education and how having a good one can help Rejoice with finding a job and thereafter support her parents financially. In the quotation above though Christina states that she does not think Rejoice is ready to enter adulthood and that she is concerned about the choices Rejoice might make because of peer pressure and her generation. What Christina describes here is the fear of early marriage or an early pregnancy which is very common amongst girls in Malawi. So, Christina can control Rejoice from entering adulthood by thinking of her and treating her as still a child.

Christina greatly depends on Rejoice and even though she loves her very much, she knows that she needs her daughter to be around to help her. Even if Christina is not doing this consciously, she has placed a tremendous responsibility on Rejoice.

> Christina: *I see that she (Rejoice) is not cruel. Even if I passed away, the little ones will not suffer. Rejoice will really try to cover up her relatives. Because I see that she understands. She takes care of me, putting water on fire for me to bath, drawing water for me, making sure that mother should have water to drink in this house, I should do this for people to eat here at home. I depend on her that I have a child, Rejoice.*

Christina here shows her appreciation, pride and trust that even if she was gone, Rejoice would continue to care for others and provide for her family. This is not always the case for care-receivers, as studies in Tanzania, Namibia and UK found that many of the mothers who were receiving care from their children expressed feelings of sadness and distress because they need their children to care for them and also that they were concerned about how this could affect their children/carers (Evans & Thomas, 2009).

For Christina, Rejoice's future is also important and Christina describes one that is already planned and follows cultural norms for young women in Malawi:

> Christina: *What I want for Rejoice's future is to complete her school. After she has completed her school, she should start working. As she is working she should then find a partner and that will make me happy because I will know that she is preparing the future of her family. And that will make me very happy because she will be helping me then.*

When Christina says that Rejoice will help her after she gets a job, she refers to financial support. It is common for other families that when children become adults, they help their families with money and/or food. However, Christina does not mean that she just wants her daughter to succeed at school, find a job and husband so she can just help her mother. The notion of ensuring education and a good marriage, as in many other societies, falls within parental responsibilities.

Although Christina needs her daughter to take care of her, she stills considers motherhood as important and wants to be a 'good mother'.

> Christina: *I admire my friends who have educated their children and now the children are able to solve their parents' problems. People then can say they are good parents; their children do not depend on them anymore but it is the children who help their parents. I myself have not enjoyed motherhood because all my children depend on me in one way or the other. But I have hopes for Rejoice. That she will make me a good mother.*

Christina's words highlight what being a good mother means for her and how important this is. Despite the hopeful message that she believes in Rejoice, there is a great responsibility for her daughter as she is the youngest one and if she does not succeed, her mother will not be able to feel that she is a good mother.

> Christina: *I did not enjoy motherhood. Because even though I managed to send my children up to form 4, none of them has succeeded. Everyone has just stayed here. Out of all these 6 children I gave birth to, Rejoice is the one I am relying on in my heart that she will help me. The way I see Rejoice being a girl child, if she started working, I so much believe that she would help me. That would change my life because I would have a child who went to school and is helping me.*

Christina in this quotation ends with the hope that her last child, Rejoice who is the youngest of all her children, will complete her secondary school education and start working so one of her children can finally start supporting Christina financially. What is noticeable is how although previously Christina acknowledged Rejoice as the person who cares for her and looks after her when she is ill, goes to the hospital, does piecework and brings some income, does childcare for her younger siblings etc., yet here Christina implies that none of her children really offer any help and that her last hope is Rejoice. This is important because it shows how complicated, fluid and contradictory their relationship is. Depending on the current family needs and circumstances, the help Rejoice provides is sometimes considered to be sufficient, while at other times not good enough. This adds more pressure on Rejoice as she has to be a better caregiving child and her support needs to be adequate as according to Christina there is no one else there to help. This of course has a tremendous impact on Rejoice whose voice is presented in the next section.

Loneliness and Responsibility

Despite the large number of people around her, despite having both parents and a very close relationship with her mother, all the caregiving roles she has and the above expectations of her mother result in Rejoice feeling burdened by the responsibility and extremely lonely. Her perspective on this is that she has to do what it is required because no one else will do it. During the care map activity (Figure 21), we asked Rejoice to draw arrows towards those who she is taking care of and arrows towards herself showing the people who are taking care of her. When she finished the activity, we observed that she had not drawn any arrows towards herself. When asked, she stated that even though she shows that she has the responsibility of taking care of her mother and others in her family, but she says that "*there is no one*" who is taking care of her.

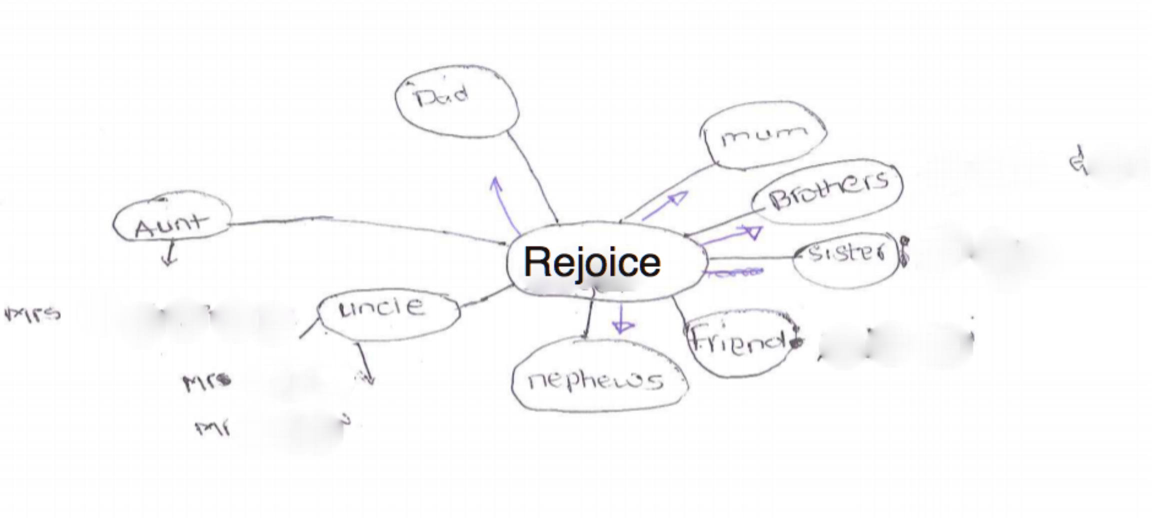


Figure 21: Rejoice Care Map

There were a few occasions during our visits we observed that Rejoice would isolate herself doing her chores or cooking and would not sit with the family. It was at these moments when it appeared that Rejoice experienced feelings of loneliness and isolation. Trying to explore this further, we asked Rejoice what happens when she gets ill; who takes care of her. Her answer was "*my relatives assist me*" but when we asked her to tell us the last time she was ill and what happened, she described:

> Rejoice: *I had skin blisters a few months ago.*
>
> Research assistant: *So, what happened?*

Rejoice: *I went to the clinic in Chileka.*

Research assistant: *Did anyone accompany you to the hospital?*

Rejoice: *Yes, my friend from the village.*

This is contrary to what most of the young people of this project have stated. It seems that Rejoice's feeling of not having anyone to take care of her may be connected to the struggle that her responsibilities bring. When asked how she feels about her responsibilities, Rejoice replies:

Rejoice: *I feel pain.*

Research assistant: *Could you explain what do you mean when you say you feel pain?*

Rejoice: *If I do not find piece work I feel pain. Because the people here at home look up to me when there is nothing to eat.*

This agrees with what her mother stated above, that Rejoice is expected to provide for her family and that they depend on her. This becomes a huge burden for her that makes her 'feel pain' when she cannot fulfil her duties. Similar to other studies about young caregivers in Namibia, where children with caregiving responsibilities stated that they 'shared' the discomfort and pain with their ill parents when they could not provide food and other needs for their ailing parent (Evans & Thomas, 2009). Although there are a number of adult family members living around their house and their young children spend all day with Christina and Rejoice, there is not as much help and support as would be expected.

Extended Family

Both Christina and Rejoice declared on numerous occasions that although extended family help them, their support is limited and not consistent. When they talk about their immediate and extended family, it appears that Christina, Rejoice and the grandchildren are on their own. Rejoice talks about their immediate family and explains further:

Rejoice: *My father is alive, but he does not work except for mat weaving. I have to find piece work especially when there is no food at home. Sometimes my relatives go to work and use that money to bring food at home. My sisters have their own families hence they concentrate and deal with their homes.*

> *And my brother has a family as well; he takes care of them and for us, we take care of our things here.*

Christina brings an example of a relative who passed away and she was the one responsible for their funeral. She explains that although she asked for help, no one gave it to her. She refers to her only extended family she has, her sister who lives in Lilongwe and after the death of their relative his sister stopped visiting with them.

> Christina: *I was waiting for someone to help me in terms of a coffin. But I do not have anyone to support me. My younger sister is the only one that remained. She is in Lilongwe, and she is doing her thing there. After this tragedy occurred, she has not visited us here until this day. There is no care; she does not even make phone calls to ask how I am, until this day. So, I know that I do not have any relative to help me or to support me. The ones to support me are my children; Rejoice is the one who tells us that 'I have found piecework, let's go mother, let's go and do this'. I do not have anyone to help me.*

Despite the limited amount of practical support Christina and Rejoice receive, their sense of helplessness affects their relationship. This might explain the co-dependent nature of their relationship within which Christina and Rejoice need each other, but feel lonely at the same time. Christina believes her other children do not help because they know Rejoice will be the one to take care of her in need.

> Christina: *I can't say if I get sick my children would carry me to the hospital, no. They would just say 'the ones who sleep with her will do it'. When I was with these boys* (her sons) *in this house, I would sleep on an empty stomach. Eileen's father, the owner of this house, even when he finds food, he won't give me and I will sleep on an empty stomach. Yesterday in the evening at his house they cooked rice and they ate but I only ate porridge. So, in that case, can I say I have help? Can I say I have someone who I can depend on for help? And that I should rely on him that I will eat what he will eat?*

Christina states her disappointment and frustration with the rest of her children who now have their own families and jobs and although they live very close to her and Rejoice, they do not offer food when they have or any other help. Christina, and subsequently Rejoice, on the other hand, have to look after her grandchildren who live in her house because her children, and Rejoice's siblings, cannot afford to care for them.

In addition to this, during the day, when the adult family members are away at work or doing other livelihood activities, the rest of the younger children and Christina's grandchildren are left with Christina and Rejoice. Christina and thus Rejoice feel responsible for the grandchildren that are left unaccompanied, but feel that this is not appreciated at all:

> Christina: *Let me say I have these grandchildren, right? All these grandchildren come to me as a grandparent, to help them, when they need something at school, whether notebooks, pens, everything that is needed at school or even school fees. They ask me that they have told us to get that, so what should we do? So, if I have the money, I just give it to them. Since they are my children and I do not have anyone. I do all that knowing that these are my children. I do not have anyone who can help me.*

Christina discusses not only the burden of child-minding and the responsibility this brings, but she also mentions that she has to meet their school needs and also presumably the expectation of feeding them during the day.

Summary of case study

This case study demonstrates the complex and often contradictory nature of caregiving relationships. It presents examples of different aspects of Rejoice's and Christina's relationships: between each other, in relation to themselves and to their immediate and extended family. There is no question that they love each other very much and that they have deep feelings of respect and appreciation for each other. But as in many other relationships, in this case, things get more complicated because of Christina's disability which limits her ability to provide for herself and other family members such as her grandchildren. That is why Rejoice assumed caregiving responsibilities and became her mother's carer and the one who also attends duties her mother cannot undertake, such as childcare.

Christina has grown to depend on Rejoice and because at the same time, her other children, and Rejoice's siblings, have their own spouses and children now and they do not offer any kind of support, Christina holds onto Rejoice. This results in

Christina placing all of her hopes for a better future and long-term support on Rejoice. Rejoice, who knows and feel these expectations, tries to embrace her role as caregiver and provide as much as she can with the outcome of having to drop out of school and when she is unable to provide what her mother and her family needs, Rejoice feels pain and is sad.

On top of that, when Rejoice is in need of support like when she needed to go to the clinic, no one from her family was available and her mother has limited mobility, so Rejoice attended her appointment with a friend. It is very difficult to define whether this relationship would be different if young caregiving was not involved and to know if Christina, who is clearly disappointed by her other children, would still place all her hopes and dreams to succeed as a mother on Rejoice. What is important to consider though is how Rejoice feels about this situation and how this affects her and her well-being. Despite the loving relationship she has with her mother, Rejoice feels burdened by her caregiving responsibilities and this in combination with the lack of resources and support system affects her well-being in a negative way. Her opportunities and mobility are limited, as she cannot access education and her social life, either because her mother needs her or because her mother is worried she might be carried away into doing something inappropriate with her peers.

This case study also concurs with many of the theories around the multidimensional nature of care (see Chapter 2) and the idea that care is relational, reciprocal and at the same time can be complex, messy and is characterised by both interdependency and dependency. Relationships and emotion matter and interlink, and therefore to improve one there is a need to focus on both. This is particularly helpful, in the next chapter (7) discussing suggestions for policy and practice, to examine how a whole family approach could help with offering appropriate and efficient support that would result in improving the outcomes for both the caregiver and care-receiver.

Exploring the spatial-temporal dimensions of care is important in this context and the next section investigates further this impact on children's and young people's caregiving experiences.

6.5 Geographies of Care

The previous section of this chapter explored family relations by presenting a case study to demonstrate that caring relationships are complex and dynamic, and can be both dependent and interdependent. Care also changes over time and space and this is important because its changes can offer a better understanding of the very complex nature of care. This second part of chapter 6 looks at the intersections of care, migration and the spatial-temporal dimensions of care. Care is frequently characterised by frequent and often unexpected mobilities which affect children and young people and their families in a variety of ways. Providing care and support to a disabled or chronically ill family member has a profound social and spatial effect on children's and young people's everyday lives.

Spatial-temporal dimensions of care are complex and impact on the ways people map and shape their lives throughout the life course (Bowlby, et al., 2010). Depending on the family needs, availability of other carers, mobility between households and access to resources, children's caregiving roles can change, increase or decrease at different times. This highlights the importance of employing a time-space framework to understand children's and young people's caring roles and activities (Evans, 2012b) (see Chapter 2). The next two sections deal with children's mobilities due to their caring roles as revealed in this research and also explore their caregiving within space and time.

6.5.1 'Care Migration'

Due to poverty and other societal circumstances, the 'expected' pattern of intergenerational care from parents to children may be disrupted. In societies where the government and other organisations cannot provide support for the vulnerable and the elderly, families need to cover this gap. This results in children and young people taking on caregiving roles and being allocated by their parents or other adult family members to family members in need of care and support. These mobilities can be described by the term '*care migration'* which is used to portray this common pattern within African societies, predominantly in relation to children and young people (Bowlby et al., 2010, p. 71). '*Generational care migration'* refers to family members' mobilities that relate to care responsibilities (Bowlby et al., 2010, p. 71). Care work can also reduce caregiving children's spatial mobilities as they have less time to attend school, develop friendships and socialise, or to participate in their community (Evans & Skovdal, 2016). This can have detrimental effects as it often results in children's poor educational outcomes and social isolation (Evans & Skovdal, 2016).

People's mobility depends on a variety of factors, both internal and external. For instance, these factors might be the specific needs of the family, the person who make the decisions and who usually controls the finance of the household, natural disasters, type of illness and/or disability, etc. (Evans & Becker, 2009). Most of the young caregiving participants in the research described in this thesis have been required to move house and sometimes move to another village or city to be with the family member who needed the care and support. The common factors that determined this decision was which child was available at the time and of the 'right' age and frequently of the appropriate gender. Although, I was unable to directly talk to the people who made the decision for the young people in this study to became caregivers, and thus, I cannot be certain about their reasons or motivations, I was able to obtain information through other family members or the children involved in the caregiving. Examples of young caregivers who had to move are detailed below.

Louise (12, F) and Eveline (11, F) are cousins and both take care of their blind grandmother, Rute (61, F). Louise used to stay with her mother, father and siblings before she started taking care of Rute, while Eveline always lived with her blind grandmother. This was until Eveline's parents got divorced and her mother returned to her own village. After this, Eveline started to live half of her time with Rute and her father, while Louise was sent to live with Rute and her uncle on a fulltime basis. This was the case though for only a couple of years until heavy rains destroyed their house and they all had to move to Rute's older sister's house, where they were still living during my fieldwork.

Daisy (13, F) has moved a lot around based on who in her family needs to be cared for. The decision is usually made by her mother. During the fieldwork period, Daisy was taking care of her maternal aunt, Elesi (51, F). She first assumed her caring responsibilities when she was 9 years old and moved in with her aunt to take care of her. Before that Daisy used to live in a different town with her father. Daisy stayed at her aunt's house for a couple of years until Daisy's mother became ill and had to be hospitalised. Then Daisy moved in with her mother in a house close to her aunt and she was taking care of both her aunt and mother with the help of extended family. Once her mother became strong again, Daisy moved back with her aunt. This was until Elesi's abusive son returned to his mother's house and both Daisy and Elesi had to move out and live with Daisy's mother. Daisy explained the reasons for her frequent moves were that "*when one of my relatives falls sick, I go there with the idea that there should be many of us there*".

Four out of the ten families who participated in this study indicated that the impact of natural catastrophic events, like heavy rains, have caused disturbance in their everyday lives causing them to move. Andrew's (19, M) house was partially destroyed by heavy rains and he had to move to different places. His grandmother, Nessie (90, F) explained that her grandson, Andrew, lives at a friend's house while she and her sister in law live under a different roof, "*we were living in this house and when it fell we went down there*".

Changes in the young person's personal life also lead to moves and changes. For instance, Samantha (17, F) got married less than a year prior to the fieldwork and after finishing school moved to a different house with her new husband, but not far from her grandmother. Her grandmother, Clara (85, F) explains what happened and how Samantha came to this decision.

> Research assistant: *When did she get married?*
>
> Clara: *Eeh! It is long ago. She got married whilst she was still going to school. She stayed with me until she finished. Soon after she finished her school, her husband came to take her to his house. So, I just accepted it.*

Considering that Samantha still has the same caring responsibilities even as a married woman living with her husband, she comments that

> Samantha: *OK. It is different to stay with my grandmother in her house than coming from here going to her house. Because when I stayed with her and something would happen to her, for example getting sick during the night, I could help her straight away. But since I stay here, it is difficult because she is*

> *now living alone. And that means I have to constantly go there and come back home. So yes, it is different.*

The preceding section explored the high level of movement for young caregivers that characterise their lives due to care work and other factors. It illustrates households' fluid nature and the continuous change care responsibilities can result in, compounded by natural disasters and poor circumstances. The next section looks at caring responsibilities through a time-space framework.

6.5.2 Time and Spaces of Care

The notion of 'caringscapes' aims to explore the complex 'actualities and possibilities of the social patterning of time–space trajectories through a range of locales significant to caring' (McKie et al., 2002, p. 914). It can thus be a useful way to conceptualise the multiple ways through which children and young people experience their caring roles through space and time (Evans, 2012a; McKie et al., 2002). When looking at time in relation to care, it is important not only to explore the actual timeframes in which caring takes place, but also how care changes over time in relation to the self, family and community (Bowlby et al., 2010). This section considers the time-space framework to further understand young people's responsibilities and individual caringscapes (see Chapter 2).

There are no available official statistics showing the number of children who take on unpaid caring roles or how many hours they spend on providing care for others in Malawi or any other sub-Saharan African country (Evans, 2012b). Data from the USA, the UK and Australia demonstrate that about 2% to 4% of young people have caregiving roles (Becker, 2007). Examining young caregivers in the UK, Evans and Becker (2009) identified there are an estimated 175,000 children with caregiving responsibilities, with 29,000 of those children providing care for more than 20 hours per week and 13,000 of them providing care for more than 50 hours per week, which is regarded to be a very high number of hours on the caregiving continuum and is expected to impact negatively on children's health, development and education.

As a consequence of the paucity of time use data on caregiving by young people in sub-Saharan Africa, Evans (2012b) conducted participatory time-use activities to gather data from young people who take care of their siblings in Tanzania and Uganda. Her findings indicate that both young girls and boys assume very high levels of extensive care work resulting in an average of 74 hours work per week by young women and 69 hours a week by young men with immense implications for their education, health, development and future lives. The study reported in this thesis did not specifically measure children and young people's hours of care work, but through observations and participants' accounts, it was evident that care was constantly being undertaken, even when young caregivers were out of home or away from the care-recipient. Practical care was more obvious to measure, but emotional care and nurturing were apparent all the time.

With respect to where caregiving takes place, as anticipated, most of the young caregivers' tasks take place in and around the household, activities such as casual labour and fetching firewood or water are undertaken beyond the proximate household (Evans, 2012b). Rosemary (18, F), for example, reports that she often has to go to the market in Limbe town to buy clothes, which she can sell to people in the neighbourhood by going from door to door. On the other hand, Andrew (19, M) has to wake up earlier than others and walk thirty minutes every day to his grandmothers' house before he can even commence his caregiving tasks. In the photo below (Figure 22) away from her home, Rejoice (17, F) is transferring bricks as paid piecework and notes that she often has to walk miles before finding casual labour opportunities.

Figure 22: Photograph of Rejoice (17, F) carrying bricks (income generating activity/piecework)

These constant movements, due to their caring responsibilities, have both negative and positive outcomes for young people's lives. For example, walking long distances can make them exhausted which affects other activities. Moreover, as Hannah (19, F) testifies when she has to be away from her home, her thoughts "*remain back to the house with her family*" creating feelings of not only worry but also guilt for being away and not with those needing help (see Chapter 5). Another example from Rosemary (18, F) shows how activities far from home can feel even dangerous on some occasions. During an informal conversation, Rosemary (18, F) explained that because she lives in an urban area, she often has to walk miles to fetch firewood. There is a forested hill about 45 minutes' walk away from her home where she usually goes, but there are men breaking stones there who shout inappropriate comments making her feel uncomfortable and unsafe. Concerns about safety in children's and young people's mobilities in sub-Saharan Africa are very common. Porter and colleagues (2011) explored children's mobilities travelling (often on foot) to school in Ghana, Malawi, South Africa and found out that the journey to school is especially dangerous for young girls in respect of their personal safety especially due to the risk of being sexually assaulted.

Despite the number of negative impacts 'travelling' might have, it is also evidence that because of these mobilities that children and young people experience positive outcomes. Similar to Evans's (2012b) findings, the caregiving children and young people who participated in this research have opportunities to socialise and develop close and supportive relationships with their community and form friendships with other people with similar routines. Children were observed in this research to enjoy a level of autonomy while they are outside for errands and usually have the flexibility to choose to attend those with their friends and regard this time as a chance to play and chat (corresponding with findings in rural Bolivia; Punch, 2000). For instance, Hannah (19, F) needs to walk about 15 minutes up the hill near her house to fetch water. She chooses to do this the same time every day as some of her friends, and this gives her the opportunity to spend time with them. Care and support also come from friends, neighbours and members of the wider community usually by providing material resources. For instance, when Chimwemwe's (17, F) and Chifunilo's (12, F) grandmother passed away, it was members of the community and the Chief those who helped with funeral costs. On other occasions, the support received is emotional, by forming strong friendships with other young people who support and comfort each other.

6.6 Conclusion

The preceding section of this chapter explored caregiving family relationships and how these relationships impact on children's caregiving experiences. Caring relationships affected by illness and/or disability and young caregiving roles demonstrate both positive and negative outcomes for both sides and are presented as a complex set of relationships. These relations between adult core care recipient and young caregiver, although contradictory, were not antithetic but interrelated. Young caregiving resulted in loving and strengthened relationships characterised by reciprocity and interdependency, which at the same time, demonstrated elements of dependency, mostly from the cared-for individual, and parental control attempts.

This agrees with the idea that care, and caring for and being cared for, is dynamic, complex and very ambivalent (Puig de la Bellacasa, 2017). This was further exemplified through the presentation of Rejoice's case study who although has a close and loving relationship with her mother, who she cares for, her story demonstrates how more complex and multifaceted their relationship is. This case study also showed that caregiving relationships are influenced by the self and the two parties involved in the relationship, but the overall experience of caring also depends on relationships young caregivers have with their immediate and extended family, and the wider community. In Rejoice's case, extended family have been unable to offer any kind of support which not only increases the sense of burden and responsibility, but also increases the obligation of care Rejoice feels as she is the only one who can do it. This has negative outcomes on Rejoice's wellbeing, she feels alone and isolated and had to drop out of school to manage her responsibilities.

This is a very different experience to Louise's (12, F) case, presented in Chapter 5, who because of having a lot of support from her extended family, experiences caregiving in a much more positive way. Evans (2012a) identified that those child-headed households who had both practical or material support, such as social capital and land, and emotional support from their extended family developed the ability to sustain their households autonomously for long periods of time. This meant that despite the negative impact of discrimination, those children and young people had a better chance of preventing extreme poverty and remaining at school instead of having to cease pursuit of formal education and work long hours to earn a living (Evans, 2015).

The later sections of this chapter looked at the family geographies of care and explored children's mobilities and time-space practices. Children and young people with caregiving responsibilities face both increased mobilities, or migration in order to care, which means that they are placed in different households to care for a relative depending on the needs of the family, or they have limited mobility due to the high level of caregiving responsibilities so they are unable to attend school, spend as much time as they want with their friends and in the community. It is noteworthy to highlight that this does not always mean that children do not form friendships or do not socialise at all. This study confirmed that the children are able to exercise agency to use what time they have, for instance, while fetching water or firewood, to spend some time with their friends and chat.

Finally, this chapter adds further important information to the two previous Chapters 3 and 4 which thus together provide a better understanding of children's caregiving experiences. Thereafter, the following chapter, Chapter 7, draws together all the foregoing information and presents an evaluation of available resources and services to then make recommendations for practice and policy.

Chapter 7. Supporting Children and Families Affected by Chronic Illness and Disability

'…. the global aid industry's attention towards the AIDS orphan crisis in Africa has led to a paradox of social justice for orphans and vulnerable children, in which their vulnerability is pitted against their empowerment'

(Cheney, 2013, p. 17)

7.1 Introduction

The preceding Chapters 4, 5 and 6 explore the notion, experiences and dimensions of childhood in Malawi and the experience of young caregiving by focusing on the individual child and their emotional geographies and experiences, as well as on their family relations. By examining caregiving children's lives and addressing the individual and family level research questions, those three chapters identified a range of needs and supports required for the children and young people and their families.

In view of that, the purpose of this chapter is to address research questions relating to support (set out in section 1.6): 'What is the role of formal (social services) and informal (peers, family, community) support? According to children and their families participating, which interventions are the most appropriate?' The chapter starts by exploring further participants' views of the kind of needs and support they require. This includes an examination of the kind of support the children and their families received at the time of fieldwork or have received in the past (section 7.2). Following this, the next section (7.3) reviews the data collected from the ten professionals interviewed (see Chapter 3) in relation to their attitudes towards children and young people with caregiving responsibilities in Malawi. Section 7.4 considers professionals' perspectives on the kind of needs and support required to effectively meet caregiving children's and their family's needs. Finally, taking into consideration the range of perspectives and statements from all the participants of this research project, section 7.5 presents suggestions for interventions that could be applied and provide relevant and adequate support to the children and their families.

Overall, this chapter illustrates the interrelations and interconnections between the needs, internal and external factors and impact children's caregiving roles, disability and chronic illness in their family have on their livelihoods. This can help understandings of the complexity of the children's and families' needs by looking at them through different lenses at an individual, family, community and government level.

7.2 Children's and Families' Views

During the fieldwork carried out for this thesis, all the children and adult family members interviewed were asked to identify what kind of needs they have, which of these are met and in what ways, and what kind of support or services they receive if needing additional support. Participants were able to identify their needs presented as a summary in Table 6. The needs presented in this table are listed in the order of the frequency mentioned. Taking into account that these families live under extreme poverty, it is understandable that the first and most significant need stated is material and financial support (Evans & Becker, 2009).

Identified Needs
1. Ensuring material and financial support for basic needs
2. Improving housing quality
3. Accessing and attending school regularly
4. Obtaining a stable income-generating activity
5. Having adequate healthcare services
6. Receiving support from extended family and community
7. Receiving emotional and spiritual support
8. Having a capital to start small business

Table 6: Children and family needs as identified by participants

In addition, the children and young people who participated in the dissemination focus group discussion (see Chapter 2), expressed their needs and wishes through the following posters and letters (Table 7).

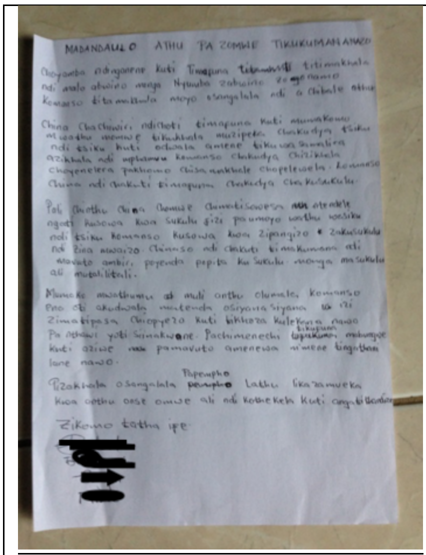
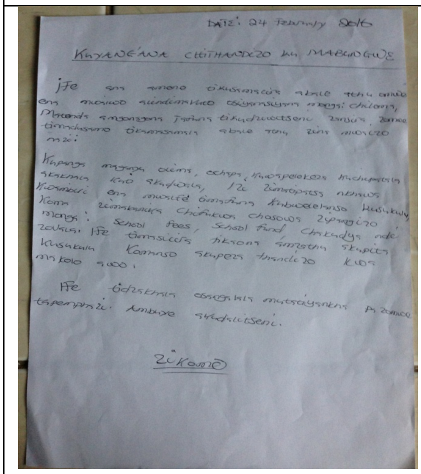
	Group1: OUR WORRIES ON WHAT WE ARE GOING THROUGH Firstly, we would like to say that we wish we could have **good homes** and live a **happy life** with our relatives. Secondly, our wish is that we should have **enough food** everyday so that the people we are taking care of should always **be strong**. Additionally, we should have food to take with us when we are going to **school**. There is another thing which troubles us most of the time that is **lacking school fees**. We always lack school fees and other **school materials**. And we also face problems in **going to and from** school because some of our schools are very far from where we live. In our families, there are other family members who are very sick and others who have a disability, these problems give us **fear that we may lose them** before their actual time. And because of these, we would like organisations to know our problems and help us to end them. We will be happy if our request will be responded with those who have the capacity to help us. Thank you,
	Group 2: LOOKING FOR HELP/SUPPORT FROM ORGANISATIONS We are children who take care of our relatives with disabilities and chronic illnesses, as well as the rest of our families. We would like to inform you of what we go through. These are some of our problems: We do **piece work** in order to get money; we **take them to the hospital** when they are sick. These **stress us out** a lot. Some of us want to go further with our **education** but we fail because we do not have the materials like **school fees**, **school fund, food** and **clothes**. We admire our friends who go to school and they have parents to give them what they want. We will be happy people if you will positively respond to this letter. God bless you.

Table 7: Focus group dissemination letters

Similarly to the needs listed in Table 6, both letters refer to material and financial support required, such as food, clothes, school fees and materials, transport, adequate housing, improved healthcare services and of course emotional support. As further explained later in this chapter, participants manage to cover only some of their needs through extended family, community or NGO help, while none of them were receiving at the time of the fieldwork or had ever received any help from the Malawi Government.

7.2.1 Previous or Current Support

Family support

Six out of the ten families who participated in this research stated that they have received or are still receiving help and support from extended family. As thoroughly explained in Chapter 6, this support can be in the form of financial help, material support such as food or clothes and non-material assistance like emotional support and advice. One of the challenging issues is that in only a few cases is this support consistent, and for most of the families this support is irregular. This means that the families in need go through periods during which they receive no help, material or other while living in extreme and dire poverty.

Church support and well-wishers

As many as six of the ten families indicated that church or well-wishers have provided, and in most cases still provide help and support in the form of food, soap or clothes, as well as offering spiritual and emotional support. This help is not regular, and availability of material support depends on whether the church has received goods from well-wishers or not. Most of the participants who do not have extended family to receive support depend heavily on this kind of help in order to meet their basic needs.

Clara (85, F) explains that her granddaughter Samantha (17, F) is the only family she has and that thereafter she depends on well-wishers from the church or her community to help.

> Clara: *I am saying that I do not have relatives to help, I am just staying alone. My relative is Samantha. Yeah. When well-wishers come to see me, they share with me some of their maize flour and I then eat. That is. But I do not have relatives to help.*

NGO support

Only three families testified that they have received support or still receive support from local NGOs. Two of those families get help from the organisations due to having a family member with HIV/AIDS and one because they are considered a child-headed household. The child-headed household occasionally gets food and clothes from a local NGO. One of the other two families was given a house and sporadically received maize from a local NGO. The second family receives help when and if needed, such as transport to the hospital from a local NGO.

For example, Elesi (51, F) explains in what ways her local NGO has supported herself and her family:

> Research assistant: *So you said that* (the local) *organisation helped you when you got admitted to the hospital. Apart from providing transport, in what other ways are they helping you?*
> Elesi: *When they told me at the hospital that I should be eating enough food, they were giving me Likuni Phala* (a type of fortified porridge)*. Right now they just gave me 4 kilogrammes*.

In addition, Memory (35, F) describes the kind of help she and her family have received which is in the form of material support such as food and clothes:

> Memory: *No, I do not get anything from them except the* (local NGO)*. The organisation provides us with soya beans, sometimes clothes. Look at us, these garments we have on were provided by* (local NGO)*. Sometimes, when the organisation notices that there is no food in my house, they buy us maize flour and relish; they also bought us the blankets and mattresses we have.*

The help these three families receive is vital but unfortunately not regular or accessible as required. All the families participated in this research project face extreme challenges not only because they are affected by chronic illness and disability or because children have significant caregiving responsibilities, but there are a number of other factors which impact on their efforts to secure adequate and stable livelihoods as well. These are examined in the next section.

7.2.2 Key Challenges

One of the main perspectives that was overwhelmingly highlighted by the participants was that the problem is not their caregiving roles, but a number of other internal and external factors. Summarising the main themes which emerged from this study, the four key challenges the children and their families are facing are (i) poverty, (ii) impacts of disability and chronic illness, (iii) issues with regularly accessing education and (iv) lack of emotional and spiritual support.

Poverty

As explained in Chapter 1, Malawi is one of the world's poorest countries and as already stated, all the children and families who participated in this study live in dire poverty. All ten families stated that they frequently lack basic material needs, such as food, clothes, shelter and money. All ten families also said that for their school-age children they lack money to pay school and exam fees, uniforms and other school materials. As observed during fieldwork visits to their homes, many of the participants live in poor housing; a situation which means they do not have good quality shelter to keep them safe and protected during difficult weather conditions, especially the annual rainy season.

Rejoice (17, F) explains that she needs money for uniform, fees and school materials to be able to attend school and when she cannot afford to obtain the requirements, she is asked to return home from school:

> Rejoice: (I need) *maybe notebooks, pens, uniform. They* (the school staff) *send us back during exam period, if we do not have a uniform. They will say 'you have a uniform go and put it on, if you do not have one, you will not sit for the exams'.*

Poverty does not only impact covering their basic needs. Many of the young people who are responsible for financially supporting their families find it hard to identify income-generating activities. This means that there are periods of time they have no income for the household at all. Lack of income and unemployment also results in young people being unable to invest in their future and having to depend on external organisations or well-wishers to provide them with financial support to start their own business. For instance, Rosemary (18, F) explains that she would like to receive financial support to start her own business and hopefully be able to financially support her family:

> Rosemary: *If it happens in future and everything goes well and maybe someone helps my sister… Then I could go back to school, and if I had good capital, I could continue my business.*

Once Rosemary becomes financially independent and stronger and her sister gets the help she needs, then she aspires to return to school and complete her education while working on her small business. For many of the families, it is not only material support that is required, but they also need specialised help to manage their chronic illness and disability. Some of those are explored in the next section.

Impact of disability and chronic illness

According to the findings of this research project, there two main themes to be addressed when discussing chronic illness and disability. One is people's understandings and perceptions of chronic illness and disabilities and the second is lack of healthcare and other services.

Stigma and discrimination are two significant issues which all of the children and their families report that they face frequently. For example, Louise's (12, F) case study in Chapter 5 describes how people consider it wrong that Louise is taking care of her blind grandmother and they are judging this by her disability. They believe that Louise should leave her grandmother alone as she is not a good person to be with because she became blind through witchcraft. Louise, however, does not agree and sees her grandmother as a person she loves and wants to take care of.

In addition, Memory (35, F) and Hannah's (19, F) family have been discriminated against due to Memory's chronic illness. Memory found out she was HIV positive when her husband got very ill and passed away because of it. Following this Memory and her children, who until then stayed with the paternal family, were asked to leave the house and the village. At first Memory did not want to move out as she did not have anywhere to go. Soon, however, people, like friends and not just her husband's relatives, started behaving differently around her and things became much harder. Memory explains how she would visit a friends' house but the people there would not share everyday cutlery utensils because they were afraid they would get infected as well:

> Memory: *When we were at our home* (previous village home), *for example, we were visiting our friends and neighbours but they wouldn't let me touch even a cup. They were saying that I am an infected person and they did not want the infection.*

Memory, Hannah and the rest of the family were lucky enough to then become known to the local organisation which offered them a house and other material support. The house was located in a different village where people did not know she had HIV/AIDS, which was like being exiled because of her illness.

Many of the participants also disclosed that they either do not receive healthcare support or that the help they get is not enough. Although the participants do not live in very remote rural areas, they all mentioned that they find it difficult to go to the central hospital in the city, as they do not have the money to take a minibus. Three of the families also mentioned that when they attend the local health centre near their house, they either have to wait for a long time to be seen or might be asked to go back the next day. Participants who stated this believed that there are not enough doctors and nurses and that the health centre staff prioritise people they know and do not treat everyone the same way. Furthermore, two of the families, both affected by disability, do not wish to request medical support because they believe that their disability was due to witchcraft and doctors would not be able to help.

Matters are even more difficult when it comes to mental health issues and mental health professionals. Findings from research with children caring for parents with mental illnesses suggest that although these children have common responsibilities with children who take care of parents with physical disabilities, they assume greater emotional care responsibilities than their peers (Aldridge, 2006). Rosemary (18, F), who takes care of her sister Mary (35, F) with mental health difficulties, believes that her sister also has heart problems and states that she is unsure of how to best help her with her health. Rosemary also reflects on the lack of healthcare support and states that she needs someone to "*help Mary feel better so she can go back to work*". With respect to mental illnesses in sub-Saharan African countries like Malawi there is very limited or even no awareness, understanding and/or support. Mary has been prescribed tablets to help her with 'her thoughts' at night but there have been no further services or training offered. Neither Mary nor the rest of the family understand what her illness means and thus, do not know how to support her and what the appropriate service or organisation which might help her would be.

Education

As mentioned in previous chapters, many of the children who participated in this study have either dropped out or attend school only on an irregular basis (see Participants Table in Appendix 19). This is primarily due to the high level of caring responsibilities and due to lack of money to pay for school fees and other school expenses such as uniforms and learning materials. These are not the only issues when it comes to school attendance though. Two of the children interviewed said that they would like their school to be more understanding when it comes to them being absent because the person they care for is unwell. Here, Louise (12, F) explains that when one of the pupils is seriously ill, her school not only understands but also provides them with money when able. But when it comes to a family member, her school does not show the same consideration.

> Louise: *When you* (a child) *are the one who is sick they might even contribute money, they say 'a friend of ours is sick, let us contribute money'. When your mother is sick they do not understand, they just say if it is your mother who is sick then you have to come back to school.*

Emotional and spiritual support

As described in Chapter 5 and throughout the rest of this thesis, the children and young people with caregiving responsibilities experience a range of emotions and difficulties due to their roles, but receive insufficient emotional support. For example, many of the participants experience feelings of guilt and sadness, as they are unable to take care of their relatives due to the financial problems or due to being too tired as a result of the high level of their responsibilities. Sometimes the participants receive informal support from their relatives or friends, but none of them receives formal support or counselling. The lack of emotional support increases children's vulnerability and also impacts on their everyday lives. For instance, many of the children stated that they could not go to school because they would be thinking of their ailing relative and be guilty of not being there for them.

Further to lack of emotional support, Nessie (90, F) explains that her need is rather a spiritual one than material.

> Nessie: *The help that I want is the way I feel, I am sick and I need to feel better. I went to the hospital, to the doctor, and he told me that I am fine. So, the help I need is for someone to pray for me. Not just to bring food, but they should say the word of God and say 'you will be fine do not worry'. And that way one is happy in their whole life.*

Nessie expresses that although her physical illness cannot be cured she would benefit emotionally from spiritual support. Indeed, spiritual care is often a key component of palliative care. A study that looked into ways to improve palliative care in Africa showed that the majority of the patients they interviewed stated that they prioritise their spiritual wellbeing over their physical health (Harding et al., 2013).

7.3 Practitioners' Views on Available Support

Ten semi-structured interviews were conducted with key informants working with orphans and vulnerable children in NGOs or government organisations in or near Blantyre, Malawi. What follows presents their views in regards to children and childhood in Malawi, and current needs and supports for children and families affected by disability and/or chronic illness.

Supports available

All ten professionals interviewed agreed that according to their knowledge at the time of fieldwork there was no organisation or service in Malawi that specifically aims to support children and young people with caregiving responsibilities for family members with chronic illness and disability. Seven out the ten professionals stated that prior to being interviewed they had not previously thought of this group of children as a group that needs specific attention or support. It was universally emphasised by the professionals that it is very common for children and young people in Malawi to have various responsibilities within their households, including house chores and childcare, so it is considered part of a normal childhood to be involved in the care of others, especially caring for younger children. Professionals were of the view that the cases where a child assumes more responsibility than usual, or a family is affected by illness or disability, it would be that case that the child and the family would fall within the 'vulnerable children and families' category and so would receive some kind of support. Identifying when a child is 'vulnerable' though and when in need for additional care support is not straightforward and there is no clear line of distinction between what is normally expected of a child and what is 'more than usual' responsibility.

For example, a local orphan and community care NGO states on its website that it supports "HIV/AIDS orphans, vulnerable children and their families". When interviewing Erin (28, F), Programme Manager at a local NGO, she stated that although the NGO does not explicitly target children with caregiving responsibilities, they have worked with families affected mostly by a chronic illness like HIV/AIDS:

> Erin: *It will usually fall within our programme interventions. First thing is usually providing food, usually, with families like that those* (affected by chronic illness or disability) *might be a lot of health issues so through* (name of NGO), *we might refer them to a person for special assistance. Then we give clothes, beddings, etc. Shelter, we do that whenever we can, but it is not always easy. Like last year we got funding for the flooding*[33]*, and there were a few child-headed families that needed that support. So usually they fall under the programme interventions. And when there are children under 5 we make sure that they access a feeding centre. And if they are too far away, we will refer them to another centre that provides food.*

While vulnerable families and children definitely benefit from this support provided by a local NGO this does not ensure that caregiving children's specific and individual needs will be met and young caregivers are not specifically recognised, identified or targeted with any specific interventions or support.

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[33] Erin here refers to the flooding that occurred in Malawi in January 2015, for example see **https://www.theguardian.com/global-development/2015/feb/10/malawi-floods-devastation-far-worse-than-first-thought**

Similarly, Maria (33, F, NGO Director) who works with street children states that she often comes in contact with children who care for disabled parents, or other disabled adults, and who assist them to beg on the streets.

> Maria: *Yeah, in the street we have a lot of blind people begging, and they have their children with them. And I hate it because I mean they are blind, they can't see, but their child can. And instead of sending them to school, they stay on the streets to move around (with) the parent.*

Maria recounts that she has encountered cases where children drop out of school to take care of their disabled family members. During the interviews, all practitioners reflected on cases they had encountered where children care for family members with chronic illness and disability and all ten agreed that children with caregiving responsibilities are affected in different ways in comparison to their peers, but do not receive any additional support. All of the practitioners identified that although the majority of families living in Malawi are facing numerous problems due to poverty and other issues, families affected by chronic illness or disability are considered particularly vulnerable.

Once the existence of caregiving children within families was discussed with the professionals during the interviews, many of them reflected on the impact this role can have for the young caregivers. Contrary to the dominant notion children and families who participated in this study shared in regards to childhoods in Malawi, the most common theme from the professionals' interviews was of young caregivers 'losing' their childhood and innocence and being different compared to their peers, which is elaborated in the following section.

Notions of childhoods

In his interview, Kondwani (32, M, government service) discussed the impact disability can have on a child and their family. He refers to the idea of 'normal' childhoods and how significant caregiving roles impact on children.

> Kondwani: *The children cannot think like other children because they are the ones who take care of their families. So, because of that, they have to think as mature people, where can I get some soap? They will be busy all the time. You*

> *will find them doing things all the time. They do not have time to play. They have to do piecework and chores. In comparison to those children who are children and they can play and go to school. These ones cannot go to school.*

Kondwani believes that those children with caregiving roles above and beyond what is usual become more mature than their peers, have busier lives and do not have time to play or go to school. He finally concludes that "*their childhood is taken away from them*".

Similarly, drawing on notions of 'normal' childhood and highlighting the emotional impact and uncertainty at being a carer, Erin (28, F, NGO, Programme Manager) explains her perspective on how children with caregiving responsibilities for chronically ill adults might be impacted.

> Erin: *I think it goes to productivity and the chance that a child might lose their parent. Children with no caring responsibilities will probably have more time to go out and play and do other things. But a child with responsibilities for someone with chronic illness… a child with caring responsibilities, they are waking up every day not knowing if their parent will live or not. I think the effect of that could be far more prolonged as for someone who has experienced loss and is moving on.*

Here Erin introduced the emotional burden a child with a chronically ill parent might feel. She talks about the fear of losing their parent unexpectedly and how the emotional impact could be sustained over a longer period than for a child who is orphaned and comes to terms with the loss of a parent. What is noteworthy is that Erin is also recognising the emotional labour this role demands and what its long-term effects might be and addressing death which is absent from people's discourse.

Maria (33, F, NGO Director) also adds that when some children care for their parents, it can be very hard for them to find food and money and thus many get involved in criminal or illegal activities.

> Maria: *The children love their parents, no matter how irresponsible or ill they are. What I notice is that they want to support them* (their parents)*. But then you have a 12-year-old who is struggling to find food for an ailing mother or an ailing grandmother. And what happens is that is making the children grow*

> *up too fast. To become independent too fast. Because they have to find money to cook. Even if that means they have to steal. So, it is quite a difficult situation. And they love their parents, and they want to support their parents but for them, the children, they aren't developing, as they should, as children.*

This quotation outlines the extremely poor conditions some of the children live under and what they might have to do in order to earn money to sustain themselves and their dependents.

As Maria and other professionals mention, many of them negotiate with different ideas of childhood that meet traditional and Western ideals. Rose (57, F) is the manager of a residential school for girls. Rose has travelled and lived for short periods in Europe, especially in Germany where the organisation which funds the girls' home is based. Rose reflects on her observations of how children grow up in Malawi and in Germany and states:

> Rose: *Children here grow by themselves like pigs. Maybe because they have too many children? I do not know. But I've seen in Europe that children have.. nowadays they are the bosses of the family.*

Rose states that according to her opinion children in Malawi tend to grow up on their 'own', which to her means growing without much adult supervision or attentiveness that results in children being left to take care of themselves like livestock. Whereas in Germany, adults allow children to have a say and because of different notions of childhoods, perhaps due to attention on children's rights and the importance of listening to children, sometimes children become the 'bosses'. Rose here describes the contrast between large families in Malawi and small families in Europe where children are considered 'economically worthless and emotionally priceless' (Zelizer, 1994).

Overall, practitioners view children and young people with caregiving roles as much more vulnerable in comparison to their peers. They all stated that this group of children need more support than the actual support they receive (or lack of it). Professionals however also highlighted that when it comes to services and intervention programmes, there are a lot of limitations and challenges. This theme is explored in the section below.

Service Limitations & Professional Love

Considering interventions there are some projects and programmes which offer support to vulnerable and orphan children. Many of the professionals describe how hard they are working to offer the best kind of support to the children and the families they are working with, using as effectively as possible, the limited resources and funding they have. Erin (28, F, NGO, Programme Manager) describes how they supported a family where two siblings, a 15-year-old boy and a 17-year-old girl, were taking care of their chronically ill mother and younger siblings, including a baby just a few months old.

> Erin: *The intervention was.... because of the verification survey, which is a one-to-one interview, we found out they needed clothes and beddings. And the family would stay in the rota for support for the one year, for example, because they will need new clothes. Unless during a visit we find out they need something else. That will be once per year. The two young people have been encouraged to go back to school, but you have to find the people in their needs. If what they need that is to feed their family then is finding out what he is doing, when he gets the money, you are just talking to him. Is he using it in the best way he can or the young lady will probably get married because she's trying to get away from her problems? But we usually keep track of these families. If that person gets married, we will follow up and if she finds a good partner and all is good then that's fine. But if she is struggling with this issue then we will try to help her and follow her especially for the sake of her child.*

Thus, this local NGO can and does give limited material support to some young caregivers and their families. Erin explains later in the interview that there are some families like the one she describes above that she emotionally stays connected with and tries to follow with as much support as she can. Many of the professionals stated that they get personally and emotionally connected with some of the people they are working with.

George (41, M, founder of a local NGO for street children), who as a child himself faced different kinds of abuse by adults within his family, states that he always wanted to help vulnerable children who are at risk of experiencing similar abusive relationships. Having this aspiration '*in his heart*', he managed to create an NGO for street children and offer them a home where they can be safe.

> George*: I developed the idea early 90s but not until early 2000 that I developed the heart. So, I developed the heart because I saw children being abused and neglected all the time…. So, I realised that I had the capacity to help children with no voice, to love children who were unloved and even accommodate them. So, I started talking to people and consult them on how to start an NGO.*

George explains that by '*loving the unloved*' he managed to find funding and offer a number of supports to children living on the streets and being at great risk of being abused and exploited.

In addition, many non-governmental and governmental organisations work with community based volunteers who want to help and usually do not earn anything. Although they do not compromise a skilful and professional personnel, they contribute to their communities and help many vulnerable families and individuals. For instance, many NGOs and government organisations use volunteers to identify families and individuals in need.

> Mike (34, M, NGO): *We have community volunteers and those are the ones who identify. So, we have created groups of volunteers in each village. The reason we create those groups is to make the work easier because they know how to identify the problem and the source of the problem and they know how to overcome and choose who is suffering and who is eligible.*

There are a lot of debates and ideas in relation to the positive and negative aspects of volunteering and this thesis does not aim to explore those debates, but to merely recognise that even in poor societies like Malawi there are groups of people who are interested in helping others and to contribute to their community. What is important however to emphasise is that, although their contribution is important, volunteers cannot replace trained staff in any way. Significantly, also, professionals identified that the volunteers can be biased towards the individuals and families they identify as the ones in need of extra support and people who are in need but might not be on the volunteers' 'radar' or might have a negative relationship with them can miss out on help from organisations. Some organisations take this into consideration and have ways of ensuring their resources are fairly shared (for instance, community mapping exercises as described by Erin in section 7.5.4).

Despite organisations' and practitioners' best intentions, all the practitioners interviewed agreed with the reported needs and limited support for children and their family members, as described in section 7.2 of this chapter. Practitioners also highlighted that the help provided by government services and organisations is inconsistent, sporadic and often insignificant. Maria (33, F, NGO Director) explains that:

> Maria: *It is tough because most interventions would not have the resources to go all out. So, what most would try, including us, to just support the child, to take the side of the child.*

The preceding section (7.3) explored the support available for caregiving children from the perspectives of the professionals interviewed. Professionals involved in this research project provided a number of notions around who is a child in Malawi, what the expectations and their roles are within a family and how they differ from children in the Global North. The main and very important issue professionals' accounts demonstrate is that young caregivers are not recognised in Malawi and that they are still invisible to policy-makers and social service providers. Young caregiving does sometimes fall under the 'vulnerable children and families' social services umbrella which means that some of the children and young people with caregiving responsibilities receive some support, usually material, albeit often limited and inconsistent. Professionals' emotional labour and caregiving for the vulnerable children and families they are working with was also identified. The next section explores professionals' understandings of the kind of challenges children and young people with caregiving responsibilities and families affected by chronic and disability face.

7.4 Practitioners' Perspectives on Young Caregiving

As detailed in Chapters 4, 5 and 6, children and young people with caregiving responsibilities face a number of hardships and challenges in Malawi. These adversities are not always solely the direct outcome of their caregiving roles, but the result of a combination of factors such as age and gender, as well as other socio-economic factors like poverty. This is important to consider as it helps to present a more holistic view of the issues children and their families are facing, as these challenges are not always directly connected with chronic illness and disability. When discussing these issues with the professional service providers there were seven main themes highlighted; (i) gender and age inequality, (ii) lack of parental support and guidance, (iii) lack of personal development, (iv) poverty and disability or chronic illness, (v) access to school and maintaining attendance, (vi) service limitations and (vii) corruption which are explored in turn below.

Vulnerability, Gender and Age Inequalities

Gender and age can play an important role in relation to vulnerability and thus, it is necessary to consider when assessing the needs of caregiving children. For example, Rose (57, F, residential home, Manager) has worked for many years with orphaned girls ensuring they get the education they should. She states that a number of the girls that she has met used to take care of relatives with chronic illness or disabilities. She further explains that girls are particularly vulnerable, especially when the adult responsible for them is ill or disabled. That is why she declares that girls must be well educated when it comes to sexual health for their own protection.

> Rose: *You see now I know what it is important and how to take care of myself from diseases. You see in the villages you cannot say no to a man. Can you imagine? There are so many rituals, like when someone dies you have no rights to say no. They say to cleanse. Even when they rape a child, those little ones, they say 'do not say anything'.*

Rose here discusses how girls in Malawi can be very vulnerable, especially when they are not aware of how to protect themselves and because other people, adults who could help and protect them, they pretend nothing bad is happening. Rose continues to explain that "*…they say do not say anything and getting raped and they do not say anything, that's a problem. What happens with girls is that girls are very much vulnerable and there's a lot of awful business happening especially with the orphans*". Rose refers to various harmful traditional cultural practices, such as initiations, widow cleansing and other forms of ritual gender based violence in Malawi. Furthermore, Mike (34, M, NGO Manager) explains that as adults have to generate income, and especially in large households, often children are left alone in the house while adults are at work. This places those children at risk of being harmed or abused as Mike explains *"people might take advantage that the parent will be away and someone will go to the house and take advantage of them* (the children)*".*

All the professionals shared examples and stories that describe gender and age inequalities and show how these power inequalities can impact on children's lives and that culturally in Malawi is very common for people not to discuss them. For instance, girls are especially socially disempowered, abused and exploited in the name of culture and tradition which is not only seriously traumatic but also for individual girls vastly increases their vulnerability. What makes it even worse is that these issues are kept secret which is a powerful tool to hide abusive relationships and which is also connected with the fear of punishment and going against cultural norms. Mike (34, M, NGO Manager) below further discusses issues of gender-based violence and that the way Malawian society tends to deal with those issues is to silence them.

> Mike: *Especially with the issue of gender–based violence, most of them won't come out. You might hear just few things but most of the things won't come out. First of all, many* (women) *face prostitution in order to feed the family but they won't say anything... They are too scared to be caught.*

What Mike introduces here is also the fear of the law and shame, as many women result in illegal prostitution or shameful relationships based on transactional sex to generate income for their families. Opting to engage in sex work has as an outcome that women are even more vulnerable to harm and although they get abused, they cannot complain or say anything to the authorities because they are too scared of the consequences. None of the families participated in this study mentioned engaging in sex work to survive, but one of the gatekeepers who helped me recruit participants informed me of two women from two different families who have been seen in Blantyre engaging in sex work. Many women who cannot generate income in other ways have also to go to the streets and beg, which can also result in being abused. Maria (33, F, NGO Director) describes the following story:

> Maria: *A family we worked with, the mother gave birth to nine children, number 8 has died but the rest are living. At one point four of them were here*

> *at* (name of NGO) *because she was living on begging. And when she goes and begs, especially on Thursdays, she has to make sure that she positions herself nicely near the mosque because when Muslims come out of the mosque, and I'm not saying anything, I'm not discriminating, I'm just stating facts. So, when the Muslims come she can get a lot of money. So, this is what she was telling us. She goes to the mosque and close to the areas where she knows she will get more money and positions herself there from the night before. But during the night she sometimes gets raped. Even by the guards. Because let's say she wants to stay outside a bank. The guards are not supposed to let anyone stay or sleep in the pavement. So, people who want to sleep there, they have to pay the guards. So, if you do not have money, they rape her.*

Children, young girls and women are in particular at risk of harm and abuse due to their age and gender, while harmful cultural traditions and poverty increase their vulnerability further. In addition, due to women's reduced income-generating choices, and overall powerlessness due to their gender, women might have to engage in transactional sex work in order to manage with the family's economic difficulties (Smith, 2002). This results in high level of STD, HIV and other infections for the young girls and women, in comparison to young boys and men (Smith, 2002). This occurs because young boys usually have sexual intercourse with similar age girls, whereas it has been observed that young girls and women also often have sexual relations with older men, who are associated with higher risk of infections (Gregson et al., 2002).

Although new studies, for instance, Beauclair and colleagues' (2018) comparative quantitative study between mixed-age HIV negative and positive populations show that HIV transmission between genders at different ages is complex to follow and evidence, it is vital to highlight young girls' increased vulnerability to infection due to poverty. According to Smith (2002), poverty often pushes young girls to develop relationships with 'sugar daddies', i.e. older men who are responsible for young girls' sexual exploitation by offering them money, gifts or other indulgences in exchange for sexual favours. In the cases where the girls and young women are infected, due to the stigma associated with sexual violence and HIV/AIDS have, they are afraid to say they have been sexually assaulted which indicates that they might have contracted HIV or other STDs and thus do not seek treatment (Smith, 2002).

Lack of parental support and guidance

Seven out of the ten professionals interviewed mentioned that lack of parental support, protection and guidance add to children's vulnerabilities, and that this is worse when the family is affected by chronic illness or disability. Maria (33, F, NGO Director) argues that children with caregiving responsibilities need emotional support and guidance, not just because of the challenges they are facing but also because their ill parents might not be able to offer it. Maria works with street children and states that she has met many young people who used to live with a parent or relative with illness or disability who have been unable to support them and advise them effectively. She has suggestions for the kind of help they need.

> Maria: *Maybe by offering, not counselling per se, like professionals but offer emotional support and advice to the child. The children will need help from the outside, they will need help with school, with thinking of their future. If the child stops school and the parent dies then the child has nothing.*

Here Maria suggests as a professional working for a child-focused NGO that caregiving children need emotional support and career advice from outside the family because of the likelihood of their being or becoming orphaned.

In Chapter 4 one of the themes discussed was the advisor role of a parent and the responsibility to ensure their child attends school and appropriately advise on personal, family and social matters. Most of the professionals interviewed shared the understanding that when a parent is disabled or chronically ill and is not able to offer this support to their child someone else should play this role. What many of the professionals also shared is the view that because of the high level of needs of the household in combination with other factors, many children drop out of school to help with the survival of the household or unintentionally make other decisions for the children which can be harmful to their children's future. Throughout this study the accounts from children and families who participated in this project highlighted the very high value they place on education. Nevertheless, what many of the professionals who participated in this study believe is that due to hardships families affected by illness and/or disability face, they have to prioritise survival of their household and need their children to do so and that sometimes going to school is a luxury they cannot afford. This was commonly seen by the professionals as a lack of appropriate guidance and advice. According to the professionals, this lack of guidance and advice can lead to a lack of personal development which is explored in the next section.

Lack of personal development

Professionals were of the view that when a child is not raised and supported adequately, then their personal development will not progress as expected. Lentwati (41, F, government service) has extensive experience working with children and vulnerable families and shared the view that children's personal development, like skills and self-esteem, is impacted most when their family is affected by chronic illness or disability. Lentwati explains that those children do not always have the chance to learn significant life skills to become strong and resilient adults.

> Lentwati: *Life skills are very important for the children; so, they are able to make decisions, have self-esteem. Because in schools there are life skills as a lesson, as a subject, but still at the community level we need to empower the girls that despite their parents being in that situation, life has to go on. We have to be resilient. Help children to be strong. Assist guardians and extended families who can look after the sick. Economic support is also vital.*

This study, as well as previous research with young caregivers, show that such children frequently exhibit significant development opportunities, decision-making, managing finance, etc., often beyond their peers because they take on adult-like roles and responsibilities, and are in many ways remarkably resilient children. In the above quotation, Lentwati mentions the importance of supporting extended family and guardians to look after ailing individuals and possibly create a support system which can help the child with their caregiving role. This concurs with the findings expressed earlier in Chapter 6 where the importance of having the support of extended family is described as imperative to how children experience young caregiving.

Poverty and disability or chronic illness

As already discussed, all the families that participated in this research stated that they are not able to adequately meet their basic needs such as food, shelter and clothing, which suggests that they live under extreme financial poverty, as well as multi-dimensional poverty (UN Development Programme, 2010). Professionals highlighted the impact poverty has on many families in Malawi and especially on those who have family members with disability and chronic illness.

Natasha (28, F), project manager at a disabilities organisation, describes how a child's livelihood can be affected by disability and poverty. She explains that when parents are chronically ill or disabled and unable to take care of their family, then the children of the family have to assume adult responsibilities and become the head of the household.

> Natasha: *For children who are growing up in this situation they will definitely stop with education. They will stop attending school. That has always been the case in Malawi for families run by children; the children do not go further with their education. Then this means they will not have the skills to find a job. And this means the levels of poverty are escalating. The graph of poverty is going up.*

Natasha shows how intergenerational poverty affects children and young people and increases overall poverty. Gender inequality, AIDS-related illnesses and severe disabilities have a significantly negative impact on the socio-economic structure of the household (Smith, 2002). When adults responsible for the household are unable to provide for their family then usually the workload falls on the healthy women and young people, who frequently become sick themselves (Smith, 2002). The high levels of sickness and poverty lead to a vicious circle of sickness which in turn increases poverty (Smith, 2002). Things become even worse when children and young people are involved in the income-generating activities of the household and have to drop out of school to help their family (Smith, 2002). Lack of education leads to inability to find steady work, which then leads to risk-related activities, such as exchanging sex for goods or money (Smith, 2002).

Access to school and maintaining attendance

Education and access to schooling are serious issues that affect caregiving children and their families. As already discussed many of the caregiving children who participated in this study had to drop out of school or manage to attend classes only on an irregular basis. But the problem is not always simply the level of caregiving responsibilities, but other gender-specific issues such as pregnancies and menstruation. For instance, Brisca (39, F, Facilitator) from an NGO for girls explains that their programme aims to keep girls in school.

> Brisca: *The aim of going in these schools is to encourage these girls to go and stay at school all the time. According to the traditions of our area, when a girl is on her menstrual periods, she is told to stay at home until she is done. But looking carefully into this, the time they are told to stay at home, teachers do not wait for these girls, rather they proceed, so such girls miss a lot of things. If they write exams you find girls are not doing well; their performance is low.*

Although this is not specific to young caregivers, it can compound absences for girl caregivers. This is also important because it falls under the wider traditional cultural practices that discriminate against girls. Rose agrees that it is girls who are struggling the most due to discrimination and as consequence are missing school. She further highlights the importance of education and that lack of education leads to further 'disability', as she explains that:

> Rose: *You see when someone does not go to school that's a great disability. And this is a disability that most of the girls are affected. In many villages, girls do not go to school even though there's free education.*

This is important because as stated above, lack of education can lead to lack of ability to find consistent income-generating activities, which can mean that young girls might opt for exchanging sexual intercourse for money or food, which can lead to further illness and increase poverty.

All of the professionals stated that they are familiar with many families that have children, especially girls, who do not attend school. They explain that this is often the case with orphaned children, child-headed households and families affected by chronic illness and disability. In spite of this, most professionals stressed that cultural attitudes towards schooling and education also play an important role.

Natasha (28, F, disabilities NGO project manager) explains her own view on this issue.

> Natasha: *There has to be a balance between going to school and doing house chores. But you will find that in Malawian culture this is not the case. They want their kids to work and do chores then go to school. And that can be because the parents themselves have never been at school or because of the circumstances.*

Natasha here discusses Malawian traditional culture and the role of children in a household, but she also talks about adults' attitudes towards education and their capacity to understand why this is important, as most of the adults, especially in rural areas are not formally educated to a wide extent. It is noteworthy to say here that Rejoice's and Christina's case study in Chapter 6 indicated that although Christina states several times that she wants Rejoice to finish school, she keeps Rejoice at home and does not let her attend school. This could be due to the fact that Christina, who has not been at school, similarly for other parents, do not understand how schooling works, and when households are in need of additional help, education is seen as a luxury rather than the necessity.

Service Limitations

Despite professionals' best intentions to support vulnerable children and families, government, charitable and voluntary organisations face a number of challenges due to limited funding, lack of resources and lack of an adequate and properly trained work force. Lentwati (41, F, government service) talks about the government district social welfare office and explains that there are eight trained Social Workers and twenty-eight child protection officers who are volunteers from the community and who mostly offer support to children who experience abuse.

> Lentwati: *We have eight social workers but apart from social workers we also have what is known community child protection workers*[34]*. They are stationed to the communities where they reside so they are the first point of contact. By their name, they are only working for children but any other social issues that*

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[34] Please be advised that the term 'child protection' in Malawi does not have the same meaning as in the UK. Child protection officers in Malawi are volunteers, (not trained social workers), who have a six-week training on child protection and their role is to assist the government social workers. Some of them are paid and some are unpaid, but it was unclear how and why this distinction takes place.

> *come out of that community; they are the first point of contact. We have about 28 of them. Out of 28 about ten are on payroll, 18 just volunteers. They provide their services for free.*

The extremely limited number of professional social workers is not the only problem. Kondwani (32, M, government service) describes staff limitations and also adds that resources and funding are also major difficulties that the social welfare office faces:

> Kondwani: *Resources are also a challenge. And also, the capacity. We are few social workers in Blantyre. Because Blantyre is close to 1 million people and we are only seven social workers. So, the work is too much. That's why we need the government to employ some more social workers. Or at least to improve the funding. You know our department is lowly prioritised in the government.*

There is a lack of a strong frontline social work workforce in Malawi as in other sub-Saharan African countries (Chitereka 2009). Temdo and Oltedal (2015) state that this is due to the fact that social work is not yet well established due to it being a young profession in Malawi. Historically, social work practice in sub-Saharan Africa primarily first began with Christian missionary charitable activities and colonisation from the nineteenth century (Chitereka 2009).

Corruption

In addition, to the lack of trained professionals and limited funding, corruption also is a major challenge that vulnerable children and their families encounter. There are many occasions that due to issues such as discrimination or corruption the available resources do not reach the families most in need. This was reported by the young caregivers who participated in this study, as well as by professional social service providers. For example, Maria (33, F, NGO Director) explains:

> Maria: *Community has like community committees who make the decisions. But in what extent these things are participatory and inclusive I would be very doubtful. Yeah, because funds come to an area or opportunity and it is always the loudest who gets help, isn't it? I can't imagine the family to go to the committee and the sick to be able to benefit something, especially the child.*

> *So, unless there is a community that is a very good community, which is inclusive, and also remembers the vulnerable, then they will get help, otherwise, it will be tough. It is very tough.*

During a follow-up dissemination meeting (see Chapter 3), Kondwani (32, M, government service) also referred to the corruption that exists in many villages. Kondwani explained that to access the government Social Welfare services individuals and families need a referral letter that only child protection officers and Chiefs can provide. Kondwani mentioned that unfortunately for many families who are not personally related to their Chief or the child protection officer, they might be missed, refused or sometimes ignored and thus never get the support they need.

7.5 Supporting Children and Young People with Caregiving Responsibilities

Malawi, like many countries in sub-Saharan Africa, is a resource poor setting challenged by a shortage of social welfare services and skilled professionals and thus the government cannot provide basic support services to protect and support individuals and communities (Evans & Becker, 2009; Tembo & Oltedal, 2015). Some of the main limitations and constraints of state-provided social services in Malawi were discussed in the preceding sections of this chapter. This section explores suggestions for quality, culturally appropriate and accessible services and interventions to support children and young people who have caregiving responsibilities. The suggestions for interventions outlined below are the outcome of all the data gathered and analysed in this project and the views of all the participants, children, families and professionals.

7.5.1 Raising Awareness

A central challenge this study encountered is the ‘invisible’ nature of young caregiving. Most of the professionals approached for interviews were surprised at first to hear that the research concerned children with caregiving responsibilities for relatives with disability or chronic illness. Some of the professionals initially thought that children with disabilities were being referred to and on a few occasions the precise research aims had to be clearly explained. The invisibility and lack of awareness of the hidden nature of young caregivers is not a new finding yet it is a very concerning one as without a better understanding of what these children's roles are and what are the adversities they are facing, there will not be any substantial support. Furthermore, it appears there is little change despite research in other countries conducted nearly two decades ago, e.g. Robson's (2000) work in Zimbabwe demonstrated that children's work contributing to home healthcare was unrecognised and invisible, and thus those children and young people with caregiving responsibilities lacked any kind of institutional recognition or programmes of support. This was also the finding of this study which took place 16 years later in Malawi and its findings show that caregiving children are still invisible and experience high level of difficulties due to the lack of recognition and institutional support. This was obvious from the early stages of the research project, for instance, as explained in Chapter 3, during participant recruitment, as gatekeepers could not easily recognise and identify families with children having caregiving responsibilities for relatives with disability or chronic illness.

The number of children and young people with caregiving responsibilities in Malawi is not known but there is evidence that indicates that they are many. For example, this study, similar to other research projects in sub-Saharan Africa, found that most children with caregiving responsibilities are caring for relatives, but not often for their own parents. In regards to the participants of this study 9 out of the 12 young participants care for grandparents, a sister or an aunt. Martin and Zulaika (2016) identified that 17% of the children in Malawi were not living with their parents and that the parents of 65.5% of those children were still alive. 98.1% of those children were living with relatives. So, the number of children in kinship care in Malawi was about 1,226,401 children in 2016, which would mean about 1 in 7 over the whole population (Martin & Zulaika, 2016). There are many reasons why children in sub-Saharan Africa do not live with their biological parents, such as orphanhood due to parental death, parental separation, or because their relative needs help with the household, income-generating activities or just wants company (Hampshire et al., 2015). Although there is no way to know how many of those children who live with a relative do so to take care of them because of chronic illness or disability, the high number of children living with their kin could be because of poverty or orphanhood, but could also be an indication that the number of young caregivers in Malawi might be much higher than what it is believed to be.

The hidden nature and invisible roles of caregiving by children can add further challenges and risks to the children and their families. This is why developing educational community-based programmes or using print media and radio to inform communities, professionals, and Malawian society more widely of the existence, role and challenges young caregivers face could be significant for developing adequate support systems for those children. Before developing programmes like those though, lack of resources, funding and sustainability should be taken into account.

Nevertheless, raising awareness of caregiving children would be unlikely to be enough to address the challenges and needs they face. Policies and interventions will need to consider raising awareness of disability and chronic illness as well. As Stella (26, F) Manager at a government organisation highlights it "*is mostly about awareness. Because, for example, people think its witchcraft and that people with disabilities are cursed*". In Malawi, as in many sub-Saharan African countries, witchcraft is considered a very serious issue and there are widespread beliefs that witches can cause harm, death, illness and bring misfortune to others (Ashforth, 2015). This way issues of stigma and discrimination can be addressed and at the same time discussions can consider other issues such as gender and poverty. For instance, data from studies on poverty, gender and disability suggest that there is a significant difference in how disability impacts on the level of poverty people experience. For example, Dhungana (2006) argues that disability does not affect men's lives the same way it affects women's lives, unless men's disability is severe because women face double discrimination due to their gender and disability. It is moreover true that women with disabilities face not only stigmatisation that results in social exclusion and marginalisation, but they are also at greater risk of emotional, mental, sexual and physical abuse and less likely to get married (Baskind & Birbeck, 2005; Dhungana, 2006; Emmett & Alant, 2006; Groce et al., 2011).

For example, Maria (33, F, NGO Director) highlights that some blind adults take their children with them on the streets to beg. Maria states that they draw on their physical impairment to ‘use’ the children and thus, keep them away from school and have them on the streets. She believes that if someone could work with the children and their parents and help them understand what having a visual impairment means, this would empower them and help them go back to school.

> Maria: *I will speak mainly for the children of disabled and chronically ill parents. For the disabled, we need to raise awareness. I mean people who are blind for example, I get it, it is tough. But do the children have to suffer as well? So, they need to raise awareness, even MACOHA to say to its members that just because they are blind, they shouldn't make their children vulnerable as well. If they want to beg they can beg for themselves. They can’t see but they know how to walk.*

Here Maria argues for empowering children by raising their awareness about disability and what this means. However, while greater awareness about disability may be desirable, what else is also necessary is to consider how to support people living with disabilities so that they will not require children’s help and will not expose their children to even greater vulnerability.

Raising awareness of social needs to combat disability discrimination can be a challenge and when developing programmes, this needs to be taken into consideration. Natasha (28, F, NGO Project Manager) explains that they work closely with a number of partners and the government and that although this is going well, there are challenges. When asked to elaborate further, Natasha mentioned that her organisation tried to raise awareness about albinism and used media, like radio, to accomplish this and to draw the government’s attention to deal with the problems surrounding individuals with albinism.

> Natasha: *For instance, our approach when advocating has to be vocal and we have to make noise. The government won’t like that and they will think we are against them. And there have been issues, for example with albinism, when government should be in the front so we make noise and make noise and they will tell us not to be on the radio and not to discuss this. But our aim was to raise awareness and that is what we did.*

This could indicate that the government opposed these conversations taking place because perhaps the government was presented as inadequate in not providing enough enlightened policies, laws and services to address issues misconceptions and myths around albinism, which often lead to discrimination, isolation and sometimes even violence against the children and adults with albinism.

Government and professionals unquestionably need to become aware of the existence of caregiving children to identify and assess their needs. Raising community awareness of children and young people with caregiving roles, as well as the needs of persons with disability and chronic illness, needs to be a very careful process so that it will not detrimentally label and further stigmatise the children and their families. Research findings indicate that government and professionals need to be very sensitive in regard to stigma and information sharing (Evans & Becker, 2009; Skovdal, 2009). In many cases, families keep their disability or chronic illness a secret due to fear of the community finding out and as a result being marginalised and labelled. Services should be culturally appropriate and to take into consideration the social, healthcare and geographical locations of caregiving children and their families, so that families are not targeted in an unhelpful way but receive the support they need. Services need to not only provide effective interventions, but also to reach families in remote rural areas as well as cities and semi-urban areas.

7.5.2 Whole Family Approach

Throughout this research project, the significance of adopting a whole family approach when designing interventions has been extensively highlighted. Although it is important, of course, to take into consideration the caregiving children's individual needs, supporting the whole family as a system can ensure that any intervention will work on a long-term basis and can be sustainable. Aldridge (2006) discusses the impacts of young caregiving and highlights that caring can become harmful and place children at risk when it "becomes long term and disproportionate" (p. 83); explaining that a significant factor impacting on the continuation and level of caregiving responsibilities is the kind and sufficiency of social care and health interventions. Earlier work with young caregivers in the UK and Tanzania concluded that in order to have and maintain effective interventions, the social care and health services and organisations need to address the needs of the families affected by illness and disability and not just the individual (Aldridge, 2006; Evans & Becker, 2009). This need to take a whole family approach is similarly applicable in Malawi in order to best ameliorate the situation of young caregivers.

This was recognised by the professionals interviewed in this study. For example, Kondwani (32, M, government service) explains how supporting a disabled parent to develop life and livelihood skills and support him/herself independently can benefit their children to have the time and be able to go to school.

> Kondwani: *Ideally, they need to be empowerment programmes. You know the households with disabled parents are facing disempowerment, so it is about building their capacities for the families. So, for the mother who is extremely disabled what we first need to provide is occupational therapy. So, they will be able to do some of the things on their own, like going to the toilet. And then we have to empower them with some skills. Or someone in the household with some skills to work to ensure that food is on the table all the time and in a way, we need to ensure that children will go to school.*

Kondwani here describes how addressing some of the practical needs adults with disability face can help all the adults and the children in the family, including children who help and care for the adult with a disability.

Family relations should be assessed to identify whether there is a need for intervention, for example, in cases where the burden of co-dependent relationships significantly affect the child and the family. For instance, Maria (33, F, NGO Director) gives the following example that demonstrates not only those complex relationships, but also how an intervention that only aims at supporting the child and not the whole family can have inadvertent and unintended negative consequences. Maria here begins by giving the background:

> Maria: *I will give you an example, we have a girl here, she was ok, she was an average student when she was at the primary school. Her father we do not know, but her mother and stepfather are both HIV positive. And because of the continuous medication, the mother also has some episodes of mental illness. And now that child has always been here* (the NGO residential facility)*, and*

> *we try not to let her go back to the family because we can't trust the stepfather. Because we know that if the stepfather will sexually abuse her, he is going to give her HIV. We have not helped the parents at all because we can't, we do not have the money and it is not in our mandate*.

Maria explains how this girl became socially and culturally different from her family and her relations with her mother changed dramatically.

> Maria: *So, over the years, I have noticed a disconnection between the child and the family. Because she is going to school, one of our donor's love, adore her. She's not doing very well at school. Her family is poor; they live in a two-room house in a low-income area. She's going to school; it is like she is a celebrity. Designer luggage and you know.*

Maria believes that if they had the capacity to target the whole family instead of just the girl, the outcome would have been much better. She states that:

> Maria: *If we had targeted both her and her family, things would have been different. If we had empowered the mother, because she is not depressed all the time, there are times she is fine. If we had empowered her with income generating activity, maybe she could have been selling things. And maybe whatever she makes she could have being given to the child. Maybe even 10 kwacha or 100 kwacha, maybe the child could feel connected. But now as it is, the child goes home, and the mother is always sick. She comes from the school with the fancy luggage and says I want to see my mother. They feel like they are different family members because of the intervention. They are not the same anymore.*

This example portrays the challenges a well-intended humanitarian intervention by external donors can have. For the case Maria describes, the child received an education and help but her ties with her family were damaged. What this could indicate is that where possible, services should reflect on their programmes to rethink and readjust interventions to bring the best outcomes possible for the whole family and not only provide support to orphan and vulnerable children.

7.5.3 Healthcare Services

Other issues concerning family members with disabilities and chronic illness are access to adequate healthcare and medical support, especially for those living in rural areas, and appropriate medication. Although chronic illness and disability are often interconnected, data from this study showed that people with disabilities are facing different challenges from those who are chronically ill and thus might require different kinds of support. MACOHA and FEDOMA are the two major organisations in Malawi that aim to provide awareness about disability and run programmes to help people with disabilities (see Chapter 3), but their efforts are not enough and do not reach a huge number of people with disabilities. They can make little impact on the many families of disabled individuals including children who take on the responsibility of providing care for their relatives who live with disabilities.

Moreover, for those people with physical and mental health disabilities, being identified, diagnosed and assessed can be a challenging issue. Natasha (28, F, NGO Programme Manager) explains that if people with disabilities were to be identified in the early stages, they could get adequate healthcare support and there would be a chance that their disability would not affect their lives in a significant way.

> Natasha: *People get diagnosed through medical services and assessments. But this service is not accessible to everyone. Not everyone will get accessed. And the assessment happens too late. Many of the disabilities if they were diagnosed at early stages, they would have been avoided. But they do not so we have a huge number of people with disabilities. So, when the assessment is done the situation is already advanced. So, assessment is done through the health services but rarely people get assessed here in Malawi.*

Although family members and communities can provide help with a number of issues in different ways, the kind of healthcare provision needed by many people with disabilities is too specialised to be replaced by unskilled and unqualified family members and communities. Maria (33, F, NGO Director) explains that there is a need for healthcare services to provide community nurses and other health professionals to support individuals with chronic illness and disability.

> Maria: *And then for those children who look after sick parents, palliative care, I think there is a need… we should have a system where nurses and health professionals could go in the houses for help and support. Then the child won't have to be overburdened. And organisations like us can help with feeding*

> *because people are starving, people are hungry. Imagine people with medication; they are worse. If that can work.*

There are very limited examples of community based help and nursing in Malawi, and most of them are implemented and facilitated by non-governmental and faith-based organisations who have very specific aims and timeframes.

7.5.4 Using Available Resources and Tools to Plan Interventions

Considering the limitations in funding and resourcing, any interventions designed should take into consideration existing available resources that could be used and how to ensure that any new programmes to support young caregivers and their families will be fair and can be sustained. For instance, Erin (28, F, NGO Programme Manager) describes one of the tools they use to identify children in need and decide how to distribute their resources. Erin describes this a social mapping exercise and explains what it is:

> Erin: *Social mapping exercise is when the community draws a physical map and this way it allows you to categorise or determine the households represented. So, it is a map that shows the geographical layout of the households within the community and then depending on the issues you are interested in they will map out which houses fall within these categories.*

Erin continues to explain that they usually do this exercise with a number of village people to ensure there will not be any excluded families. This is how this works:

> Erin: *For example, you will first draw the landmarks, and then you will draw the different households, and you have first to explain what is a household. Then the next thing is having drawn all the houses you ask them to indicate which houses are female-headed and which are child-headed and then you could agree and say what kind of things would you say would describe a house that is doing well, that is average, and that is poor. So, after you have agreed on these things, you usually use things like grass and colour or pink or shades to indicate different households. So, you have a female household that is very poor, and you have one that is well off.*

Once the mapping exercise is completed, they can then identify the most emerging needs and which are the most vulnerable families.

> Erin: *For example, in the last mapping exercise we did, we identified which houses are completely damaged, which is partially damaged and the community wanted to identify female and child headed households. It helps you with distributions of interventions. If you only have the capacity to help 500 people and that village has 1000 people you try to distribute intervention fairly, but also by looking which compound is the most vulnerable.*

Another suggestion is made by Kondwani (32, M, government services), who describes that by helping a family take advantage of the land they already have, they could have enough food for their household.

> Kondwani: *Because most of the families have gardens and if the neighbours could ensure they use them we could ensure that households have enough food. Because it is most challenging to have food and have soap.*

This means that a family would need help with fertilisers, seeds, tools, labour, etc. and there are ongoing government programmes such as subsided fertiliser and farm inputs provision which are intended to assist the poorest subsistence households to have greater food security.

Throughout this fieldwork research, the evidence gathered suggests that using extended family, neighbours and community to assist young caregivers and their families can prove to be invaluable and instrumental. When extended family cannot help, community might be able to provide support. Neighbours, church, community committees and external organisations can be a great source of support, especially to vulnerable families. Kondwani (32, M, government services) states that:

> Kondwani: *It depends on the type of the community. If the community is sensitive and aware of the vulnerable families, they do assist. We have seen that in some of the households that have been included in food programmes as well as other programmes under the capacity of vulnerable groups. Other communities will build them a house or provide for other needs. Like some organisations, international and religious, will provide some support.*

In the absence of provision from the state, it was indeed found in the research for this thesis that the extended family was the only source offering support and assistance to children and young people with caregiving responsibilities. For instance, in Chapter 5, Louise (12, F), who has a lot of support from her extended family, experiences young caregiving in a much more positive way, than Rosemary (18, F) who has no help and experiences caregiving as a substantial burden.

In Louise's (12, F) case the strong support she has from her extended family and the well-working family system means that the responsibility does not burden her the same way as other carers feel. However, this support needs to be ensured and maintained. Louise will reach an age soon during which she will probably start being interested in relationships with boys. Although very resilient and creative already, her grandmother could benefit from training on how to do things on her own to become more independent. Her grandmother will become older, and at some point, she is going to need more intense care than the kind of care she needed during the fieldwork visits reported in this study. It is also important to ensure that Louise will remain at school and complete her education.

Although the extended family has hitherto and foreseeably will, especially in sub-Saharan Africa, continue to operate as a social welfare system offering social protection (Apte & Grieco, 1994; Chitereka 2009), the help extended families offer might not be consistent or adequate. For instance, Kondwani (32, M, Social Worker) explains that on some occasions where the extended family has no financial resources to offer food or other materials, they might offer supervision and protection to the children who are in need of support.

> Kondwani*: In the extended family cases, it is about sometimes providing some food. But most of the households are poor, so continuing to provide support all the time is hard. But in intervals, they provide support, some soap. But for the children who are there and they are responsible* (for providing food), *they* (extended family) *might offer some supervision and protection to the household. And maybe they maintain the house; it is responsibility for extended family.*

The wider question to raise is whether this ideal of support from the extended family would be enough or even challenging the notion that extended family should be responsible for the provision of social protection and welfare. Within this line of thought, is the question of where the state is responsible and what they can or should be offered by the way of welfare support in a resource-poor African setting.

7.6 Conclusion

Firstly, this chapter explored research participants' perspectives of the kind of needs and supports they stated they require as young caregivers and their family members. It then examined the kind of support the children and their families received at the time of fieldwork or have received in the past finding it to be limited mostly to support from extended family and religious organisations. Following this, the next section 7.3 investigated the data collected from the interviews with professional social service providers in relation to their attitudes towards children and young people with caregiving responsibilities in Malawi. This chapter tackled the last set of research questions at community level on services, support and interventions. It took into account professionals' perspectives on the kind of needs and supports required to put in place in order to effectively meet children's and their family's needs. Finally, considering widely the perspectives and statements from all the participants of this research project, four indicative suggestions for interventions and programmes were offered that could be applied to provide relevant, adequate and culturally appropriate support to vulnerable caregiving children and their families. These are raising awareness of young caregivers, supporting the whole family as a system, improved healthcare provision for people with chronic illness and/or disabilities, and eradicating corruption for a fairer distribution of limited state resources.

Chapter 8. Discussion & Conclusions

8.1 Introduction

This research project has explored the day-to-day experiences and emotional geographies of children with caregiving responsibilities for family members living with chronic illness and disability in Malawi. The research was undertaken within the context of a growing number of research studies detailing the experiences of caregiving children and young people both in Global North and Global South. Much of this literature emphasises the negative impacts of young caregiving and refers to Western notions of 'lost childhood', such as loss of innocence and 'ideal childhood' which entails a carefree childhood with no adult-like responsibilities like working or caring for other (Bauman et al., 2006; Bauman & Germann, 2005; James & James, 2004; Seymour, 2005) (see Chapter 2).

There are also a growing number of studies of young caregiving in sub-Saharan Africa. Their focus remains mostly on children's practical responsibilities, the day-to-day experiences of caring and coping mechanisms employed to face the hardships, rather than the emotional impact caring has on the family environment as a whole (for example Cluver et al., 2011; Evans, 2011; Evans & Becker, 2009; Robson, 2000; Skovdal, 2010). In order to examine caregiving children's lifeworld, this thesis explored the meanings of caregiving, looked at emotional experiences and emotional geographies and at the family as a whole system. It did this in order to gain a better understanding of the experiences, needs and outcomes of young caregiving. Thus, the aim of this PhD study was to respond to this gap identified in the literature by focusing on emotional geographies and the impacts of young caregiving within the family, in order to identify suggestions for policy and practice.

While being very careful about not reducing or minimising the adversity the children and young people with caregiving responsibilities face, this thesis explores additional characteristics of their role as young caregivers. It, therefore, offers a more nuanced and comprehensive understanding than previous work and thus, a more careful and useful conceptualisation of their role as caregivers. It argues that children and young people with caregiving responsibilities are resilient, competent and resourceful individuals who despite the hardships they face, not only manage to undertake high levels of responsibilities, but are also individuals who have aspirations so they long and plan for a better future for themselves and their families. In doing so, this thesis makes two further important points. Firstly, it presents in-depth accounts of the very complex and dynamic emotional experiences of caregiving in relation to the self, the family member with the disability and/or chronic illness and the extended family and wider community. Secondly, accounts are given of family relations and caregiving roles between the child and the adult care-recipient, the family and the community. The experience of caregiving is not only negative or positive, it is complex, fluid and often affected by other factors such as poverty, extended family and (lack of) services. Raising awareness and creating support systems within the community and extended families to support the children with the caregiving roles and also the individual person with the chronic illness or disability are key factors when making policy and practice recommendations.

The next section (8.2) of this chapter seeks to answer the research questions presented in Chapter 1 and discuss the findings of this PhD research with regard to wider literature. The following section (8.3) explores the contributions of this thesis to research, knowledge, policy and practice. Next, section 8.4 discusses the limitations of this study and then, section 8.5 makes suggestions for future research. This chapter ends with a final note (section 8.6) and concludes the thesis through a brief reflective summary of this research project.

8.2 Summary of the Main Findings – answering the research questions

This research project set out to answer four main research questions on the following areas:

1. Being a caregiving child in Malawi (who/what is a child? How do children and young people understand and describe caregiving? Where is caretaking place? How/when do children become caregivers? What are children’s caregiving roles? What are the ways through which children and young people show their agency?);
2. Emotional experiences and emotional geographies of young caregiving (what are children’s and young people’s emotional experiences and emotional

geographies of caring for family members (parents, siblings, grandparents, other adult relatives) with chronic illness and/or disability?);

3. Family relationships and young caregiving (how are family geographies constructed when children caring is involved? How are family relations affecting or are affected by young caregiving? What are children and young people different roles and how do these intersect?);

4. Services and support (what is the role of formal (social services) and informal (peers, family, community) support? According to children and their families participating, which interventions are the most appropriate?).

The subsections below set out responses to these research questions and present a summary of the key findings of the research undertaken for this thesis.

8.2.1 Being a Caregiving Child in Malawi

The study found that the research participants described children as individuals who are under 18 years old, defined by their biological age; as people who are not mature enough to be adults and who do not have the thinking capacity or intelligence to be independent individuals; and as persons who 'belong' to their family. According to the child and adult participants, family life and family ties are important aspects of being a child, as children are regarded as family-assets who actively contribute to their household and who as future adults will continue to contribute by providing financial or other material help. Some of the narratives gathered describe children as individuals who need guidance and support, who need education and their friends. In addition, the research also revealed that children need to be taught and then sustain Malawian traditions, i.e. cultural appropriations and norms, for the next generation.

The children and young people who participated in this research project displayed variable levels of agency depending on their situation and age. The findings of this study demonstrate that Malawian caregiving children exhibit their agency in everyday life activities, making decisions for themselves and their education, the people they care for, and on some occasions, displayed resistance to adult power. This was not always the case though, and in addition, it was identified that cultural norms such as gender and age hierarchies also play a significant role.

This was particularly apparent in deciding to allocate a caregiver to the person with the chronic illness or disability. Age hierarchies play a vital role, as elders are the ones who usually make the decisions and the cultural expectation is that younger individuals need to listen to and respect older persons. In line with previous gender stereotypes and gender divisions of labour in Malawi, the research found that girls and women usually assume caregiving roles, but this study further demonstrated that boys can also assume caregiving responsibilities for both male and female relatives. Based on factors such as gender, age, availabilities and household needs in families affected by illness and disability, some children assume caregiving roles for family members with disability or illness, and they were either asked to become caregivers by adult family members, decided for themselves or due to the circumstances it fell to them as there was no one else available.

The study found the children's caregiving roles include household chores, like cleaning and cooking, healthcare tasks to support the ailing person, personal care, such as bathing and feeding, childcare of younger children in the household, emotional and practical support, spiritual care and income-generating activities. Some of the children had to permanently drop out of school to fulfil their caregiving roles, while others attended school on a part-time or full-time basis.

8.2.2 Emotional Experiences and Emotional Geographies of Young Caregiving

The children and young people who participated in this study demonstrated a variety and range of emotional experiences which were interlinked with their caregiving roles, as well as other factors such as socio-economic circumstances, including poverty, lack of resources and support. Children overall spoke of feelings of love, devotion and gratitude for the person they were taking care of and described a strong sense of pride in their caregiving roles. They also described feelings of guilt and sadness, especially when unable to meet the needs of the person they are caring for. These emotional experiences were attributed by the participants to challenges they face due to financial need, lack of material resources and other services and not due to their caregiving roles. Overall, the children and young people experience caregiving in a positive way, but being unable to satisfactorily fulfil their caregiving roles and responsibilities resulted in negative emotional affects.

Most of the participants of this study also stated that they frequently felt tired, experienced both physical and emotional exhaustion, due to the combination of high level of responsibilities and lack of money and support. Young caregiving children also identified other social issues causing a negative effect on their experiences as caregivers including stigma due to their care-recipient’s illness or disability, and social isolation due to dropping out of school or being unable to participate in community events due to care responsibilities for their ailing relative.

The three case studies presented in Chapter 5 presented an in-depth account of young caregivers’ emotional experiences to demonstrate that emotional experiences of caregiving are complex, dynamic and interlink with many other factors alongside caregiving roles. It was also identified that children participating in the research experienced senses of both proximity and distance in relation to themselves, family members and community. It also emerged in the findings that in some cases temporary feelings of both physical and emotional distance from their caregiving roles could result in feeling closer to the person cared for. Finally, it was observed that children and young people created spaces of home and safety, some of which were physical places associated with relaxation and enjoyment, as well as imaginary spaces of hope and future where children’s and young people’s dreams and aspirations would be met.

8.2.3 Family Relationships and Young Caregiving

Family relationships involving young caregiving are shown in the previous chapters to be complex and dynamic, subject to change over time and influenced by a range of factors. The family members participating in the research mostly described strong and positive relationships between the young caregivers and adult care-receivers. Such positive relationships resulted in positive experiences of caregiving and it was identified that caregiving has the capacity to strengthen these family carer-care recipient relationships. Relationships also were thought to be a place of safety, where mutual love, respect and caregiving takes place.

Caregiving relationships can be reciprocal and interdependent and at the same time can be characterised by a sense of dependency. The power in these relationships constantly shifts and there was evidence of adults holding onto their carers, but also of the caregiving children resisting that power.

Family geographies of care were explored in relation to children's mobilities and time-space caregiving practices. It was revealed that children and young people with caregiving responsibilities face both (i) increased mobilities, being moved into different households from the one they were born into, in order to care for a family member with disability or chronic illness; and (ii) limited mobilities due to restraints their caregiving responsibilities have on everyday life and so they are often unable to attend school and spend time with their friends and in the wider community. This does not suggest that children do not form friendships or do not socialise at all, as the study also showed that the children with caregiving roles find other creative ways to develop and maintain social relations, for example, while walking with others to fetch water or firewood.

8.2.4 Services and Support

One of the main findings of this study was that participants highlighted that it was not the caregiving roles and needs which caused most of the challenges they were facing, but rather a number of other internal and external determining factors. In summary, the four main challenges identified are (i) poverty, (ii) impacts of disability and chronic illness, (iii) issues with regularly accessing education, and (iv) lack of emotional and spiritual support. The findings of this study showed that at the time of the fieldwork in and around Blantyre, Malawi there were no NGOs or government services that specifically support children and young people with caring responsibilities. There was a range of organisations and services supporting vulnerable children and families, and families affected by disability and chronic illness were often included in this group.

There was one government service supporting people with disabilities but none of the families who engaged in the research reported that they had received any kind of support from the service or even knew about it. Malawi, like many countries in sub-Saharan Africa, has a chronic shortage of social welfare services and skilled professionals and therefore cannot provide basic social services to protect and support individuals and communities. The aim of this thesis is not to advocate whether children should or should not have caregiving responsibilities, as this depends highly on the socio-economic cultural and geographical context in considering the constructions of childhood throughout the analysis chapters (as explained earlier Chapters 4 to 7). However, an outcome of this thesis is to advocate for better conditions and support for this particular group of children and young people. Taking into consideration this study's findings and the particular needs and lack of services in Malawi, four indicative recommendations are made for policy and practice: 1. Raising awareness; 2. Adopting a whole family approach; 3. Improving healthcare services for people with chronic illness and disabilities; and 4. Fair distribution of resources. What should be clarified here, is that there are many other recommendations for interventions that could be made to support children and families affected by chronic illness and disability and that the four intervention recommendations above are the direct outcome of the particular needs and vulnerabilities faced by the participants of this study.

8.3 Contributions

This section presents the contributions of this thesis in relation to research, knowledge, policy and practice this research project makes. This section examines the findings against current research and identifies the ways these results can add to the existing scholarship.

8.3.1. Methodological and Theoretical Contributions

Contribution to research with children and young people

What this thesis argues is that when researching with children and young people they should be viewed beyond their relationship to their social environments. Also, general ideas of childhood and spatiality and relations to the physical environment should be taken into consideration as well. Combining social and geographical research can offer opportunities for a more comprehensive understanding and thus conceptualisation of children's lifeworld. For example, Punch (2004) examined children's use of time and space in Bolivia and concluded that children's resistance to their parents' power is a complex process which needs to be researched through not only children's relations with adults, but also in regards to how children use space and time. Punch (2004) found that children used strategies to avoid doing what they are asked or to cope with the frequently difficult tasks when those are unavoidable, by using space and time away from adult surveillance which offers them some freedom with the limitations adult power sets. This echoes the findings of the research presented in this study, according to which children and young people with caregiving responsibilities often employ the autonomy they have when away from their adult relatives to either enjoy themselves while completing a task or escape the heavy burden of the responsibilities and instead relax (Chapters 5 & 6).

Reflexivity is a vital part of the research and analysis process. This study agrees with Evans and colleagues' (2017) standpoint which argues the significance of researchers reflecting on their own background and emotional experiences of the particular topic under research. They argue that embracing an intimate dialogue, which can often be uncomfortable, between the researcher and the data throughout the research process, can offer invaluable insights, particularly when conducting cross-cultural research and analysis on emotions (Evans et al., 2017). Indeed, reflecting on my own emotional experiences of the research process, on a number of occasions I felt uncomfortable in relation to the participants, to the research assistants, to the data and to the process of analysis and interpretation. There were many moments when I experienced discomfort but, as discussed in Chapter 3, being able to only partially help the families I worked with, such as by giving their names to the Social Welfare Office, was one of the most difficult emotions I had to deal with.

Supervision, writing my reflective diary and when possible conversations with the others helped to use these uncomfortable emotions as part of a useful and learning process. It is important though to highlight that feeling uncomfortable was only one of the emotions I experienced amongst a sea of other feelings such as feeling excited, happy, scared, unsure, tired and many others which at different points in the research could be experienced all together at the same time or just one at a time. One example of a difficult situation I faced, and equally experienced difficult emotions, was when one of the families disclosed a domestic abuse incident by a male family member. I made the child protection referral to the Social Welfare Office and discussed this with the NGO working with the family but in reality, this abuse was not addressed and the situation was not resolved as I would have liked. I felt that I had no control, I felt helpless and angry for the participants and for not being able to support the family. At that point, I thought that I had the choice of ending my involvement with the family, or staying with the difficult emotions and continuing my data collection. I discussed this with my research assistant and my supervisors and decided that I would first talk to the family about what they thought and if they wanted to continue being part of the study. The family was very keen to continue and following further conversations with my research assistant, the decision was to continue but if the particular male relative was around and we felt that something was not going well, then we would leave the house immediately and seek help.

Despite difficult feelings, deMarrais and Tisdale (2002) argue that “emotional engagement has the capacity to expand research in this colleague’s situation, the emotional connection to work-related and gender-related oppression gave her the passion, energy, and interest needed to work on this project” (p. 120). They continue to explain that researchers should have strategies for dealing with their own and participants’ feelings before entering fieldwork in an ethical and caring way (deMarrais & Tisdale, 2002). They also highlight there might be a time when researchers should be able to recognise that they need to step back from research and reflect on their emotions and situation before being able to continue (deMarrais & Tisdale, 2002). My supervision and peer support from other PhD students offered opportunities to step back and reflect on my emotions and dealing with difficult situations throughout my fieldwork.

Contribution to literature on the social studies of childhoods

The social study of children (see Chapter 2) established that childhood is a social construction which is culturally, historically and geographically specific (James et al., 1998). This project contributes to the ever-growing body of literature on childhoods across time and space by presenting in-depth work on the socially constructed nature of contemporary childhoods for caregiving children in Southern Malawi. Hence, this project confirms that children and childhood in

Malawi, as in many countries in sub-Saharan Africa, are not and should not be defined by western notions of childhood. The material put forward in this thesis identifies the central role of work in young caregivers and therefore, agrees with Robson's (2004b) position that less emphasis should be given to the idealised notion of childhood in the Global North as a period of innocence and opportunity to play, and that the focus should be shifted towards the reality of children's formal and informal work in the Global South in order to ensure this work takes place under circumstances appropriate for the children.

Thus, the research undertaken for this thesis contributes to work by scholars who are critical of how they represent children and childhood, especially in the context of global childhoods (Evans & Skovdal, 2016). This study contributes to the call for the complexity and diversity of African childhoods to be considered against the extremely challenging realities those children face due to the social, economic and political circumstances they are living in, while avoiding misrepresentations of African children as passive victims who have no control over their lives (Ntarangwi, 2015).

Contribution to theories of emotions and emotional geographies

This research project also contributes to the wider and growing field of emotional geographies. The exploration of caregiving emotional experiences in the preceding chapters (especially Chapter 5) showed that emotions are complex and are shaped by and shape the roles and everyday lives of caregiving children and young people in Malawi. There are a lot of contributing factors, such as relations with the ailing person, the family and the community, the level of poverty and support from services or extended family, and other support systems, such as friendships and religion/faith. So, it is difficult to pinpoint exactly how these factors affect emotional experiences. Evans and Thomas (2009) found that some caregiving children use a sense of pride to feel better in regards to their caregiving roles, but in this study, this was not that clear although they were genuinely proud of their roles and accomplishments.

Scholarly attention to the spatiality of emotions in relation to care has been introduced by Milligan and Wiles (2010) and Giesbrecht and colleagues (2017) who explored the sense of proximity and distance in caregiving relationships in regards to the physical and emotional aspects of their relationships. This way the complex and fluid nature of emotional experiences when caregiving was demonstrated. To explore this further, this thesis used these concepts of emotional geographies to map children's and young people's senses of proximity and distance in relation to themselves, the family members they are caring for and the wider extended family and community. The personal, relational and affective aspects of caregiving indicated that both positive and negative lived experiences produce complex relationships with the self and others. While some occurrences create a sense of proximity and encourage close relationships, other elements can create distance that can have adverse impacts on the individual.

The children and young people who participated in this study used spaces, both real and imaginary, to relax, feel stronger and regain hope. This further illustrates children's ability and competence to use their own self and other resources - material, emotional and social – to feel empowered and develop their strengths. Many studies have discovered that children and young people with caregiving responsibilities acquire mechanisms to cope with their roles by using support by extended family, friends, and members of their community to deal with the hardships (Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009). The findings of this study agree with this and has also discovered that, in order to deal with anger and anxiety, children and young people seek out and construct their own spaces/places to feel safe and relaxed which are usually located away from home. When exploring their geographical sense of caregiving it was identified that distance from their role, taking a step back to focus on themselves, was a great benefit for most of the participants. This echoes Milligan and Wiles's (2010) argument that in caring relationships, geographical distance results in emotional proximity.

In discourses about emotional experiences, relational experiences play a significant role. What this study highlighted was the reciprocity of relationships and that caregiving does not occur one-way, but creates a complex interwoven map of relational networks. Skovdal (2009) argues that when becoming a caregiver, this reciprocity, mutual love and devotion play a more important role than cultural expectations and family needs. Participants in this study undoubtedly developed strong and close relationships with their care-recipients but for most of them (nine out of the twelve participants) caregiving roles were allocated to them by the authority and direction of adult relatives or because there was no one else to take this role. While participants understood their caregiving roles not as labour, but as something undertaken out of mutual love and respect, one of the scholarly contributions of this thesis is to conceptualise their work as a form of emotional labour.

Contribution to the literature on care and meanings of care

Overall, the research undertaken for this thesis revealed that for the children and young people who participated in this study their caregiving roles were viewed by them as positive ones. This finding is similar to the work of Evans & Skovdal (2016) in respect to caregiving children in sub-Saharan Africa but is in contrast to Lane and colleagues (2015) whose research about young carers in South Africa concluded that most of the participants found caregiving as being a negative aspect of their lives. Similar to the findings of Evans and Becker’s (2009) study in the UK and Tanzania, children’s emotional attachments and relationships with other significant family members were found in Malawi to also bring positive outcomes.

Adding to the growing body of geographical research on care, this study also furthers understandings of the geographical roles of caregiving and time (i.e. care is 24/7) and space (i.e. care takes place mostly in the home but also outside the home for activities such as fetching water or going to the clinic) practices and how these further help identification of what kind of needs these young carers have. Children and young people with caregiving roles undertake high level of responsibilities including household tasks, healthcare tasks for the ailing person, personal care, childcare, practical and emotional care, spiritual care and income-generating activities.

These findings support many earlier studies (for instance, Bauman et al., 2006; Cluver et al. 2009; Evans & Becker, 2009; Katz, 2004; Robson & Ansell, 2000; Skovdal 2009), but add a new dimension of spiritual care. Spiritual care is something that is frequently mentioned within the context of being a support mechanism and the role religion and faith plays in providing with both material and emotional support vulnerable individuals and families. What this research study found is that both the children with caregiving roles and their adult care-receivers identified that spiritual care, such as praying for the ailing person to get well or attending their spiritual needs like transporting them to church or reminding them to pray, is a very important part of the work undertaken by young caregivers.

As other research identified (Evans & Skovdal, 2016; Robson et al. 2006), this study demonstrated that caregiving children acquire a key role in ensuring the needs of the relatives with the disability and illness are met and also play a significant role in the survival of the whole household as they frequently assume caregiving roles for other members of the family.

As discussed in Chapter 2, intersectionality is a very useful concept through which to examine and understand the multiplicity of people's lived experiences within which gender, race, age and other categories interact with each other and thus should not be regarded or examined in isolation (Hankivsky, 2014). As Evans and Thomas (2009) suggest, this study examined the interactions and intersections of gender, age, poverty and stigma while exploring caregiving relationships. The findings demonstrate that factors such as age, gender, social background impact on the way participants experience and provide care and thus, the lens of intersectionality can allow better exploration of the complexity of gender relations in a caregiving context. For example, both young male caregiving participants highlighted throughout their narratives the practical and emotional challenges they have faced in caring for female relatives, while the third male young caregiver in the research discussed how he experiences caregiving for his grandfather in a much more positive way as he was chosen to be his grandfather's caregiver due to his ability to carry his grandfather around. Thus, gender, age and stigma/shame/pride interact in complex ways for these young men in their caregiving situations.

The findings also demonstrate a number of differences and similarities amongst the participants' experiences of caregiving. With regard to differences amongst the participants' experiences, in addition to the impact caregiving roles for male participants caring for female relatives has, another noteworthy difference to highlight is the experience of taking care of a family member with mental health problems. Mental distress can be a very complex and demanding situation to deal with in comparison to physical disability or chronic illness. For example, throughout this thesis and specifically in the analysis chapters, it is evident that for Rosemary (who cares for her sister, Mary, with mental health problems) her caregiving role was experienced in a very different way to that of her peers, especially as her understanding about her sister's condition is that she has physical ill health - heart problems. This of course does not mean that the other caregivers did not face challenges, rather that the type of challenges presented are different depending on the situation and needs of the care-recipient.

Participants caring for family members with HIV/AIDS also shared a number of similarities and differences in relation to their peers. For example, their caregiving responsibilities change depending on the state of their relative's health, which can be unpredictable due to infections, access to medication, etc. On the other hand, participants who cared for relatives with a disability stated that their responsibilities remain mostly the same. Another significant difference is the stigma families affected by HIV/AIDS experienced which was not as prevalent with other conditions. Caring for grandparents instead of parents or siblings often meant that participants had to live away from their immediate family, in some cases even in different villages from their parents and siblings. The impact this had on the young caregivers varied with some of the participants stating that they wanted to stay with their grandparent and it felt like their grandparent was their parent, while other participants explained that they miss their parents and siblings.

Location also played a very important role in the way the participants experienced their caregiving roles, as for example, those living in urban areas had access to healthcare clinics and electricity, but did not have access to land unlike those living in rural areas. Participants highlighted both the positive and negative impacts of their place of residence on their caregiving experiences, but what was similar was that all the participants were able to acknowledge the limitations and advantages characterising the place where they lived yet, they did not feel as if they had any choice to move even if they wanted to. Finally, participants with extended families had much more support compared with their peers with no extended family and hence those with no extended family or additional support experienced caregiving in a more negative way as they had to assume greater responsibilities.

8.3.2 Practical Contributions

The findings and outcomes of this thesis are intended to be beneficial to practitioners and professionals working with vulnerable children and families to help them raise awareness and understanding of this particular group of children and young people among themselves and more widely. Cultural norms in Malawi determine that all children are active members of their household and assume a number of household chores. In families affected by chronic illness and disability, often it is children and young people who are allocated to take care of the ailing individuals. This results in those children and young people assuming a much higher level of responsibility and this can have a negative impact on their wellbeing and formal education. This does not mean that caregiving children are passive individuals with no competencies and abilities. On the contrary, this study showed that they develop a number of strengths and acquire skills that typically their peers do not demonstrate. This is important to acknowledge when working with this population of children because it offers a better understanding of their needs and therefore the ability to provide more effective support.

For the young caregivers and their families, the main adversities and vulnerabilities identified by the research arose from poverty, lack of resources and services. The main protective factors were a positive identity of caregiving (as found by Skovdal, 2009), extended family support (similar to findings of Evans & Thomas, 2009) and any kind of support, although limited from local services and organisations. In line with other studies (e.g. Evans & Becker, 2009; Robson et al., 2006; Skovdal et al., 2009) positive outcomes of caregiving roles include strengthened family relationships, learning new skills, maturity and development of personal qualities, a sense of pride and commitment. Negative outcomes of caregiving include missing education, stress and guilt when unable to provide for the person in need due to limited resources and money, and tiredness due to the demanding level of responsibilities. As other scholars have stated (e.g. Evans & Becker, 2009; Robson et al., 2006; Skovdal, 2009) the participants in the research recounted in this thesis overwhelmingly attributed negative meanings of caregiving due to poverty and the lack of social and government support.

In terms of the available support and services for children and young people with caregiving responsibilities, there was nothing formally available at the time of fieldwork. Even more concerning was that, as Robson stated as early as in 2000, there was still a complete lack of awareness of this population of children amongst professionals in NGO, services and government.

8.4 Limitations

All research is undertaken within the context of limitations. Some of the limitations of this study are explored in this section. Firstly, during the initial stage of designing the data collection strategy, due to time and funding constraints, I was unable to travel to Malawi and conduct a pilot study. This would have helped with being more prepared and having some initial evidence with which I could review my proposed research methods and questions. In addition, on reflection after conducting the research, it would have been beneficial to conduct more than one focus group discussion. As explained in Chapter 3, due to limited time and finances, only one group discussion was conducted which turned into a dissemination workshop, rather than a focus group discussion. This had overwhelmingly positive feedback from the participants who stated that this was the best part of the study and that they not only enjoyed it but felt much better from meeting with other young people with similar roles. More group discussions like those, could not only generate more data, but also have a positive outcome in participants' lives.

Another limitation was that I did not have the opportunity to go to the capital city Lilongwe and approach government ministries to identify relevant policy and legislation. At the time of my research design, I anticipated that it would be easy to access Malawian government policies and legislation relevant to the situation of young caregivers but there are difficulties in accessing these online. As I am unable to return to Malawi due to finance and time constraints, I have been unsuccessful in gathering all the necessary documentation. This means that this project offers a number of broad policy recommendations, but does not analyse or evaluate the current policy situation.

In addition, during data analysis, any questions and uncertainties that arose in regards to the data collection could not be answered and clarified as participants and research assistants live in Malawi. As it was not possible to contact them without travelling there again, some of the questions remain unanswered. Yet, the findings of this study do add to the current literature and research studies about young caregiving in Malawi and reflect the experiences of young caregivers in sub-Saharan Africa generally.

8.5 Recommendations for Future Research

This research project attempted to answer the research questions presented in this thesis (section 1.6) and in doing so, as many other social research projects, created a number of additional questions. There are five main ideas and questions for research that this project provoked. These are, firstly, to explore whether caring for individuals with mental health issues poses differences with regards to caring for someone with physical illness or disability; secondly, to look further at the relationship between education and young caregiving; thirdly, to explore further the relation between young caregiving and religious faith; fourthly, to investigate street children and young caregiving which was a theme that arose from the interviews with the professionals and personal observations; and lastly, it would be beneficial to explore young caregiving in the context of social work education in Malawi. These five directions for future possible research which arise from this study are expanded upon below.

Although this was not explored in-depth, the data gathered for this thesis suggest that there are differences when caring for an adult with physical disability or chronic illness and caring for an adult who has mental health issues. This should be further investigated as the caregiving children and their family members in situations of mental health illness have different kind of needs and require different interventions and support compared to those in situations of physical ill health or physical disability. Most of the existing research is with young caregivers looking after adults with physical health problems and disabilities rather than mental health illness or conditions. Mental health is poorly understood and largely untreated in much of Africa so this could be a challenging, but highly valuable research direction worth pursuing.

Schooling and education emerged as prominent challenges for the participants throughout the research project. Two of the many themes that could be further explored as outcomes of this research are firstly to investigate long-term outcomes of school non-attendance for young caregivers and secondly, to conduct a research project investigating staff awareness of and responses to young caregiving. Children and their families in this study recognised the importance of education and how finishing school could result in finding a job, but many, due to poverty and other circumstances such as illness and disability, had to keep their children off school, or some of the participants attended school only on a part-time basis. It would be very useful to further explore what kind of impacts this has on the overall education, and thereafter, employability for the young caregivers. In addition, some of the participants stated that one of the reasons they dropped out of school was that teachers did not understand the impact their caregiving roles have on their everyday lives and therefore, did not support them and did not allow them to enter class on arriving at school late because of their caregiving roles. It would thus be valuable to research more from the perspective of education providers by conducting observation and interviews at schools including school staff.

One of the key findings identified in this project was the role religion and faith plays in young caregiving, not only as a support system, but also as a caregiving responsibility. Therefore, it would be valuable to explore further the part religion and church involvement plays as support system and how church/religion addresses young caregiving and families affected by disability or chronic illness. In addition, another theme that arose but this project could not address at the time of fieldwork was street children and young caregiving. In the interviews with the professionals, this emerged as an issue of concern as a number of children were reported being taken from their families to the streets to help adults with disabilities to beg and earn money and then stay with those adults, who are usually relatives, to take care of them. Finally, another key finding this project revealed was lack of awareness of young caregivers by NGO professionals and government social workers. It would thus be beneficial to work with social work staff and students to understand their own understanding of young caregiving (or lack of) and need for appropriate interventions.

8.6 A Final Note

This research project aimed to present children and young people with caregiving responsibilities in an accurate and thoughtful way by offering them the platform to have a voice and share their experiences, thoughts and feelings. Although these voices have been represented through myself, the author of this thesis, by using qualitative mixed methodology, I endeavoured to portray their thoughts and feelings as fully as possible. What this project has demonstrated is that the children and young people who participated in this research are resilient and competent individuals are trying to do their best for their families and themselves and should not be represented as vulnerable and passive victims in need. This kind of negative representation is not only inaccurate and simplistic, but also harmful for the caregiving children and young people and their families. The children and young people who participated in this study have a number of incredible strengths which should be acknowledged and further developed. Furthermore, this thesis is a testament to the challenges and vulnerabilities these children and young people are facing, which should of course, not be dismissed. There is a significant need to raise awareness, challenge and shift policy and practice, advocate for fair distribution of existing resources and eliminating corruption in order to make effective contributions to these children's lives. I hope my thesis goes some way towards doing this.

References

Abebe, T. & Ofosu-Kusi, Y. (2016) Beyond pluralizing African childhoods: Introduction. *Childhood*, 23(3), p. 303-316.

African Union (2006) *African Youth Charter*. Ethiopia: African Union.

Aitken, S. (ed.) (2013) *Global Childhoods: Globalization, Development and Young People*. Oxon: Routledge.

Aitken, S.C. (1994) *Putting children in their place*. San Diego: Association of American Geographers.

Aitken, S.C. (2001) *Geographies of young people: The morally contested spaces of identity*. New York: Routledge.

Alanamu T., Carton B. & Lawrance B.N. (2018) Colonialism and African Childhood. In Shanguhyia, M. & Falola, T. (eds) *The Palgrave Handbook of African Colonial and Postcolonial History*. New York: Palgrave Macmillan, p. 389-412.

Alderson, P. (2004) Ethics. In Fraser, S., Lewis, V., Ding, S., Kellet, M. & Robinson, C. (eds) *Doing Research with Children and Young People*. London: SAGE, p. 97-112.

Alderson, P. & Morrow, V. (2011) *The Ethics of Research with Children and Young People, A Practical Handbook*. London: SAGE.

Aldridge, J. (2006) The experiences of children living with and caring for parents with mental illness. *Child abuse review*, *15*(2), p. 79-88.

Aldridge, J. & Becker, S. (1993) *Children who care: Inside the world of young carers*. Loughborough: University of Loughborough.

Aldridge, J. & Becker, S. (1997) *Prevention and intervention: Young carers and their families.* Loughborough: University of Loughborough.

Aldridge, J. & Becker, S. (1999) Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy*, 21(3), p. 303-320.

Aldridge, J. & Becker, S. (2003) *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. Bristol: Polity Press.

Aldridge, J. & Sharpe, D. (2007) *Pictures of young caring*. Loughborough: University of Loughborough.

Anders A. (2012) Lessons from a Postcritical Ethnography, Burundian Children with Refugee Status, and Their Teachers, *Theory into Practice*, 51(2), p. 99-106.

Anderson, K. & Smith, S.J. (2001) Editorial: emotional geographies. *Transactions of the Institute of British Geographers*, 26(1), p. 7-10.

Andreouli, E., Skovdal, M. & Campbell, C. (2013) 'It made me realise that I am lucky for what I got': British young carers encountering the realities of their African peers. *Journal of Youth Studies*, 16(8), p. 1038-1053.

Ansell, N. (2005) *Children, youth and development*. Oxon: Routledge.

Ansell, N. (2009) Childhood and the politics of scale: descaling children's geographies?. *Progress in Human Geography,* 33(2), p. 190-209.

Apte, N. & Grieco, M. (1994) Urbanization, caring for the elderly people and the changing African family: The challenge to social policy. *International Security Review,* 47(3-4), p. 111-121.

Aries, P. (1962) *Centuries of Childhood: A Social History of Family Life*. Oxford, England: Vintage Books.

Arksey, H. & Knight, P. (1999) *Interviewing for Social Scientists*. London: SAGE.

Ashforth, A. (2015) Witchcraft, justice, and human rights in Africa: cases from Malawi. *African studies review*, 58(1), p. 5-38.

Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1(3), p. 385-405.

Banks, G. & Scheyvens, R. (2014) Ethical Issues. In Scheyvens, R. (ed.) in *Development Fieldwork: a practical guide* (2nd Edition). London: SAGE Publications, p. 160-187.

Barter, C. & Renold, E. (2000) 'I wanna tell you a story': Exploring the application of vignettes in qualitative research with children and young people. *International Journal of Social Research Methodology*, 3(4), p. 307-323.

Bartos, A.E. (2013) Children sensing place. *Emotion, Space and Society*, 9, p. 89-98.

Baskind, R. & Birbeck, G. L. (2005) Epilepsy-associated stigma in sub-Saharan Africa: The social landscape of a disease. *Epilepsy & Behaviour,* 7(1), p. 68-73.

Bauman, L., Foster, G., Silver, E., Berman, R., Gamble, I. & Muchaneta, L. (2006) Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies,* 1(1), p. 56-70.

Bauman, L. & Germann, S. (2005) Psychosocial impact of the HIV/AIDS epidemic on children and youth. In Foster, G. Levine, C. & Williamson, J. (eds) *Generation at risk*. New York: Cambridge University Press.

Beauclair, R., Hens, N. & Delva, W. (2018) The role of age-mixing patterns in HIV transmission dynamics: Novel hypotheses from a field study in Cape Town, South Africa. *Epidemics*.

Becker, S. (2000) Young carers. In Davies, M. (ed) *The Blackwell encyclopedia of social work*. Oxford: Blackwell, p. 378.

Becker, S. (2007) Global perspectives on children's unpaid caregiving in the family: research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, 7(1), p. 23-50.

Becker, S., Aldridge, J. & Dearden, C. (1998) *Young Carers and their Families*. Oxford: Blackwell Science.

Bessell, S. (2009) Indonesian Children's Views and Experiences of Work and Poverty. *Social Policy and Society,* 8(4), p. 527–540.

Blazek, M. (2013) Emotions as practice: Anna Freud's child psychoanalysis and thinking–doing children's emotional geographies. *Emotion, Space and Society*, 9, p. 24-32.

Blazek, M. (2015) Children's emotional geographies: Politics of difference and practices of engagement. In Hackett, A., Procter, L. & Seymour, J. (eds) *Children's Spatialities: Embodiment, Emotion and Agency.* Palgrave Macmillan: London, p. 95-111.

Blazek, M. & Windram-Geddes, M. (2013) Editorial: Thinking and doing children's emotional geographies. *Emotion, Space and Society*, 9, p. 1-3.

Boakye-Boaten, A. (2010) Changes in the concept of Childhood: Implications on Children in Ghana. *The Journal of International Social Research*, 3(10), p. 104-115.

Bondi, L. (2008) On the relational dynamics of caring: a psychotherapeutic approach to emotional and power dimensions of women's care work. *Gender, Place and Culture*, *15*(3), p. 249-265.

Bondi, L., Davidson, J. & Smith, M. (2005) Introduction: Geography's 'Emotional Turn'. In Davidson J., Bondi L. & Smith M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing, p. 1-16.

Bourdillon M. & Musvosvi, E. (2013) What can children's rights mean when children are struggling to survive? The case of Chiweshe, Zimbabwe. In Twum-Danso Imoh, A. & Ansell, N. (eds) *Children's Lives in an Era of Children's Rights the Progress of the Convention on the Rights of the Child in Africa* [eBook]. Oxon: Routledge, p. 105-112.

Bowlby, S. (2012) Recognising the time–space dimensions of care: caringscapes and carescapes. *Environment and Planning-Part A,* 44(9), p. 2101-2118.

Bowlby, S., McKie, L., Gregory, S. & MacPherson, I. (2010) *Interdependency and Care over the Lifecourse*. Oxon: Routledge.

Boyden, J. (1997) Childhood and the policy makers: A comparative perspective on the globalization of childhood. *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood,* 2, p. 190-229.

Boyes, M.E. & Cluver, L.D. (2013) Relationships among HIV/AIDS orphanhood, stigma, and symptoms of anxiety and depression in South African youth a longitudinal investigation using a path analysis framework. *Clinical Psychological Science,* 1(3), p. 323-330.

Bradley, M.M. & Lang, P.J. (2000) Measuring emotion: Behavior, feeling, and physiology. In Lane R. & Nade L. (eds) *Cognitive neuroscience of emotion.* Oxford: Oxford University Press, p. 242-276.

Bradshaw M. & Stratford, E. (2005) Qualitative Research Design and Rigour. In Hay I. (ed) *Qualitative Research Methods in Human Geography* (2nd Edition). Oxford: Oxford Polity Press, p. 67-76.

Brockington, D. & Sullivan, S. (2003) Qualitative Research. In Scheyvens, R. & Storey D. (eds) *Development Fieldwork* [eBook]. London: SAGE, p. 58-75.

Brown, M.A. & Stetz, K. (1999) The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qualitative Health Research*, 9(2), p. 182-197.

Bruseberg, A. & McDonagh, D., (2003) Organising and Conducting a Focus Group: The Logistics. In Langford, J. & McDonagh, D. (eds) *Focus Groups: supporting Effective Product Development*. London: Taylor & Francis, p. 22-45.

Bryman, A. (2008) *Social Research Methods* (3rd Edition), Oxford: Oxford University Press.

Bunge, W. (1969) *The first years of the Detroit geographical expedition: A personal report*. Detroit: Society for Human Exploration.

Bunge, W. (1973) The geography. *The Professional Geographer*, 25(4), p. 331-337.

Burr, R. & Montgomery H. (2003) Children and rights. In Woodhead, M. & Montgomery, H. (eds) *Understanding Childhood: An Interdisciplinary Approach.* Milton Keynes: Wiley, p. 135-178.

Cabanac, M. (2002) What is emotion?. *Behavioural Processes,* 60(2), p. 69-83.

Cameron, J. (2005) Focusing on the Focus Group. In Hay I. (ed) *Qualitative Research Methods in Human Geography* (2nd Edition). Oxford: Oxford Polity Press, p. 116-132.

Castree N., Kitchin R., & Rogers A. (2013) *A Dictionary of Human Geography* (eBook). Oxford: Oxford University Press.

Cheney, K.E. (2013) Conflicting protectionist and participation models of children's rights. Their consequences for Uganda's orphans and vulnerable children. In Twum-Danso Imoh, A. & Ansell, N. (eds) *Children's Lives in an Era of Children's Rights the Progress of the Convention on the Rights of the Child in Africa* [eBook]. Oxon: Routledge, p. 17-33.

Chitereka, C. (2009) Social work in a developing continent: The case of Africa. *Advances in Social Work*, 10(2), p. 144-156.

Christensen, P. (2004) Children's Participation in ethnographic research: issues of power and representation. *Children and Society*, 18, p. 165-176.

Christensen, P. & James, A. (2000) Researching Children and Childhood Cultures of Communication. In Christensen, P. & James, A. (eds) *Research with Children: Perspectives and Practices*. London: Routledge, p. 1-9.

Christensen, P. & Prout, A. (2002) Working with ethical symmetry in social research with children. *Childhood*, 9(4), p. 477-497.

Christiansen, C., Utas, M. & Vigh, H.E. (2006) Introduction. In Christiansen, C., Utas, M. & Vigh, H.E. (eds) Navigating Youth Generating Adulthood: Social Becoming in an African Context. Nordisksa Afrikainstitutet: Sweden, 9-30.

Christou, A. (2011) Narrating lives in (e)motion: Embodiment, belongingness and displacement in diasporic spaces of home and return. *Emotion, Space and Society*, 4(4), p. 249-257.

Christou, M. & Spyrou, S. (2012) Border encounters: How children navigate space and otherness in an ethnically divided society. *Childhood*, 19(3), p. 302- 316.

Clark, A. & Moss, P. (2011) *Listening to Children: The Mosaic Approach* (2nd Edition) [eBook]. London: National Children's Bureau.

Clark, A., McQuail, S. & Moss, P. (2003) *Research Report RR445: Exploring the field of Listening to and consulting with Young Children*. London: Department for Education and Skills.

Clemensen, N. (2016) Exploring ambiguous realms: Access, exposure and agency in the interactions of rural Zambian children. *Childhood*, *23*(3), p. 317-332.

Cluver, L. (2011) Children of the AIDS pandemic. *Nature*, 474(7349), p. 27-29.

Cluver, L., Operario, D. & Gardner, F. (2009) Parental illness, caregiving factors and psychological distress among children orphaned by acquired immune deficiency syndrome (AIDS) in South Africa. *Vulnerable children and youth studies*, 4(3), p. 185-198.

Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2011) 'I Can't Go to School and Leave Her in So Much Pain': Educational Shortfalls Among Adolescent 'Young Carers' in the South African AIDS Epidemic. *Journal of Adolescent Research*, p. 1-25.

Cluver, L.D., Orkin, M., Boyes, M.E., Gardner, F. & Nikelo, J. (2012) AIDS-orphanhood and caregiver HIV/AIDS sickness status: effects on psychological symptoms in South African youth. *Journal of Pediatric Psychology,* 37(8), p. 857-867.

Collis, M. (2005) Mourning the Loss' or 'No Regrets': Exploring Women's Emotional Responses to Hysterectomy. In Davidson J., Bondi L. & Smith M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing Ltd, p. 33-48.

Connell, R. W. (2005) Change among the gatekeepers: Men, masculinities, and gender equality in the global arena. *Signs: Journal of Women in Culture and Society*, *30*(3), 1801-1825.

Connolly, P. (2008) Race, Gender and Critical Reflexivity in Research with Young Children. In Christensen, P. & James, A. (eds) *Research with Children: Perspectives and Practices*. (2nd Edition) [eBook]. Oxon: Routledge, p. 173-204.

Conradson, D. (2003) Geographies of care: spaces, practices, experiences. *Social & Cultural Geography,* 4(4), p. 451-454.

Conradson, D. (2005) Freedom, space and perspective: moving encounters with other ecologies. In Davidson J., Bondi L. & Smith M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing Ltd, p. 103-116.

Cree, V. (2003) Worries and problems of young carers: issues for mental health. *Child and Family Social Work,* 8(4), p. 301-309.

Cruz E.V. & Higginbottom G. (2013) The use of focused ethnography in nursing research. *Nurse Researcher*. 20(4), p. 36-43.

Dahlblom, K., Herrara, A., Peña, R., & Dahlgren, L. (2009) Home Alone: Children as Caretakers in León, Nicaragua. *Children & Society*, 23, p. 43-56.

Davidson, J. (2003) *Phobic geographies: The phenomenology and spatiality of identity.* Aldershot: Ashgate.

Davidson, J. & Milligan, C. (2004) Embodying emotion sensing space: introducing emotional geographies. *Social & Cultural Geography,* 5(4), p. 523-532.

Davidson, J. & Smith, M. (2003) Bio-phobias/techno-philias: Virtual reality exposure as treatment for phobias of 'nature'. *Sociology of Health & Illness,* 25(6), p. 644-661.

Davis, J.M. (2000) Disability Studies as Ethnographic Research and Text: Research Strategies and Roles for Promoting Social Change?. *Disability & Society*, 15(2), p. 191-206.

Davis, K. (2008) Intersectionality as buzzword A sociology of science perspective on what makes a feminist theory successful. *Feminist Theory,* 9(1), p. 67-85.

Day, C. (2016) Education and employment transitions: the experiences of young people with caring responsibilities in Zambia. *Labouring and Learning*, 1-26.

De Boeck, F. & Honwana, A. (2005) Introduction: Children & Youth in Africa. In Honwana & De Boeck (eds) *Makers & Breakers: Children and Youth in Postcolonial Africa*. James Currey: Oxford, 1-18.

De Lissovoy, N. (2015) *Education and Emancipation in the Neoliberal Era: Being, teaching, and power*. Palgrave Macmillan: New York, 131-146.

Dearden, C. & Becker, S. (1998) *Young carers in the United Kingdom: a profile*. London: Carers National Association.

Dearden, C. & Becker, S. (1999) The experiences of young carers in the UK: the mental health issues. *Mental Health Care*, 2(8), p. 273-276.

deMarrais, K. & Tisdale, K. (2002) What Happens When Researchers Inquire Into Difficult Emotions?: Reflections on Studying Women's Anger Through Qualitative Interviews, Educational Psychologist, 37:2, 115-123.

den Besten, O. (2010) Local belonging and 'geographies of emotions': Immigrant children's experience of their neighbourhoods in Paris and Berlin. *Childhood*, 17(2), p. 181-195.

Department for International Development (DfID) (2018) *DFID Malawi Profile, Policy paper*. https://www.gov.uk/government/publications/dfid-malawi-profile-july-2018.

Department of Health (DoH) (2010) *Improving the Health and Well-being of People with Long Term Conditions*. London: Department of Health Publications.

Dhungana, B.M. (2006) The lives of disabled women in Nepal: vulnerability without support. *Disability & Society*, 21(2), p. 133-146.

Dickens, L. & Lonie, D. (2013) Rap, rhythm and recognition: Lyrical practices and the politics of voice on a community music project for young people experiencing challenging circumstances. *Emotion, Space and Society,* 9, p. 59-71.

Doran, T., Drever, F. & Whitehead, M. (2003) Health of young and elderly informal carers: analysis of UK census data. *British Medical Journal,* 321, p. 1388.

Dowling R. (2005) Power, Subjectivity, and Ethics in Qualitative Research. In Hay I. (ed) *Qualitative Research Methods in Human Geography* (2nd Edition). Oxford: Oxford Polity Press, p. 19-29.

Dunn, K. (2005) Interviewing. In Hay I. (ed) *Qualitative Research Methods in Human Geography* (2nd Edition). Oxford: Oxford Polity Press, p. 77-105.

Dyck, I. (1999) Body troubles: women, the workplace and negotiations of a disabled identity. In Bulter R. & Parr H. (eds) *Mind and body spaces: Geographies of illness, impairment and disability.* London: Routledge, p. 119-137.

Earley, L. & Cushway, D. (2002) The parentified child. *Clinical child psychology and psychiatry*, 7(2), p. 163-178.

Eatough, V. & Smith, J. (2006) I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology,* 97(4), p. 483-498.

Edwards, C.P., Gandini, L. & Forman, G.E. (2012) *The hundred languages of children: the Reggio Emilia experience in transformation* (3rd Edition) [eBook]. California: Praeger.

Ehrenreich, B. & Hochschild, A.R. (2003) *Global woman: Nannies, maids, and sex workers in the new economy*. Great Britain: Granta Books.

Elliott, J. (2005) *Using Narrative in Social Research* [eBook]. London: SAGE.

Emmett T. & Alant E. (2006) Women and disability: exploring the interface of multiple disadvantage. *Development Southern Africa*, 23(4), p. 445-460.

Emond, R. (2005) Ethnographic Research Methods with Children and young People. In Greene, S. & Hogan, D. (eds) *Researching Children's Experience: Approaches and methods.* London: SAGE, p. 123-140.

Equality Act (2010) Chapter 1. Norwich: The Stationery Office. Available at: http://www.legislation.gov.uk/ukpga/2010/15/section/6 (accessed 22/04/2015).

Evans, B. (2008) Geographies of youth/young people. *Geography Compass,* 2(5), p. 1659-1680.

Evans, R. (2005) Social Networks, Migration, and Care in Tanzania. *Journal of Children and Poverty,* 11(2), p. 111-129.

Evans, R. (2010) Children's caring roles and responsibilities within the family in Africa. *Geography Compass,* 4(10), p. 1477-1496.

Evans, R. (2011) 'We are managing our own lives...': Life transitions and care in sibling-headed households affected by AIDS in Tanzania and Uganda'. *Area*, 43(4), p. 384-396.

Evans, R. (2012a) Safeguarding inherited assets and enhancing the resilience of young people living in child- and youth-headed households in Tanzania and Uganda. *African Journal of AIDS Research* 11, p. 177–89.

Evans, R. (2012b) Sibling caringscapes: Time–space practices of caring within youth-headed households in Tanzania and Uganda. *Geoforum,* 43(4), p. 824-835.

Evans, R. (2014) Children as caregivers. In Ben-Arieh, A., Casas, F., Frones, I. & Korbin, J. (eds) *Handbook of child well-being* [eBook]. Dordrecht: Springer, p. 1893-1916.

Evans, R. (2015) HIV-related stigma, asset inheritance and chronic poverty: Vulnerability and resilience of widows and caregiving children and youth in Tanzania and Uganda. *Progress in Development Studies*, 15(4), p. 326-342.

Evans, R. (2016) Achieving and evidencing research 'impact'? Tensions and dilemmas from an ethic of care perspective. *Area*, 48(2), p. 213-221.

Evans, R. (2019) Interpreting family struggles in West Africa across Majority-Minority world boundaries: tensions and possibilities. *Gender, Place & Culture*, 1-16.

Evans, R. & Becker, S. (2009) *Children caring for parents with HIV and AIDS: Global issues and policy responses.* Bristol: Policy Press.

Evans, R., Ribbens McCarthy, J., Bowlby, S., Wouango, J. & Kébé, F. (2017) Producing emotionally sensed knowledge? Reflexivity and emotions in researching responses to death. *International Journal of Social Research Methodology*, 20(6), p. 585-598.

Evans, R. & Skovdal, M. (2016) Defining children's rights to work and care in Sub-Saharan Africa: Tensions and challenges in policy and practice. In Kallio K., Mills S. & Skelton T. (eds) *Politics, Citizenship and Rights*. Geographies of Children and Young People, vol 7. Springer: Singapore, p. 3-20.

Evans, R. & Thomas, F. (2009) Emotional interactions and an ethics of care: Caring relations in families affected by HIV and AIDS. *Emotion, Space and Society*, 2(2), p. 111-119.

Evans, S.L., Robson, E. & Willis, K. (1997) The Logistics of Undertaking Fieldwork in 'Developing Areas'. In Robson, E. & Willis, K. (eds) *Postgraduate fieldwork in developing areas: a rough guide* (2nd Edition). Developing Areas Research Group (DARG) of the Institute of British Geographers, p. 7-18.

Ezzy, D. (2002) *Qualitative Analysis: Practice and Innovation*. London: Routledge.

Fang, W. & Ellwein, M. (1990) Photography and Ethics in Evaluation. *Evaluation Review*, 14(1), p. 100-107.

Fereday, J. & Muir-Cochrane, E. (2008) Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5(1), p. 80-92.

Flyvbjerg, B. (2001) *Making social science matter: why social inquiry fails and how it can count again*. Cambridge: Cambridge University Press.

Flyvbjerg, B. (2006) Five misunderstandings about case-study research. *Qualitative inquiry*, 12(2), p. 219-245.

Fontana, A. & Frey, J.H. (2005) The interview: From neutral stance to political involvement. In Denzin, N.K. & Lincoln, Y.S. (eds.) *The Sage Handbook of Qualitative Research* (3rd Edition). Thousand Oaks, CA: SAGE, p. 695-728.

Foster, G. & Willamson, J. (2000) A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS,* 14(3), p. 275-284.

Frankfort-Nachmias, C. & Nachmias, D. (2008) *Research Methods in the Social Sciences* (7th Edition). USA: Worth Publishers.

Freeman, M., DeMarrais, K., Preissle, J., Roulston, K., & St. Pierre, E. A. (2007) Standards of evidence in qualitative research: An incitement to discourse. *Educational researcher*, 36(1), 25-32.

Frijda, N.H. (2009) Emotion experience and its varieties. *Emotion Review,* 1(3), p. 264-271.

Gallacher, L. (2005) 'The terrible twos': Gaining control in the nursery? *Children's Geographies,* 3(2), p. 243-264.

Gallacher, L. & Gallagher, M. (2008) Methodological Immaturity in Childhood Research? Thinking through 'participatory methods'. *Childhood*, 15(4), p. 499-516.

Gallagher, M. (2009) Ethics. In Tisdall, E.K.M., Davis, M.J. & Gallagher, M. (eds) *Researching with Children and Young People: research design, methods and analysis*. London: SAGE, p. 11-28.

Gates, M. & Lackey, N. (1998) Youngsters caring for adults with cancer. *Journal of Nursing Scholarship,* 30, p. 11-15.

Giesbrecht, M., Williams, A., Duggleby, W., Sethi, B., Ploeg, J. & Markle-Reid, M. (2017) Feelings of distance and proximity: exploring the emotional geographies of men caregiving for family members with multiple chronic conditions. *Social & Cultural Geography*, p. 1-21.

Gilbert, L. & Walker, L. (2009) "They (ARVs) are my life, without them I'm nothing"-experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa". *Health & place,* 15(4), p. 1123-1129.

Gilbert, L. & Walker, L. (2010) 'My biggest fear was that people would reject me once they knew my status…': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health & Social Care in the Community*, 18, p. 139–146.

Goldie, P. (2009) Getting feelings into emotional experience in the right way. *Emotion Review,* 1(3), p. 232-239.

Goldson, B. (1999) *Youth Justice: Contemporary policy and practice*. Aldershot: Ashgate Publication Ltd.

Gough, K., Langevang, T., & Owusu, G. (2013) Youth employment in a globalising world. *International Development Planning Review*, *35*(2), 91-102.

Greeff, A.P. & Loubser, K. (2008) Spirituality as a resiliency quality in Xhosa-speaking families in South Africa. *Journal of Religion and Health*, 47(3), p. 288-301.

Greene, S. & Hill, M. (2005) Researching children's experience: methods and methodological issues. In Greene, S. & Hogan, D. (eds) *Researching Children's Experience: Approaches and methods.* London: SAGE, p. 1-21.

Gregson, S., Nyamukapa, C.A., Garnett, G.P., Mason, P.R., Zhuwau, T., Caraël, M., Chandiwana, S.K. & Anderson, R.M. (2002) 'Sexual mixing patterns and six differentials in teenage exporter to HIV infection in rural Zimbabwe', *The Lancet*, 359(9321), p.1896-1903.

Greig, A. & Taylor, J. (1999) *Doing research with children*. London: SAGE.

Greig, A., Taylor, J. & MacKay, T. (2013) *Doing Research with Children: A practical guide* (3rd Edition). London: SAGE.

Groce N., Kembhavi G., Wirz S., Lang R., Trani J.F. & Kett M. (2011) *Poverty and disability– a critical review of the literature in Low and Middle-Income Countries*. Leonard Cheshire Disability and Inclusive Development Centre, University London College: London.

Gutierrez, C.O. & Hopkins, P. (2014) Introduction: young people, gender and intersectionality. *Gender, Place & Culture,* 22(3), p. 383-389.

Hackett, A., Procter, L. & Seymour, J. (2015) Introduction: Spatial Perspectives and Childhood Studies. In Hackett, A., Procter, L., & Seymour, J. (eds) *Children's Spatialities: Embodiment, Emotion and Agency,* Palgrave Macmillan: London, p. 1-17.

Hajdu, F., Ansell, N., Robson, E., Van Blerk, L. & Chipeta, L. (2011) Income-generating activities for young people in southern Africa: Exploring AIDS and other constraints. *The Geographical Journal*, 177(3), p. 251-263.

Hammersley, M. & Atkinson, P. (2007) *Ethnography: Principles in Practice* (3rd Edition) [eBook]. Oxon: Routledge.

Hampshire, K., Porter, G., Agblorti, S., Robson, E., Munthali, A. & Abane, A. (2015) Context matters: Fostering, orphanhood and schooling in Sub-Saharan Africa. *Journal of Biosocial Science*, 47(2), p. 141-164.

Hankivsky, O. (2014) Rethinking Care Ethics: On the Promise and Potential of an Intersectional Analysis. *American Political Science Review,* 108(2), p. 252-264.

Hanlon, N. (2012) *Masculinities, care and equality: Identity and nurture in men's lives.* Hampshire: Palgrave Macmillan.

Harding, R., Selman, L., Powell, R. A., Namisango, E., Downing, J., Merriman, A., Ali, Z., Gikaara, N., Gwyther, L. & Higginson, I. (2013) Research into palliative care in sub-Saharan Africa. *The Lancet Oncology*, 14(4), p. 183-188.

Hargreaves, A. (2001) Emotional geographies of teaching. *The Teachers College Record*, 103(6), p. 1056-1080.

Held, V. (2006) *The ethics of care: Personal, political, and global.* Oxford: Oxford University Press.

Hemming, P.J. (2007) Renegotiating the primary school: children's emotional geographies of sport, exercise and active play. *Children's Geographies*, 5(4), p. 353-371.

Henderson, P. (2015) New Directions in Child and Youth Research in Africa. In Ntarangwi, M. & Massat, G. (eds) *Engaging Children and Youth in Africa: Methodological and Phenomenological Issues*. Cameroon: Langaa Research & Publishing CIG, p. 61-94.

Hennessy, E. & Heary, C. (2005) ‘Exploring Children’s views through Focus Groups.’ In Greene, S. and Hogan, D. (eds), *Researching Children’s experience: Approaches and Methods*. London: SAGE, p. 236-252.

Hertz, R. (1997) *Reflexivity & voice*. London: SAGE.

Heywood, C. (2001) *A history of childhood.* Cambridge: Polity Press.

Hoggart, K., Lees, L. & Davies, A. (2002) *Researching Human Geography*. London: Arnold.

Hollos, M. (2002) The Cultural Construction of Childhood: Changing conceptions among the Pare of northern Tanzania. *Childhood*, 9(2), 167-189.

Holloway, S.L. (2014) Changing children's geographies. *Children's Geographies,* 12(4), p. 377-392.

Holloway, S.L. & Pimlott-Wilson, H. (2011) Geographies of children, youth and families defining achievements, debating the agenda. In Holt, L. (ed) *Geographies of children, youth and families: An international perspective.* London: Routledge, p. 9-24.

Holloway, S.L. & Valentine, G. (2000a) Children's Geographies and the New Social Studies of Childhood. In Holloway S. & Valentine G. (eds) *Children's Geographies: Playing, Living, Learning.* London: Routledge, p. 1-26.

Holloway, S.L. & Valentine, G. (2000b) Spatiality and the new social studies of childhood. *Sociology,* 34(4), p. 763-783.

Holloway, S.L., Valentine, G. & Bingham, N. (2000) Institutionalising technologies: masculinities, femininities and the heterosexual economy of the IT classroom. *Environment & Planning A*, 32(4), p.617-633.

Holmes, R.M. (1998) *Fieldwork with children*. London: SAGE.

Holt, L. (2007) Children's sociospatial (re)production of disability within primary school playgrounds. *Environment and Planning D*, 25(5), p. 783-802.

Holt, L. (2011) Introduction. Geographies of children, youth and families: disentangling the socio-spatial contexts of young people across the globalizing world. In Holt, L. (ed) *Geographies of children, youth and families: An international perspective.* Oxon: Routledge, p. 1-8.

Holt, L., Bowlby, S. & Lea, J. (2013) Emotions and the habitus: Young people with socio-emotional differences (re) producing social, emotional and cultural capital in family and leisure space-times. *Emotion, Space and Society,* 9, p. 33-41.

Horton, J. & Kraftl, P. (2006) What else? Some more ways of thinking and doing ‘children's geographies’. *Children's Geographies,* 4(1), p. 69-95.

Horton, J., Kraftl, P. & Tucker, F. (2008) The challenges of ‘Children's Geographies’: a reaffirmation. *Children's Geographies,* 6(4), p. 335-348.

Horwitz, A., Reinhard, S. & Howell-White, S. (1996) Caregiving as reciprocal exchanges in families with seriously mentally ill members. *Journal of Health and Social Behaviour*, 37, p. 149-162.

Hosking, M., Whiting, G., Brathwate, C., Fox, P., Boshoff, A., & Robbins, L. (2000) Cultural attitudes towards death and dying: A South African perspective. *Palliative Medicine*, 14(5), p. 437-439.

Howard, S. (1997) Methodological issues in overseas fieldwork: experiences from Nicaragua's Northern Atlantic Coast. In Robson, E. & Willis, K (eds). *Postgraduate fieldwork in developing areas: a rough guide* (2nd Edition). Developing Areas Research Group (DARG) of the Institute of British Geographers, p. 19-37.

Hubbard, G., Backett-Milburn, K. & Kemmer, D. (2001) Working with emotion: issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology*, 4(2), p. 119-137.

Hutchby, I. & Moran-Ellis, J. (1998) *Children and social competence: Arenas of action*. London: Psychology Press.

Izard, C.E. (2009) Emotion theory and research: highlights, unanswered questions, and emerging issues. *Annual Review of Psychology,* 60, p. 1-25.

James A. & James, A.L. (2004) *Constructing childhood: Theory, policy and social practice*. London: Palgrave Macmillan.

James, A. (2001) Ethnography in the Study of Children and Childhood. In Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (eds) *Handbook of Ethnography* [eBook]. London: SAGE, p. 246-258.

James, A. (2009) Agency. In Qvortrup, J., Corsaro, W. & Honig, M. (eds) *The Palgrave Handbook of Childhood Studies*, Basingstoke: Palgrave Macmillan, p. 34-35.

James, A. & James, A. (2004) *Constructing childhood: Theory, policy and social practice.* Hampshire: Palgrave Macmillan.

James, A. & James, A. (2012) *Key concepts in childhood studies.* London: SAGE.

James, A. & Prout, A. (1997) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* (2nd Edition). London: Routledge.

James, A., Jenks, C. & Prout, A. (1998) *Theorising Childhood*. Cambridge: Polity Press.

James, S. (1990) Is there a 'place' for children in geography?, *Area*, 22(3), p. 278-283.

Jenks, C. (2000) Zeitgeist research on childhood. In Christensen, P. & James, A. (eds) *Research with Children: Perspectives and Practices*. London: Routledge, p. 62-76.

Jones, O. (2005) An ecology of emotion, memory, self and landscape. In Davidson J., Bondi L. and Smith M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing Ltd, p. 205-218.

Katz, C. (2004) Growing up global. *Economic Restructuring and Children's Everyday Lives.* Minneapolis: University of Minnesota Press.

Kaufman, N.H. & Rizzini, I. (2002) *Globalization and children: Exploring potentials for enhancing opportunities in the lives of children and youth.* US: Springer Science & Business Media.

Kehily, J.M. (2009) Understanding childhood: An Introduction to Some Key Themes and Issues. In Kehily, J.M. (ed) *An Introduction to Childhood Studies* (2nd Edition). Milton Keynes: Open University Press, p.1-21.

Keith, L. & Morris, J. (1995) Easy targets: a disability rights perspective on the 'children as carers' debate. *Critical Social Policy*, 15(44-45), p. 36-57.

Keith, M. & Pile, S. (1993) *Place and the Politics of Identity*. London: Routledge.

Kindon, S., Pain, R. & Kesby, M. (2010) Participatory Action Research, origins, approaches and methods. In Kindon, S., Pain, R. & Kesby, M. (eds) *Participatory Action Research and Methods, Connecting people, participation and place*. Oxon: Routledge, p. 9-18.

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E. & Bajenja, E. (2007) Family caregivers in rural Uganda: the hidden reality. *Health Care for Women International*, 28(10), p. 856–871.

Kjørholt, A.T. (2007) Childhood as a symbolic space: searching for authentic voices in the era of globalisation. *Children's Geographies,* 5(1-2), p. 29-42.

Klocker, N. (2007) An example of 'thin' agency. Child domestic workers in Tanzania. In Panelli, R., Punch, S. & Robson, E. (eds) *Global perspectives on rural childhood and youth: Young rural lives.* Oxon: Routledge, p. 83-94.

Konstantoni, K. (2012) Children's peer relationships and social identities: exploring cases of young children's agency and complex interdependencies from the Minority World. *Children's Geographies*, 10(3), p. 337-346.

Kraftl, P. (2006) Building an idea: the material construction of an ideal childhood. *Transactions of the Institute of British Geographers*, 31(4), p. 488-504.

Kraftl, P. (2012) Utopian Promise or Burdensome Responsibility? A Critical Analysis of the UK Government's Building Schools for the Future Policy, *Antipode*, 44, p. 847-870.

Kraftl, P. (2013) Beyond 'voice', beyond 'agency', beyond 'politics'? Hybrid childhoods and some critical reflections on children's emotional geographies. *Emotion, Space and Society*, 9, p. 13-23.

Laird, S.E. (2012) Construction of the Child in Ghanaian Welfare Policy. In Twum-Danso Imoh, A. & Ame, R. (eds) *Childhoods at the Intersection of the Local and the Global*. UK: Palgrave Macmillan, p. 94-120.

Lambie, J.A. & Marcel, A.J. (2002) Consciousness and the varieties of emotion experience: a theoretical framework. *Psychological Review,* 109(2), p. 219-242.

Lane, T., Cluver, L. & Operario, D. (2015) Young carers in South Africa: tasks undertaken by children in households affected by HIV infection and other illness. *Vulnerable Children and Youth Studies: An International Interdisciplinary Journal for Research, Policy and Care*, 10(1), p. 55-66.

Langevang, T. (2008) 'We are managing!' uncertain paths to respectable adulthoods in Accra Ghana. *Geoforum*, 39, 2039–2047.

Langford, J. & McDonagh, D. (2003) 'Introduction'. In Langford, J. & McDonagh, D. (eds) *Focus Groups: supporting Effective Product Development*. London: Taylor & Francis, p. 1-18.

Laurier, E. (2003) Participant Observation. In Clifford N.J. & Valentine G. (eds) *Key Methods in Geography*. London: SAGE, p. 133-148.

Lazaro, M.C. (2018) *Grandfathers Caring for Orphaned Grandchildren in Rural Southern Malawi: Invisible in Plain Sight?*. (Doctoral dissertation, The University of Hull).

Longhurst, R. (1997) 'Going Nuts': Re-presenting Pregnant Women. *New Zealand Geographer,* 53(2), p. 34-39.

Longhurst, R. (2003) Semi-structured Interviews and Focus Groups. In Clifford N.J. & Valentine G. (eds), *Key Methods in Geography*. London: SAGE, p. 117-132.

Lund, R. (2007) At the interface of development studies and child research: rethinking the participating child. *Children's Geographies*, 5(1-2), p. 131-148.

Mackley, K.L., Pink, S. & Moroșanu, R. (2015) Knowing the world through your body: children's sensory experiences and making of place. In Hackett, A., Seymour, J. & Procter, L. (eds) *Children's Spatialities: Embodiment, Emotion and Agency.* London: Palgrave Macmillan, p. 21-38.

Maclntyre, R. (1996) Nursing loved ones with AIDS. In Gordon, S., Benner, P. & Noddings, N. (eds) *Caregiving: Readings in Knowledge, Practice, Ethics, and Politics*. Philadelphia: University of Pennsylvania Press, p. 141-152.

Martin, F. & Zulaika, G. (2016) "Who Cares for Children? A descriptive study of care - related data available through global household surveys and how these could be better mined to inform policies and services to strengthen family care." *Global Social Welfare,* 3, p. 51-74.

Martin, R. (2006) Children's perspectives: roles, responsibilities and burdens in home- based care in Zimbabwe. *Journal of Social Development in Africa*, 21(1), p. 106- 129.

Matthews, H. & Limb, M. (1999) Defining an agenda for the geography of children: review and prospect. *Progress in Human Geography*, 23(1), p. 61-90.

Matthews, H., Limb, M., & Taylor, M. (1998) The Geography of Children: some ethical and methodological considerations for project and dissertation work. *Journal of Geography in Higher Education*, 22(3), p. 311-324.

Matthews, H., Limb, M. & Taylor, M. (2000a) The 'street as thirdspace'. *Children's Geographies: Playing, Living, Learning,* 8, p. 63.

Matthews, H., Taylor, M., Percy-Smith, B. & Limb, M. (2000b) The Unacceptable Flaneur The Shopping Mall as a Teenage Hangout. *Childhood,* 7(3), p. 279-294.

Mauthner, M. (1997) 'Methodological aspects of collecting data from children: Lessons from three research projects'. *Children & Society*, 11, p. 16-28.

Mayall, B. (2000) 'Conversations with children: working with generational issues.' In Christensen, P. & James, A., (eds) *Research with Children: Perspectives and Practices*. London: Falmer Press, p. 120-135.

Mayall, B. (2013) *A history of the sociology of childhood*. London: Institute of Education Press.

McCracken, J. (2012) *A History of Malawi: 1859-1966*. Suffolk: James Currey.

McEwan, C. & Goodman, M.K. (2010) Place geography and the ethics of care: introductory remarks on the geographies of ethics, responsibility and care. *Ethics, Place and Environment,* 13(2), p. 103-112.

McKie, L., Gregory, S. & Bowlby, S. (2002) Shadow times the temporal and spatial frameworks and experiences of caring and working. *Sociology,* 36 (4), p. 897-924.

McLennan, S., Storey, D. & Leslie, H (2014) Entering the field. In Scheyvens, R. (ed) *Development Fieldwork: a practical guide* (2nd Edition). London: SAGE Publications, p. 143-159.

McNamee, S. (2016) *The Social Study of Childhood*. London: Palgrave.

McNamee, S. & Seymour, J. (2012) Towards a sociology of 10–12 year olds? Emerging methodological issues in the 'new' social studies of childhood. *Childhood*, p. 1-13.

Milligan, C. & Wiles, J. (2010) Landscapes of care. *Progress in Human Geography* 34(6), p. 736–754.

Mizen, P. & Ofosu-Kusi, Y. (2007) Researching with, not on: Using Photography in Researching Street Children in Accra, Ghana. In Smith, M. (ed) *Negotiating Boundaries and Borders (Studies in Qualitative Methodology, Volume 8)* Emerald Group Publishing Limited, p. 57-81.

Mmari, K. (2011) Exploring the relationship between caregiving and health: Perceptions among orphaned and non-orphaned adolescents in Tanzania. *Journal of Adolescence,* 34(2), p. 301-309.

Montgomery, H. (2003) Childhood in time and place. In Woodhead, M. & Montgomery H. (eds) *Understanding Childhood: an interdisciplinary approach.* Milton Keynes: Wiley, p. 45-84.

Morgan, L.D. (1997) *Focus Groups as Qualitative Research* (2nd Edition). London: SAGE.

Morris, J. (1991) *Pride against prejudice: Transforming attitudes to disability.* London: The Women's Press.

Morris, J. (1997) A Response to Aldridge & Becker - disabilty rights adn the denial of young carers: the dangers of zero-sum arguments. *Critical Social Policy,* 17, p. 133-135.

Morris, S.M. & Thomas, C. (2005) Placing the dying body: emotional, situational and embodied factors in preferences for place of final care and death in cancer. In

Davidson J., Bondi L. & Smith M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing Ltd, p. 19-31.

Moss, P. (1999) Autobiographical notes on chronic illness. In Bulter, R. & Parr, H. (eds) *Mind and body spaces: Geographies of illness, impairment and disability.* London: Routledge, p. 155-166.

Mukherji, P. & Albon, D. (2010) *Research Methods in Early Childhood: An Introductory Guide*. London: SAGE.

Murray, L. & Mand, K. (2013) Travelling near and far: Placing children's mobile emotions. *Emotion, Space and Society,* 9, p. 72-79.

National Statistical Office (NSO) (2008) *Population and Housing Census Results*, Zomba, Malawi: National Statistical Office.

National Statistical Office (NSO) (2014) *Malawi MDG Endline Survey 2014, Key Findings*. Zomba, Malawi: National Statistical Office.

National Statistical Office (NSO) (2017) *Fourth Integrated Household Survey (IHS4): Household Socio-Economic Characteristics Report*. Republic of Malawi.

National Statistical Office (NSO) and ICF Macro (2011) *2010 Malawi Demographic and Health Survey: Key Findings*. Calverton, Maryland, USA: NSO and ICF Macro.

Nkosi, T., Kipp, W., Laing, R. & Mill, J. (2006) Family caregiving for AIDS patients in the democratic republic of Congo. *World Health & Population*, 8(3), p. 4-13.

Ntarangwi, M. (2015) Children’s Lives and Children’s Voices: An Exploration of Popular Music’s Representation of Children in East Africa. In Ntarangwi, M. & Massart, G. (eds) *Engaging Children and Youth in Africa: Methodological and Phenomenological Issues*. Cameroon: Langaa Research and Publishing CIG.

O‘Kane, C. (2000) The Development of Participatory Techniques: Facilitating Children’s Views About the Decisions Which Affect Them. In Christensen, P. & James, A. (eds) *Research with Children: Perspectives and Practices*. London: Routledge, p. 136-159.

Olenja, J.M. (1999) Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health,* 24(3), p. 187-199.

Oliver, M. & Barnes, C. (2012) *The new politics of disablement.* Palgrave Macmillan.

Olsen, R. (1996) Young Carers: Challenging the facts and politics of research into children and caring, *Disability & Society*, 11(1), p. 41-54.

Olwig, K.F. & Gullov, E. (2003) *Children's places: Cross-cultural perspectives*. Oxon: Routledge.

Oppong, C. (1973) *Growing up in Dagbon*. Accra: Ghana Publishing Company.

Panelli, R. (2002) Young rural lives: strategies beyond diversity. *Journal of Rural Studies,* 18(2), p. 113-122.

Panelli, R., Punch, S. & Robson, E. (eds) (2007*) Global perspectives on rural childhood and youth - Young rural lives*. London: Routledge.

Parr, H. (2000) Interpreting the 'hidden social geographies' of mental health: ethnographies of inclusion and exclusion in semi-institutional places. *Health & Place,* 6(3), p. 225-237.

Payne, R. (2012) Agents of support: intra-generational relationships and the role of agency in the support networks of child-headed households in Zambia. *Children's Geographies*, 10(3), 293-306.

Philipps, J. (2018) A Global Generation? Youth Studies in a Postcolonial World. *Societies*, 8(1), 14.

Philo, C. (2000) "The Corner-Stones of My World": Editorial Introduction to Special Issue on Spaces of Childhood. *Childhood: A Global Journal of Child Research,* 7(3), p. 243-256.

Phiri, D.T. & Abebe, T. (2016) Suffering and thriving: Children's perspectives and interpretations of poverty and well-being in rural Zambia. *Childhood*, 23(3), p. 378-393.

Phiri, D.T. (2016) Rural children's role in buffering household poverty through ganyu (piecework) in Zambia. *Children's Geographies*, 14(6), p. 685-700.

Pillow, W. (2003) Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International journal of qualitative studies in education*, 16(2), p. 175-196.

Polit, D.F. & Beck, C.T. (2017) *Nursing research: Generating and assessing evidence for nursing practice* (10th Edition). London: Lippincott Williams & Wilkins.

Popke, J. (2006) Geography and ethics: everyday mediations through care and consumption. *Progress in Human Geography,* 30(4), p. 504.

Porter, G., Hampshire, K., Abane, A., Tanle, A., Munthali, A., Robson, E., Mashiri M. & Maponya, G. (2011) Young people's transport and mobility in sub-Saharan Africa: the gendered journey to school. *Documents d'analisi geografica*, 57(1), p. 61-79.

Porter, K. (1996) The Agency of Children, Work and Social Change in the South Pare Mountains, Tanzania. *Anthropology and Work Review,* 17(1-2), p. 8-19.

Prout, A. (2004) *The future of childhood* Routledge.

Puig de la Bellacasa, M. (2017) *Matters of Care: Speculative Ethics in More Than Human Worlds*. Minneapolis: University of Minnesota Press.

Punch, S. (2000) Negotiating independence in rural Bolivia. In eds Holloway S. and Valentine G. *Children's geographies: Playing, living, learning.* London: Routledge, p. 48-62.

Punch, S. (2001) Household division of labour: generation, gender, age, birth order and sibling composition. *Work, Employment & Society,* 15(4), p. 803–823.

Punch, S. (2002a) Research with children: The same or different from research with adults? *Childhood*, 9(3), p. 321-341.

Punch, S. (2002b) Interviewing strategies with young people: 'The Secret Box', Stimulus Material and Task-Based Activities. *Children and Society*, 16(1), p. 45-56.

Punch, S. (2003) Childhoods in the majority world: Miniature adults or tribal children? *Sociology,* 37, p. 277–295.

Punch, S. (2004) Negotiating Autonomy: Children's Use of Time and Space in Rural Bolivia. In Lewis, V., Kellett, M., Robinson, C., Fraser, S. & Ding, S. (eds) The Reality of Research with Children and Young People. London: SAGE publications, p. 94-114.

Punch, S. & Tisdall, E.K.M. (2012) Exploring children and young people's relationships across Majority and Minority Worlds. *Children's Geographies,* 10(3), p. 241-248.

Qvortrup J. (1994) Childhood matters: an introduction. In Qvortrup J., Bardy M., Sgritta G. & Wintersberger, H. (eds) *Childhood Matters: Social Theory, Practice and Politics*. Aldershot: Avebury Press.

Qvortrup, J. (2009) Childhood as a Structural Form. In Qvortrup, J., Corsaro, W.A. & Honing, M.S. (eds) *The Palgrave Handbook of Childhood Studies*. New York: Palgrave MacMillan, p. 21-33.

Reay, D. and Lucey, H. (2000) "I do not really like it here but I do not want to be anywhere else": Children and inner city council estates. *Antipode*, 32(4), p. 410-426.

Reisenzein, R. & Doring, S. (2009) Ten perspectives on emotional experience: Introduction to the special issue. *Emotion Review,* 1(3), p. 195-230.

Rice, P. & Ezzy, D. (1999) *Qualitative research methods: A health focus*. Oxford: Oxford University Press.

Riessman, C.K. (2000) Analysis of personal narratives. In Gubrium J.F. & Holstein J.A. (eds) *Handbook of Interviewing*. London: SAGE.

Rifkin, S. & Pridmore, P. (2001) *Partners in Planning. Information, Participation and Empowerment*. London: TALC/Macmillan Education Ltd.

Robinson, C. & Kellett, M. (2004) Power. In Fraser, S., Lewis, V., Ding, S., Kellet, M. & Robinson, C. (eds) *Doing Research with Children and Young People*. London: SAGE, p. 81-96.

Robson, E. (2000) Invisible carers: young people in Zimbabwe's home-based healthcare. *Area*, 32(1), p. 59-69.

Robson, E. (2001) Interviews worth the tears? Exploring dilemmas of research with young carers in Zimbabwe. *Ethics, Place & Environment*, 4(2), p. 135-142.

Robson, E. (2002) 'An Unbelievable Academic and Personal Experience': Issues around teaching undergraduate field courses in Africa. *Journal of Geography in Higher Education,* 26(3), p. 327-344.

Robson, E. (2004a) Children at work in rural northern Nigeria: patterns of age, space and gender. *Journal of Rural Studies,* 20(2), p. 193-210.

Robson, E. (2004b) Hidden child workers: young carers in Zimbabwe. Antipode, 36(2), 227-248.

Robson, E. & Ansell, N. (2000) Young Carers in Southern Africa: Exploring stories from Zimbabwean secondary school students. In Holloway, S. & Valentine, G. (eds) *Children's Geographies: playing, living, learning.* London: Routledge, p. 174-193.

Robson, E., Ansell, N., Huber, U.S., Gould, W.T.S. & van Blerk, L. (2006) Young caregivers in the context of the HIV/AIDS pandemic in sub-Saharan Africa. *Population, Space and Place*, 12(2), p. 93–111.

Robson, E., Bell, S. & Klocker, N. (2007a) Conceptualizing agency in the lives and actions of rural young people. In Panelli, R., Punch, S. & Robson, E. (eds) *Global Perspectives on Rural Childhood and Youth: Young Rural Lives*. Oxon: Routledge, p. 135-148.

Robson, E., Horton, J. & Kraftl, P. (2013a) Children's Geographies: reflecting on our first ten years. *Children's Geographies,* 11(1), p. 1-6.

Robson, E., Panelli, R. & Punch, S. (2007b) Conclusions and future directions for studying young rural lives. In Panelli, R., Punch, S. & Robson, E. (eds) *Global perspectives on rural childhood and youth: Young rural lives.* Oxon: Routledge, p. 219-228.

Robson, E., Porter, G., Hampshire, K. & Munthali, A. (2013b) Heavy loads: children's burdens of water carrying in Malawi. *Waterlines*, 32(1), p. 23-35.

Saur, M., Semu, L. & Hauya Ndau, S. (2005) *Nkhanza, Listening to People's Voices: A Study of Gender-Based Violence Nkhanza in three Districts of Malawi*. Zomba, Malawi: Kachere Series.

Sayer, A. (2005) *The Moral Significance of Class*. Cambridge: Cambridge University Press.

Serpell, R. (1996) Cultural models of childhood in indigenous socialization and formal schooling in Zambia. *Images of Childhood,* p. 129-142.

Seymour, J. (2005) Entertaining Guests or Entertaining the Guests: Children's Emotional Labour in Hotels, Pubs and Boarding Houses. In Goddard, J., McNamee, S., James, A. & James, A. (eds) *The Politics of Childhood: International Perspectives, Contemporary Developments*. UK: Palgrave Macmillan, p. 90-106.

Seymour, J. (2007) Treating the hotel like a home: the contribution of studying the single location home/workplace. *Sociology*, 41(6), p. 1097-1114.

Seymour, J. (2011) On not going home at the end of the day: spatialized discourses of family life in single-location home/workplaces. In Holt, L. (ed) *Geographies of children, youth and families: An international perspective*. Oxon: Routledge, p. 108-120.

Seymour, J. (2015) Approaches to children's spatial agency: Reviewing actors, agents and families. In Hackett, A., Seymour, J. & Procter, L. (eds) *Children's Spatialities: Embodiment, Emotion and Agency.* London: Palgrave Macmillan, p. 147-162.

Sharp, L. (1996) The Work Ideology of Malagasy Children: Schooling and Survival in Urban Madagascar. *Anthropology and Work Review,* 17(1-2), p. 35-42.

Shifren, K. (2009) *How Caregiving Affects Development: Psychological Implications for Child, Adolescent and Adult Caregivers*. Washington, DC: American Psychological Association.

Sinclair, R. (2004) Participation in practice: Making it meaningful, effective and sustainable. *Children & society*, 18(2), p. 106-118.

Skelton, T. (2001) Girls in the club: researching working girls' lives. *Ethics, Place and Environment*, 4(2), p. 167-173.

Skovdal, M. (2009) *Young carers in Western Kenya: Collective struggles and coping strategies*. (Doctoral dissertation, The London School of Economics and Political Science (LSE)).

Skovdal, M. (2010) Children caring for their "caregivers": exploring the caring arrangements in households affected by AIDS in Western Kenya. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22(1), p. 96-103.

Skovdal, M. (2011) Examining the trajectories of children providing care for adults in rural Kenya: implications for service delivery. *Children and Youth Services Review*, 33(7), p. 1262-1269.

Skovdal, M. Campbell C. & Onyango V. (2013) Supporting 'Young Carers' in Kenya: From Policy Paralysis to Action. *Child Care in Practice*, 19(4), p. 318-339.

Skovdal, M. & Daniel, M. (2012) Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa. *African Journal of AIDS Research*, 11(3), p. 153-164.

Skovdal, M., Ogutu, V. O., Aoro, C. & Campbell, C. (2009) Young carers as social actors: coping strategies of children caring for ailing or ageing guardians in Western Kenya*. Social Science & Medicine*, 69(4), p. 587–95.

Skovdal, M. & Ogutu, V.O. (2012) Coping with hardship through friendship: the importance of peer social capital among children affected by HIV in Kenya. *African Journal of AIDS Research*, 11(3), p. 241-250.

Smith, F. & Barker, J. (2000) Contested Spaces Children's Experiences of Out of School Care in England and Wales. *Childhood,* 7(3), p. 315-333.

Smith, M.K. (2002) Gender, poverty, and intergenerational vulnerability to HIV/AIDS, Gender & Development, 10(3), 63-70.

Smith, S.J. (2005) States, markets and an ethic of care. *Political Geography,* 24(1), p. 1-20.

Stewart-Withers, R., Banks, G., McGregor, A. & Meo-Sewabu, L. (2014) Qualitative Research. In Scheyvens, R. (ed) Development Fieldwork: a practical guide (2nd Edition). London: SAGE Publications, p. 59-80.

Tembo, M.J. & Oltedal, S. (2015) Social work and families in child welfare in Malawi: Social workers considerations when placing a child outside the home. *Journal of Comparative Social Work*, 10(1).

The National Bank (2018) Malawi: Poverty and Equity Data. http://povertydata.worldbank.org/poverty/country/MWI.

Thomas, F. (2007) Eliciting emotions in HIV/AIDS research: a diary-based approach. *Area,* 39(1), p. 74-82.

Thomson, F. (2007) Are Methodologies for Children keeping them in their Place?. *Children's Geographies*, 5(3), p. 207-218.

Thomson, J.L. & Philo, C. (2004) Playful spaces? A social geography of children's play in Livingston, Scotland. *Children's Geographies,* 2(1), p. 111-130.

Tisdall, E.K.M. & Punch, S. (2012) Not so 'new'? Looking critically at childhood studies. *Children's Geographies,* 10(3), p. 249-264.

Tisdall, E.K.M., Cree, V.E. & Wallace, J. (2004) Children in Need? Listening to children whose parent or carer is HIV positive. *British Journal of Social Work,* 34(8), p. 1097-1113.

Tisdall, E.K.M., Davis, J., M, & Gallagher, M. (2009) *Researching with Children & Young People. Research Design, Methods and Analysis*. London: SAGE.

Tronto, J.C. (1993) *Moral boundaries: A political argument for an ethic of care.* London: Routledge.

Tucker, F. & Matthews, H. (2001) 'They do not like girls hanging around there': conflicts over recreational space in rural Northamptonshire. *Area,* 33(2), p. 161-168.

Twum-Danso Imoh, A. (2012) The Convention on the Rights of the Child: A Product and Facilitator of a Global Childhood. In Twum-Danso Imoh, A. & Ame, R. (eds) *Childhoods at the Intersection of the Local and the Global.* UK: Palgrave Macmillan, p. 17-33.

Twum-Danso Imoh, A. (2016) From the singular to the plural: Exploring diversities in contemporary childhoods in sub-Saharan Africa. *Childhood*, 23(3), 455-468.

Twum-Danso Imoh, A. (2019) Terminating Childhood: Dissonance and Synergy between Global Children's Rights Norms and Local Discourses About the Transition from Childhood to Adulthood in Ghana. *Human Rights Quarterly*, 41(1), 160-182.

Twum-Danso Imoh, A. & Ame, R. (eds) (2012) *Childhoods at the Intersection of the Local and the Global*. UK: Palgrave Macmillan.

Twum-Danso Imoh, A., Bourdillon, M. & Meichsner, S. (2019) Introduction: Exploring Children's Lives Beyond the Binary of the Global North and Global South. In Twum-Danso Imoh, A. et al. (eds.), *Global Childhoods beyond the North-South Divide*. Palgrave Studies on Children and Development, Palgrave Macmillan, 1-10.

UNAIDS (2017) *Malawi: country factssheets*. Available at: http://www.unaids.org/en/regionscountries/countries/malawi (accessed December 2018).

Underdown, A. (2002) 'I'm Growing Up Too Fast': Messages from Young Carers. *Children and Society*, 16, p. 57-60.

UNICEF (1989) *Convention on the Rights of the Child*. Geneva: United Nations.

United Nations Development Programme (2010) *Human Development Report. The Real Wealth of Nations: Pathways to Human Development*. Geneva: United Nations.

Urry, J. (2005) The place of emotions within place. In Davidson, J., Bondi, L. & Smith, M. (eds) *Emotional geographies.* Aldershot: Ashgate Publishing Ltd, p. 77-83.

Valentine, G. (1996) Children should be seen and not heard: the production and transgression of adults' public space. *Urban Geography,* 17(3), p. 205-220.

Valentine G. (2005) Tell me about…: using interviews as a research methodology. In Flowerdew R. & Martin D. (eds) *Methods in Human Geography, A guide for students doing a research project* (2nd Edition). London: Pearson Education Limited, p. 110-127.

Van Blerk, L. & Ansell, N. (2007) Participatory Feedback and Dissemination with and for Children: Reflections from Research with Young Migrants in Southern Africa. *Children's Geographies,* 5(3), p. 313–324.

Vanderbeck, R.M. (2008) Reaching critical mass? Theory, politics, and the culture of debate in children's geographies. *Area*, 40(3), p. 393-400.

Walker, A. (1996) *Young carers and their families: A survey carried out by the social survey division of ONS on behalf of the department of health Stationery Office London*. London: Stationery Office.

Walker L. (2007) HIV/AIDS; Challenging stigma by association. In Burke, P. & Parker, J. (eds) *Social Work and Disadvantage*. London: Jessica Kingsley Publishers, p. 79–96.

Walker, L., Reid, G. & Cornell, M. (2004) *Waiting to happen: HIV/AIDS in South Africa; the bigger picture*. Boulder, Colo.: Lynne Rienner.

Wang, C., Yi, W., Tao, Z. & Carovano, K. (1998) Photovoice as a participatory health promotion strategy. *Health Promotion International*, 13(1), p. 75-86.

Wells, K. (2009) *Childhood in global perspective.* London: Polity Press.

Widdowfield, R. (2000) The place of emotions in academic research. *Area*, 32(2), p. 199-208.

Wiles, J. (2003) Daily geographies of caregivers: mobility, routine, scale. *Social Science & Medicine*, 57(7), p. 1307-1325.

Winchester, H.P.M. (2005) Qualitative Research and its Place in Human Geography. In Hay I. (ed) *Qualitative Research Methods in Human Geography* (2nd Edition). Oxford: Oxford Polity Press, p. 3-18.

Winton, A. (2005) Youth, gangs and violence: analysing the social and spatial mobility of young people in Guatemala City. *Children's Geographies,* 3(2), p.167-184.

Wood, B.E. (2013) Young people's emotional geographies of citizenship participation: Spatial and relational insights. *Emotion, Space and Society,* 9, p. 50-58.

Wood, N. & Smith, S.J. (2004) Instrumental routes to emotional geographies. *Social & Cultural Geography,* 5(4), p. 533-548.

Woodhead, M. (1996) *In search of the rainbow: Pathways to quality in large-scale programmes for young disadvantaged children. early childhood development: Practice and reflections number 10.* ERIC.

Woodhead, M. (2009) Childhood Studies. Past, Present and Future. In eds Kehily, M.J. *An Introduction to Childhood Studies* (2nd Edition). Milton Keynes: Open University Press.

Woodhead, M., Montgomery, H. & Burr, R. (2003) Adversities and resilience. In Montgomery, H., Burr, R. & Woodhead, M. (eds) *Changing Childhoods, local and global*. Milton Keynes: Wiley, p. 1-44.

Woods, R. (2013) *Children's moral lives: an ethnographic and psychological approach* [eBook]. Oxford: Wiley-Blackwell.

Yelland, N. & Saltmarsh, S. (2013) Ethnography, Multiplicity and the Global Childhoods Project: reflections on establishing an interdisciplinary, transnational, multi-sited research collaboration. *Global Studies of Childhood*, 3(1), p. 2-11.

Yin, R.K. (2003) *Case study research: Design and methods* (3rd Edition). Thousand Oaks: SAGE.

Young L. & Barrett H. (2001) 'Adapting Visual Methods: Action Research with Kampala Street Children'. *Area*, 33(2), p. 141-152.

Zelizer, V.A.R. (1994) *Pricing the priceless child: The changing social value of children* New York: Basic Books.

Zhang, L., Li, X., Kaljee, L., Fang, X., Lin, X., & Zhao, G. (2009) I felt I have grown up as an adult: caregiving experience of children affected by HIV/AIDS in China. *Child: Care, Health and Development, 35*, p. 542-550.

Zhang, Y. & Wildemuth, B. (2009) Unstructured interview. In Wildemuth, B. (ed) *Applications of Social Research Methods to Questions in Information and Library Science Westport*, CT: Libraries Unlimited, p. 222-231.

Appendices

Appendix 1 - Example of Information Sheet for children under 12 years old (English & Chichewa)

Hello,

My name is Kalia.

I would like to know your ideas and feelings about caring for sick adults.

Could you help me?

Muli bwanji,

Dzina langa ndi Kalia.

Ndikufuna kudziwa malingaliro ndi maganizo anu pa zosamalira odwala achikulire.

Kodi mutha kundithandandiza?

Appendix 2 - Child Consent Form Under 5s (English & Chichewa)

Would you like to take part in my research study?

Kodi mukufuna kutenga nawo mbali mu kafukufuka wanga?

It is ok to say 'No'!!

Palibe vuto ngati munena kuti 'Ayi'!!

Appendix 3 - Child Consent Form 5-12 years old (English & Chichewa)

Consent Form – Fomu Yopempha Chilolezo

	YES	NO
I have been given enough information about this study Ndapatsidwa uthenga okwanira wa zokhudza kafukufukuyu	🙂	☹
It has been explained to me how the information I give will be used Andifotokozera momwe zomwe ndikukambirana nayo akazigwiritsire ntchito	🙂	☹
I agree to talk to the researcher about my experiences of providing care to adults Ndikuvomereza kuwafotokozera ochita kafukufukuwa zokhuza zomwe ndimadutsamo/ndikudziwapo m'moyo wanga pamene ndikupereka chisamaliro kwa achikulire	🙂	☹
I understand that I can leave at any time and do not have to answer all the questions if I don't want to Ndikuzindikira kuti nditha kusiya kutenga mbali (mu kafukufukuyu) nthawi iliyonse ndipo sindili owumilizidwa kuyankha mafunso onse ngati sindikufuna	🙂	☹
I understand that the researcher wants to spend some days with me and I agree with this Ndikuzindikira kuti ochita kafukufukuwa akufuna kucheze nane masiku ena/angapo ndipo ndikuvomereza kutero	🙂	☹
I agree to be interviewed by the researcher Ndikuvomereza kucheza nawo ochita kafukufukuwa komanso kuyankha mafunso awo	🙂	☹
I agree to participate to group discussions with other children Ndikuvomereza kutenga nawo mbali mu zokambirana za pagulu ndi ana ena	🙂	☹
I am happy for you to record what I say Ndiri wokondwa kuti mujambule zomwe ndikukuuzani	🙂	☹
I give permission for my words to be used in a report but understand that my name will not be mentioned Ine ndikupereka chilolezo kuti mutha kugwiritsa ntchito zomwe tikambirane mu lipoti lanu komano dzina langa silizatchulidwa	🙂	☹
I agree to participate to the photography exercise and I understand that the researcher will use my photos confidentially Ndikuvomereza kutenga nawo mbali mu zojambula ndipo ndikuzindikira kuti ofufuzawa azagwiritsa ntchito zithunzi zanga mwachinsinsi	🙂	☹

Name/Thumbprint/Dzina/chidindo cha chala.. Date/Tsiku ....

Appendix 4 - Young People's Information Sheet & Consent Form (English)

Hello,

About me…
My name is Kalia Kaparounaki and I am a student at the University of Hull in England. I am conducting research for my studies with children who are taking care of sick family members.

My research…
I am very interested in your ideas and feelings about caring for sick adults. The purpose of collecting this information is to find out what are the most appropriate ways to provide young people like you and families like yours with support.

What taking part involves…
I will arrange in agreement with you to spend some time with you and your family and during this time, I might ask a few questions. The meetings will take place at your home or any other place you feel comfortable at. If you agree, I will audio record our conversations and keep notes so that I can keep an accurate record of what everyone says. The recordings and notes will only be accessible to me and I will not name or identify anyone who takes part in the study. Additionally, I might ask you to participate in group discussions and by signing this, you agree to participate at the group discussions as well. Finally, I would like to let you know that I will ask your parent's or guardian's permission.

Risks…
There will be no discomforts or physical risks associated with your involvement in this project. Some of the questions I will be asking, however, may draw out some emotional discomfort. I am trained to support you if you wish to talk about any issues that come up during our conversations. If nevertheless you feel uncomfortable, please let me know and we will stop the discussion immediately if you wish.

Benefits…
I am hoping that there will benefits for children and communities in Malawi by understanding what kind of needs you and your family have and how those could be met.

Confidentiality…
I will ensure that your identity will remain protected. I do not intend to use your or anybody else's name in my reports. All the notes I will take will be stored in a secure place.

Your rights and further information…
You have the right to withdraw from the research at any time for any reason. Your participation in this study is voluntarily, you can stop at any time without penalty or judgement. You may also refuse to answer any of the questions. You just need to let me know. If you talk to me about things that involve significant harm to you or to others, I might have to inform relevant professional who will be able to help you. If you have any questions about the research or if I can offer you any further information, please let me know so we can arrange a time to talk.

Thank you for your time and for considering taking part in this research project.

All the Best,
Kalia

Name: ______________________________

Signature/Thumbprint: ______________________________

Date: ______________________________

Appendix 5 - Young People's Information Sheet & Consent Form (Chichewa)

Moni,

Za ine...
Dzina langa ndi Kalia Kaparounaki ndipo ndine wophunzira pa sukulu ya ukachenjedwa ya Hull ku magalande (England). Ndikuchita kafukufuku ndi ana omwe akusamalira odwala m'banja.

Kafukufukuyu...
Chidwi changa chagona pofuna kuphunzira/kumva zambiri za malingaliro ndi maganizo anu pa zosamalira odwala akuluakulu mb'anja mwanu komanso zomwe motheradutsamo tsiku ndi tsiku pamene mukupereka chisamalirochi. Cholinga chake ndicho kufuna kupeza njira zoyenerera zomwe ana ngati inu (omwe akusamalira odwala akuluakulu) ndi mabanja angathandiziridwe.

Kodi kutenga nawo mbali mu kafukufuyu kukutanthauza chani...
Ndidzakhala ndikubwera pakhomo panu kwa kwa milungu ingapo (masabata angapo) ndi kucheza nanu komanso nditha muzakufunsani mafunso malingana ndi zomwe ndikuziona. Nthawi yomafunsoyi titha kudzakhala panyumba panu pano kapena kwina kulikonse komwe inu mudzakhale omasuka. Ngati muvomereza/mulora, ndizajambula/ndizatepa zocheza zathu pa lekodi komanso ndizizalemba zomwe tikukambirana kuti zizandithandize kusungu bwino zonse zimene aliyense wafotokoza m'kucheza kwathu. Kupatula ineyo, palibe wina aliyense amene azathe kumvera zojambulazi/zotepazi kapena kuwerenga zomwe ndizalembezi ndipo sindidzalemba maina kapena kuchita zinthu zokuzindikilitsani inu kapena ena onse otenga mbali mu kafufukuyu kwa anthu ena. Kuonjezera apo (kucheza kwathu kwa inu ndi ine), nditha kuzakupemphani kuti mutenge nawo mbali pa zokambirana za pagulunso. Pomaliza, ndafuna ndikudziwitseni kuti ndidzawapempha makolo kapena okusungani kuti andipatse chilolezo choti mukhale nawo mu kafukufukuyu.

Kodi pali zoopysa zilizonse potenga nawo mbali mu kafukufukuyu...
Sipadzakhala choopysa chinachiliconse ngakhale zokhuzana ndi kuthupi zobwera chifukwa cha kutenga nawo mbali kwanu mu kafukufukuyu. Ena mwa mafunso omwe ndidzakufunseni mwina atha kubweretsa maganizo opweteka mothertima mwanu. Ine ndidaphunzitsidwa bwino kupereka uphungu wa nkhani zoterezi ndipo ngati mutafuna ndilankhule nanu pazimenezi pamene tikucheza mutha kuzandiuza. Komanso ngati muona kuti simuli omasuka kukamba nkhani zina pamene tikucheza, chonde mudzandidziwitse mwachangu ndipo ngati mutafuna kutero, nthawi yomweyo ndidzasiya kukufunsani mafunso ena obweretsa kuwawidwa muntima.

Pali Ubwino wanji pakutenga nawo mbali mu kafukufukuyu...
Kupyolera mu kafukufukuyu, ndikukhulupilira kuti padzakhala phindu kwa ana ndi anthu a m'dera lino komanso ku Malawi kuno, makamaka pothandiza anthu kuzindikira ndi kumvetsa bwino zambiri zokhuza zimene inu ndi banja lanu mukuzisowa pamene mukuyang'anira odwala aakulu ndinso, mmene mungakwaniritse kupeza zosowa zanuzo.

Zosunga Chinsinsi pa zomwe mwagawana/mwakambirana nane mu kafukufukuyu...
Ndidzayesetsa kuonetsetsa kuti zokuzindikiritsani inu zikhale zotetezedwa. Ine ndilibe malingaliro ofuna kudzagwiritsa ntchito dzina lanu kapena la winaaliyense mu malipoti langa. Zolembedwa zonse zimene ndizatolere mu kafukufukuyu zidzasungidwa malo abwino otetezedwa.

Za ufulu wanu ndi zina zambiri...
Muli ndi ufulu wochoka mu kafukufukuyu nthawi ina iliyonse pachifukwa china chilichonse. Kutenga nawo mbali mu kafukufukuyu ndi kosaumilizidwa, ndipo mutha kusiya nthawi ina iliyonse ndipo palibe chibalo kapena mlandu wina uliwonse ngati mutero. Muthanso osayankha mafunso ena pamene tikucheza. Chofunika ndi kungondidziwitsa ngati mukufuna kutero. M'kucheza kwathu, ngati muzakambe zinthu zina zomwe ndizoopyseza moyo wanu kapena wa ena, ine ndizadziwitsa anthu ena oyenerera omwe azatha kukuthandizani moyenerera. Ngati muli ndi mafunso ena aliwonse okhuza kafukufukuyu kapena ngati mufuna kudziwabe zambiri, chonde ndiuzeni/ndidziwitseni kuti tikonze nthawi yoti ndizakuyimbireni foni/lamya kuti ndizatambasule zambiri zokhuza kaufukufukuyu.

Zikomo chifukwa cha nthawi yanu komanso kulingalira kuti mutenge nawo mbali mu kafukufukuyu.

Zabwino zonse,
Kalia

Dzina: ____________________

Siginetcha: ____________________

Tsiku/Deti: ____________________

Appendix 6 - Parent/Guardian Information Sheet and Permission Letter (English)

Hello,

My name is Kalia Kaparounaki and I am a student at the University of Hull in England. I am conducting research for my studies with children who are taking care of sick family members.

In my research, I will talk to children and young people, both girls and boys, and discuss their ideas and feelings about caring for sick adults. As the parent or guardian of a young person who might be in the study, I want to ask your permission for your child to take part. After you have heard more about the study, and if you agree, then the next thing I will do is ask the young person for their agreement as well.

Both children and parents/guardians have to agree independently before I can begin. I will arrange in agreement with you to spend some time with your family and might ask a few questions. The meetings will take place at your home or any other place you feel comfortable at. If you agree, I will audio record our conversations and keep notes so that I can keep an accurate record of what everyone says.

All children and young people have the right to leave the research at any time for any reason if they so wish. You just need to let me know. If the young people talk to me about things that involve significant harm to them, your family or to others, I will have to inform the appropriate authorities. Additionally, young people's anonymity will be kept throughout the research. If you have any questions about the research or if I can offer you any further information, please let me know so we can arrange a time for me to call you to discuss the research.

Thank you for your time and for considering taking part in this research project. If you would like your child to participate, please fill out the form below and return it to me.

All the best,
Kalia

Name: ______________________________

Signature: ______________________________

Date: ______________________________

Appendix 7 - Parent/Guardian Information Sheet and Permission Letter (Chichewa)

Moni,

Dzina langa ndi Kalia Kaparounaki ndipo ndine wophunzira pa sukulu ya ukachenjedwa ya Hull ku magalande (England). Ndikuchita kafukufuku ndi ana omwe akusamalira odwala m'banja.

Mu kafukufuku wangayu, ndiakhala ndikukambirana ndi ana komanso achinyamata (anyamata ndi atsikana omwe) pa za malingaliro ndi maganizo pa zosamalira odwala akuluakulu monga makolo. Inuyo monga kholo kapena wosunga ana kapena achinyamata amene atha kukhala nawo mu kafukufukuyu, ndikufuna ndikupempheni chilolezo chondilora kuti wwana wanu atenge nawo mbali mu kafukufukuyu. Ndikatha kukufotokozerani zambiri zokhuza kafukufukuyu ndipo ngati mukuvomera kupereka chilolozo, ndidzamufunsanso mwana kapena wachinyamata wanu ngati akuvomereza/akulora kutenda nawo mbali mu kafukufukuyu. Ana komanso makolo kapena osunga anawa ayenera kupereka chilolozo aliyense payekhapayekha mosaumilizidwa ndisanayambe kafukufuku wangayu. Mukavomereza kutenga nawo mbali mu kafukufukuyu, ndidzakhala ndikubwera pakhomo panu kwa masiku angapo ndi kucheza nanu komanso ndizizakufunsani mafunso malingana ndi zomwe ndikuziona. Nthawi yomafunsoyi titha kudzakhala panyumba panu kapena kwina kulikonse komwe inu mudzakhale omasuka. Ngati muvomereza/mulora, ndizajambula zocheza zathu komanso kulemba zomwe tikukambirana kuti zizandithandize kusungu bwino zonse zimene aliyense wafotokoza m'kucheza kwathu.

Ndafuna mudziwe kuti ana ndi achinyamata onse ali omasuka kusiya kutenga nawo mbali mu kafukufukuyu nthawi ina iliyonse pa chifukwa chilichonse ngati afuna/akufuna kutero. Mudzangondiuza kuti ndidziwe. Ngati ana kapena achinyamata andifotokozera zinthu zina zokhuza nkhaza kapena zoopsyeza moyo wanu kapena ena, ine ndizadziwitsa oyenerera monga a polisi. Kuonjezera apo, dzina kapena zozindikiritsa ana ndi achinyamata onse otenga mbali onse zizakhala zotetezedwa bwino mu nthawi yonse mu kafukufukuyu kuti wina aliyense (kupatula ine ndi aphunzitsi anga ku mangalande) asathe kuwazindikira. Ngati muli ndi mafunso okhuza kafukufukuyu kapena ngati mufuna kudziwabe zambiri, chonde ndiuzeni/ndidziwitseni kuti tikonze nthawi yoti ndizakuyimbireni foni/lamya kuti ndizatambasule zambiri zokhuza kaufukufukuyu.

Zikomo chifukwa cha nthawi yanu komanso kulingalira kuti mutenge nawo mbali mu kafukufukuyu. Ngati mukuvomereza/mukulora kuti mwana wanu kuti atenge nawo mbali, lembani dzina lanu, siginetcha, and tsiku/deti pa malo omwe mwapatsidwa pansipa ndipo mukamaliza mundibwezere fomuyu.

Zabwino zonse,
Kalia

Dzina:

Siginetcha:

Tsiku/Deti:

Appendix 8 - Adult Consent Form (English)

Hello,

About me…
My name is Kalia Kaparounaki and I am a student at the University of Hull in England. I am conducting research for my studies with children who are taking care of sick family members.

My research…
I am very interested in your opinions and ideas about children caring for sick adults. The purpose of collecting this information is to find out what are the most appropriate ways to provide family like yours with support.

What taking part involves…
I will arrange in agreement with you to spend some time with your family and might ask a few questions. The meetings will take place at your home or any other place you feel comfortable at. If you agree, I will audio record our conversations and keep notes so that I can keep an accurate record of what everyone says. The recordings and notes will only be accessible to me and I will not name or identify anyone who takes part in the study.

Risks…
There will be no discomforts or physical risks associated with your involvement in this project. If nevertheless you feel uncomfortable, please let me know and we will stop the discussion immediately.

Benefits…
I am hoping that there will benefits for children and communities in Malawi by understanding what kind of needs you and your family have and how those could be met.

Confidentiality…
I will ensure that your identity will remain protected. I do not intend to use your or anybody else’s name in my reports. All the notes I will take will be stored in a secure place.

Your rights and further information…
You have the right to withdraw from the research at any time for any reason. Your participation in this study is voluntarily, you can stop at any time without penalty or judgement. You may also refuse to answer any of the questions. You just need to let me know. If you talk to me about things that involve significant harm to your children, your family or to others, I might have to inform relevant professional who will be able to help you. If you have any questions about the research or if I can offer you any further information, please let me know so we can arrange a time to talk.

Thank you for your time and for considering taking part in this research project.

All the Best,
Kalia

Name: ______________________________

Signature: ______________________________

Date: ______________________________

Appendix 9 - Adult Consent Form (Chichewa)

Moni,

Za ine...
Dzina langa ndi Kalia Kaparounaki ndipo ndine wophunzira pa sukulu ya ukachenjedwa ya Hull ku magalande (England). Ndikuchita kafukufuku ndi ana omwe akusamalira odwala m'banja.

Kafukufukuyu…
Chidwi changa chagona pofuna kuphunzira/kumva zambiri za malingaliro ndi maganizo anu pa zosamalira odwala akuluakulu mb'anja mwanu komanso zomwe motheradutsamo tsiku ndi tsiku pamene mukupereka chisamalirochi. Cholinga chake ndicho kufuna kupeza njira zoyenerera zomwe ana omwe akusamalira odwala (omwe akusamalira odwala akuluakulu) ndi mabanja awo angathandiziridwe.

Kodi kutenga nawo mbali mu kafukufuyu kukutanthauza chani...
Ndidzakhala ndikubwera pakhomo panu kwa kwa milungu ingapo (masabata angapo) ndi kucheza nanu komanso nditha muzakufunsani mafunso malingana ndi zomwe ndikuziona. Nthawi yomafunsoyi titha kudzakhala panyumba panu pano kapena kwina kulikonse komwe inu mudzakhale omasuka. Ngati muvomereza/mulora, ndizajambula/ndizatepa zocheza zathu pa lekodi komanso ndizizalemba zomwe tikukambirana kuti zizandithandize kusungu bwino zonse zimene aliyense wafotokoza m'kucheza kwathu. Kupatula ineyo, palibe wina aliyense amene azathe kumvera zojambulazi/zotepazi kapena kuwerenga zomwe ndizalembezi ndipo sindidzalemba maina kapena kuchita zinthu zokuzindikilitsani inu kapena ena onse otenga mbali mu kafufukuyu kwa anthu ena.

Kodi pali zoopysa zilizonse potenga nawo mbali mu kafukufukuyu...
Sipadzakhala choopysa chinachiliconse ngakhale zokhuzana ndi kuthupi zobwera chifukwa cha kutenga nawo mbali kwanu mu kafukufukuyu. Ngati muona kuti simuli omasuka kukamba nkhani zina pamene ndikukufunsani mafunso ena, chonde mudzandidziwitse mwachangu ndipo ngati mutafuna kutero, nthawi yomweyo ndidzasiya kukufunsani.

Pali Ubwino wanji pakutenga nawo mbali mu kafukufukuyu...
Kupyolera mu kafukufukuyu, ndikukhulupilira kuti padzakhala phindu kwa ana ndi anthu a m'dera lino komanso ku Malawi kuno, makamaka pothandiza anthu kuzindikira ndi kumvetsa bwino zambiri zokhuza zimene motherazisowa pamene mukuyang'anira odwala, ndinso mmene mungakwaniritsire kupeza zosowa zanuzo.

Zosunga Chinsinsi pa zomwe mwagawana nane mu kafukufukuyu...
Ndidzayesetsa kuonetsetsa kuti zokuzindikiritsani inu zikhale zotetezedwa. Ine ndilibe malingaliro ofuna kudzagwiritsa ntchito dzina lanu kapena la winaaliyense mu malipoti langa. Zolembedwa zonse zimene ndizatolere mu kafukufukuyu zidzasungidwa malo abwino otetezedwa.

Za ufulu wanu ndi zina zambiri...
Muli ndi ufulu wochoka mu kafukufukuyu nthawi ina iliyonse pachifukwa china chilichonse. Kutenga nawo mbali mu kafukufukuyu ndi kosaumilizidwa, mutha kusiya nthawi ina iliyonse, ndipo palibe chibalo kapena mlandu wina uliwonse ngati mutero. Muthanso osayankha mafunso ena pamene tikucheza. Chofunika ndi kungondidziwitsa ngati mukufuna kutero. M'kucheza kwathu, ngati muzakambe zinthu zina zomwe ndizoopyseza moyo wanu kapena wa ena, ine ndizadziwitsa anthu ena oyenerera omwe azatha kukuthandizani moyenerera. Ngati muli ndi mafunso ena aliwonse okhuza kafukufukuyu kapena ngati mufuna kudziwabe zambiri, chonde ndiuzeni/ndidziwitseni

kuti tikonze nthawi yoti ndizakuyimbireni foni/lamya kuti ndizatambasule zambiri zokhuza kaufukufukuyu.

Zikomo chifukwa cha nthawi yanu komanso kulingalira kuti mutenge nawo mbali mu kafukufukuyu.

Zabwino zonse,
Kalia

Dzina: ______________________________

Siginetcha: ______________________________

Tsiku/Deti: ______________________________

Appendix 10 - Statement of consent: Use of cameras and study participation (English)

Purpose of photography
The purpose of this exercise is to give you a chance to speak out and show adults in your community and abroad what your life is like, what you like about it and what you would like to see changed. After the photos have been processed we will talk about the pictures individually or in groups.

Procedures
If you choose to take part in this exercise you will be asked to take photos showing 'A typical day in your life'. I would like you to answer three questions through these photographs: 1) 'How is care involved in your life?' 2) 'What do you like about your everyday life?' 3) 'What would you like to change?' You must always seek permission from the people you photograph. After processing the photos; we will meet up and talk about some of the photos, what they mean and what they represent. In signing this form, you also agree to participate in the group discussion.

Risk and discomforts
There will be no discomforts or physical risks associated with your involvement in this project. Some of the questions I will be asking, however, may draw out some emotional discomfort. I am trained to support you if you wish to talk about any issues that come up during our conversations. If nevertheless you feel uncomfortable, please let me know and we can stop the discussion immediately if you want.

Confidentiality
Every effort will be taken to protect your identity. I am not asking for your name and no participant will be identified in any report of this study or its results. However, your face may appear on photos. After you have completed the interview/FGD, I will store the information in a secure place. I store all information in a locker. I might use some of the photos for my PhD thesis but I will make sure that people's faces will not be recognizable.

Right to refuse
Your participation in this exercise is voluntarily, which means you do not have to do it if you do not want to. You can stop at any time without penalty or judgment. You may also refuse to answer any of the questions. You must always seek agreement of the people whom you photograph and inform them that they have a right to refuse.

Agreement:
CHILD 'I have read or have had read to me the information provided above. I voluntarily agree to participate in this exercise – knowing that I can refuse to answer any of the questions and stop participating without any penalty. I will receive a copy of all photos; however, I give the researcher permission to use my photos confidentially. I will also make sure that any people I photograph agrees and is aware of the purpose of this exercise'
PARENT/GUARDIAN 'I have read or have had read to me the information provided above. I allow my child to participate in this exercise – knowing that he/she can refuse to answer any of the questions and stop participating without any penalty. He/she will receive a copy of all photos; however, I give the researcher permission to use the photos confidentially'

Thank you for your time and for considering taking part in this research project.

All the Best,
Kalia

Name (child):

Signature/Thumbprint:

Date:

Name (guardian):

Signature:

Date:

Appendix 11 - Statement of consent: Use of cameras and study participation (Chichewa)

Cholinga cha zinthunzi (ma foto)
Cholinga cha zinthunzizi ndi kukupatsani mwayi woti muonetse akuluakulu m'dera lanu komanso kunja kwa dziko lino momwe moyo wanu wa tsiku ndi tsiku umakhalira, chomwe chimakusangalatsani mmoyo wanuwo, komanso chomwe mukufuna chitasintha mmoyo wanuwo. Zinthunzi zikajambulidwa ndi kutsukitsidwa, ndidzakambirana zomwe zili pachinthunzicho aliyense payekhapayekha komanso m'magulu.

Ndondomeko
Ngati musankha/muvomera/mulora kutenga nawo mbali, ndidzakufunsani kuti mujambule/mutole zithunzi zokhunza "tsiku lanu mmoyo mwanu (motherapanga chani)". Kupyolera mu zinthunzi zanuzo, ndikufuna tizacheze ndipo mudzandiyankhe mafunso atatu awa: 1) Kodi kusamala ena (monga akulu) kumabwera njira ziti mmoyo wanu?' 2) Ndi chani chomwe motherakonda chokhudza mmoyo wanu wa tsiku ndi tsiku?' 3) 'Ndi chani chomwe mungafune chitasintha mmoyo wanu wa tsiku ndi tsiku?'

Zoopysa zilizonse potenga nawo mbali mu kafukufukuyu
Sipadzakhala choopysa chinachiliconse ngakhale zokhuzana ndi kuthupi zobwera chifukwa cha kutenga nawo mbali kwanu mu kafukufukuyu. Ena mwa mafunso omwe ndidzakufunseni mwina atha kubweretsa maganizo opweteka mothertima mwanu. Ine ndidaphunzitsidwa bwino kupereka uphungu wa nkhani zoterezi ndipo ngati mutafuna ndilankhule nanu pazimenezi pamene tikucheza mutha kuzandiuza. Komanso ngati muona kuti simuli omasuka kukamba nkhani zina pamene tikucheza, chonde mudzandidziwitse mwachangu ndipo ngati mutafuna kutero, nthawi yomweyo ndidzasiya kukufunsani mafunso ena obweretsa kuwawidwa muntima.

Zosunga Chinsinsi pa zomwe mwagawana/mwakambirana nane mu kafukufukuyu
Ndidzayesetsa kuonetsetsa kuti zokuzindikiritsani inu zikhale zotetezedwa. Sindikufunsani dzina lanu and palibe wina aliyense otenga nawo mbali amene ndidzamutchula mu lipoti la kafukufukuyu. Komano ndafuna mudziwe kuti nkhope yanu itha kudzaoneka pazithunzi zina. Tikamaliza zokambirana zathu, ndidzasunga zomwe mutandiuze mmalo abwino olokedwa kotero kuti zizakhala zotetezedwa. Ndafuna mudziwe kuti nditha kudzagwiritsa ntchito zithunzi zanu zina mu lipoti la maphunziro anga a ukadaulo (PhD), komano ndizayesetsa kuti nkhope zanu ndizazizimbayitse kuti anthu asazakuzindikireni.

Ufulu wokana kutenga nawo mbali
Kutenga nawo mbali mu kafukufukuyu ndi kosaumilizidwa, choncho mutha kukana ngati simukufuna. Muli ndi ufulunso kusiya nthawi ina iliyonse ndipo palibe chibalo kapena mlandu wina uliwonse ngati mutero. Muthanso kukana kuyankha mafunso ena pamene tikucheza ngati mutafuna kutero. Chinthu chofunika kwambiri kuti mudziwe ndicho chakuti muyenera nthawi zonse kupempha chilolezo kwa anthu ena omwe akufuna kukhala nawo pa chithunzi/foto, ndipo adziwitseninso kuti ali ndi ufulu kukana kukhala nawo.

Mgwirizano
MWANA: 'Ine ndawerenga kapena andiwerengera zonse zomwe zalembedwa mu fomu iyi pamwambapa zokhuza kafukufukuyu. Ndikuvomereza, mosawumilizidwa, kuti nditenga nawo mbali pa zojambula zithunzi (ma foto), ndipo ndikuzindikira kuti nditha kusiya kutenga mbali mu kafukufukuyu nthawi iliyonse, komanso nditha osayankha mafunso ena ngati ndifuna kutero ndipo sipadzakhala chibalo kapena mlandu uliwonse ngati nditero. Ndidzapatsidwa kope ya zinthunzi zonse (ma foto onse); komano ndikupeleka chilolezo kwa ochita kafukufukuwa kuti atha kugwiritsa ntchito zithunzizi potsata ndondomeko ya chinsinsi mu kafukufuku. Ndidzachita chothekera (udzakhala udindo wanga) kuti anthu onse omwe ndidzawajambule azakhala kuti alola kutero komanso akudziwa cholinga chowajambula zinthunzizi.

KHOLO/WOSUNGA MWANA: ‘Ine ndawerenga kapena andiwerengera zonse zomwe zalembedwa mu fomu iyi pamwambapa zokhuza kafukufukuyu. Ndikulola mwana wanga kuti atenge nawo mbali pa zojambula zinthunzizi, ndikudziwa/ndikuzindikira kuti kuti iye ali ndi ufulu okana kuyankha mafunso ena komanso atha kusiya kutenga mbali mu kafukufukuyu popanda chibalo kapena mlandu wina uliwonse. Ndamvetsetsa kuti iye andalandira kope ya zinthunzi zonse (ma foto onse); komano ndikupeleka chilolezo kwa ochita kafukufukuwa kuti atha kugwiritsa ntchito zithunzizi potsata ndondomeko ya chinsinsi mu kafukufuku.

Zikomo chifukwa cha nthawi yanu komanso kulingalira kuti mutenge nawo mbali mu kafukufukuyu.

Zabwino zonse,
Kalia

Dzina (mwana):
Siginetcha:
Tsiku/Deti:

Dzina (kholo):
Siginetcha:
Tsiku/Deti:

Appendix 12 - Information Sheet and Consent Form for Professionals and Practitioners (English)

Hello,

My name is Kalia Kaparounaki and I am a student at the University of Hull in England. I am conducting research for my studies with children who are taking care of sick family members. The purpose of collecting this information is to find out what are the most appropriate ways to provide these families with support.

I would like to talk to you about your opinions and ideas about children caring for sick adults and services provided for these families and children. The meetings will take place at your office or any other place you feel comfortable at. If you agree, I will audio record our conversations and keep notes so that I can keep an accurate record of what everyone says. The recordings and notes will only be accessible to me and I will not name or identify anyone who takes part in the study.

There will be no discomforts or physical risks associated with your involvement in this project. If nevertheless you feel uncomfortable, please let me know and we will stop the discussion immediately. I am hoping that there will benefits for children and communities in Malawi by understanding what kind of needs you and your family have and how those could be met. I will try to ensure that your identity will remain protected. I do not intend to use your or anybody else's name in my reports. All the notes I will take will be stored in a secure place.

You have the right to withdraw from the research at any time for any reason. Your participation in this study is voluntarily, you can stop at any time without penalty or judgement. You may also refuse to answer any of the questions. You just need to let me know.

If you have any questions about the research or if I can offer you any further information, please let me know so we can arrange a time to talk.

Thank you for your time and for considering taking part in this research project.

All the Best,
Kalia

Name: ______________________________

Signature: ______________________________

Date: ______________________________

Appendix 13 - Professional's Information Sheet and Consent Form (Chichewa)

Moni,

Dzina langa ndi Kalia Kaparounaki ndipo ndine wophunzira pa sukulu ya ukachenjedwa ya Hull ku magalande (England). Ndikuchita kafukufuku ndi ana omwe akusamalira odwala m'banja mwawo.

Ndikufuna kuphunzira/kumva malingaliro ndi maganizo anu pa za ana omwe akusamalira odwala akuluakulu mb'anja mwawo komanso zomwe a boma kapena mabungwe amachita/angachite pofuna kuthandiza anawa and mabanjawa. Zokambirara zathu zitha kuzakhala ku ofesi kwanu kapena malo ena aliwonse omwe inu muli omasuka. Ngati muvomereza/mulora, ndidzajambula/ndidzatepa zocheza zathu pa lekodi komanso ndizidzalemba zomwe tikukambirana kuti zidzandithandize kusungu bwino zonse zimene aliyense wafotokoza m'kucheza kwathu. Kupatula ineyo, palibe wina aliyense amene azathe kumvera zojambulazi/zotepazi kapena kuwerenga zomwe ndizalembezi ndipo sindidzalemba maina kapena kuchita zinthu zokuzindikilitsani inu kapena ena onse otenga mbali mu kafufukuyu kwa anthu ena.

Sipadzakhala choopysa chinachiliconse ngakhale zokhuzana ndi kuthupi zobwera chifukwa cha kutenga nawo mbali kwanu mu kafukufukuyu. Ngati muona kuti simuli omasuka kukamba nkhani zina pamene ndikukufunsani mafunso ena, chonde mudzandidziwitse mwachangu ndipo ngati mutafuna kutero, nthawi yomweyo ndidzasiya kukufunsani. Kupyolera mu kafukufukuyu, ndikukhulupilira kuti padzakhala phindu kwa ana ndi anthu a m'dera lino komanso ku Malawi kuno, makamaka pothandiza anthu kuzindikira ndi kumvetsa bwino zambiri zokhuza zimene motherazisowa pamene mukuyang'anira odwala, ndinso mmene mungakwaniritsire kupeza zosowa zanuzo. Ndidzayesetsa kuonetsetsa kuti zokuzindikiritsani inu zikhale zotetezedwa. Ine ndilibe malingaliro ofuna kudzagwiritsa ntchito dzina lanu kapena la winaaliyense mu malipoti langa. Zolembedwa zonse zimene ndizatolere mu kafukufukuyu zidzasungidwa malo abwino otetezedwa.

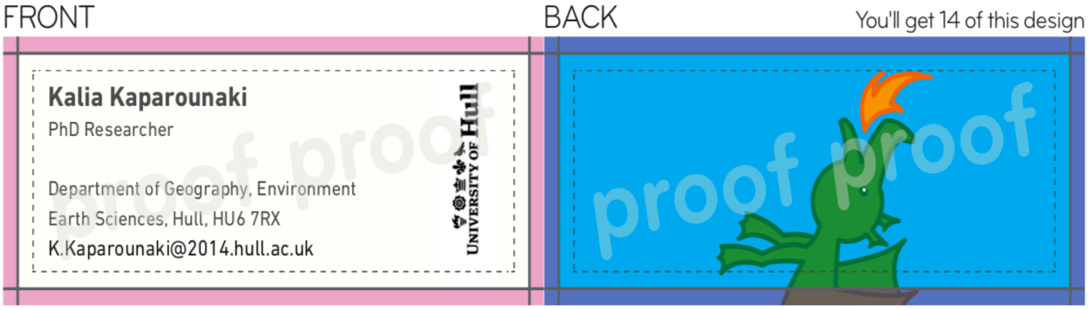
Muli ndi ufulu wochoka mu kafukufukuyu nthawi ina iliyonse pachifukwa china chilichonse. Kutenga nawo mbali mu kafukufukuyu ndi kosaumilizidwa, mutha kusiya nthawi ina iliyonse, ndipo palibe chibalo kapena mlandu wina uliwonse ngati mutero. Muthanso osayankha mafunso ena pamene tikucheza. Chofunika ndi kungondidziwitsa ngati mukufuna kutero.

Ngati muli ndi mafunso ena aliwonse okhuza kafukufukuyu kapena ngati mufuna kudziwabe zambiri, chonde ndiuzeni/ndidziwitseni kuti tikonze nthawi yoti ndizakuyimbireni foni/lamya kuti ndizatambasule zambiri zokhuza kaufukufukuyu
Zikomo chifukwa cha nthawi yanu komanso kulingalira kuti mutenge nawo mbali mu kafukufukuyu.

Zabwino zonse,
Kalia

Dzina:
Siginetcha:
Tsiku/Deti:

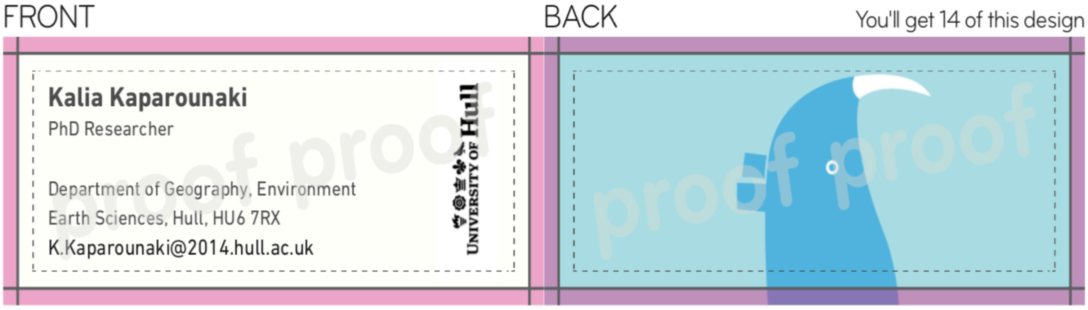
Appendix 14 - Researcher's Contact Information Cards



Kalia Kaparounaki
PhD Researcher

Department of Geography, Environment
Earth Sciences, Hull, HU6 7RX
K.Kaparounaki@2014.hull.ac.uk

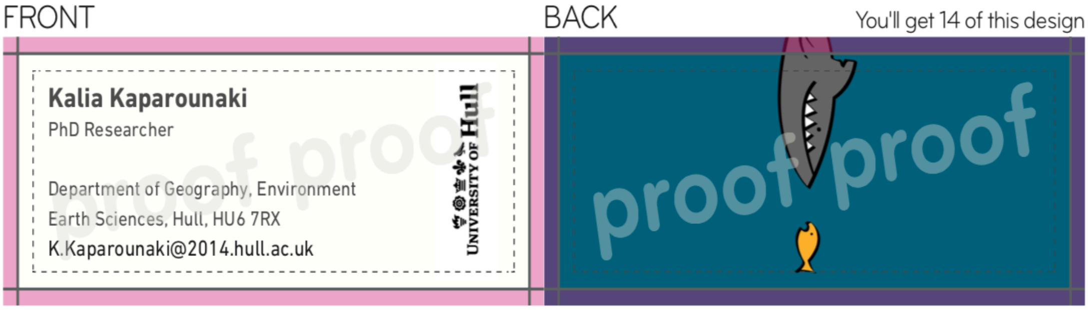
UNIVERSITY OF Hull



Kalia Kaparounaki
PhD Researcher

Department of Geography, Environment
Earth Sciences, Hull, HU6 7RX
K.Kaparounaki@2014.hull.ac.uk

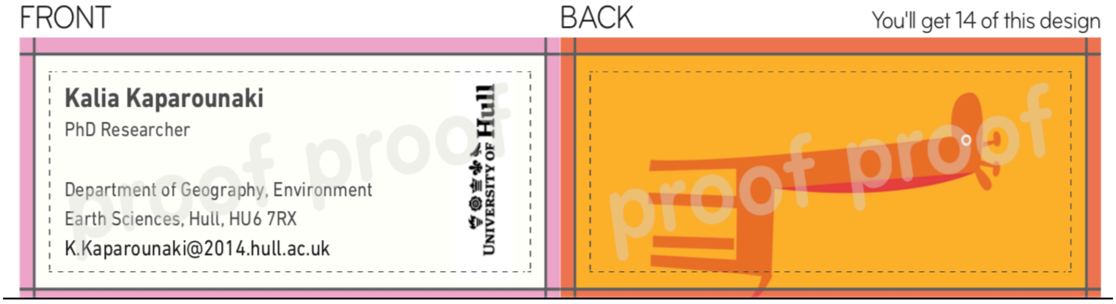
UNIVERSITY OF Hull



Kalia Kaparounaki
PhD Researcher

Department of Geography, Environment
Earth Sciences, Hull, HU6 7RX
K.Kaparounaki@2014.hull.ac.uk

UNIVERSITY OF Hull



Kalia Kaparounaki
PhD Researcher

Department of Geography, Environment
Earth Sciences, Hull, HU6 7RX
K.Kaparounaki@2014.hull.ac.uk

UNIVERSITY OF Hull

*I obtained a mobile sim card after arriving in Malawi and added that Malawian mobile number on the cards before distributing them to the participants

Appendix 15 - Cards to facilitate ongoing informed consent

Appendix 16 – Affiliation Letter

THE CATHOLIC UNIVERSITY OF MALAWI

UNIVERSITY CAMPUS
P.O. Box 5452 Limbe, Malawi
TEL: 01 916 015 / 01 916 098
Email: registrar@cunima.ac.mw

23rd April 2015

National Commission for Science and Technology
Lingadzi House, City Centre
Private Bag B303,
LILONGWE 3,
Malawi.

Dear Sir/Madam,

AFFILIATION FOR MS KALLIOPI KAPAROUNAKI

I am writing in support of Ms **Kalliopi Kaparounaki**'s research proposal with the title '*Caring Children in Malawi - Children's Work within Families affected by Illness and Disability*'. The Catholic University of Malawi verifies the academic affiliation of Ms Kaparounaki.

The vision of the Catholic University is to be the centre of excellence for quality holistic education in every field of knowledge for the good of the people of Malawi and beyond. Ms Kaparounaki's project will contribute to the social sciences discipline and further the knowledge and understanding of children and young people with care-giving responsibilities in Malawi. Ms Kaparounaki is currently a PhD candidate in Human Geography at the University of Hull.

The Catholic University of Malawi is looking forward to welcoming Ms Kaparounaki in Malawi.

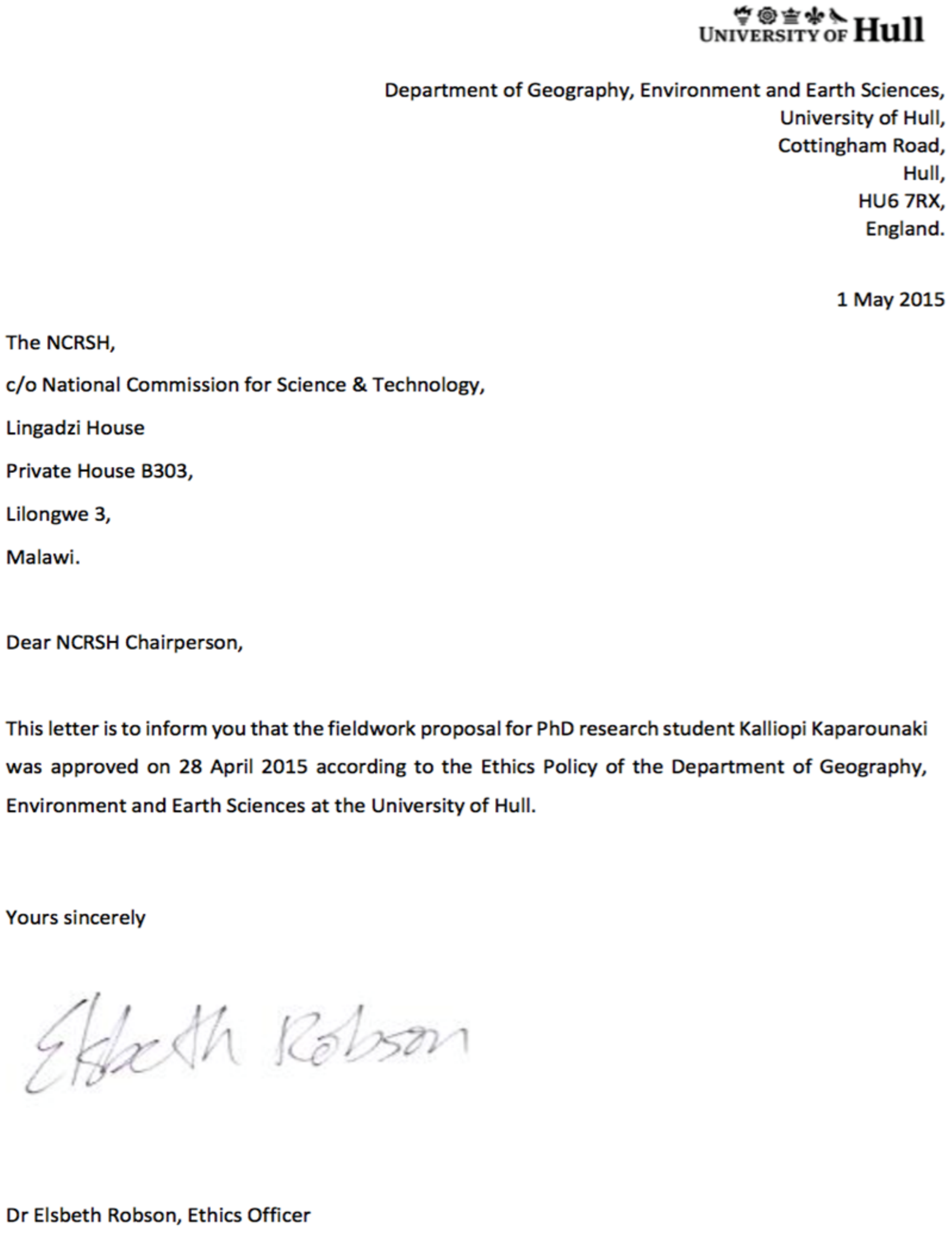
Yours Sincerely,

Prof. A.G. Phiri
VICE CHANCELLOR

All official correspondences to be addressed to the Vice Chancellor

1

Appendix 17 – Letter of ethical approval (University of Hull)



UNIVERSITY OF Hull

Department of Geography, Environment and Earth Sciences,
University of Hull,
Cottingham Road,
Hull,
HU6 7RX,
England.

1 May 2015

The NCRSH,
c/o National Commission for Science & Technology,
Lingadzi House
Private House B303,
Lilongwe 3,
Malawi.

Dear NCRSH Chairperson,

This letter is to inform you that the fieldwork proposal for PhD research student Kalliopi Kaparounaki was approved on 28 April 2015 according to the Ethics Policy of the Department of Geography, Environment and Earth Sciences at the University of Hull.

Yours sincerely

Elsbeth Robson

Dr Elsbeth Robson, Ethics Officer

Appendix 18 – Research Ethics Approval (National Commission for Science & Technology, Malawi)

NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House
Robert Mugabe Crescent
P/Bag B303
City Centre
Lilongwe

Tel: +265 1 771 550
+265 1 774 189
+265 1 774 869
Fax: +265 1772 431
Email:directorgeneral@ncst.mw
Website:http://www.ncst.mw

Ref No: NCST/RTT/2/6 **3 July, 2015**

Kalliopi Kaparounaki
C/O The Catholic University of Malawi
P.O Box 5452
Limbe

Dear Kalliopi Kaparounaki,

RE: RESEARCH ETHICS APPROVAL OF PROTOCOL P.05/15/36: CARING CHILDREN IN MALAWI- CHILDREN'S WORK WITHIN FAMILIES AFFECTED BY ILLNESS AND DISABILITY

Having satisfied all the ethical, scientific and regulatory requirements, procedures and guidelines for the conduct of research in the social sciences sector in Malawi, I am pleased to inform you that the above referred research study has officially been approved. You may now proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this letter. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research in the Social Sciences and Humanities in a format that is available at the secretariat. Once the study is finished, you are required to furnish the Committee and the Commission with a final report of the study.

Wishing you a successful implementation of your study.

Yours Sincerely

Martina Chimzimu
NCRSH ADMINISTRATOR AND RESEARCH OFFICER
HEALTH, SOCIAL SCIENCES AND HUMANITIES
For: CHAIRMAN OF NCRSH

Appendix 19 - Details of Participants – Children & Families

	Name	Age	Gender	Attending school [1]	Education Level[2]	Location	Caring For	Age	Relationship	Disability/Illness	No of Visits
Participants (children and young people)	1.Hannah	19	F	Dropped out	Standard 7	Rural	Memory	35	Mother	HIV	11
	2.Louise	12	F	F/T	Standard 5	Semi-urban	Rute	63	Grandmother	Blindness	13
	3.Eveline	11	F	F/T	Standard 5						
	4.George	17	M	Dropped out	Standard 8	Rural	Esnat	41	Mother	HIV	9
	5.Rejoice	17	F	P/T	Form 2	Rural	Christina	52	Mother	Chronic Skin Condition	10
	6.Andrew	19	M	P/T	College (Business Management)	Urban	Nessie Aisha	90 105	Grandmother Grandmother	Mobility problems Heart problem	10
	7.Chimwemwe	17	F	Dropped out	Form 2	Rural	Helen	95	Grandmother	Heart problem	11
	8.Chifunilo	10	F	F/T	Standard 4						
	9.Matias	16	M	P/T	Form 2	Semi-urban	Masamba	82	Grandfather	Mobility problems	8
	10.Samantha	17	F	Dropped out	Form 2	Urban	Clara	85	Grandmother	Mobility problems	8
	11.Rosemary	18	F	Dropped out	Form 3	Urban	Mary	35	Sister	Mental Health Problems	10
	12. Daisy	13	F	F/T	Standard 7	Semi-	Elesi	51	Maternal Aunt	HIV	7

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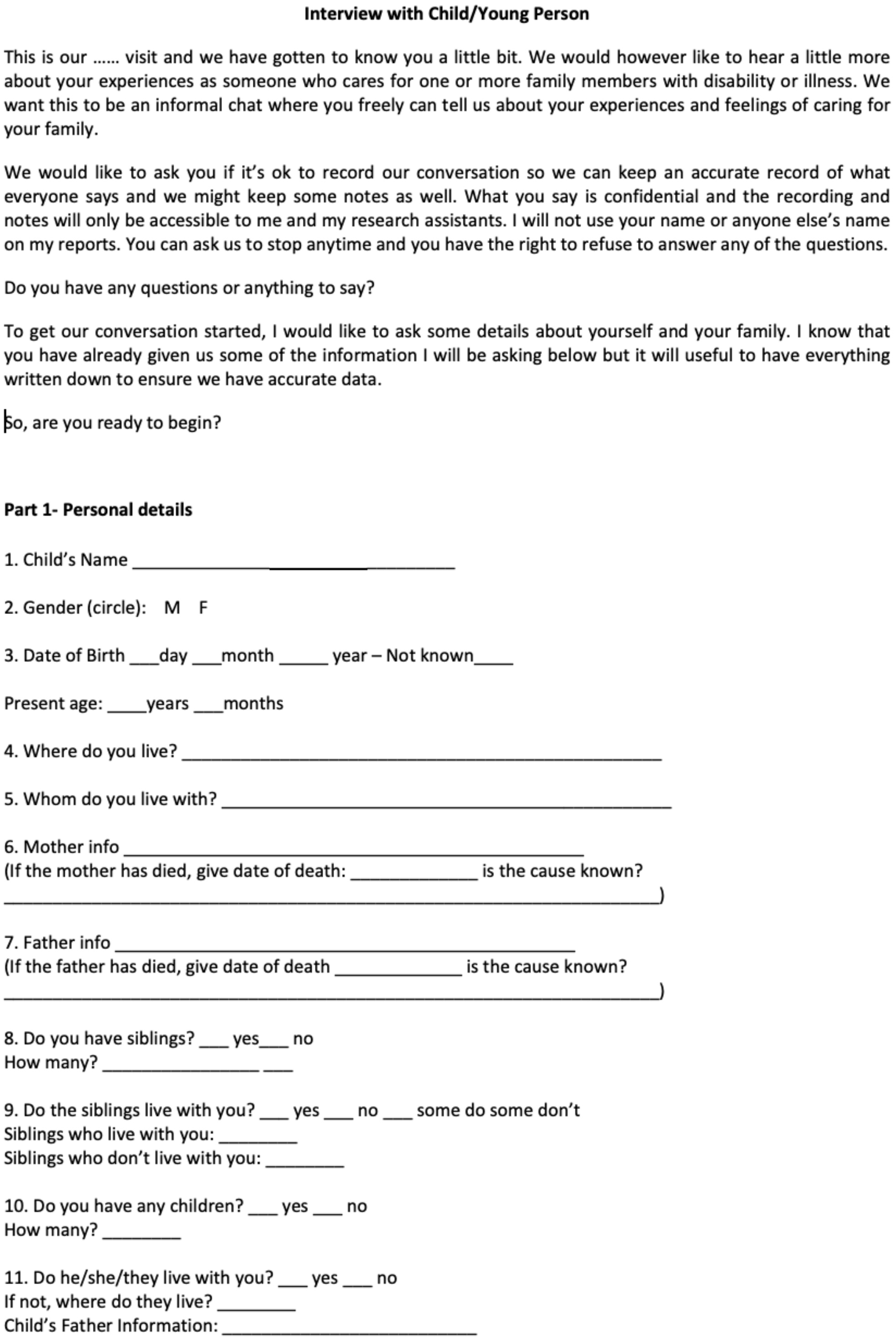
[1] School attendance depends on various reasons, such as ability to pay school fees, caring responsibilities, pregnancy, etc.

[2] In Malawi primary school education lasts eight years and is referred to as Standard 1 to Standard 8. Secondary school education lasts four years and is referred to as Form 1 to Form 2.

Appendix 20 - Details of Participants – Professionals

	Participant's Name	**Gender**	**Age**	**Role**
1	Natasha	F	28	NGO Project Manager
2	Brisca	F	39	NGO Facilitator
3	Stella	F	26	Public Relationships Officer (government organisation)
4	Lenwati	F	41	Social Worker (government organisation)
5	Mike	M	34	NGO Project Manager
6	George	M	41	NGO Founder
7	Erin	F	28	NGO Programme Manager
8	Rose	F	57	NGO Manager
9	Maria	F	33	NGO Executive Director
10	Kondwani	M	32	Social Worker (government organisation)

Appendix 21 – Semi-structured Interview Questions (Children & Young People)



Interview with Child/Young Person

This is our …… visit and we have gotten to know you a little bit. We would however like to hear a little more about your experiences as someone who cares for one or more family members with disability or illness. We want this to be an informal chat where you freely can tell us about your experiences and feelings of caring for your family.

We would like to ask you if it's ok to record our conversation so we can keep an accurate record of what everyone says and we might keep some notes as well. What you say is confidential and the recording and notes will only be accessible to me and my research assistants. I will not use your name or anyone else's name on my reports. You can ask us to stop anytime and you have the right to refuse to answer any of the questions.

Do you have any questions or anything to say?

To get our conversation started, I would like to ask some details about yourself and your family. I know that you have already given us some of the information I will be asking below but it will useful to have everything written down to ensure we have accurate data.

So, are you ready to begin?

Part 1- Personal details

1. Child's Name ______________________________

2. Gender (circle): M F

3. Date of Birth ___day ___month _____ year – Not known____

Present age: ____years ___months

4. Where do you live? ____

5. Whom do you live with? ____

6. Mother info ____
(If the mother has died, give date of death: _____________ is the cause known?
____)

7. Father info ____
(If the father has died, give date of death _____________ is the cause known?
____)

8. Do you have siblings? ___ yes___ no
How many? ________________ ___

9. Do the siblings live with you? ___ yes ___ no ___ some do some don't
Siblings who live with you: ________
Siblings who don't live with you: ________

10. Do you have any children? ___ yes ___ no
How many? ________

11. Do he/she/they live with you? ___ yes ___ no
If not, where do they live? ________
Child's Father Information: __________________________

12. Is there anyone else who lives with you in the house? ___ yes ___ no
If yes, who? ________

13. Do you take care of someone? ________
Who? ___________________________

14. Is there anyone who looks after you and/or your siblings/children? ___ yes ___ no
If yes, who? ________

15. Do you go to school? ______
What standard, form or class level? _____________

Part 2 – Main questions

Childhood/children general:

1. What is a child? How would you define a child?
2. Would you describe yourself as a child or an adult? (why?)
3. How is the life of a child (of any child, not necessarily of children who look after others) here at the village/township/city?
4. Can you explain what a child (of any child, not necessarily of children who look after others) does in a day like today?

Concept of Care:

5. What does caring for others mean to you? How would you describe care?
6. Can you tell me how would you define/describe a child or young person who takes care of family members with disability or chronic illness?
7. In what ways do you think parents/adults care for children? Can you give me an example?
8. In what ways do you think children care for others (siblings/adults)? Can you give me an example?

Child's/Young person's Caring Role

9. Is there anyone you are looking after / caring for?
10. Can you explain how you are caring for them?
11. Can you tell me what you do in a day like today?
12. What time do you go to bed/ wake up? How have you been sleeping lately?
13. How and when did you become the carer of your……………………….?
14. Family map Activity- can you explain to me who you are caring for and who is caring for you by drawing arrows on this family map?
15. (if applicable) You said that you are caring not only for your ……. (person with disability/chronic illness) but also for the rest of the family who live with you. How is that for you? Is taking care of someone with a disability /chronic illness and someone with no disability/chronic illness different? If yes, in what ways?
16. How have you been feeling lately?
17. What happens if you are not feeling well or you are sick? (when was the last time/ what happened then?)

Relationships with Care Receiver

18. How would you describe your relationship with …………?
19. Can you tell us 3 things you like about your relationship with ………… and 3 things you would like to change?
20. How would you describe your relationships with the rest of the family?

Children/Young People & Community/School

21. Now in your community, do you think your life is different from the life of other children/young people? In what ways?
22. How does this make you feel?
23. Do you have any friends? How often do you see them? What do you usually do with them?
24. Do you have any romantic relationship with someone?
25. How are you doing at school?
26. How often are you going? When was the last time you went?
27. Is school aware of your circumstances? Do they understand? Do you feel you are getting any support?

Support & Services

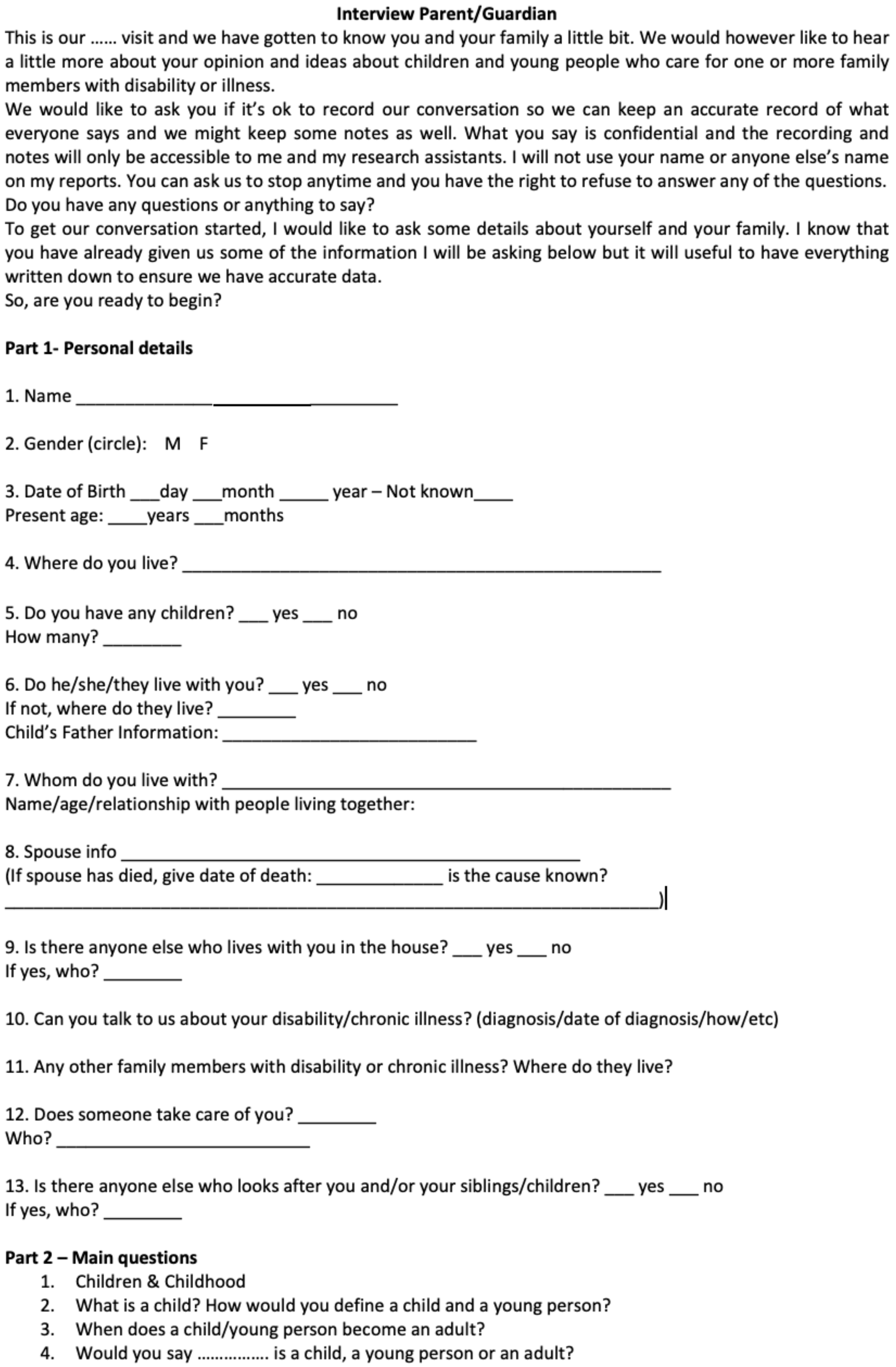
28. Children/ young people like yourself who take care of other people, where can they get support from?
29. Is there anyone helping you? Who is helping you? In what ways?
30. What kind of help do you need? Where could you receive this help from?

Part 3 - Ending

31. Thank you very much for your answer. How did you find the questions? How are feeling after our conversation?
32. Do you have any questions or do you want to tell us anything we haven't discussed already?

Zikomo kwambiri!

Appendix 22 – Semi-structured Interview Questions (Parents & Guardians)



Interview Parent/Guardian

This is our …… visit and we have gotten to know you and your family a little bit. We would however like to hear a little more about your opinion and ideas about children and young people who care for one or more family members with disability or illness.

We would like to ask you if it's ok to record our conversation so we can keep an accurate record of what everyone says and we might keep some notes as well. What you say is confidential and the recording and notes will only be accessible to me and my research assistants. I will not use your name or anyone else's name on my reports. You can ask us to stop anytime and you have the right to refuse to answer any of the questions. Do you have any questions or anything to say?

To get our conversation started, I would like to ask some details about yourself and your family. I know that you have already given us some of the information I will be asking below but it will useful to have everything written down to ensure we have accurate data.

So, are you ready to begin?

Part 1- Personal details

1. Name ____

2. Gender (circle): M F

3. Date of Birth ___day ___month _____ year – Not known____
Present age: ____years ___months

4. Where do you live? ____

5. Do you have any children? ___ yes ___ no
How many? ________

6. Do he/she/they live with you? ___ yes ___ no
If not, where do they live? ________
Child's Father Information: ___________________________

7. Whom do you live with? ____
Name/age/relationship with people living together:

8. Spouse info ____
(If spouse has died, give date of death: _____________ is the cause known?
____)

9. Is there anyone else who lives with you in the house? ___ yes ___ no
If yes, who? ________

10. Can you talk to us about your disability/chronic illness? (diagnosis/date of diagnosis/how/etc)

11. Any other family members with disability or chronic illness? Where do they live?

12. Does someone take care of you? ________
Who? ___________________________

13. Is there anyone else who looks after you and/or your siblings/children? ___ yes ___ no
If yes, who? ________

Part 2 – Main questions

1. Children & Childhood
2. What is a child? How would you define a child and a young person?
3. When does a child/young person become an adult?
4. Would you say ……………. is a child, a young person or an adult?

5. How is a child (any child, not just a carer) brought up in your community? How is life like for a child here?

Concept of Care

1. In general, what does caring for others mean to you? How would you describe care?
2. How would you define a child/young person who cares for family member(s) with disability or chronic illness?
3. In general, in what ways do you think parents/adults care for children? Can you give me an example?
4. In what ways do you think children care for others (siblings/adults)? Can you give me an example?
5. Who usually cares for family members with disability and/or chronic illness?

Living situation/ short background

1. How long have you been living in this house?
2. Where did you used to live before? Why did you move?
3. How did that make you feel?
4. Can you tell us where you get income from/who generates it?
5. How have you been feeling lately?
6. How often do you need to go to clinic/doctor? When was the last time? How and who with did you go?
7. Can you explain to us what you usually do in a day like today?

Child's/ young person's caring responsibilities & feelings

1. Who looks after you? Since when? Why ……….? Who made the decision?
2. How does ………… look after you? What does she/he do in a day like today?
3. Can you list her/his main duties? (how often)
4. What happens when …………… is away or not feeling well?
5. How do you think she/he feels when she/he is responsible for you and /or your family?
6. Do you think …………'s life is different in comparison with other children/young people at the same age? In what ways?

Relationships with Carer

1. How would you describe your relationship with …………?
2. Can you tell us 3 things you like about your relationship with ……… and 3 things you would like to change?
3. How would you describe ……………….'s relationship with the rest of the family?
4. Does …………… have any friends or other relationships? How would you describe them?
5. Community/extended family
6. Do you receive any help/support from extended family? What kind/how often?
7. Do you receive any help/support from community? What kind/how often?
8. Do you feel you need additional support? What kind of support would you need?

Future aspirations

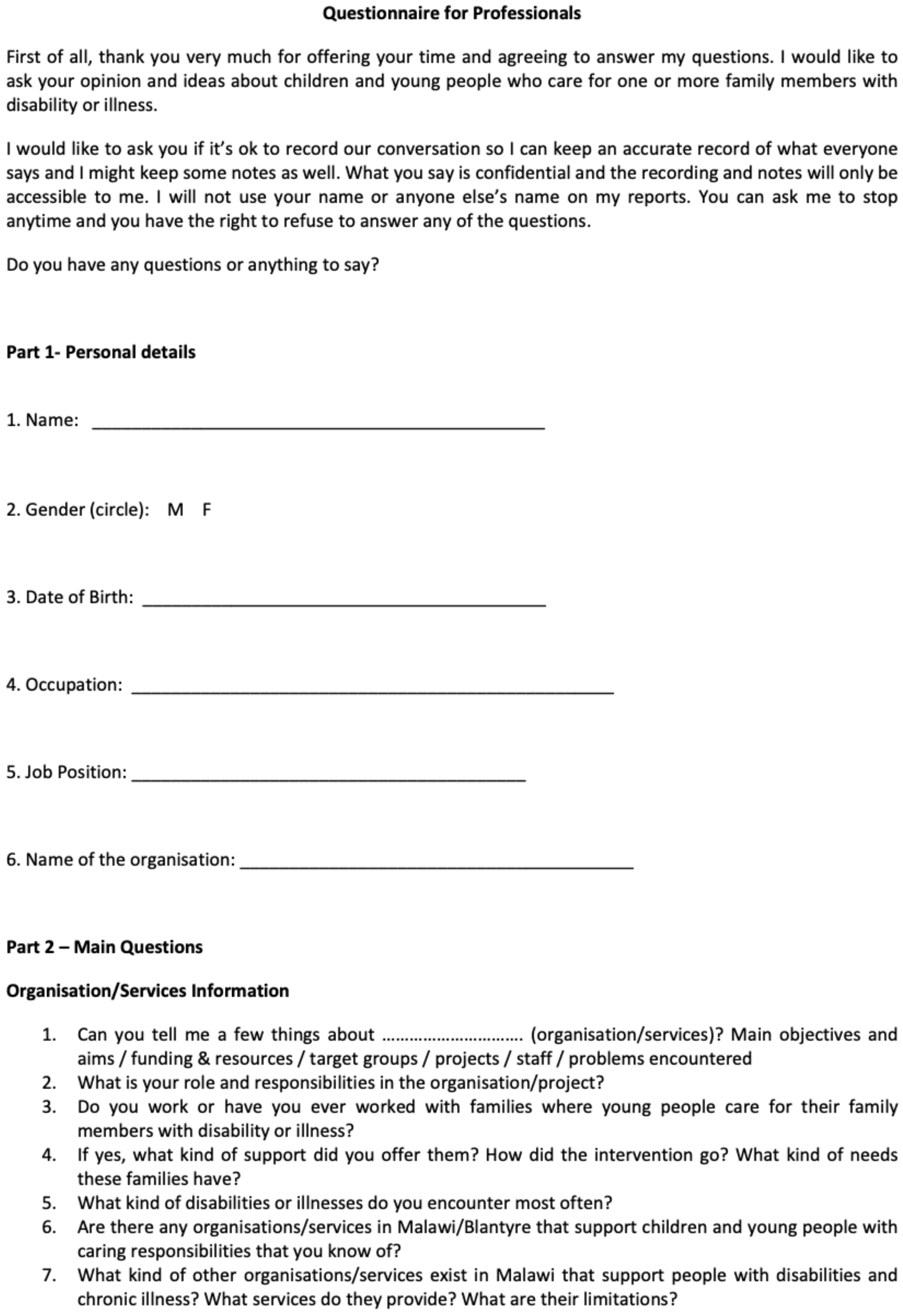
1. What would you like for yourself and your family in the future?
2. What do you think …………'s future will be like?

Part 3 - Ending

1. Thank you very much for your answer. How did you find the questions? How are feeling after our conversation?
2. Do you have any questions or do you want to tell us anything we haven't discussed already?

Zikomo kwambiri!

Appendix 23 – Semi-structured Interview Questions (Professionals)



Questionnaire for Professionals

First of all, thank you very much for offering your time and agreeing to answer my questions. I would like to ask your opinion and ideas about children and young people who care for one or more family members with disability or illness.

I would like to ask you if it's ok to record our conversation so I can keep an accurate record of what everyone says and I might keep some notes as well. What you say is confidential and the recording and notes will only be accessible to me. I will not use your name or anyone else's name on my reports. You can ask me to stop anytime and you have the right to refuse to answer any of the questions.

Do you have any questions or anything to say?

Part 1- Personal details

1. Name: ____

2. Gender (circle): M F

3. Date of Birth: ____

4. Occupation: ____

5. Job Position: ____

6. Name of the organisation: ____

Part 2 – Main Questions

Organisation/Services Information

1. Can you tell me a few things about ………………………… (organisation/services)? Main objectives and aims / funding & resources / target groups / projects / staff / problems encountered
2. What is your role and responsibilities in the organisation/project?
3. Do you work or have you ever worked with families where young people care for their family members with disability or illness?
4. If yes, what kind of support did you offer them? How did the intervention go? What kind of needs these families have?
5. What kind of disabilities or illnesses do you encounter most often?
6. Are there any organisations/services in Malawi/Blantyre that support children and young people with caring responsibilities that you know of?
7. What kind of other organisations/services exist in Malawi that support people with disabilities and chronic illness? What services do they provide? What are their limitations?

Children & Childhood

8. In your opinion, what is it like to be a child in Malawi? How would you define children and young people? What does it mean to be a child? Who is a child? What is the difference between a child and an adult in Malawi?
9. How is a child (any child, not just a carer) brought up in your community? How is life like for a child here?
10. When and how does a child/young person become an adult?

Care

11. In your opinion, in what ways do you think parents/adults care for children? Can you give me an example?
12. In your opinion, in what ways do you think children care for others (siblings/adults)? Can you give me an example?
13. According to your experience, who usually cares for family members with disability and/or chronic illness in Malawi?
14. What are thoughts on children and young people who care for family members with disability and illness? What is life like for them?
15. Do you think children's and young people's with caring responsibilities life is different in comparison with other children/young people at the same age? In what ways?

Community/extended family

16. According to your experience, what kind of support, if any, extended family offer to their relatives where children and young people take care of disabled and ill family members?
17. According to your experience, what kind of support, if any, communities offer to families where children and young people take care of disabled and ill family members?

Future aspirations

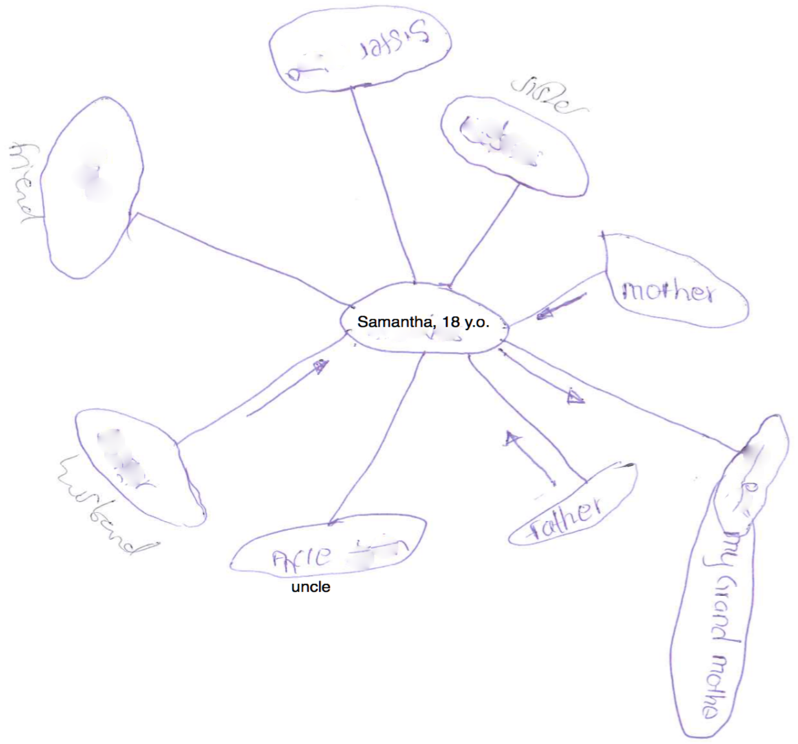
18. What do you think children's and young people's with caring responsibilities future will be like? Can you give me examples of real cases you have encountered?
19. In your opinion, what else should be done to support these children and young people?

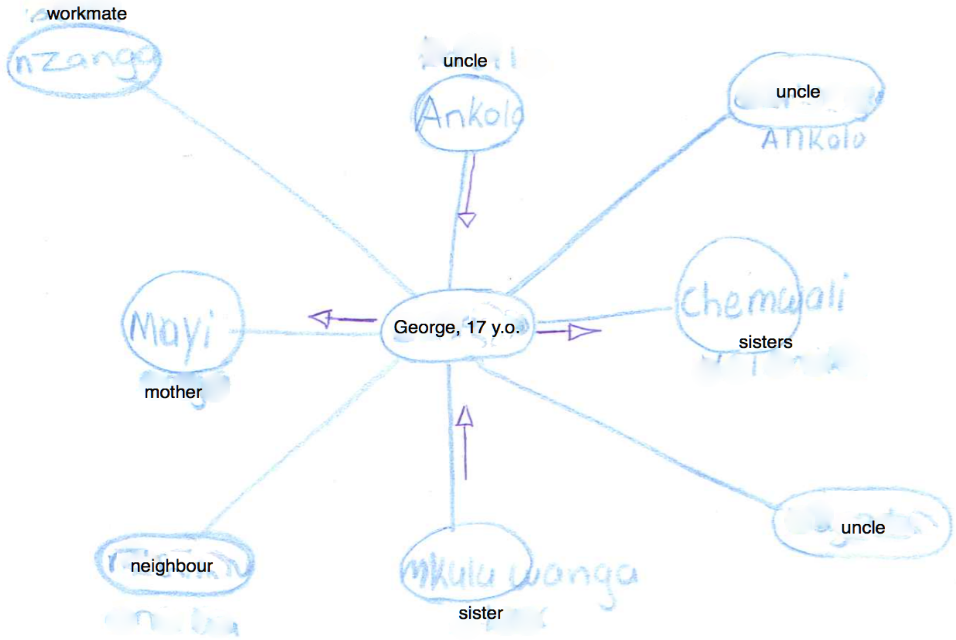
Part 3 - Ending

20. Thank you very much for your answer. Do you have any questions or do you want to tell me anything we haven't discussed already?

Zikomo kwambiri!

Appendix 24 – Examples of Care Map Activity

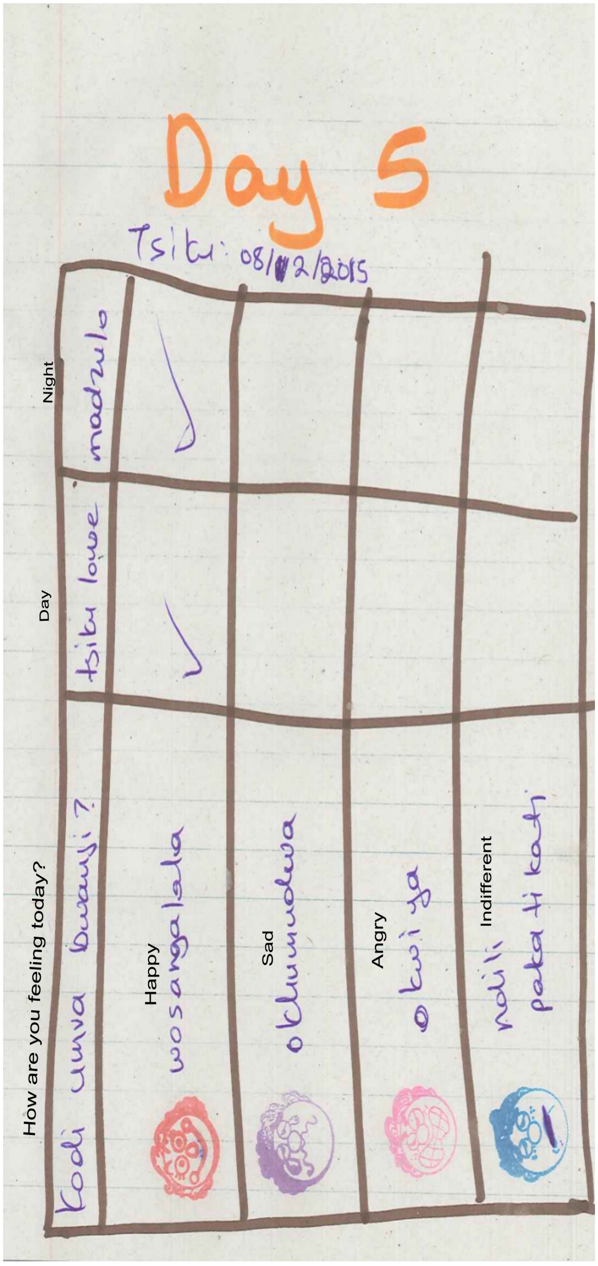




Appendix 25 – Example of Photo Activity

'*I wish I could build a nice house for my grandmother so that she should be living a happy life, (.....), because she will know she will be safe even in rainy season*', Chimwemwe, 17 y.o.

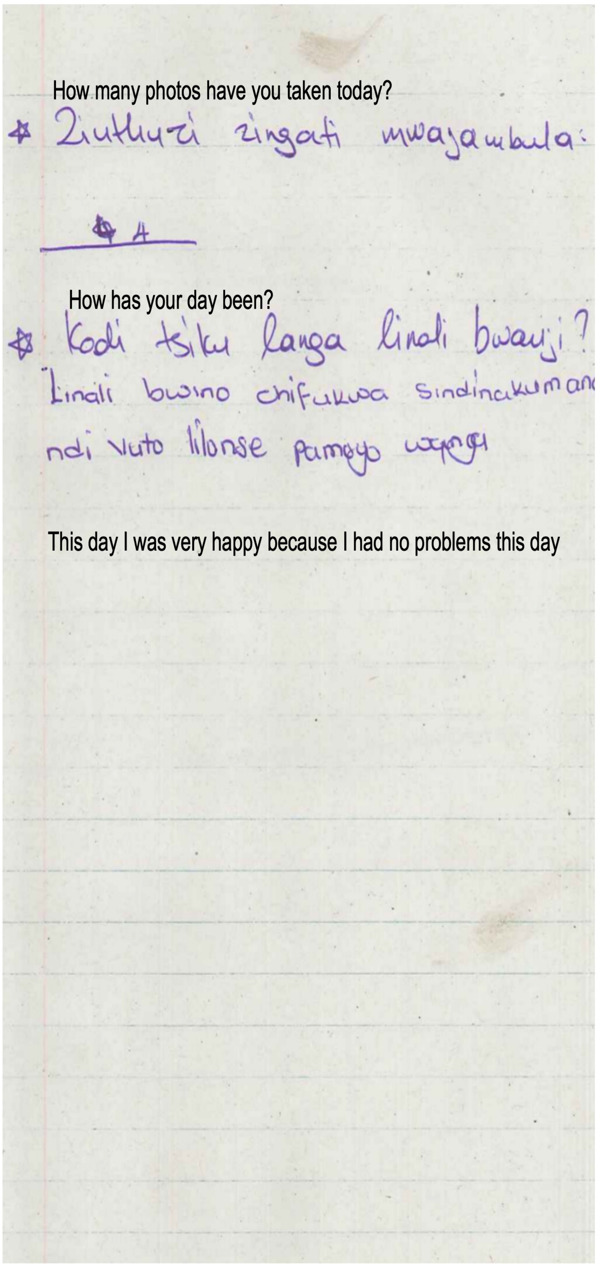
Appendix 26 – Example of Diary Activity



Day 5

Tsiku: 08/[illegible]2/2015

How are you feeling today? Kodi unva bwanji ?	Day tsiku lonse	Night madzulo
Happy wosangalala	✓	✓
Sad okhumudwa		
Angry okwiya		
Indifferent ndili pakati kati		



How many photos have you taken today?

✡ Ziuthuzi zingati mwajambula:

✡ 4

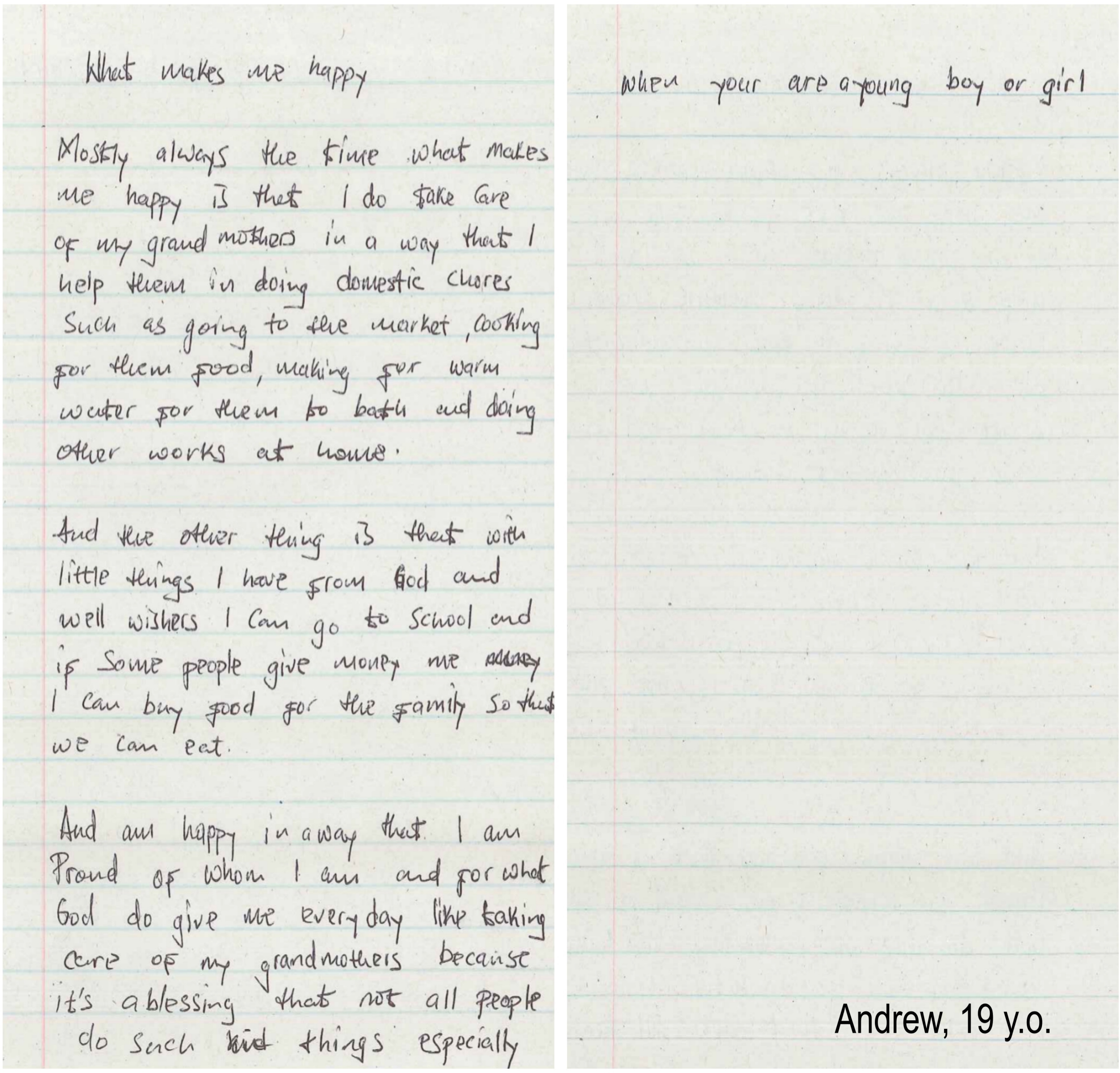
How has your day been?

✡ Kodi tsiku langa linali bwanji?

Linali bwino chifukwa Sindinakuman
ndi vuto lilonse pamoyo wanga

This day I was very happy because I had no problems this day

Appendix 27 – Example of Essay Activity



What makes me happy

Mostly always the time what makes me happy is that I do take care of my grand mothers in a way that I help them in doing domestic chores Such as going to the market, cooking for them food, making for warm water for them to bath and doing other works at home.

And the other thing is that with little things I have from God and well wishers I Can go to School and if Some people give money me ~~money~~ I Can buy food for the family So that we can eat.

And am happy in away that I am Proud of whom I am and for what God do give me everyday like taking care of my grandmothers because it's a blessing that not all people do such ~~kind~~ things especially when your are a young boy or girl

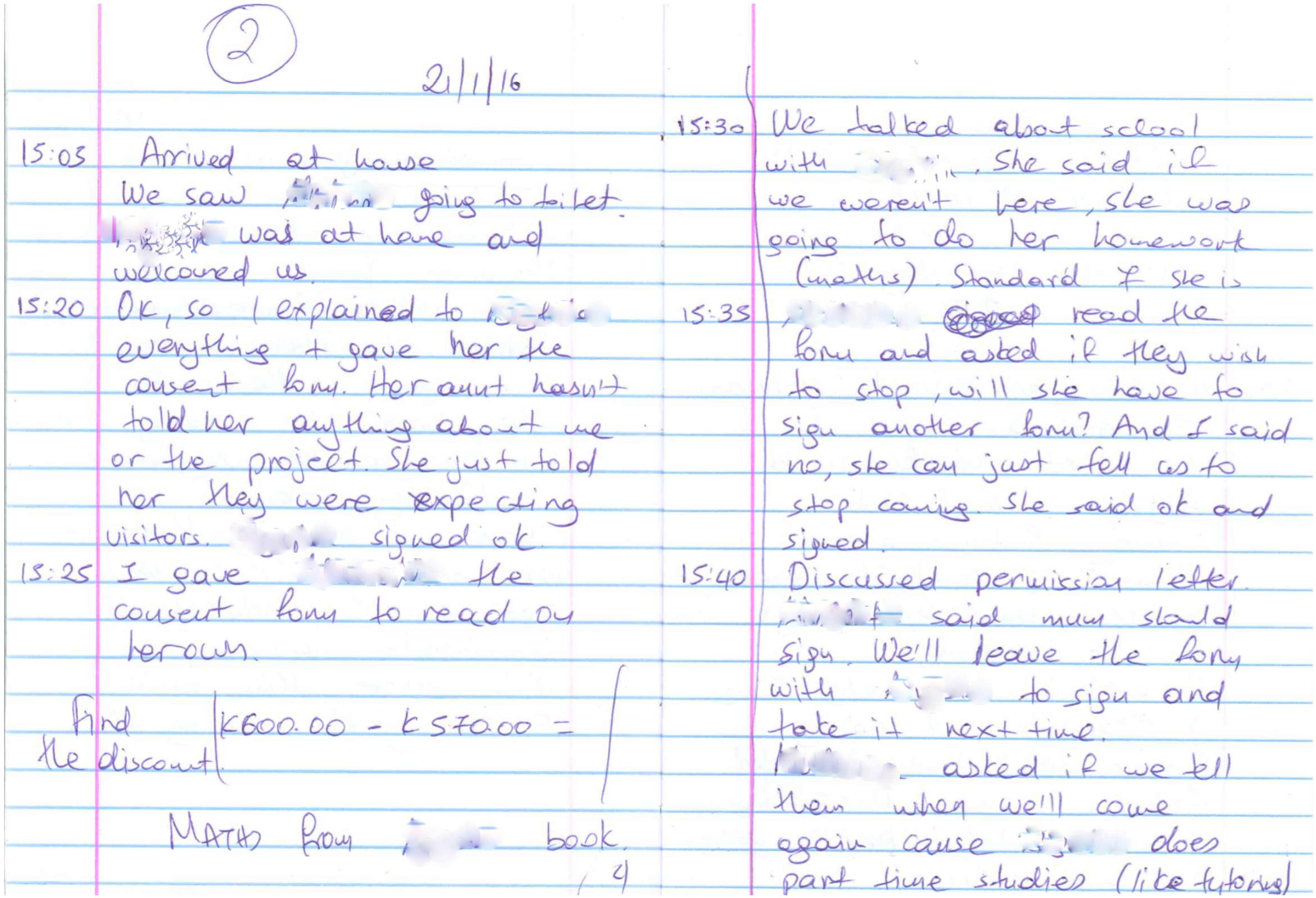
Andrew, 19 y.o.

Appendix 28 – Examples of Unstructured Interview Activity

Appendix 29 – Example of Drawing Activity

George, 17 y.o.

Appendix 30 – Example of Fieldnotes



②

21/1/16

15:03 Arrived at house
We saw [redacted] going to toilet.
[redacted] was at home and
welcomed us.
15:20 Ok, so I explained to [redacted]
everything + gave her the
consent form. Her aunt hasn't
told her anything about me
or the project. She just told
her they were expecting
visitors. [redacted] signed ok.
15:25 I gave [redacted] the
consent form to read on
her own.

Find the discount | K600.00 - K570.00 =

MATHS from [redacted] book.

4

15:30 We talked about school
with [redacted]. She said if
we weren't here, she was
going to do her homework
(maths). Standard 7 she is
15:35 [redacted] read the
form and asked if they wish
to stop, will she have to
sign another form? And I said
no, she can just tell us to
stop coming. She said ok and
signed.
15:40 Discussed permission letter.
[redacted] said mum should
sign. We'll leave the form
with [redacted] to sign and
take it next time.
[redacted] asked if we tell
them when we'll come
again cause [redacted] does
part time studies (like tutoring)

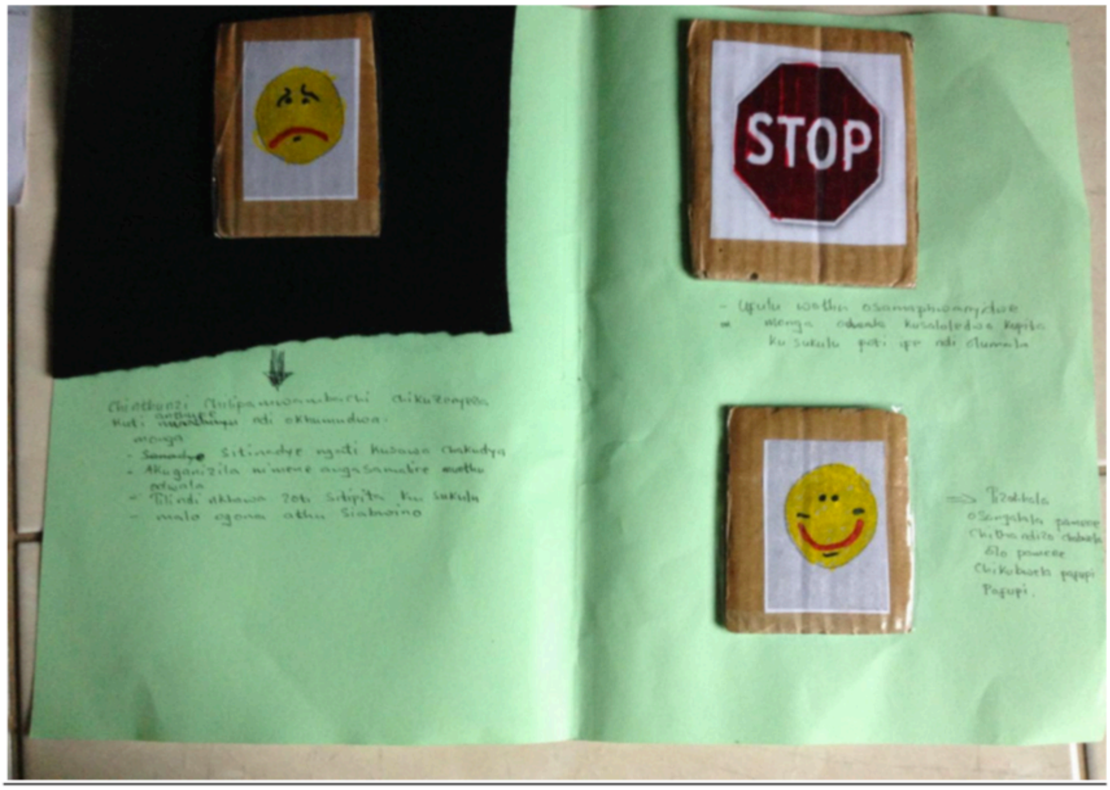
Appendix 31 – Focus Group Discussion Posters and Letters

Focus Group Discussion Posters & Letters

(24th February 2016, Nancholi, Malawi)

1. **Group A**:

Poster:



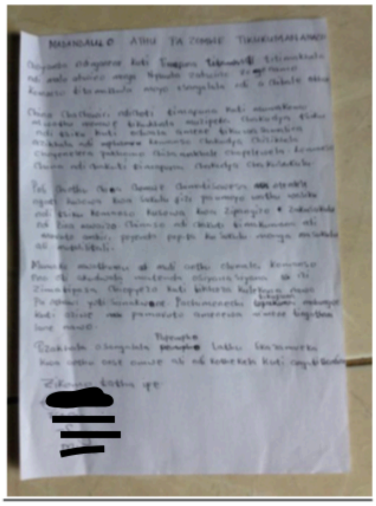
*The picture above demonstrates that we are sad people with things like:

- We have not eaten anything because we lack food
- We thinking/worried how we will take care of a sick person
- We are stressed that we might not finish our education
- The places we sleep (*our houses*), are not in a good condition

*Our rights should not be abused, like not to be allowed to go to school because we are disabled.

*We will be happy people if we will receive the assistance we need and if it will be coming often.

Letter:



[redacted]

OUR WORRIES ON WHAT WE ARE GOING THROUGH

Firstly, we would like to say that we wish we could have good homes and a live a happy life with our relatives.

Secondly, our wish is that we should have enough food everyday so that the people we are taking care of should always be strong. Additionally, we should have food to take with us when we are going to school.

There is another thing which troubles us most of the time that is lacking school fees. We always lack school fees and other school materials. And we also face problems in going to and from school because some of our schools are very far from where we live.

In our families there are other family members who are very sick and others who have a disability, these problems (*those mentioned above*) give us fear that we may lose them before their actual time. And because of these, we would like organisations to know our problems and help us to end them.

We will be happy if our request will be responded with those who have the capacity to help us.

Thank you,

[redacted]

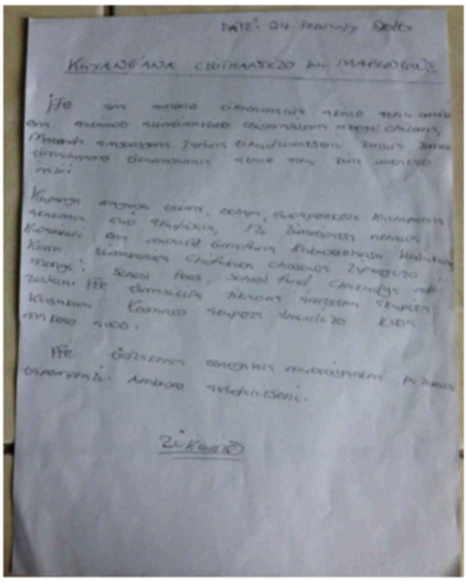
2. **Group B:**

Poster:

THESE PICTURES DEMONSTRATE HOW WE TAKE CARE OF OUR RELATIVES

- This picture shows that I go to the hill to fetch firewood for cooking for the whole family
- My grandmother is blind and the picture demonstrates how I take care of her by guiding her
- This is how I make money to help my mother who is sick
- Apart from other responsibilities this is how I help my mum if there is a problem like leakage of the roof

Letter:



LOOKING FOR HELP/SUPPORT FROM ORGANISATIONS

We are children who take care of our relatives with disabilities and chronic illnesses, as well as the rest of our families. We would like to inform you of what we go through. These are some of our problems:

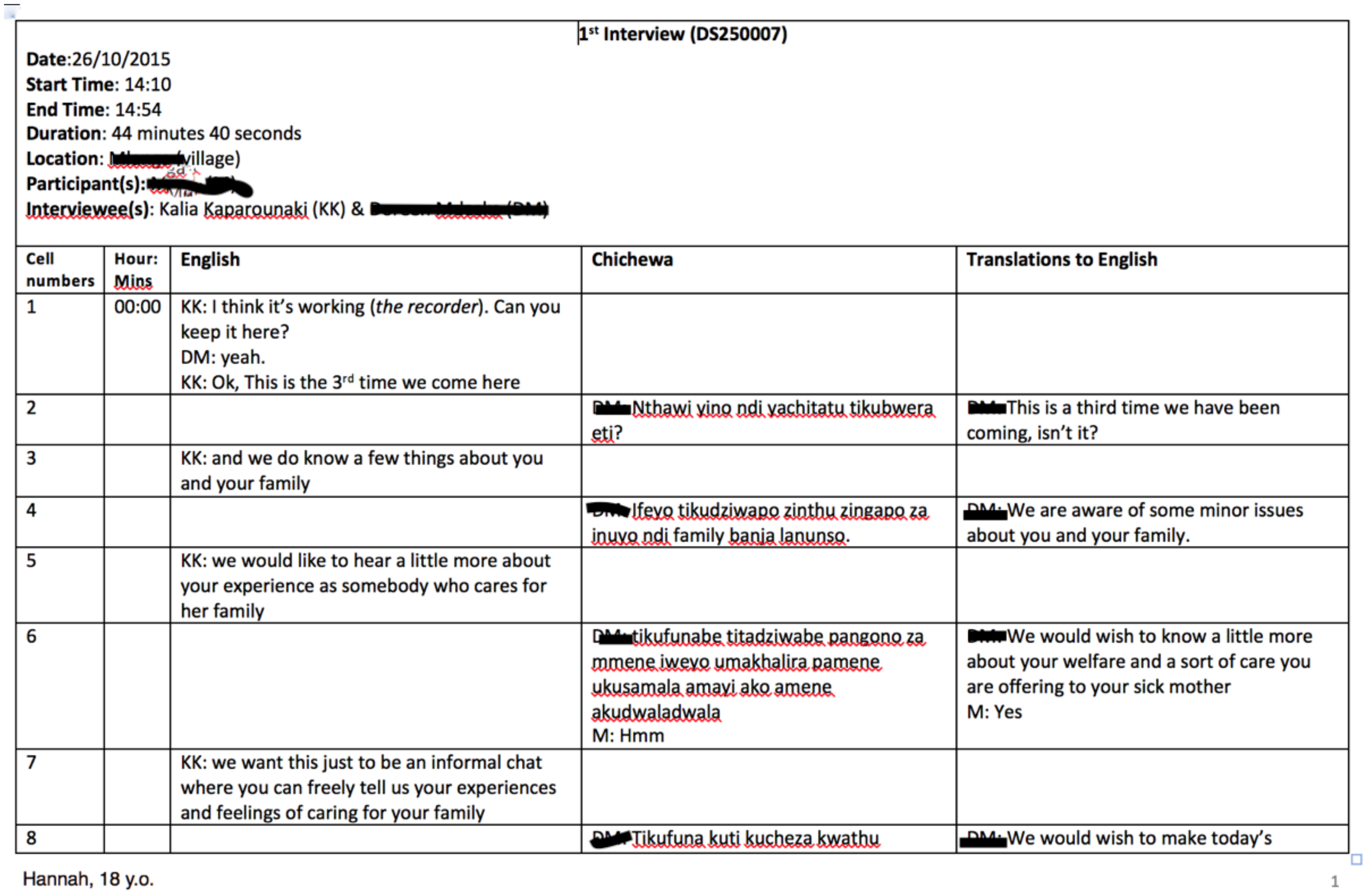
we do piece work in order to get money; we take them to the hospital when they are sick. These stress us out a lot. Some of us want to go further with our education but we fail because we do not have the materials like school fees, school fund, food and clothes. We admire our friends who go to school and they have parents to give them what they want.

We will be happy people if you will positively respond to this letter.

God bless you.

Thank you.

Appendix 32 – Example of Interview Transcriptions



1st Interview (DS250007)

Date:26/10/2015
Start Time: 14:10
End Time: 14:54
Duration: 44 minutes 40 seconds
Location: [redacted]village)
Participant(s):[redacted]
Interviewee(s): Kalia Kaparounaki (KK) & [redacted]

Cell numbers	Hour: Mins	English	Chichewa	Translations to English
1	00:00	KK: I think it's working (*the recorder*). Can you keep it here? DM: yeah. KK: Ok, This is the 3rd time we come here		
2			[redacted]Nthawi yino ndi yachitatu tikubwera eti?	[redacted]This is a third time we have been coming, isn't it?
3		KK: and we do know a few things about you and your family		
4			[redacted]Ifeyo tikudziwapo zinthu zingapo za inuyo ndi family banja lanunso.	[redacted]We are aware of some minor issues about you and your family.
5		KK: we would like to hear a little more about your experience as somebody who cares for her family		
6			[redacted]tikufunabe titadziwabe pangono za mmene iweyo umakhalira pamene ukusamala amayi ako amene akudwaladwala M: Hmm	[redacted]We would wish to know a little more about your welfare and a sort of care you are offering to your sick mother M: Yes
7		KK: we want this just to be an informal chat where you can freely tell us your experiences and feelings of caring for your family		
8			[redacted]Tikufuna kuti kucheza kwathu	[redacted]We would wish to make today's

Hannah, 18 y.o.

1