“How do young adults experience and understand the impact of growing up with a sibling with cerebral palsy within the Kenyan context?”

A thesis submitted to the University of Manchester for the degree of Professional Doctorate in Counselling

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**TITLE:** How do young adults experience and understand the impact of growing up with a sibling with cerebral palsy within the Kenyan context?

**ABSTRACT**

The study explored the experiences of young adults who have a sibling with cerebral palsy living in Nairobi, Kenya in order to establish how they made sense out of the experience of growing up with a sibling with CP. The study used a qualitative approach with an Interpretative Phenomenological Analysis (IPA) whereby six participants all young adults aged between eighteen and twenty four years, were interviewed using semi-structured interviews. Data analysis was undertaken according to IPA guidelines. The findings generated four super ordinate themes namely: increased sense of reward, emotional impact, family relationships and public relations. The findings revealed that there was a direct impact on sense of psychological well-being both negatively and positively. On one hand, the young adults experienced feelings of stigma, fear about the future, anger and a sense of responsibility. While on the other hand they experienced personal growth in terms of a sense of personal development and some concrete rewards. In conclusion, the study demonstrated the potential for personal development in the group studied and made a contribution to understanding the disabling impact of society on the lives of sibling due to disability by association.
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DEDICATION

I dedicate this thesis to my wonderful daughter “Techillah” without whom this study could not have taken place. Thank you for the opportunity you gave me to love and serve you. You are so special to me!

I also dedicate it to Peter Muhanda of CPSK and members of CPSK as a whole with special appreciation to the young adults who were my participants who defied all odds to share with me their life experiences.

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<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AFUB</td>
<td>African Union of the Blind (Kenya)</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>CPSK</td>
<td>Cerebral Palsy Society of Kenya</td>
</tr>
<tr>
<td>DP</td>
<td>Disabled People</td>
</tr>
<tr>
<td>GOK</td>
<td>Government of Kenya</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>KES</td>
<td>Kenya Shillings</td>
</tr>
<tr>
<td>KNBS</td>
<td>Kenya National Bureau of Statistics</td>
</tr>
<tr>
<td>KNCHR</td>
<td>Kenya National Commission on Human Rights</td>
</tr>
<tr>
<td>LCD</td>
<td>Leonard Cheshire Disability</td>
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<td>MGCSD</td>
<td>Ministry of Gender, Children and Social Development (Kenya)</td>
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<td>MOE</td>
<td>Ministry of Education</td>
</tr>
<tr>
<td>NCPWD</td>
<td>National Council for People with Disabilities</td>
</tr>
<tr>
<td>PWDS</td>
<td>People with Disabilities</td>
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<tr>
<td>UNCRPD</td>
<td>UN Convention on the Rights of Persons with Disabilities</td>
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CHAPTER 1 – INTRODUCTION

1. Introduction

This chapter introduces the thesis which explored the experiences of young adults who have siblings with Cerebral Palsy (CP), living in Nairobi, Kenya. It begins by providing a personal reflection on my role as the researcher and the position taken within this research, followed by a presentation of the aims, rationale and objectives of the study. The terminologies used are specified and a definition of disability and cerebral palsy and how disability is understood from a cultural perspective within the Kenyan context provided. A focus is given to the context within which the research was done hence a brief description of the context is stipulated.

Finally a structure of the thesis is provided.

1.1. Overview

The study explored the lived experiences of young adults who have a sibling with cerebral palsy residing in Nairobi, Kenya in order to explore how they make sense of the experience of growing up with a sibling with CP.

The study was conducted using an Interpretative Phenomenological Analysis (IPA) methodology, whereby six participants, aged between eighteen and twenty four years, were interviewed using semi-structured interviews. Data was subjected to an Interpretative Phenomenological Analysis and the findings discussed.

Arising from the position I took as an insider in this research, I begin by offering a personal reflection in the next section.

1.2. A Personal Reflection

Bowling and Ebrahim (2005) maintain that qualitative research is based on the assumption that individuals influence the outcome of research by their attributes and perspectives. As a qualitative researcher therefore, one cannot eliminate their presence in a research (Stiles, 1993; McLeod,
Stemming from this, I chose to be as open and transparent as possible about my personal orientation, context and internal processes as I carried out this research, to allow the context of the researcher and the position taken to be understood. By so doing, I aimed at shedding some light on how my values impacted on the research process and, in turn, how the research impacted on me personally and professionally. Etherington (2004) argues that, as one tells their story alongside those of other people, one is changed by it. While carrying out this research, I was open to these changes both in my personal and professional life, in order for me to translate the knowledge acquired into my personal life and professional work as well.

My being also influenced to some extent the decisions I made in this research and therefore I wish to shed some light on my background. I am an African female born in Kenya, middle aged and a mother of four children aged 25, 23, 18 and 14 years. My eldest child is a daughter who is 25 years, currently working, while the second born is a son who is a third year student at a local university pursuing a degree in medicine. The third born is a daughter aged 18 years and has Cerebral Palsy (CP), while the last born is a daughter aged 14 years in her first class in high school. Being a mother to a child with CP, who has three young adults without CP, I embarked on this research journey with some prior understanding of what happens to young people who have a sibling with CP, having closely observed how my own children relate with, and react to their sibling’s condition. In view of the above, I came to this study from a social-cultural context that could not be ignored as it partly influenced what I wished to explore.

Arising from this background, my eldest daughter had challenged me with her personal experiences during the initial stages of this research that I highlight below from my reflexive journal. Her experiences drew my attention to her fears about the future that led me to think closely about other issues involved for her.
I was walking on the streets of Nairobi when certainly I met my eldest daughter who was pursuing her first degree course at a local University. She seemed overwhelmed with negative feelings that made me to enquire what I could do to help. She told me that she had been thinking about my sickness for a while. I wondered why this was so, since I had fully recovered from Malaria (a simple ailment) I thought. She told me that “you are the glue that holds our family together”. She went on to ask, what would happen to the so called “Special Daughter” when you are gone? I was surprised at this question and tried to find out what she meant. When I inquired what she meant - she informed me that she meant when I am dead! I was dumbfounded - caught by surprise but assured her that I was not going to die after all as I had fully recovered. She then wished me good health in order to take care of my CP daughter and we parted........

Personal Journal 30th June, 2011

This incident took place while I was still drafting and re-drafting the research question. As I reflected on these words more deeply, I became aware that my daughter must have been speaking volumes that I needed to reflect on and address. To talk about the ‘so called special child’ left me with a number of questions, since in my view I was giving all my children equal attention hence there was no child I thought was ‘a special child’. However, this incident accelerated my motivation to undertake this study in order to understand not only what my daughter meant at that time, but also what other young people who have a sibling with CP experience. It is expected that results from this study will not only benefit her but also benefit her siblings, as well as other families with sibling with a CP condition.

My prior knowledge, therefore, was based on how I had learnt from my children that having a sibling with CP could have a negative impact in terms of a sense of receiving less attention as well as through my own personal experience as a mother of a CP child, my own experience of social stigma, misunderstanding, my personal challenges and distress which led me to seek counselling support and ultimately becoming a counsellor as a result.

Over time, I managed to work through my challenges as a mother and to take my daughter with CP for outings despite the stigma I had experienced and now I am an advocate for those disabled children who may be hidden because their family members are dealing with personal issues similar to those that I went through. As an insider to this research problem, I was therefore aware that the journey I wished to make would not only touch my emotions but also be transformational to my life. As Denzin (1989) put forward, research can benefit individuals therapeutically and leave
marks that are transformational in their lives hence I was open to this transformation and therapeutic adventure. I can acknowledge that this research has been a learning process as well as a therapeutic one for me. Again, in line with Etherington’s (2004) view that research provides an opportunity for growth for the researcher, I have grown both personally and professionally.

Culturally, I am Luhya (Luhya is one of the 42 ethnic communities in Kenya) and was brought up in a rural setting in the Western part of Kenya. It is the second largest community in Kenya, accounting for 14% of the total population of Kenya (Kenya National Bureau of Statistics [KNBS], 2010). Having grown up in a rural setting, I interacted closely with the Luhya culture during my formative years, which emphasises the need for respect and valuing of disabled people for who they are. In this culture, disabled people are encouraged to live with the condition as a challenge and not question why they became disabled. However, the same culture also views disability as a curse, misfortune or bad omen and disabled people are usually avoided at all costs. This kind of negative cultural views led to disabled people being hidden from the public and a woman who gave birth to a disabled child as a first born could be sent away (excommunicated) from the family because it was viewed as a contamination of her matrimonial family with a disabled offspring.

I am a Professional Counsellor who has undergone various trainings in counselling, practicing at the work-place for the past fourteen years. During my MA in Counselling Studies, I conducted a study in the field of disabilities which explored the experiences of parents of children with cerebral palsy and this led me to start working closely with clients who were parents of children with cerebral palsy together with their children with and without CP. I have therefore been working with some clients who are siblings of children with CP on a voluntary basis since the year 2008. In my professional practice, I have valued disabled people and their families as unique individuals who deserve respect and attention.

In view of my insider role, resulting from my personal, cultural and professional backgrounds, therefore, there were different understandings about disability that I came with to this study.
1.3. Definition of Cerebral Palsy and Disability

The World Health Organization (WHO) defines disability as:

“an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment may include physical, sensory and cognitive or developmental disabilities”

(Disabled World, 2013 p.1).

However, Thomas (1999, p.60) defines disability as “a form of social oppression involving social imposition of restriction of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing”. In defining disability, Thomas (1999) emphasises the barriers involving physical, social and emotional issues that restrict the lives of disabled people that constitute disability. Stemming from a Social Model of Disability, this definition emphasises the environmental and social restrictions as the major causes of disability rather than the impairment. This differs with the Medical Model of Disability that defines disability as a restriction or lack of ability to perform certain activities in a normal manner (Burry, 2000). The Medical Model of Disability emphasises illness and impairment as the major challenges for disabled people thereby orienting its definition to individuals as opposed to society.

The Kenyan Disability Act (GOK, 2003, p.1) describes disability as:

“a physical, sensory, mental or other impairment including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation”.

What I observe from the Kenyan and WHO’s definitions are that both definitions recognize individual limitations as well as social and environmental factors as determinants of how disability is defined. However, a review of other definitions will be undertaken later in the study in chapter two.

Cerebral palsy (CP) is defined as:

“a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occur in the development
of infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or a seizure disorder” (Bax et al., 2005 p.572).

Further, Alvarez (2009) defines CP as a non-progressive but unchanging disorder of movement or posture due to an injury or anomaly of the developing brain. More recently, Aisen et al. (2011, p.1) defined CP as “motor impairment that limits activity frequently accompanied by impaired cognition, communication, sensory perception, behavioural abnormalities, seizure disorders or a combination of these conditions”.

The Cerebral Palsy Society of Kenya (CPSK, 2011) and Aisen et al. (2011) define cerebral palsy as developmental disability caused by brain damage, before, during or after birth that affects the brain and as a result affects an individual’s ability to move and control his or her muscles. CP can be mild, moderate or severe and can affect individuals differently (Bax et al., 2005). Some of the symptoms that are common in CP are seizures that accounts for one third of CP cases globally while cognitive disturbances and pain account for 50% (Aisen et al., 2011). Pain is mainly caused by muscle spasm, muscle strain, skin breakdown and dental caries (Aisen et al., 2011).

Identification of CP, like any other form of disability in the Kenyan context, is undertaken by medical personnel, parents or care givers and where it is not detected early it can be identified during placement in school or major institutions of learning (Kamundia, 2013; Ministry of Education, 1995). Further to this, a number of steps have been put in place by the government to manage CP and any other forms of disability by ensuring it is detected early and referred to medical facilities for management. Moreover, Cerebral Palsy Society of Kenya, a non-governmental organization, has developed a framework for supporting those families with CP children by identifying, assessing and placing them for medical and psychological support within their institution (CPSK, 2011). However, there is no evidence at this point to show how well this has been implemented or its impact on early detection rates.

The next section focuses on the terminologies used in the research.
1.4. Terminology used

Carrying out a research on disability can be a sensitive affair in terms of language use within the research as it can be perceived either positively or negatively. I have therefore carefully selected the words to be used in this research. The word ‘disabled people’ is preferred over ‘People with Disabilities’. This is because the Social Model of Disability acknowledges that disability is caused by the way society is organised rather than the person’s impairment: hence these people are referred to as disabled people (Oliver, 1990; Goodley, 2011) implying they are disabled by society. Oliver (1990) also argues from a social model point of view that one can never separate the individual from the impairment, hence, he also prefer the term disabled people. This term is preferred in the United Kingdom (UK) where the Social Model of Disability has been embraced (Goodley, 2011). However, in the United States of America (USA) where the minority group model of disability has been adopted, the term people with disabilities that constitute a minority position in society is favoured (Goodley, 2011). I have decided to follow the conventions of the social model of disability and use the term ‘disabled people’.

1.5. The research topic

The main research question was, “How do young adults experience and understand the impact of growing up with a sibling with cerebral palsy within the urban Kenyan context?”

The purpose of the study was to answer the above question by addressing the following objectives.

1. To understand the impact of CP on the psychological well-being of the non-CP sibling.

2. To explore experiences of young adults growing up with a sibling who has CP.

3. To explore the individual meaning-making young adults who have a sibling with CP attach to their role.
The study focused on siblings because this is where my interest lay. Moreover, few studies from a Kenyan context have examined siblings who have a sibling with CP who, in my view and based upon my personal and professional experiences, may have experienced a number of psychological issues. Dodd (2004) asserts that siblings impact on each other because they share family, home, friends, environment, experience, joys and sadness from infancy to adulthood. Their relationship is one of the longest as they share a number of things with each other, hence, understanding what happens to them is important. In addition, the relationship between siblings is an important one that is both physical and emotional and one that lasts a lifetime (Heller & Arnold, 2010). I therefore wanted to understand the impact of CP on this relationship with an emphasis on the impact on the psychological wellbeing of the non-CP sibling as well as the meaning they attach to their role. Again, Heller & Arnold (2010) argue that inter-sibling relationship has a stronger structure than other relationships; hence the reason I undertook to focus on this relationship. Arguably, parent and child relationships are equally important; however, my interest was particularly on siblings.

The next section focuses on the aims and rationale for the study.

1.6. Aims and Rationale for the study

The aim of this study was to find out how young people experience and understand the impact of being a sibling of a child with CP.

The study, using an Interpretative Phenomenological Analysis [IPA] approach, sought to explore some of the key issues involved in the lives of young people who have a sibling with CP, within the urban Kenyan context. My intentions are that the findings from this study will help counsellors and other professionals dealing with this population to gain an understanding of the issues involved, as well as inform the wider population with an emphasis on those who have siblings with CP. McLeod (1999; 2001) urges researchers to carry out research that can contribute to people’s wellbeing. As a mother to a child with CP, I have valued the contributions of others and would also like to make a contribution to the welfare of others through this study. It was my background and witnessing issues involved for the young people who have a sibling with CP, that accelerated
my desire as a practitioner to contribute to the psychological wellbeing of those involved, as well as my desire as a parent to a child with CP to contribute to the psychological wellbeing of my children who are siblings of a child with CP which led me to do this research. Again, as a professional counsellor, my desire was to play a role in the psychological wellbeing of disabled people with an emphasis on siblings of children with CP and, in turn, contribute to the welfare of other Kenyans affected with general disabilities and others from a global context, through findings from this study.

Monk and Wee (2008) pointed to a shortage of literature on disability from an African perspective. It was because of this shortage that I hoped to supplement the existing literature through this study. Lyons (2011) further highlights the need to contribute to the literature in the field of health in the Kenyan context. Since my study addressed a phenomenon in the field of health, I also expect to make a contribution to the literature in this field of health from this context. Moreover Sanders and Wilkins (2009) urge researchers to carry out research that contributes to the pool of knowledge and advance professionalism. I will therefore contribute to the pool of knowledge and partly fill the gap to the limited literature in this area through findings from this study.

Further, as a member of a non-governmental organization where parents of children with CP and their children are registered, I have a desire to contribute to the psychological well-being of members of this society through findings from this research. I therefore hope to disseminate the findings to the members of this society through a special forum with them once the study is concluded.

1.7. A brief description of the context

The study was carried out in Nairobi, Kenya; hence the need to give a brief background of this context. Kenya is a home to approximately forty million people with more than 80% of them living in rural areas as reported by the 2009 census report (KNBS, 2010). Nairobi is the capital city of Kenya with a population of 3,138,369 million (KNBS, 2010). It is an urban setting that enjoys a cultural diversity because all the major Kenyan ethnic groups are represented in this city (KNBS, 2010).
The majority of Kenyans ascribe to a religion. The religious groups comprise of 82.5% Christians, while the remaining 17.5% consist of other smaller groupings with the Muslims being the majority at 11% (KNBS, 2010). The country has 42 ethnic groups commonly known as tribes which subscribe to different cultures. Culture is defined as set of basic assumptions and values, beliefs, procedures and behaviours that are shared by a group of people which directs each member’s behaviour within the group (Spencer-Oatery, 2008). The 42 communities or ethnic groups are classified into Bantu, Nilote and Cushite (KNBS, 2010).

With about 42 communities, cultural diversity has been a breeding ground for conflict. A study by Makoloo (2005) revealed that ethnicity can be a risk in the medium to long-term in terms of causing conflict. There have been occasional conflicts brought about by politics, social, economic and cultural discrimination (Makoloo, 2005; Yieke, 2010) in the past. Land distribution was another source of ethnic conflict as communities struggled over land resources in Kenya (Yieke, 2010).

Makoloo (2005), in highlighting the politics of ethnicity in Kenya, pointed to the prevalence of marginalisation of ethnic minorities within communities in Kenya. Women and others within minority groups such as children, older people and disabled people suffer because they are left to fight for their issues within these marginalised ethnic groups (Makoloo, 2005). A disabled woman who comes from a minority group may therefore suffer double marginalisation, firstly because of her gender and secondly because of her ethnic minority background.

The diversity of cultural views about disability has shaped how disabled people have been treated from different cultural backgrounds in Kenya. While the vast majority of the literature points to negative traditional attitudes towards disability (for example, Gona, Hartley and Newton (2006) points to disability being caused by witchcraft, evil spirits or punishment from God) others have shown positive traditional attitudes towards disability as a blessing from God and a sign of good things in the family (Ruto and Ogechi, 2002). In chapter two, I will be discussing how a number of cultural views about disability from diverse cultural backgrounds within Kenya have shaped how disability is understood.
The national language is Kiswahili while the official language is English (GOK, 2010). A number of Kenyans speak two languages (bilingual) or three (trilingual) whereby they speak the national language, an official language and a mother tongue if they grew up in rural areas. For those who grow up in urban areas, they normally speak the national language and the official language with a few words from their mother tongue. Others may speak several languages depending on their interest in other languages as they interact with people from diverse backgrounds. Sign language and Braille has also been promoted by the new Kenyan constitution and has been adopted as a means of communication in Kenya (GOK, 2010). However a review of its application show that this has not been fully embraced as revealed in the report by Kenya National Commission of Human Rights (KNCHR, 2014). This report revealed that only special schools have embraced sign language with a few hospitals, courts and media groups adhering to this requirement.

The Kenyan economy depends substantially on rain-fed agriculture (Wiesmann, Kiteme and Mwangi, 2014), which contributes 25% of the Gross Domestic Product [GDP]. A research study by Ng’ang’a (2013) carried out in Central Kenya revealed that a number of disabled people engage in agricultural activities. However, this engagement can be problematic for certain forms of disabilities, like mental and physical disabilities (Ng’ang’a, 2013). Gachetha (2009) pointed to her own physical disability as a challenge that hindered her capacity to engage in agricultural activities. Lack of resources like land and finances also hinders disabled people in actively engaging in agriculture (Ng’ang’a, 2013).

A government report by Mukobe (2013) pointed out that disabled people in Kenya are generally economically deprived. Their deprivation result from barriers like poverty, stigma, marginalisation and limited access to certain rights and benefits. These barriers lead disabled people to be ill prepared for the labour marke, hence the challenges they face. Although Kiarie (2014) highlighted that facilities that cater for disabled people are concentrated in major towns, a government report pointed out that the majority of disabled people reside within rural areas (Mukobe, 2013). There is therefore a disparity between the available facilities and where disabled people reside. The nation also suffers from lack of welfare systems to cater for the needs of disabled people and their family members. However, this point will be expounded in chapter two.
Disabled people in Kenya are not a homogeneous group, as some of them come from rich backgrounds while others come from poor backgrounds and they are impacted differently depending on their background, location, status and gender (Mugo et al., 2010). For instance, being rich and disabled means you have better access to basic human rights, while being poor and disabled may mean a deprivation of human rights resulting from marginalisation due to your status in society (AFUAB, 2007). Despite recent government initiatives in the area, disabled people generally still face substantial disadvantage and this shall be discussed in detail in chapter two.

Urbanisation is an important factor to consider in this context. Urbanisation is taking place rapidly (Hope, 2013). This is due to a concentration of essential services like medical, financial, employment opportunities and recreational services that are mainly found in major towns (Hope, 2013). A number of people elect to move to towns in search of employment and other amenities like hospitals, schools and social places that are concentrated in towns (Blum, 2007; Hope, 2013). This kind of movement affects disabled people who are also expected to move closer to the essential services.

The major transport system in Kenya is the road network, which covers most parts of the country (Wiesmann et al., 2014). However, this mode of transport poses challenges to disabled people, as those with physical disabilities struggle with lack of accessible public transport that can take care of their wheelchairs (Kabue, 2015; KNCHR, 2014) and personal needs. They experience challenges in boarding and disembarking from public transport due to narrow entrances, steep stairs and lack of grabs, not to mention lack of audio messages to direct the blind (Kabue, 2015; KNCHR, 2014) in public transport.

The Kenya National Commission on Human Rights (2014) revealed that a number of buildings do not have ramps to cater for the needs of disabled people in this context. More recently at a conference for the Kenya National Secretaries Association (KENASA, 2015), Ipalei, a disabled person, in addressing participants on disability mainstreaming, pointed out how disabled people are disadvantaged by the non-disabled who do not consider building ramps instead of lifts in the majority of buildings in Kenya as the non-disabled can comfortably use ramps. He challenged non-disabled people that, if all buildings were designed with ramps instead of lifts, both disabled people and non-disabled people could comfortably access buildings.
Kenya attained its independence from British Colonial rule in 1963 and became a republic in 1964 (Makoloo, 2005). Prior to this, the British people came and settled in Kenya's most fertile land which was known as the White Highlands (Makoloo, 2005). After independence, this land was returned to the Republic of Kenya and this has been a major source of conflict to date as identified by Makoloo (2005). However, a positive impact of colonialism in Kenya can be in terms of the development of infrastructure and the transport system. The Kenyan railway transport system that was valuable in reforming the transport industry in Kenya was built during this time (Kenya World Education, 2015). The railway has been a major transport system that connected Kenya to neighbouring countries. Another key area where development originated from the British rule is in the area of disability. Kiarie (2014) states that the earliest legislation on disabled people was developed during colonial rule. Thus the major institutions that took care of disabled people were built at that time: hence the progress being experienced in the field of disability originated from the colonial rule (Mwendwa, 1964). Consequently, the legacy of the British colonial rule is still being felt in the Kenyan context in terms of development and disability.

The country has a state corporation known as the National Corporation for People with Disabilities (NCPWD) that was established in November, 2004, following the enactment of the Disability Act (GOK, 2003). This corporation has played a major role in championing for the rights of disabled people in Kenya (NCPWD, 2014). Its role is to mainstream disability issues in all aspects of social, cultural, economic and political development. The NCPWD works closely with the media by calling for press conferences, writing articles, features, doing radio and TV presentations to raise awareness on the rights of disabled people, in order to reduce stigma and promote an inclusive society (NCPWD, 2014).

1.8. Disability and current government policy

In Kenya, disability is said to affect approximately 10% of the total population (Ministry of Planning and National Development, 2006) while KNBS (2009) estimated the prevalence rate at 3.5%. The prevalence rate of CP is estimated at 2.5 out of every one thousand children (CPSK, 2011). Based
on the 2007 household survey on disabilities, approximately 79% of the disabled people live in rural areas.

A rise of public attention on disability in the Kenyan context can be traced to the 1980s when the United Disabled Persons of Kenya (UDPK) movement - an umbrella body for the disabled that was formed to take over the functions of disability groups and champion for activities of all disabled people nationwide - took a central role in spearheading the activities that were being run by several smaller disabled people’s organizations (AFUB, 2007). From its inception, this body has worked closely with the government to review policy, plan and evaluate the policies in place for disabled people. It was through this body that a task force was formed, which incorporated some disabled members of the government and pushed for policy change. This stimulated the passing of the 2003 Disability Act (AFUB, 2007), which marked the first major initiative put in place in Kenya to address the issues of disabled people. UDPK also teamed up with other bodies that represented various disability groups, civil society organizations and churches to pursue the representation of the constitutional requirements of the disabled community within the current Constitution (GOK, 2010). Their efforts were rewarded when their agenda was accepted and incorporated into the Kenyan constitution.

Hence, there has been progress experienced in the field of disability in terms of policy. Progress in the field of disability in Kenya has been made in terms of policy development through NCPWD that mainstreams disability issues in all aspects of socio-cultural, economic and political development (Kamundia, 2013). Further to this, the government also offers training to persons with disabilities and facilitates access to government procurement and disposal opportunities (NCPWD, 2014). In addition, 30% of all government tenders are to be awarded to this group (National Council for People with Disabilities (NCPWD, 2014). Gatere and Shale (2014) in a study that sought to establish the progress in the implementation of the award of 30% of government contracts to the special group of young people, women and disabled people confirmed that a number of these special groups were accessing these government opportunities. This was further confirmed in a concept paper by the Kenyan government to the United Nations (UN) conference held in New York which reported that the government initiative on procurement saw about 3,208
women enterprises, 2,474 young people’s enterprises and 72 disabled people enterprises benefit with Kenya Shilling (KES) 8.2 billion worth of tenders awarded by the government (GOK, 2015).

Access to information is another important part of human rights (KNCHR, 2014). In order for all inclusive information, disabled people have a right to freedom of expression and access to information on equal basis with others, through all forms of communication channels of their choice. However, a report by the KNCHR (2014) revealed that dissemination of information through the mass media was limited for disabled people. For instance, a number of TV channels fail to add a sign language translator to cater for the needs of people with hearing impairments (KNCHR, 2014).

Overall, however, although Kenya has put in place a legislative and policy framework to protect disabled people within its jurisdiction, a report by KNCHR (2014) revealed gaps in terms of implementing these laws in relation to infrastructure, health services, education, work and employment. It reported that implementation levels are slow, poor or missing. Further to this a report by AFUB (2007) revealed that, despite legislation put in place to take care of the rights of disabled people in Kenya, disabled people still experience inequality, disrespect and are excluded from mainstream society. Despite the developing legislative framework in the field of disability, the nation still lacks of an all-inclusive system that can cater for the needs of disabled people and their family members (Mukobe, 2013).

1.9. Description of study methods and participants

The study utilised a qualitative research methodology to explore experiences of six young people who have a sibling with cerebral palsy (CP), living in Nairobi, Kenya. The emphasis was on how the young people experienced being a sibling of a child with CP and how they understood and made sense of it. Out of the six young people who took part in this study, there were two females and four males aged between eighteen and twenty-four years. Four of the participants were Christians while two were Muslims. The study used semi-structured interviews to collect data that was analysed using an Interpretative Phenomenological Analysis (IPA) approach.
1.10. The structure of the thesis

The thesis is divided into six chapters. Chapter one contains the introduction of the study; the second chapter contains the literature review and aims at contextualising the study within the existing literature. The third chapter explores the methodology and methods adopted. It further highlights how ethical and trustworthiness issues were addressed and discusses the stance taken in the study as an insider. The fourth chapter presents the analysis of the findings from the study. The fifth chapter discusses the findings in light of the literature reviewed earlier in chapter two and highlights the original contribution to knowledge. The sixth chapter provides a summary of the findings and its contribution to knowledge, critiques the study, makes recommendations for further research and potential application, and ends with a final reflexive statement. Finally, a reference list and appendices of relevant reference material used in this study are provided.
CHAPTER 2 - LITERATURE REVIEW

2. Overview of the Chapter

This chapter entails a review of the literature that set the stage for the study of the experiences of young adults who have a sibling with cerebral palsy living in Nairobi, Kenya. The research addresses the question of how young adults who have a sibling with CP experience their role as siblings of a child with CP and the potential impact that this has on their psychological wellbeing. The chapter also provides an introduction to literature that will help contextualize the findings. Finally a conclusion to the chapter is provided.

2.1. The literature review

I begin this section by looking at what the literature review involved, the inclusion and exclusion criteria for literature reviewed and what was put in place in order to conduct this review.

Hart (1998 p.13) defines a literature review as:

"the selection of available documents (both published and unpublished) on the topic, which contain information, ideas, data and evidence written from a particular stand point to fulfill certain aims or express certain views on the nature of the topic and how it is to be investigated, and the effective evaluation of these documents in relation to the research being proposed”.

The purpose of a literature review is therefore to acquire an understanding of the topic, what has already been done in the field, how it was done and the key issues in the area of research. To effectively review literature there is the need to have inclusion and exclusion criteria (McLeod, 2001).

Randolph (2009 p.4) argues that “deciding how wide to cast the net is a critical step in conducting a review”. Lam and Kennedy (2005) on their part assert that if the inclusion criterion is too broad,
this might compromise the standard of the study and lower the confidence in the final result of the study. A set of inclusion and exclusion criteria therefore helped to focus my review. Hart (1998) argues that a literature review should focus on the historical developments in the field of study, while Nyandemo (2012) and Mugenda and Mugenda (2003) on their part highlight that a review of literature should sharpen the theoretical framework of the research. In line with this, I commence with a summary of the historical context that focuses on the theoretical aspect of disabilities. I look at models of disabilities that may provide an insight into issues that relate to the experiences of young adults who have a sibling with CP. This review of theoretical models is an international one and provides an insight into how disability is understood from a global context. Reviewing the historical aspect and focusing the review on the theoretical aspect was necessary in broadening my understanding and that of my readers about the topic under study, as well as showing that previous research had been undertaken on the topic. In so doing, I and my reader are enabled to locate the study within the academic framework and deepen an understanding of the issues involved.

The review also provides literature available on the psychological experiences of young adults who have a sibling with CP. While my focus was on the experiences of siblings of those with CP, other forms of disabilities were considered in this review. This is because the Social Model views disability from a general point of view in terms of impairments, physical, intellectual and sensory and mental illness (Barnes et. al., 2002), understanding disabled people as sharing a common phenomenon of being “systematically oppressed and discriminated against” (Lang, 2007 p.3). However, I was aware that siblings of children with other forms of disability could be impacted differently; hence I have acknowledged where other forms of disabilities have been reviewed. The research studies that I reviewed demonstrated both positive and negative impact on siblings, which led me to introduce literature on post-traumatic growth and disability by association as theoretical contextualization for both.

Considering the fact that this study was undertaken within an African context, it was important to review literature from this context specifically in order to set the stage for the study. Kenya is characterised by cultural diversity and its people inhabit different socioeconomic positions (Hope, 2013), factors which might be expected to impact on the experiences of siblings of those with CP.
Hence the review has considered the cultural and social economic status of Kenya in order to contextualize the potential impact of CP on the psychological well-being of the non-CP sibling. Randolph (2009) further highlighted the importance of the language used in the review. I included only those studies that were written in English in my review because I was familiar with it. Again, in keeping with the current trends in the field of study, I focused on studies that were published between the year 2000 and 2015 as the year of publication was an important factor to consider in identifying the current trends in my field of study. The above inclusion criteria are what provided the rationale for the headings that have been included in this chapter.

As indicated, I excluded studies undertaken prior to 2000 unless they were addressing key theoretical aspects as a way of identifying the current trends in the field of study as argued by Hagen Zanker and Mallet (2013). Again I excluded studies that looked at the impact of CP on parents, grandparents or caregiver as the phenomenon may have been experienced differently. Again, excluded from this review were studies that were not written in English. My focus was on qualitative research in general but I have included quantitative material, e.g. the rates of poverty, to help contextualization.

Finally, Hart (1998) argues that for one to carry out a scholarly review one requires a mastery of skills to systematically review literature across disciplines. In agreeing with this, I follow by providing the strategies I used to search for literature in the next section.

2.1.1. Literature search strategies

In order to identify literature for this study, I carried out a systematic literature search to establish the relevant literature that addressed my research question namely: "How do young adults experience and understand the psychological impact of growing up with a sibling with cerebral palsy within a Kenyan context?" I accessed electronic resources such as journals, e-books and articles via the University of Manchester Library. This led me to credible databases like Psych Info, Pub med and Medline that were relevant to the field of study.
For me to effectively carry out the search, I began by breaking down the research topic into smaller components and began searching using key words and phrases related to my topic, such as “disabilities”, “Cerebral palsy”, “cerebral palsy within Kenyan context” “cultural views about disabilities”, “models of disabilities”, “the psychological models of understanding disabilities” and “coping with psychological issues”, as a starting point. These key words and phrases were modified as the study progressed to include other key words or remove other words in order to focus the search.

A number of key studies were identified, which I examined before selecting the most applicable ones. Some of the studies cited led me to others which were also relevant for this study. However, it should be noted that not all the literature perused has been included in this review as some of it only acted as a pointer to others, thereby increasing the knowledge base and understanding of the topic.

To access some of the relevant electronic literature while off campus, I used shibboleth as a tool that led me to use my university access rights to access some restricted literature. My access rights to the Kenya Association of Professional Counsellors (KAPC) library, made it possible for me to peruse relevant books, articles and journals within the library that were critical in building, strengthening and constructing my literature base. I also visited some of the home (Kenyan) universities, to peruse both published and unpublished (grey materials) in their libraries. This was important in broadening my understanding of the subject considering that this study was carried out within the Kenyan context.

In conclusion, the search for literature was a continuous process that enabled me to review further literature on the topic which was relevant in contextualizing the findings as the study progressed. This was in agreement with Hart’s (1998) point of view that literature can begin before one embarks on the research process and it is bound to go on even after the project is concluded.
2.2. Models of Disability

There are a number of models of disabilities that have shaped how disability is understood in different contexts (Devlieger, 2005). These models were generally developed within the West and at different historical points. They thus need to be understood within these geographical, cultural and historical contexts. Moreover, within different societies, conflicting understanding coexist at any one time. In Great Britain, for instance, it can be argued that the medical, social and charity model all currently influence popular understanding. While the medical model was the first to be documented among these models, the moral model has been in existence longer than this model. On the other hand the social model was developed in reaction to the medical model by disabled people themselves. In order to expand on how disability is understood and interpreted in various contexts, I have reviewed some of these models in this section. This will set the stage for my study on experiences of young adults who have a sibling with CP.

2.2.1. Medical Model of Disability

The Medical Model of disabilities that originates from the West pioneered in documenting the issues of disability (Ghosh, 2012). Historically the Medical Model sprung up in the 1800s (Goodley, 2011). This model defines disability as a restriction or lack of ability to perform an activity in a normal manner that is attributed to illness and impairment (Burry, 2000). The Medical Model sees disabilities as a problem of the individual caused by disease, trauma or other related health conditions that require treatment, rehabilitation and cure (Burry, 2000; Langtree, 2010). It has led to ways in which professionals in the field have defined appropriate ways of responding to different kinds of disability from a medical point of view (Langtree, 2010). The major emphasis of this model is to rehabilitate the individual to restore the person to normalcy (Goodley, 2011); hence rehabilitation forms a major part of treatment of disabilities. This model is an influential one not only in the West but in medical settings elsewhere, including Kenya, and potentially feeds into popular notions of disability as residing in the individual. While this model can be criticised for over-emphasising the medical aspect (Langtree, 2010) and ignoring the psychological challenges that disabled people encounter, medical diagnosis is often an important first step in accessing support services across different societies.
2.2.2. The Social Model of Disability

The social model of disability has its roots in the Social Relational Model of disability. The social relational model defines disability as a "form of social oppression involving the social imposition of restrictions of activity on people with impairments and socially engendered undermining of their psycho-emotional well-being (Thomas, 1999 p.60). The social relational model was overshadowed by the emerging of its offspring, the Social Model of Disability (Thomas, 2004).

The Social Model of Disabilities (SMD) was developed from the disabled people’s movement both in Europe and United States in the 1970s and 1980s (Ghosh, 2012). It aimed to advance the rights of disabled people and their inclusion in mainstream society (Thomas, 1999). Disability was seen as

"the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1976: 14).

From this definition, disability is seen as a restriction of activity which excludes people with impairment from involvement in social activities in mainstream society. The SMD maintains that "disability is the outcome of social barriers that restrict the activities of the people with impairment" (Thomas, 2004 p.570). This model understands disability from a social context and views disability as a social problem, as it emphasises the attitudinal, environmental and organizational barriers that debar disabled people from participating in major domains of social life (Thomas, 1999; Barnes, 2012; Carson, 2009; Priestly, 2009; Wasserman et al., 2013).

The Social Model of Disability is a major theoretical underpinning that identifies disability as something that happens as a result of our relationship with a disabling world which restricts the activities of the people with impairment (Thomas, 2004). Its emphasis is on the rectification of environmental factors which influence greatly how disabled people function (Wasserman, Bluestein and Putnam, 2013).
A critique of the Social Model is that it denies illness, pain or medication and concentrates on the society’s attitudes (Humphrey, 1994), as a major issue for disabled people. Lang (2001) from a Social Model point of view argues that if the society’s attitudes were dealt with, the psychological issues or challenges faced by disabled people and their families would be resolved. However, the Social Model of disabilities has made a major contribution to the disability field through its acceptance in the political platform as a tool to secure the rights of disabled people through ensuring that they enjoy the status of full citizens within the society (Lang, 2001).

Ghosh (2012) in his paper suggests that society excludes disabled people through thinking, language, the built environment, power, structural and information; hence disability is not just about impairment but about barriers that affects individuals and significant others. According to the social model of disability, it is about the barriers that one has to deal with. Further to these Langtree (2010) emphasises the collective responsibility of society as necessary for integration of disabled people into society. The social model therefore might help shed light on how such barriers might adversely impact on the lives of siblings.

This model has become influential in terms of shaping policy on a global basis. However, arguably there has been limited progress made in terms of implementing the changes necessary as highlighted in this model, both in the West and in Africa. Hence it would be useful to establish how far these changes have been implemented for participants in my study, who are from an African context. The study therefore will be looking through the social model of disability lenses at how the non-CP siblings interact with a disabling environment due to their sibling’s condition and the impact it has on their psychological wellbeing.

2.2.3. The International Classification of Functioning

The International Classification of Functioning (ICF) model of disability is, “a universal model that captures the complexities of disabilities” (Goodley, 2011 p.19). This model was developed by the World Health Organization and officially endorsed in 2001 by all its members at the 54th World Health assembly held in Australia to describe functioning and disability (WHO, 2001) from a global front. The approval of ICF by the WHO assembly marked a step in understanding disabilities from
a global front as this model has been accepted by majority of nations to define disability. It acknowledges that human beings are prone to deterioration in life and this can lead to disability. Therefore disability is not seen as something for a few but part of human experience (Konstanjeseck, 2011). This model focuses on broader aspects of an individual to provide proper management of the condition (Kostanjeseck, 2011). Disability from this model is understood through both individual and social consequences (WHO, 2001). It thus combines the social model of disabilities and the medical model to broaden an understanding of disabilities (Goodley, 2011).

This model defines functioning and disability as multi-dimensional concepts relating to “the body functions and structures of people, the activities people do and the life areas in which they participate and the factors in the environment that affect these experiences” (Australian Institute of Health and Welfare, 2004, p.1). Disability is seen as an interaction between health conditions, environmental and personal factors (Goodley, 2011). This model provides a framework that supports better policies and services to meet the needs of disabled people (Australian Institute of Health and Welfare, 2004).

This model has been implemented in various settings and sections since its inception. By being accepted globally, therefore, the ICF model can facilitate legislation that governs disability through assessment, planning and measuring changes that can bring about certain interventions in the field of disabilities (Konstanjseck, 2011). A number of laws in the Kenyan context were put in place in response to this model, which emphasises the implementation of major frameworks to govern disability from a political platform. However, this model has been critiqued because of pursuing universalism. It is regarded as in danger of ignoring the cultural aspects on which impairments and disabilities are created (Goodley, 2011). It therefore can under emphasise the cultural context within which disability is understood.

### 2.2.4. The Affirmation Model of Disability

The Affirmation Model of Disability, on its part, identifies disability as a normal form of human difference (Swain and French, 2000). This model as proposed by Swain and French (2000) originated from a movement by disabled people within the West which focused on the positive side
of disability. Disabled individuals are viewed as normal people who are only distinct because of their disability. Also, disabled people are to be appreciated and valued for who they are irrespective of their race, sex, gender, and impairment (Swain and French, 2000). This model bears resemblance to some of the cultural views from the Kenyan context where there is some evidence that the Kisii and Nandi communities consider disabled people as normal people who are only different (Ogechi and Ruto, 2002). This model which aims at promoting a positive view of disability can also be useful in highlighting how within certain societies positive views about disability can be identified. However, the model can be criticised for ignoring the disabling impact of society and the reality of disabled people’s lives.

### 2.2.5. The Moral Model of Disability

The Moral Model of Disability is the oldest model of disability (Goodley, 2011) which originated from religion (Langtree, 2010). This model reflects long held attitudes towards disabled people across the world. These views existed within Britain and arguably remnants of this are still evident in contemporary British society. As a society with a religious background, these attitudes are also still prevalent in the Kenyan society. This model views disabilities as a defect caused by moral lapses or sins or a test of an individual’s faith (Goodley, 2011). The Moral Model believes that people are morally responsible for their own disability and that families are held responsible for their disabilities (Goodley, 2011; Langtree, 2010) whether good or bad. For instance, disability may be viewed as a result of a bad act by the parents or some form of punishment due to certain actions in someone’s family.

On a positive note in certain instances, disability may be viewed positively as a gift from above (Devlieger, 2005). The Moral Model can lead on one hand to an acceptance of the disability as disabled people are seen as in touch with God and spiritual embodiments while, on the other hand, there can be profound shame and a hiding of disabled people for fear of being labelled sinful (Goodley, 2011). Considering that Kenyans ascribe to both cultural and religious affiliation, this model seems relevant in terms of illuminating some of the issues involved for siblings who have a sibling with CP.
2.2.6. The Tragedy or Charity Model of Disability

The Tragedy or Charity Model of Disability depicts disabled people as victims who are in need of help and pity (Langtree, 2010). Depending on the level of disability, this model understands disabled people as not being capable of doing many things on their own. For instance “they cannot walk, talk, see, learn or work and therefore they depend on others for support” (Handicap International, 2015 p.1). Evidence for the existence of such attitudes can be pointed to in the range of voluntary organisations worldwide aimed at supporting disabled people. For instance in the Kenyan context, a number of Christian organisations work closely with the government to support disabled people (Kenya Disability Directory, 2010).

The Charity Model views disabled people as victims of their impairment as they mainly depend on others for their survival (Handicap International, 2015). Disabled people according to this model are to be provided with charity as they are deemed to be in dire need of support (Langtree, 2010) all the time.

Considering that the young adults in this study were depended on by their siblings with CP, this model is useful in illuminating how disabled people and their families are viewed by society.

2.2.7. The Empowering Model of Disability

The empowering model is aimed at empowerment of disabled people rather than providing an explanation for disability. It encourages people to decide on the kind of treatment and services they wish to engage in (Langtree, 2010). This shifts power from professionals and vests it in disabled people to pursue their goals (Disability Diversity, 2010; Langtree, 2010). This model, like the social model, aims at shifting society’s attitudes as well as influencing policy. It views disability as having natural causes and attempts to encourage change within society by empowering the disabled individual. This model views disabled people as people who are in a position to make their own decisions and are capable of handling their own issues as long as a conducive environment is provided to facilitate this. It empowers them to take full control of their lives and
moves power vested in the society to the individuals with disabilities themselves. This model works on the assumption that disabled people and their families are in a position to come up with goals and to pursue them (Langtree, 2010). The empowering model has some relevance to the current study as it vests power with disabled people and family members; hence it may shine light on the sense of empowerment the young adults in this study experience within the Kenyan context.

It is apparent from this review that models of disability have shaped how disability is understood from different contexts. The medical model emphasises the medical aspect of disability, the social model emphasises the social barriers as major challenges faced by disabled people, and the ICF understands disability through both individual and social consequences while the affirmation model accepts disability as difference. The moral model views disability as caused by moral decay, the tragedy model views disabled people as victims in need of mercy, and finally the empowering model focuses on empowering disabled people to take charge of their lives. All these models therefore potentially provide insight into the attitudes surrounding disability within Kenya and the challenges faced by disabled people and by extension, their families and in particular siblings.

Having looked at the models of disabilities, I now move to an explicit exploration of Kenyan views.

### 2.3. Kenyan cultural views about disability

In this section, I focus on the Kenyan cultural views about disability. By highlighting the Kenyan cultural views about disability, I will be setting the stage for how the young adults experience the phenomenon from this context.

Being home of the 42 communities, Kenya enjoys a diverse cultural background and this may point to differing views about disability from the different community groupings (Ogechi and Ruto, 2002). This is in agreement with views by Eksay et al. (2012), who looked at disability from an African point of view and posit that disability was perceived differently across culture and that it has shaped the kind of services disabled people receive.
Culture can be defined as a traditional method of passing cultural heritage from one generation to another (Eksay et al, 2012) in written or oral form. This may be in terms of food, dressing, beliefs and values that are strongly held by a particular society. Spencer-Oatey (2008 p.3) defined culture as a "set of basic assumptions and values, orientations to life, beliefs, policies, procedures and behavioural conventions that are shared by a group of people that influence each member’s behaviour and his or her interpretation of the meaning of other people’s behaviour”. However, there is a huge amount of literature debating the meaning of culture, too vast to be within the scope of this study.

In general, attitudes towards disability are depicted in a negative light e.g. ‘In Africa, children with disabilities and their families face a long standing history of stigma, discrimination, and exclusion from mainstream society’ (ACPF, 2014 p.36). The idea of disability ‘as curse’ is prevalent among Kenyan communities (Wa-Mungai, 2009). Although research undertaken on this topic is limited, some studies, from this context, have shown evidence of divergent reactions towards disabilities (Mugo, Oranga and Singal, 2010: Ogechi and Ruto, 2002). Ogechi and Ruto (2002) examined how disability was portrayed among the Kisii and Kalenjin communities, through personal names and proverbs. This study focused on the naming patterns of two communities as well as reviewing the proverbs used in the two communities. This revealed that, in terms of language use, social stigma was not always attached to one in terms of the disability in itself, but rather on its impact on the individual’s ability to function as a member of the society. Disability in these communities went beyond physical impairments and therefore one was not regarded as disabled if they met social obligations. Again, in order to examine the use of names and proverbs, Ogechi and Ruto (2002) examined names that identify certain disabilities in their naming systems to establish the connotation they held. The results from their review revealed that the names had positive connotations that they argued were used to demystify disabilities. The names, which began as nicknames eventually developed and were adopted for use by non-disabled people in the two communities. The authors argued that this demonstrated the demystification of disability. Again, it was argued that a number of proverbs discouraged negative perceptions towards disabled people in the communities studied and encouraged positive affectionate feelings towards disabled individuals. However, language use can only be regarded as suggestive of attitudes. Also this was
only a small scale localised study that looked at only two communities. Hence the findings cannot be generalised to the Kenyan situation as a whole.

Monk and Wee (2008) on the other hand examined the range of attitudes towards people with physical disabilities in a study carried out in Bondo in Western Kenya. The people of Bondo belong to the Luo community, residing in Nyanza Province, a province in the Western part of Kenya that represents a percentage of 15% of the total population of Kenya (KNBS, 2010). This study, examined the attitudes towards disabled people, using the International Classification of Functioning (ICF) model of disability that focuses on disabilities through both individual and social contexts and established that the society held some positive attitudes towards disabled people that made them feel accepted. This mixed methods study looked at attitudes towards disability through interviews and document collection (Monk and Wee, 2008). Findings from this study showed that, overall, attitudes were more positive than expected within a rural area, although traditional, negative attitudes still continued (Monk and Wee, 2008). Perceived causes of disability in this community included accidents and illness, traditional causes, natural causes, poverty and ageing. Moreover, as disability was largely seen as beyond an individual’s control, disabled people tended to be supported. However, again, this was small scale study and hence the findings communicate attitudes from a small section of Kenyans only.

Another study done by Gona, Hartley and Newton (2006) focused on the cultural views about disability from the people of Kilifi in the coastal region of Kenya. Kilifi is one of the towns in the coastal region, which has a population of about 1,109,735 people (KNBS, 2010). The study, which had a total of 144 participants, among them village elders, women groups and teachers, employed the Participatory Rural Appraisal (PRA) approach to identify perception about disabilities. The PRA method involved collecting views from those people who deal with disabled individuals to identify their perceptions about disability. Results from this study which were subjected to a thematic analysis revealed that people in this community believed that disability was caused by traditional beliefs like witchcraft, evil spirits and punishment from God (Gona et. al., 2006). Views from this community reflect the moral model of disabilities that views disabilities as a defect caused by moral lapses or sins or a test of an individual’s faith (Goodley, 2011).
The Kenya National Commission on Human Rights (KNCHR) carried out a survey in 12 counties to evaluate how far the government had fulfilled its obligation to protect, promote and fulfill the rights of disabled people within its jurisdiction and found that disabled people still faced cultural stigmatization as they interacted with society. An example was given by a visually impaired participant who confirmed he was referred to as a ‘beggar’ even when he did not engage in begging. This kind of labeling lowered his self-esteem and stigmatized him as a result.

Arguably, there have been mixed views and reactions about disabled people in Kenyan context. Some have been treated well while others have been mistreated depending on the traditional beliefs of the particular community and what they believed was the origin or cause of disability. Even from the same cultural background, divergent views have been identified which has impacted on how disabled people have been handled or treated. (Gona, Hartley and Newton, 2006; Ogechi and Ruto, 2002; Mugo et al., 2010). The majority of these cultural views seem to dwell on the physical dimension of disability (Mbugua-wa-Mungai, 2014).

Religious beliefs have also shaped how disabled people have been treated in the Kenyan context. From a Christian point of view, there were both negative and positive views about disability (Abosi, 2003; Gona, Hartley and Newton, 2006). Some of the positive views included disability as a favour from God or a gift from God (Gona et. al., 2006); while some of the negative views involved a belief in disability as a curse, punishment for the sins committed or the work of evil spirits (Gona et. al, 2006; Abosi, 2003). For instance, results from a study conducted by Gona et al. (2006) in Kilifi, Kenya revealed that disability was attributed to evil spirits in terms of calamities or punishment from God. An example is where a woman committed adultery with a brother in-law, she would give birth to a child with disability because of the sins committed. This fits with the moral model (Goodley, 2011) although again on a positive note it would be viewed as having faith in one’s ability to manage the condition (Devlieger, 2005; Goodley, 2015).

We see therefore that while traditional attitudes are portrayed as generally negative, this obscures variation in attitudes and the presence of, or potential for more positive attitudes in certain communities. What is missing from literature is clear evidence of how attitudes may have shifted in urban areas such as Nairobi. Wa-Mungai (2014) is pessimistic about the extent of change.
arguing that negative attitudes towards disability in Kenya are a 'persistent universal phenomenon'. The potential for vicarious stigmatization of siblings one could argue is evident.

2.4. Welfare support for disabled people in the Kenyan context

In the Kenyan context, the status of disabled people has been given emphasis through the Kenyan policy frameworks as reflected in the Kenyan Disability Act (GOK, 2003) and the Kenyan Constitution (GOK, 2010). However, these two policy frameworks are silent when it comes to siblings of disabled people. This notwithstanding, a number of steps have been put in place to ensure that disabled people enjoy a barrier free life and are able to participate fully in society (Mugo and Oranga, 2010). When this is done, they will have a positive impact on siblings who are also affected due to disability by association (experiences due to being related with a disabled person) – this shall be expounded later in the review.

A paper by Mugo et al. (2010) on testing young people’s transition in Kenya critically analysed the nature and range of challenges that young disabled people in Kenya encounter. Drawing from secondary data, government statistics, policies and official documents and data from one school for the blind in Nairobi, Kenya, they identified a number of loopholes within the Kenyan systems in terms of policies in place where disabled young people were not taken care of. It revealed policy gaps where young disabled people were overlooked in national youth policies as there were no clear policies in place to address the issues faced by young disabled people. Some of the gaps that were identified in this study were policy gaps, education gaps, employability and gender gaps. These gaps by extension impact on siblings who are expected to play a role in their sibling’s life.

Mugo et al.’s (2010) findings point to systems put in place that do not seem to adequately provide for the needs of disabled young people hence the reason the authors recommended the need for more research in this area in order for policy makers to make use of existing knowledge. These findings also brought to the fore some of the issues young disabled people face in Kenya. Although this study did not target the siblings of disabled individuals, it shone some light on what disabled people in Kenya might encounter and the potential secondary impact on the families of disabled people.
A focus on the developments in the welfare of disabled people through the KNCHR (2014) revealed a number of challenges still being encountered by disabled people in the Kenyan context. In terms of accessibility, the monitoring revealed that most building sampled were inaccessible with steep staircases and no ramps some with narrow doors that do not accommodate the wheelchairs (KNCHR, 2014). In terms of transport, most transport is inaccessible to disabled people who have either to be carried to board and alight from the vehicles (KNCHR, 2014). The report also pointed to lack of access to information by disabled people due to the mode of transmission which are newspapers, television and radio and internet that are too costly or inaccessible to disabled people (KNCHR, 2014). For instance, lack of wheelchairs, access to transport increases responsibilities of family, restricts potential movement of siblings as well as disabled siblings. Another challenge pointed to was work and employment where very few disabled people find opportunities in formal employment (KNCHR, 2014). Lack of formal employment for disabled people means disabled people have to fit in the limited family resources and this may have an impact on siblings who may miss out on family resources and these issues have a knock-on impact potentially for family members.

Murugami (2009), in a paper on identity and disability conducted in Kenya, argued that physical restriction still bars disabled people from accessing public utilities and transport, leading them to depend on others for assistance, hence lowering their self-esteem. For instance, disabled people feel stigmatised if they are to be carried by the non-disabled onto public transport because care may not be given to their decency and dignity (Murugami, 2009). Again they are concerned that public transport owners feel that disabled people take too much time to board public transport, hence their rights to public transport is infringed on. However, it can be argued that this paper may not have considered the progress made after the promulgation of the Kenyan Constitution (GOK, 2010).

The government of Kenya has put in place some mechanisms to empower disabled people to live independently by providing financial support and relief from taxation (National Council for People with Disabilities, 2011). However financial support is only available to those perceived as having severe disabilities (NCPD, 2011) while relief from taxation is available only to those in employments
This kind of support is expected to supplement what the family offers (GCSD, 2012), thereby potentially relieving constraints on families and improving their economic status, thereby improving the economic environment for siblings. However, the potential impact of these measures is reduced by their selective nature. There is a general need to look at whether the policies that govern the welfare of disabled people in Kenya are addressing their needs and the needs of their families effectively. A study carried out in Western Kenya by Monk and Wee’s (2008) revealed that disabled people did not receive any welfare support. The study, which also assessed how government facilities were utilised by disabled people and their families in one community, revealed that the only services available for disabled people were underutilised. This is a pointer to how government resources that are available may be underutilised.

Lack of access to education is one of the challenges disabled people in Kenya face (Mugo et al, 2010; Kiarie 2014; KNCHR, 2014). Kiarie (2014) examined the legislation put in place to contribute to the development of special education in Kenya and the United States. This paper argued that Kenya was still dealing with access and physical environmental challenges for the children with disabilities. It pointed to some of the challenges faced by people with physical disabilities in marginalised areas in North Eastern Kenya, which included a lack of special school facilities (Kiarie, 2014). Disabled children from marginalised areas are expected to travel long distances in search of such facilities. Kiarie (2014) further revealed that although people with physical disabilities received vocational training, they found it difficult to acquire jobs due to stiff competition from their counterparts who were able. Such challenges were also confirmed by a report by KNCHR (2014). The above which pointed to lack of educational access for their disabled sibling means increased care needs which may be undertaken by a non-CP sibling.

Considering that a number of issues disabled siblings experience happen because of their role within family, it would be useful to look at the family structure and role of the family in disability issues.
2.4.1. The role of the sibling in the care of a disabled sibling

The role of siblings in caring for a disabled sibling is an important one to consider in this review. Generally, Kenyan traditional families operated as part of a larger community (Ndurumo, 1993). Issues were dealt with at community or wider family level and whenever something happened to one member of the community, the community members came together to support each other and to share in any problem because a problem became lighter when shared by members of that community (Mukuria & Korir, 2006). It was similar if one of the family members had something to rejoice about, as the entire family came together to rejoice or celebrate. Extended families were therefore available to provide care and social support, thereby lessening the burden of care expected from a nuclear family, as highlighted by Ndurumo (1993) and Hope (2013). Although disability was generally viewed negatively, there was some sense of responsibility for care from the extended family.

However, the scenario where the community is available to provide care and ease the burden of the entire family seems to be changing (Hope, 2013). Care has been increasingly left to nuclear families to deal with, as families in Kenya are preferring to ascribe to a nuclear family structure rather than a collective one (Mukuria & Korir, 2006; Rombo et al., 2014). Individuals are preferring to have a family of father, mother, children and grandparents (Mukuria & Korir, 2006) as opposed to a larger community that existed in the past (Ndurumo, 1993). Furthermore, the Kenya Integrated Household Budget Survey undertaken in 2005/2006 revealed that 61.3% of people in Kenya were in monogamous families, while 13.9% were in polygamous relationships (KNBS, 2008). This was a decline from the past where polygamous families were the order of the day (Mbiti, 1969).

The family structures in Kenya have had an influence on how disability is understood and responded to. As indicated above, the family is currently the major source of support to disabled people (NCPD, 2011); any changes in family structure may affect how the sibling with CP and the non-CP siblings are treated and the responsibilities that siblings are required to undertake. Children traditionally play an active role within the family economy by undertaking family chores (Ekstrand, 1994). Ekstrand (1994) examined children’s perception of child rearing norms and value of culture.
in Kenya, India and Sweden. This research which compared results from three countries, from three continents, established that children in Kenya and India have a strong family relationship as opposed to Swedish children who depended on social welfare systems. In Kenya, necessary chores at home were performed by children and this is not identified as child labour under the Children’s Act (GOK, 2007). In most cases children performed such tasks without any pay as this was part of family obligation while in Sweden; the study revealed that there were no demands on the child to perform family chores.

In the Kenyan context, family chores were performed as a primary responsibility by children and school was seen as secondary (Ekstrand, 1994). However, with the emergence of the new constitution and the introduction of free primary education, the emphasis has been on children attending school as a primary responsibility (GOK, 2010). However, this does not reduce their role of undertaking family chores whenever they are at home; hence the siblings are impacted in terms of caring for their siblings and attending school and this potentially impacts on their academic performance. A number of studies have shown that children and young people especially girls and young women are taking on caring roles for chronically ill, disabled and elderly relatives (Mophosho et al., 2009). This has a heavy impact on the girl child, who may be the non-CP sibling. It will thus be useful to establish whether the young adults in this study were involved in the care giving and whether gender plays any important role in determining this role.

On average, educated people in Kenya tend to prefer fewer children than those with no education (Kenya Population Data Sheet, 2011). However, this has a potential impact where there is a disabled member, as care obligations placed on siblings may be increased within the smaller family units. Conversely, the high levels of poverty in Kenya connected with disability mean that many families containing disabled members face severe economic hardship, whatever their family size. This is compounded by the lack of a comprehensive support system for care which further makes disabled people dependent on the nuclear families for social, financial, material and psychological support (Mugo et al., 2010), thereby impacting not only on non-disabled siblings’ lifestyles but potentially their sense of wellbeing.
2.5. **The psychological Impact of disability on non-disabled sibling**

There is some evidence that living with a sibling with disability can have both negative and positive effects on the typically growing sibling (Seligman and Darling, 2009). Seligman and Darling (2009) in their book ‘ordinary families, special children’ examined how families deal with and react when they have someone who is disabled and the effects this has on them, found that this can have both positive and negative effects. This book that was written in the United States looked at childhood disabilities and its effects on the family life as a whole (Seligman and Darling, 2009). In one of the chapters that focused at the siblings of children with disabilities, it was observed that living with a sibling with a disability can have both positive and negative effects on the non-disabled sibling similar to what people undergo when faced with traumatic experiences (Tedeschi and Calhoun, 1995). This study which was undertaken in the West, pointed to useful findings about the sibling of a disabled person. While findings from the west are not directly transferable to an African context, they point to the potential for both positive and negative effects of disability and therefore helped inform the current study.

I go on to discuss first the potential positive impact and the notion of posttraumatic growth and then move on to look at the negative ones.

### 2.5.1. The Positive Impact and notion of Posttraumatic growth

Joseph (2009) acknowledges that there is a likelihood of positive effects in traumatic events when she said that “there is personal gain to be found in suffering”. This personal gain is what Tedeschi and Calhoun (1999) referred to as Post traumatic Growth (PTG).

Tedeschi and Calhoun (1999) define Post traumatic Growth as a construct of positive psychological changes that happened to an individual who has undergone a stressful and traumatic life experience. Again, Chelser (2004: p1) defined PTG “as the experience of expression of positive life change as an outcome of a trauma in one’s life” His experiences of dealing with young people who survived cancer provide useful evidence of growth in the following areas: (a) new and greater strength, (b) greater empathy and compassion for others, (c) greater psychological maturity – they
feel more mature than their age mates (d) a deeper appreciation for life and (e) new life priorities, they do not feel so materialistic and greater sense of existentialists – they get to understand their purpose in life (Chelser, 2004).

Tedeschi and Calhoun (1995), found that exposure to traumatic experiences can lead to positive growth in certain people. They argued that although negative events tend to produce negative psychological effects, they also can lead to positive psychological growth as well. This was observed when referring to their earlier work that focused on individuals who had undergone a traumatic life event. The traumatic event included bereavement, injury producing accidents, separation and divorce of parents, relationship break up, criminal victimization, academic problems and unwanted pregnancy. This event had to have occurred at least within 5 years of the study. Results from this study revealed growth in three key areas (Tedeschi and Calhoun, 1995, 2006). The three major domains where change was likely to occur are (a) in the perception of self, (b) in the relationship with others and (c) in the general philosophy of life. This challenges the theory of Posttraumatic Stress Disorder (PTSD) that focuses on negative effects in traumatic events.

In their view, change in self occurs where an individual who is deemed vulnerable emerges strongly after an adversity. This may cause a re-defining of certain goals in life. This did not imply the absence of distress but that the individual has devised positive ways of dealing with adversity. In line with Tedeschi and Calhoun (2006) one has been weighed, tested and proven stronger as a result.

Arising from trauma, individuals can experience some growth in terms of relationship with others (Tedeschi and Calhoun, 1996). They might feel some greater connection to people and more so to those in difficult situations. Such people value and seek to form intimate relationships and closeness within the family, as the challenges help them to identify who their ‘rea’l friends are (Tedeschi and Calhoun, 2006). A study by McConnell et al. (2014) looking at families who were raising disabled children found that where the relationships were good, they were likely to experience good outcomes in terms dealing with the effects of disability.
A changed philosophy in life means there is a changed perception of what matters most for one after a traumatic event (Tedeschi and Calhoun, 2006). People tend to appreciate themselves for what they have as they no longer take anything for granted (Tedeschi and Calhoun, 2006).

Again, Tedeschi and Calhoun (2006) confirm that by managing one’s life crisis, it can give one the ability to handle future crisis through the experiences learnt from the previous crisis.

### 2.5.2. The potential positive impact of living with a disabled sibling

A number of studies have documented the positive impact of having a disabled sibling on non-disabled siblings (Dodd, 2004; Maher and Salmon, 2005; Earley, Cushway and Cassidy, 2007; Waters et al., 2005). This section reviews literature on some of the positive impact this is found to have had on the non-disabled siblings.

A UK study by Dodd (2004) that looked into issues that arose for families where there was a disabled child identified mixed responses among siblings. This study, which took place over a period of eight years, is one of the relatively few long-term studies undertaken in the area. In this study, some siblings reported positive responses while others reported negative feelings in relation to their disabled sibling. Some of the positive ones from the siblings’ reports included: having someone to play with, being happy in the company of disabled siblings and having friends who appreciate their sibling with disability (Dodd, 2004). Positive impacts were also observed in a number of studies in terms of acceptance and high level of maturity (Mophosho et al., 2010), positive relationships (Connors and Stalker, 2003) and closeness in the family (Earley et al., 2007; Burke, 2010). While these findings are not directly transferable to the Kenyan context, they highlight the potential for both positive and negative responses from siblings concerning their experiences.

From an African point of view, a South African study by Mophosho et al., (2010), focused on siblings’ perception about their sibling with CP and how these perceptions and interaction affected their life as a sibling. This study, which was qualitative, focused on four children aged between nine and eighteen years whose siblings had CP. They were observed and interviews carried out to
establish the impact of CP on the siblings of disabled children. The findings that were subjected to a thematic analysis revealed characteristics that were positive, and these were grouped into six themes. All participants accepted that their brother had CP and that they had adjusted to it, as demonstrated through the high levels of maturity and resilience about their brother with CP. The results further revealed that participants were happy about their disabled sibling (Mophosho et al., 2010). The participants were engaged in caring tasks and they helped their sibling willingly. Another important finding was that the majority of them had good relationship with each other and was close to the sibling with CP. It is therefore evident that the siblings experienced some positive growth in this study. This study although done elsewhere in Africa, has relevance to the current study because it targeted the siblings’ perception of their sibling with CP that this study has explored. However, Mophosho et al.’s (2010) study targeted participants as young as eight years, who may have had a limited interaction with their sibling. Again, the participants were all boys hence the study missed out on experiences by girls. It will thus be useful to establish from both girls and boys how they experience the phenomenon.

2.5.3. Negative impact of disabilities

A number of studies have documented the negative impact of having a disabled sibling on non-disabled siblings due to disability by association. Disability by association is where one is affected by virtue of their relationship with a disabled individual (Burke, 2010). Burke (2010) in a study which drew from two studies he undertook in the UK, looked at the impact of childhood disability on brothers and sisters in the family. The studies utilised both qualitative and quantitative data drawn from 116 families with 344 children where 118 had a disability. Burke labelled the experience of siblings as ‘disability by association’ – which means they experience disability due to the interactive effect of living with a disabled brother or sister (Burke, 2010). Negative effects were identified among them anxiety about the future caring role, vicarious stigma and restriction from social activities (Burke, 2010). It will thus be useful to find out whether the young adults in this study also experienced vicarious stigma as a result of their sibling’s condition.
2.5.3.1. Anxiety and concern about the future

Anxiety about the future has been identified where a sibling has a disabled brother or sister (Connors and Stalker, 2003). A good example of concern about the future was identified in a study by Connors and Stalker (2003) who looked at the views and experiences of disabled children and their siblings. This UK study focused on the accounts of 24 brothers and sisters of disabled children aged six to nine years old and identified worry about the future as one of the major concerns experienced by the siblings. Some of the worries involved concern at seeing parents distressed due to their sibling’s condition; worry that their disabled sibling might not play with others and a sense of responsibility about the child’s well-being. Worry about the possibility of the sibling giving birth to a disabled child was another concern expressed in this study. This study revealed that siblings look to the future with anxiety because of the high level of responsibilities that would befall them. It is these roles the siblings think would fall on them in the future that were a major source of concern (Connors and Stalker, 2003).

A study by Earley, Cushway and Cassidy (2007), also conducted in the UK, looked at children’s perceptions of experiences of care giving and revealed anxiety about the future as a major concern as well. This study that explored experiences of 17 young care givers aged ten to sixteen used a thematic analysis to analyse participants’ words. It revealed that participants worried about their transition to adulthood. A 13 year old commented that caring responsibilities would get in his way of having a girlfriend and it hurt that he would never live on his own in future (Earley, et al., 2007), as he was bound to take on caring roles. It is evident from the review that siblings worried about their future and that of their sibling with disability with an emphasis on future caring roles and giving birth to a disabled child. Anxiety was also experienced in a study by Burke (2010). At some point, my daughter confronted me with a question concerning who will take care of my daughter with CP when I die. Although this question surprised me, it was an eye opener that made me to reflect more closely on my daughter’s concern. Moreover, this became a pointer to some of the issues involved for young adults who have a sibling with CP.
2.5.3.2. Restrictions on the non-disabled sibling

Restriction on the non-disabled sibling has been identified in a number of studies (Earley et al., 2007; Connors and Starker, 2013; Burke, 2010; Seligman and Darling, 2009; Moyson and Roeyers, 2012). For instance, a phenomenological study by Moyson and Roeyers’ (2012) that looked at how the young siblings of children with intellectual disability defined their quality of life as a sibling confirms this. The authors interviewed 50 siblings from 37 families aged between 6 and 14 years in Belgium. The findings, which were subjected to a grounded theory analysis revealed that the siblings preferred to have a life of less restriction. This meant that they preferred to be siblings without their disabled sibling and longed for individual attention without their sibling with disability and valued the time of ‘not having to be a siblings of a disabled child for a while’ (Moyson and Roeyers, 2012 p.94). However, participants in this study also enjoyed staying indoors as long as it was not imposed on them or hampered their own activities (Moyson and Roeyers, 2012).

In Burke’s (2010) study, restriction was experienced in terms of social life whereby they found it difficult to do things together as a family, thereby missing out on activities other siblings without a disabled sibling experience. This involved lack of time to go on holidays together, lack of the freedom to bring their friends home due to fear of discrimination and prejudice hence missing out on social life (Burke, 2010).

Seligman and Darling’s (2009) view further confirm that restriction may mean that non-disabled siblings lose out on childhood and interferes with their emotional well-being (Seligman and Darling, 2009). However, when considering the transferability of such findings to the Kenyan context, one must take into account not only cultural differences but also how economic and social factors might impact differently on siblings within a Kenyan context.

2.5.3.3. Stigma and discrimination

Goffman (1963) traces stigma to the Greek reference to bodily signs on individuals which signified their status in society. Such people included slaves, criminals or traitors who were deemed ritually polluted and were to be avoided at all costs. Currently, the term is being used even where no labels to categorise individuals according to society are found. Stigma therefore
refers to disgrace (Goffman, 1963), although the consequences still involve avoidance and being hidden from society, similar to what was experienced in the past. Byrne also defined stigma as,

“fear, resulting in a lack of confidence. Stigma is loss, resulting in unresolved mourning issues. Stigma is not having access to resources... Stigma is being invisible or being reviled, resulting in conflict. Stigma is lowered self esteem and intense shame, resulting in decreased self worth. Stigma is secrecy..... Stigma is anger, resulting in distance. Most importantly, stigma is hopelessness, resulting in helplessness” (Byrne, 2000 p.66).

Stigma therefore encompasses all the above characteristics as highlighted by Byrne (2000). In order to understand the concept of stigma, Link and Phelan (2001) applied five components that involved labelling, stereotypes, separating, loss of status and a combination of all the above that converge into stigma and discrimination. Stigma has been identified as a factor in many chronic illness and disabilities (Senkel and Wong, 2010). Social philosophers view disability as a source of discrimination and oppression (Waserman et al., 2005). Similarly stigma has been reported in families where there is a disabled child and this has been experienced by other family members other than disabled members (Goffman, 1963) and this is referred to as vicarious stigma (Goffman, 1963; Ostman and Kjelli, 2002). Vicarious stigma, involves stigma by virtue of one’s association with a stigmatised individual. An example of stigma by association was reported by Burke (2010) in the UK, where discrimination by family members of an individual with disability were experienced in terms of ethnicity and disability. This example tells of the stigma experienced by family members of an individual with disabilities (Burke, 2010) who were not disabled themselves.

In Africa, which contains the majority of the world’s disabled children, the ACPF (2014) report revealed that a number of them and their families experienced stigma and discrimination. From this context, Nartley (2013) looked at the impact of stigma on the psychological well being of siblings of children with intellectual disabilities from four schools based in Ghana. Having utilised a correlational survey to assess the psychological well being of 69 siblings of children with intellectual disabilities, this study established that, where positive relationships developed, there was positive
psychological wellbeing maintained irrespective of the presence of stigma. This means that even although stigma was present, it did not negatively impact on the non-disabled sibling who had developed positive inter sibling relationships. The study findings, therefore implied that developing of quality positive sibling relationship among siblings can help to maintain positive psychological well being in an intellectually disabled person and their siblings irrespective of the presence of stigma. Therefore, the study generated useful results by eliciting siblings’ perception from their own frame of reference (Nartley, 2013).

From a Kenyan context, a number of studies have identified stigma resulting from negative societal attitudes (Opini, 2012, Kiarie, 2014; KNCHR, 2014; Mugo and Oranga 2010). Opini (2010) points to stigma experienced in two institutions of higher learning in Kenya and found that disabled people in Kenya still experience stigma caused by cultural, societal and economic factors. However, these studies were done on small scale and cannot be generalised to the Kenyan situation. This notwithstanding, it will be useful to establish whether stigma was experienced by non-disabled siblings in the current study.

2.6. Conclusion

The review has identified how disability has been understood at different times within different contexts. This has been undertaken through the exploration of the various models of disability identified in literature. The review has established how, within different societies and specifically within Kenya, different and potentially conflicting understanding about disability may coexist at any one time. The development of these models of disability have helped lead to a deeper understanding about disabilities. From the later twentieth century, the social model of disability has played a key role in shifting understandings and it is hoped that this study will contribute to the ongoing debates and development within the model.

The review has further revealed that the majority of studies undertaken on this topic originate from the west. There has been limited research generally focussing on the experience of disability within Kenya and none on the specific topic of siblings’ experience of living in a family with a
sibling with CP. This study therefore provides a valuable contribution to the existing literature by highlighting how the phenomenon is experienced within the Kenyan context.

While some of the studies from the West have highlighted positive psychological effects, others have highlighted negative ones. The review has brought up the negative psychological impact on non-CP siblings, for instance, feelings of stigma, restriction from social activities and concern about the future. The review has also pointed to positive experiences such as perceived personal development resulting from living with a disabled sibling. This highlights the importance of beginning an exploration of both the potentially positive and negative experiences of siblings within Kenya. The concept of disability by association is useful in the analysis of more negative experiencing. In terms of positive impacts, the posttraumatic growth model provides a useful lens that helps to identify and explore how positive growth can be experienced alongside more negative reactions to perceived difficulties.

It can be argued that the field of disability has not been static as many researchers continue to carry out studies in this field; thus a researcher can only add up to the vast literature within this field. However, this study is an important contribution to the research base within Kenya relating to disability and cerebral palsy in particular. Importantly, as a qualitative research study, it shines light on the lived experience of family members where there is a disabled family member, an under-explored area of research within Kenya. As an IPA study, it will help provide rich depictions of individual Kenyan experience. While there have been some qualitative studies undertaken on related topics from a Kenyan context, different methodologies were applied. Hence, it will be useful to hear what an IPA study can bring to an understanding of this phenomenon from this context. By concentrating on the experiences of non-disabled siblings it adds a Kenyan dimension to international research on the topic.

The study itself, as an important addition to the limited research in the area is likely to benefit the population under study and, benefit “Cerebral Palsy Society of Kenya” where the study was carried out. It will also add to the literature from a global perspective concerning issues to do with disability with an emphasis on cerebral palsy and inform counselling training to incorporate learning gained from this review.
3. **Introduction**

This chapter explores and discusses the issues involved in identifying and selecting an appropriate methodological approach underpinning the research; it provides a justification for the methods utilised for the collection of data and highlights how data was analysed.

A consideration is given to the relevance and appropriateness of the method identified in studying experiences of young adults who have a sibling with CP within the Kenyan context. I then provide a reflection on the entire process of research and how ethical issues were taken into account.

3.1. **Overview of research question and aims of the study**

A number of qualitative researchers reject the formulation of a hypothesis prior to conducting research (Pietkiewiez and Smith, 2012). Instead, qualitative researchers aim at generating a rich description of how a phenomenon is experienced. In particular, IPA focuses on experiences and/or understanding of a particular phenomenon (Smith et al., 2009) which, in most cases, is psychological. In this regard, I had a clear understanding about what I wanted to establish with my study. My aim was to gain an understanding of the psychological issues involved for young adults residing in Nairobi, Kenya, who have a sibling with CP, exploring their psychological experiences and how they made sense of the issues involved. The research question that I sought to address was:

“How do young adults experience and understand the impact of growing up with a sibling who has cerebral palsy within the urban Kenyan context?”

I developed some objectives to help ensure I addressed the research question, as recommended by Smith et al. (2009). These objectives were:-

1. To understand the impact of CP sibling on the psychological well-being of the non-CP sibling.
2. To explore the experiences of young adults growing up with a sibling who has CP.
3. To explore the individual meaning-making young adults who have a sibling with CP attach to their role.

In addition to the above objectives, I formulated a number of interview questions that were intended to reflect and respond to these objectives. According to Rojon and Saunders (2013), interview questions in an IPA study ought to be exploratory in nature. Exploratory questions that are broad and open can elicit a rich detailed description of a phenomenon (Smith & Osborn, 2007; Smith et al., 2009). In tandem with this, I generated broad and open questions that were geared towards eliciting a rich detailed description of the phenomenon as listed below:

1. Share with me the knowledge you have about CP?
2. Talk about the condition of your sibling with CP.
3. How do you relate with your sibling with CP?
4. Could you talk about any significant event you have had with your sibling with CP?
5. Could you talk about any stressful issues you had as a result of your sibling with CP?
6. What fears or hopes do you have about the future of your sibling with CP?

The first two were introductory questions, aimed at exploring the young adults’ individual understanding of CP and how it affected their sibling. These questions were geared towards helping to gain an understanding of how the young adults made sense of their sibling’s condition. These were followed by question three and four, that were intended to address objective two and three and were aimed at helping them to explore their experiences and the sense they made out of them. Question five and six addressed objective one, which was aimed at eliciting the impact of their sibling’s condition on the young adult’s psychological well-being.

Although the questions were designed to address specific objectives, the questions were merely to guide the flow of conversation in the interviews and to ensure desired content was covered. They were not cast in stone as highlighted by Pietkiewiez and Smith (2012). Individual questions might prove redundant, as the interviewee may have already talked about that particular area. Although I had some prior understanding of mainly negative experiences, the questions were designed in such a way to encourage exploration of both negative and positive experiencing in order to respond to
my overall research question. Further discussion on the interview questions shall be included in section 3.7. Although the questions were helpful in addressing the research question, a critique of some of the questions is included in the limitation of the study in section 6.2.

Nyandemo (2012) highlights the importance of being open to an approach to research that provides answers to a particular research question. In agreeing with these views, I set out to identify a methodological approach that best fitted with my objectives and one that could adequately provide answers to the above research question. My methodology of choice was Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) which involved semi-structured interviews with young people living in Nairobi, Kenya who had a sibling with CP.

In the next section, I move to explain what led me to decide on the methodology for this study.

3.2. **Qualitative or quantitative methodology**

I began by discerning whether a qualitative or quantitative approach reflected more appropriately my research question and my world view, which led me to clarify their differences. Quantitative research is interested in statistical procedures and quantification whereas qualitative research is mostly concerned about the meaning making people attach to their experience (Sanders and Wilkins, 2010). Quantitative researchers tend to work with neutrally detached individuals who take part from an external frame of reference (Guba and Lincoln, 1994), while qualitative researchers tend to work from an internal frame of reference as co-constructors of knowledge (Guba and Lincoln, 1994). A quantitative approach is connected with empirical research that is characterised by empirical indicators that represent the truth (Sale, Lohfield and Brazil, 2002,) while qualitative research is interested more in the lived experiences of participants and their description of a phenomenon (Fossey, Harvey, McDermott, and Davidson, 2002). Although qualitative and quantitative research tends to serve different purposes, these two methods complement each other in research (McLeod, 2011). This reflects the view expressed by Sanders and Wilkins (2008) that qualitative or quantitative researches demonstrate different ways of thinking and working that serve different purposes. The purpose of my study thus led me to qualitative research.
Qualitative research aims to contribute to an understanding of how knowledge about the world is socially constructed (McLeod, 2011). Its major aim is to provide an understanding and represent the experiences and actions of people as they encounter them through different situations (Elliot, 1999; Willig, 2001; McLeod 2011). This study had a particular interest in understanding how young adults who have a sibling with CP experience and understand their daily interaction with their sibling with CP. Researchers using qualitative research tend to embrace the view that there is no single reality as far as people’s perceptions are concerned, but rather multiple realities – which means that there are multiple ways of making sense of a given situation (Hartley and Muhit, 2000). Again, McLeod (2011,p.3) argues that “we inhabit a social, personal and relational world that is complex, layered and one that can be viewed from different perspectives”. This is in tandem with my view that, although the young adults had experienced a similar experience, there might have been multiple ways each one made sense of these experiences.

I chose a qualitative rather than a quantitative methodological approach because of the strength and depth with which explorations are conducted and the emphasis on rich description, which gives the reader a wider perspective of the phenomenon (Meyer and Arison, 2002; Lyons, 2011). My interest was to bring to light the voices of the young adults who have a sibling with CP from a Kenyan context and a qualitative approach was ideal for researching such an area where little was known from a Kenyan context in line with Morse (2000). Further to this, I was interested in a study that would involve me from an internal frame of reference (Guba and Lincoln, 1994), as opposed to one that I would take part in as a neutrally detached researcher from an external frame of reference (Sanders and Wilkins, 2010). This was partly because I had some foreknowledge of the topic, which I brought to the study. Moreover, as Guba and Lincoln (1994) comment, an investigator in a qualitative research and the objects of the research are interactively linked, so that findings are mutually created within the context of the situation which shapes the inquiry.

3.3. Qualitative Methodology

Methodology can be defined as:-
"the strategy, plan of action, the process or design lying behind the choice and use of a particular method and linking the choice and the use of the method to the desired outcomes” (Crotty 1998 p.3).

Methodologies make assumption about the nature of the world and how it should be studied (Chamberlain, 2011). This agrees with McLeod’s (2001) view that methodology is about the researcher deciding on what can be known and how it can be known. In my understanding, methodology is a framework for making certain choices within research and deciding on how research should be conducted. Following my understanding about the world, I was open to a number of choices to make, as shall be highlighted later.

When designing this research, a number of methodologies were explored. Firstly, Polkinghorne (2005) and Lennie & West (2010) argue that the area of study should determine the method of inquiry, not the other way round. Crotty (1998) reflects that researchers rarely use epistemology and ontology as a starting point because they have a question they wish to answer in the most appropriate way; therefore they begin by looking at method before turning back to epistemology and ontology. McLeod (2011), on his part, argues that methodological choice in qualitative research is determined by the underlying principles of ontology, the epistemological stance and the research question the researcher wishes to answer. My stance was influenced by all of these standpoints in that I began by looking at the research question before making a decision on what methodology to be used. After this was done, I turned to the epistemological and ontological stances underpinning different methodologies to assess their fit with both my research question and my world view. Having identified the research topic before turning to methodology, this further led me to decide on the tools to be used for collecting data.

3.4. A Phenomenological Approach

The study adopted a phenomenological approach because of its appropriateness in studying lived experiences. McLeod (2011) states that phenomenology seeks to understand the essence of our everyday experiences. This reflects Finlay’s (2009) view that phenomenology aims at providing a detailed description of the life world or lived experiences with the aim of going beyond everyday
‘natural’ understandings of the phenomenon. However, phenomenological studies have distinct ways of working depending on the phenomenon under investigation and the kind of knowledge being sought (Finlay, 2009). One can either do a descriptive or interpretative study depending on a number of factors (Willig, 2008). Sandelowski (2000, p.336) offers the following distinction.

“Descriptive studies offer a comprehensive summary of an event in the everyday terms of those events, while interpretative studies move away from purely descriptive towards an attempt to analyse or interpret accounts within differing analytical frameworks.”

Both Finlay (2009) and Pringle et al. (2010) describe descriptive phenomenology as research that aims at unveiling the structural meaning of a phenomenon while interpretative phenomenon focuses on experience through interpretation. The role of the researcher in interpretative research is to make sense of participants’ experiences and this is what distinguishes it from descriptive approaches whose primary goal is to describe experiences (Giorgi and Giorgi, 2008). A key difference is the emphasis on ‘epoche’ or bracketing of any presuppositions and the application of the reduction in descriptive phenomenology, in order to discover the essence of experiences and this makes it to differ with interpretative phenomenology (Giorgi, 2011). Bracketing involves holding back one’s beliefs about what he or she knows about the subject (Chan, Fung and Chien, 2013). However, in interpretative phenomenology, the researcher’s prior understandings are seen as potentially important to developing and accessing understanding of the phenomenon throughout the research process hence they cannot be bracketed (Koch, 1995). Such an approach therefore had the potential to embrace my experience as part of a Kenyan family with a child with CP. After considering the two approaches, I opted for an interpretative phenomenology approach that emphasises interpretation of experience as a core principle in order to draw a deeper understanding of how participants made sense of their experiences. I further agreed with views by Smith et al. (2009) that to understand experience, one needs to establish different meanings people put on their being in a relational world. Hence the young adults who had been in a relationship with their sibling with CP had different meanings attached to their experiences that could be unveiled through an interpretative analysis.
3.5. Choosing Interpretative Phenomenological Analysis

My proposal to carry out this research was considered by the University of Manchester ethics panel in the year 2011 and approval granted. At this stage, I had proposed to use thematic analysis, informed by Braun and Clarke (2006) for my research. However, during the discussion and in response to a suggestion by a member of the panel that looked at my role in the research, I opted to change my methodological approach to IPA. This panel felt that I had some prior knowledge about the topic that I needed to incorporate into the study through a methodology that accepted an insider role. We thus agreed that I explore other methodologies that more specifically incorporate the insider role within my research as a starting point. I therefore went back to look in depth at some of the qualitative methodologies like grounded theory, phenomenological approaches and narrative analysis. While a number of approaches offered the possibility of incorporating my insider role, I chose to adopt a phenomenological approach and in particular IPA.

In IPA, the research process is a dynamic one whereby the researcher takes an active role in the process (Smith and Osborn, 2004; Smith, 2007). As stated earlier, the researcher’s role in IPA specifically includes an attempt to access an insider’s perspective, therefore making my insider role a potentially useful one (Conrad, 1987). Further, IPA implicates the researcher’s own view of the world as well as the interaction between researchers and participants in the construction of understanding (Willig, 2001), hence my preference for this method. The insider role as suggested by the panel therefore was compatible with an IPA study and was one of the reasons I chose it.

IPA began in the field of psychology in the mid-1990s, to study psychological experiences (Smith et al., 2009) and has become a rapidly embraced and commonly used qualitative methodology in psychology (Smith, 2011). My study having explored psychological experiences also fitted well with IPA. IPA rests on the assumption that, human beings are sense making creatures and the accounts they produce reflect an attempt to make sense of their experiences (Heidegger, 1927). According to Smith (2007), one does not pluck experience straightforwardly from a participant’s head but through a process of interpretation, which is one of the underpinnings of IPA. It therefore fits with undertaking research in the field of psychology that sought to understand how young adults make sense of their experiences as siblings of a child with CP.
Biggerstaff and Thompson (2008, p.215) highlighted the following:

“IPA’s theoretical underpinnings stem from phenomenology that originated with Husserl’s attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation) and with symbolic interactionism, which posits that the meaning an individual ascribes to events are of central concern but are only accessible through an interpretative process”

This has similarities with the description provided by Smith et al., (2009 p.16) of IPA as focussed on “a systematic examination of the content of consciousness of our lived experience which is the very stuff of life”.

IPA is theoretically underpinned by three key principles namely phenomenology, hermeneutic and idiography that I turn to in the next section.

3.5.1. Phenomenology

Phenomenology is a major underpinning of IPA which aims at studying experience and provides ways of examining and comprehending human experience (Smith et al., 2009). It has its roots in the work of Edmund Husserl (1927) who believed that all philosophy ought to be a description of an experience. It therefore aims at identifying unique experiences (Smith, 2004). According to Husserl (1970), the life world of an individual is their pre-reflexive experiencing of the world. The nature of experience before it is subjected to a meaning-making process is the subject matter of what he called phenomenology (Husserl, 1970).

Heidegger (1927) introduced the notion of ‘dasein’ or being-in-context into phenomenology. For Heidegger any inquiry about experience brought in an assumption about the world in terms of our existence (McLeod, 2011). According to Heidegger (1927), we are always a person-in-context; we are part of the world and simultaneously in relationship with it – we have a worldly existence, we share the world and thrive in making relationships. Relationships are therefore important as
they determine the worldliness of our existence (Husserl, 1970). I preferred a Heideggerian influenced phenomenology for my study as it aimed at understanding the young people’s relationship to the world and attempted to make meaning of their experiences about a phenomenon (Larkin, Watts and Clifton, 2006). McLeod (2011) defines existentialism as a philosophical perspective whose goal is to understand the experience of being in the world. Harper and Thompson (2012) highlight existentialism as being interested in representing the most difficult experiences that individuals find hard to talk about. My goal as researcher, therefore, was to understand what it was like to have a sibling who has CP and how their interaction in a world of relationships is perceived by the young people who were in touch with the phenomenon due to their relationship with their sibling with CP.

3.5.2. Hermeneutics

IPA is further underpinned by hermeneutics, the theory of interpretation or meaning making (Smith et al., 2009). IPA accepts that one cannot directly experience another person’s experience but one can only try to make sense of it through an interpretative process. Hermeneutics has its roots in religious texts with an initial purpose of uncovering God’s true message within the bible (McLeod, 2013). This was later developed by Heidegger (1927) to move toward the hermeneutic of existence within phenomenology. For Heidegger, every encounter with the world involved an interpretative process, informed by one’s traditions and pre-suppositions (Heidegger, 2002).

On his part, Gadamer (1975) argued that we inevitably bring pre-conceptions or ‘horizons of understanding’ to any encounter. This provides not only the basis for dialogue but also potential insight into shared understanding. While we can have some conscious insight into our preconceptions, such insight is inevitably limited and we may only become aware of some of our preconceptions within the research process itself. While as researchers we should work to make conscious our pre-conceptions, we can only present the preconceptions of which we are aware of at any one moment. This supports views by McLeod (2013 p.30) that “every act of hermeneutic understanding begins with a pre-understanding that places the investigations in relation to the text or topic”. In agreement with McLeod (2013), my involvement in this research has been acknowledged throughout.
In hermeneutics, the double hermeneutic is used to provide different levels of interpretation. Double hermeneutics involves the researcher’s effort to make sense of the participant trying to make sense of what is happening to them at the moment (Smith, 2011). In one of the levels, which involve the participant and the researcher, the participant tries to make sense of their world while the researcher tries to make sense of the participant’s sense-making process (Smith 2008; Smith et al., 2009). The process involves the researcher taking an active role and employing a number of skills (Smith, 2007) during the research process, to bring to the fore the participant’s experiences. The interpretation involves both participant and researcher engaging, whereby the participant makes sense of the personal world while the researcher tries to make sense of the participant trying to make sense of their social world (Smith, 2007).

Another form of double hermeneutics involves what Ricoeur (1970) identifies as the hermeneutics of empathy and the hermeneutics of suspicion. The hermeneutic of empathy means to adopt the insider perspective, see what it is like from the participant’s view and ‘stand in their shoes’ (try to understand what an experience is like from the participant’s point of view) (Smith, 2004). The hermeneutics of suspicion aim at uncovering meaning that participants may not be aware of, for example, how unconscious processes might guide their actions; obscure their understandings (Smith, 2007; Smith et al., 2009). The hermeneutics of questioning is more of a ‘central ground’ alternative to that of suspicion, whereby the experiencing of participants is questioned from differing viewpoints. In line with an IPA stance, I adopted the hermeneutics of empathy in my initial analysis of participants’ accounts while I adopted the hermeneutic of questioning in the discussion.

Another dynamic within the hermeneutic circle relates to the continuous development of new horizons of understanding. The researcher has some preconceptions which he brings with to the research and as he or she interacts with the understanding of the participant, a new horizon of understanding is created. This new level of understanding is carried to the next participant as the research progresses in line with Gadamer (1975). A new horizon of understanding is a stage at which a researcher impacts on the research as well as the research impacting on the researcher (Corbin and Buckle, 2009). At this stage, the researcher is not able to bracket as his or her
preconceptions form part of meaningful dialogue that is important in an IPA study. In IPA research, while the researcher should take care not to simply impose their meaning-making on the data, they should simultaneously utilise their awareness of their own shifting conceptions to help inform the research process (Chan et al., 2013).

3.5.3. Idiography

IPA is further underpinned by an idiographic approach which is concerned about the particular individual level of accounts and therefore is committed to individual contributions (Smith et al., 2009). IPA’s idiographic nature locates participants in their context, exploring personal perspectives and starts from a detailed examination of a single case before producing any general statements (Smith, 2004; Smith et al., 2009: Smith 2011). It contrasts with the nomothetic principles that study how certain phenomena recur under certain conditions (Smith, 2004). For this study, I considered individual contributions as unique in their context and valuable for the research (Smith, 2004).

A good IPA study will not only present shared themes but also point to ways these themes connect with particular individuals (Smith, 2011). The study ensured that individual contributions were maintained throughout the analytical process by not only starting with individual contributions but also referring to individual contributions throughout the analytical process. This has been demonstrated in the findings where participant’s contributions have been personalized.

Having focused on the nature of IPA in this section, the next section focuses on epistemology and ontology underpinning IPA.

3.5.4. Epistemology and Ontology

Epistemology is defined as a philosophy that is concerned with the nature, source and scope of knowledge (Willig, 2008; McLeod, 2011; Sanders and Wilkins, 2010). McLeod (2011) has defined epistemology as the way in which people gain knowledge about the world and how they come to agree or differ with certain beliefs. In essence, the basic assumption is about what counts as
reality and truth. My epistemological stance was symbolic interactionism which pays due attention to both the socially constructed nature of our understandings and the role of personal agency in individual meaning-making (Blumer, 1969; Braun and Clarke, 2013). It reflects the role of the social and individual in knowledge construction.

Ontology, on its part involves the study of existence or being (Heidegger and Krell, 1927). It describes how we understand the nature of reality (Guba and Lincoln, 1994; Sanders and Wilkins, 2010; McLeod, 2011; Smith et al., 2009). My ontological position was relativism which embraces the possibility of multiple realities or meaning.

3.6. Research methods

3.6.1. Participants and sampling

The emphasis in IPA is generally placed on recruiting small samples (Langdridge, 2007; Smith et al., 2009). Smith et al. (2009) provides a useful guideline of about four to ten participants for researchers carrying out a doctorate research (Smith et al., 2009) while three to six are regarded as sufficient for those undertaking an MA project. Langdridge (2007) on his part points to five or six participants as sufficient for student projects. I chose six participants because they were reasonably within the proposed guidelines by Smith et al. (2009) for carrying out a doctorate programme. This choice of sample size was partly due to the difficulties of accessing the participants who were over 347 kilometers away from my residence in addition to the constraints of time and resources. However, the confidence I had in producing sufficiently detailed data in an under explored area further led me to work with six participants as per an IPA study (Smith et al., 2009).

3.6.1.1. Inclusion and exclusion criteria of participants

Sampling in an IPA study is not about constructing a culturally or socially representative sample as the aim is not generalisation; instead sampling focuses on participant’s experiences of the phenomenon being researched, and aims for small samples (Smith et al, 2009). Recruitment of participants for an IPA study is based on constructing a relatively homogeneous sample who have the characteristics being sought and who can meaningfully inform a study (Langdridge, 2007;
Smith et al., 2009; Pietkiewiez and Smith 2012). Robinson (2014) confirms that homogeneity can be achieved in different ways; for example, demographic, experiential, and relational homogeneity, and urges researchers to be more specific in the identification of homogeneity. In this research, I considered a number of issues to attain homogeneity, for instance, the age of the non-CP sibling, the duration they had interacted with the phenomenon as well as the relationship with the CP individual. After considering these potential variables, I decided on the following inclusion criteria: -

i) A young adult aged between 18 and 30 years.

ii) Living with a sibling who has CP at the time of research.

iii) Should have lived with the sibling for at least three years.

iv) Unknown to the researcher.

v) Psychologically stable i.e. with no signs of emotional distress.

Excluded from the research were those young adults who: -

i) Were below 18 years.

ii) Had not lived with their sibling for three or more years.

iii) Were known to the researcher for instance clients, family members and acquaintances

iv) Displayed signs of emotional distress.

Ethical consideration also played an important role in the way I excluded people from the research. For instance, I excluded those below 18 years because they were young and not in a position to give consent without a significant adult (Kenya National Youth Policy, 2006; McLeod, 2003). I further excluded people known to me, for instance, my clients, family members and acquaintances because of the potentially sensitive nature of the research as well as pre-existing relationships (Magnusson and Marecek, 2015). My ex-clients were excluded because this would compromise our previous relationship. People who displayed signs of distress were also excluded in line with McLeod’s (2011) and Bond’s (2004) view that one should not carry out research that can cause
distress to participants. In order to ensure no one in distress took part in the study, I assessed their emotional status using my counselling skills before recruiting them to the study. Following from such assessment, I identified one participant who was in dire need of psychological support and was excluded on these grounds. Instead of involving the participant in the research, I utilised the session to offer initial counselling to this participant and referred him for further counselling at an Institution I had identified for more support. Again, because I was aware about the effect of talking about sensitive issues arising from my professional background as a counsellor and researcher, I was cautious and sought consent at every stage. If I sensed any signs of distress, I checked whether the participant wished to terminate or continue with the interview in line with West and Byrne (2009). However, none of the participants chose to withdraw during the interview on these grounds.

To identify potential participants, I used referrals from a gatekeeper as well as snowballing as stated in Smith (2007) and Smith et al. (2009). A gatekeeper is someone who has some contacts with potential participants and refers them to the researcher. This gatekeeper belonged to a non-governmental organization where the children with CP are registered as members and was able to refer me to the potential participants in this study. Five of the participants were recruited through this method. Snowballing on the other hand begins with a convenient sample of a few participants who are asked to contact their friends or acquaintances to determine their willingness to participate in a study (Mugenda and Mugenda, 2003). They, in turn, contacted others to take part in the research. Through this system, I was able to access one participant who was referred by another participant. I chose the two methods to complement each other as suggested by McLeod (2001) and partly due to fear that I could not get a sufficient number of participants with the time frame I had. McLeod (2001) highlights the importance of combining more than one method because what one method cannot achieve can be achieved through the alternative. The demographic data for the participants have been highlighted in the next section.
### 3.6.2. The participants’ demographic data

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Age</th>
<th>Sex</th>
<th>Religion</th>
<th>Age of Sibling with CP</th>
<th>Number of other siblings in the family</th>
<th>A brief description of the participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luunga</td>
<td>19</td>
<td>Female</td>
<td>Christian</td>
<td>3</td>
<td>3</td>
<td>Just completed high school</td>
</tr>
<tr>
<td>Jazala</td>
<td>22</td>
<td>Male</td>
<td>Christian</td>
<td>10</td>
<td>4</td>
<td>A technician by profession</td>
</tr>
<tr>
<td>Khasoa</td>
<td>18</td>
<td>Female</td>
<td>Muslim</td>
<td>14</td>
<td>2</td>
<td>Final year at high school</td>
</tr>
<tr>
<td>Kubuyo</td>
<td>18</td>
<td>Male</td>
<td>Christian</td>
<td>19</td>
<td>3</td>
<td>3rd year at high school</td>
</tr>
<tr>
<td>Khayecha</td>
<td>24</td>
<td>Male</td>
<td>Muslim</td>
<td>3</td>
<td>7</td>
<td>A technician by profession</td>
</tr>
<tr>
<td>Manguya</td>
<td>19</td>
<td>Male</td>
<td>Christian</td>
<td>14</td>
<td>3</td>
<td>Just completed high school</td>
</tr>
</tbody>
</table>

Table 3.1

There were six participants aged between 18 and 24 years. All of them were living with their sibling who has CP at the time of interviews and their siblings with CP were aged between 3 to 19 years. There were two females and four males. Five of the young adults were older than the CP sibling while one was younger. Two participants were Muslims while four were Christians. All the participants resided in Nairobi and had other siblings in the family. Except for one family, where the father had died, the rest had both parents. Fictitious names have been used to safeguard the identity of the participants in line with McLeod (2003).

### 3.6.3. Language of Participants

Phenomenological studies are interested in experiences and to capture these experiences one requires language as a tool (Willig, 2008). Crotty (1998) supports the view that language is central in human interaction. For any interaction to take place, one requires a symbol or language to communicate with others to capture their views. This fits with symbolic interactionism, which is about basic social interaction, where we enter the perceptions, attitudes and values of a community, becoming a person in the process as one puts himself in the other person’s position (Crotty, 1998; Smith et al., 2009). Crotty (1998) highlights the importance of dialogue in symbolic
interactionism as it directs the researcher towards understanding the views of the participant. In order for me to understand the views of my participants, I needed a medium to do so, hence language was this medium of interaction.

In particular, the English language was chosen as the medium of communication for this research. Being an official language for Kenya (GOK, 2010), English language was preferred because of being a universal language within this multilingual society that had grown up in an urban setting. All interviewees chose to be interviewed in English though a few of them could switch between English and Kiswahili, to emphasise or clarify a point. Switching between languages came in to reinforce a point or where a participant missed a word, they would turn to Kiswahili for the same. This is a common phenomenon in the Kenyan context where many people are comfortable using more than one language during conversations. I accommodated them whenever they switched language; partly because of having grown up in this context I have experienced a similar phenomenon of switching languages.

3.7. Data collection methods

The major tools of collecting qualitative data are interviews, focus group discussions, individual observations, questionnaires or case studies (Guba and Lincoln, 1994; Smith 2007; Smith et al., 2009; Shaw 2001; Willig, 2001). Many IPA researchers have utilised semi-structured interviews to collect data (Smith et al, 2009; Smith and Osborn, 2007, Smith 2007; Smith, 2008). Smith (2011) argues that IPA requires an intensive qualitative analysis of detailed personal accounts from participants, which can be easily collected through semi-structured interviews. Semi-structured interviews allow one to follow ideas, probe responses and investigate motives and feelings (Bell, 1999), which are important in qualitative research. Semi-Structured interviews are more suitable for collecting sensitive data as they allow room for clarification (Kvale and Brinkmann, 2009) at the same time it gives participants space to reflect on their feelings and the freedom to share what they find meaningful to share. Such issues led me to the adoption of a semi-structured interview format.
An interview can be regarded as a social encounter. In research, it is characterised by the interviewer inviting the interviewee to speak on an issue of interest to the interviewer in order to collect data to use in a research study (Smith, 2008). This contrasts with a counselling encounter, within which the interviewer encourages the interviewee to talk on an issue of interest to the interviewee for therapeutic gain. Although the two serve different purposes, they both involve highly developed interpersonal skills (Smith, 2008). I was therefore confident using semi-structured interviews because of my training and experience in counselling where semi-structured interviews that are commonly referred to as “our stock in trade” (Sanders and Wilkins, 2010, p.136). The advantage of the semi-structured interview is that it enables the researcher to achieve depth of exploration by getting below the surface (Ritchie et al., 2014), whereby the interviews begin at a surface level but then develop through enhanced skills by the interviewer to a depth of exploration.

I personally carried out the six semi-structured interviews whereby five were held in a place that was familiar to participants while one interview was carried out in a participant’s home. These venues were preferred by the participants. The interviews lasted between forty-five minutes and one hour. The interviews were audio recorded in order to capture clearly the participant’s content.

3.8. Data Analysis

To analyse the data, I prescribed to the principles of IPA as stipulated in Smith et al. (2009). I looked at individual transcripts and later on integrated them to reach an all-inclusive table of master themes that reflected the experiences of all the participants in the study. However, unlike other qualitative methods, IPA analysis involves a flexible analytic development, moving from particular to shared experiences (Smith et al., 2009). Analysis in IPA has some similarities with thematic analysis in terms of searching for themes across data. However, IPA differs from thematic analysis in that thematic analysis is more concerned about similarities in constructing themes as opposed to differences (Gibson, 2006) whereas IPA is concerned with both convergence and divergence (Smith et al., 2009). Again the emphasis in IPA is rooted in the phenomenological, in the individual subjective experience, which is not necessarily so in thematic analysis.
After collection of data was complete, the recorded data was transferred to a line-numbered transcript (Smith et al., 2009). My major focus was to record the spoken words and include non-verbal utterances, significant pauses and hesitation which were all useful data. This was then subjected to the six stages as proposed by Smith et al. (2009 p.79-107), highlighted below.

Stage 1: Reading and re-reading.

Stage 2. Initial noting.

Stage 3. Developing emergent themes.

Stage 4. Searching for connections across emergent themes.

Stage 5. Moving to the next case.

Stage 6. Looking for patterns across cases.

Stage 1: Reading and re-reading

Before embarking on the analysis, I took several turns of just listening to the tapes to gain a grasp of what my participants said before transcribing the data. Once data was transcribed, I followed the six stages stipulated by Smith et al. (2009). However, this was not followed to the letter as there were some minor deviations which I acknowledge. Smith et al. (2009) describe the steps as mere ‘guidelines’ and argue that researchers should maintain flexibility while analyzing IPA data. The first stage was an active engagement with data, which involved bonding with the data by reading the data several times before subjecting it to analysis. Because I had recorded my data on an audio recorder, I listened to it forth and back and compared it with my transcript in order to have an initial grasp of what my participants said. As I listened and re-read the transcript, I recorded some of the most powerful recollections about the interview in a notebook. This was intended to help me bracket off for a while in order to remain focused on the data. My major aim at this stage was to enter an active engagement with the data (Smith et al., 2009) that resonates with McLeod’s (2011) view that qualitative researchers should immerse themselves into data. Repeated reading helped me to gain an initial understanding of the overall structure of the interview.
Stage 2: Initial noting

The second stage involved working with my first participant’s data by reading it severally as highlighted by Smith et al. (2009) and Pietkiwiecz and Smith (2012). Every time I read the transcript, I captured anything new or significant that I posted within the initial notes. Further to these, I engaged in a line by line focus of the data, whereby I was interested in the contents and the language used by participants, which I noted down in the right margin. Of great interest were the descriptive and psychological words which are the major focus of an IPA study (Smith et al., 2009), that were accessed by capturing content, language use and participant’s initial sense-making. However, no data was discarded at that moment because I knew that I would be falling back to it from time to time. A sample of this stage is provided as Appendix E.

Stage 3: Developing emergent themes.

Thirdly, I shifted from working with participant’s data to working more with my initial exploratory notes as stipulated in Smith et al. (2009). I transformed the initial notes into concise phrases in order to capture what I found in the data. My main focus was to put forth psychological words, moving back and forth to what participants said all the time. This was geared towards helping me to come up with a concise statement of my understanding weaved in participants words. At this level, I brought in my understanding of what the participants said, to arrive at tentative initial themes. These were a reflection of the participant’s words and my initial interpretation, which I recorded in the left margin of the transcript in agreement with Smith and Osborn (2007). These exploratory comments involved focusing at the transcript and recalling what I had learnt through the initial notes. The process involved more of my staying with participants’ experiences. To demonstrate this, a sample of this process has been provided as Appendix F.

Stage 4. Searching for connections across emergent themes

The fourth stage involved developing a chart or mapping out how the themes fitted together for a particular participant. This stage involved focusing on constructing an individual thematic map. At this stage, I introduced an excel worksheet to help me capture all the data as I looked across the individual text, drawing together the emergent themes and producing a structure that enabled me to point out to interesting and important aspects of the participant’s individual accounts as stipulated in Smith et al. (2009).
Stage 5. Moving to the next case.

The fifth stage involved moving to the next participant’s transcript and subjecting it to the same process while setting aside for a while ideas from the first and subsequent cases, to be incorporated into the analysis later on. This was done to honour the idiographic nature of IPA that recognizes participant’s particular contribution to the study. This applied to all the six participants. To differentiate participants’ accounts, I used a different color for each participant when entering individual participant’s data on the computer.

Stage 6. Looking for patterns across cases.

Finally, the sixth stage involved a creative role of looking for connections, relationships and reconfiguring or relabeling themes across cases to capture the important things about the young people’s experiences by posing the table of themes on the wall so that I could easily look across them to identify patterns. Arising from this, I created a table of Super-ordinate themes that I present in Appendix G.

3.8.1. The analytic process

While I followed the stages above, the process of analysis did not occur in a linear way. It involved moving back and forth between the above steps in order to increase the understanding of the whole as well as reveal differences and similarities in various narratives, which resulted in new themes that revealed or reflected the experiences (Smith and Osborn, 2003) of the young people who have a sibling with CP. The themes have been modified, hence, a number of times in order to capture developing insights into their experiences.

This movement reflects the hermeneutic circle (Heidegger 1927; Smith and Osborn, 2003. I went through the process of looking at data from one participant while at the same time looking at data from other participants and identifying commonalities and differences between them, trying to make sense of individual participant’s data (Ricoeur, 1976). Smith (2007) confirms that interpretation involves moving back and forth, being open to revision and supplementation, which I have done. Smith argues that it takes the efforts of a researcher to reach the final interpretation
and come out of the hermeneutic circle as the circle could become endless (Smith, 2007; Smith et al., 2009; Smith, 2011). Having gone through the process I realised the need to communicate the developed understandings/meanings (McLeod, 2001) of the lived experiences of the participants and this is how I navigated out of the circle.

3.9. Ethical issues

Before embarking on this research and during the entire process of the study, ethical guidelines guided my decisions. As a qualitative researcher, I had an ethical responsibility towards, amongst others, my participants, the university, my counselling profession and involved organisations (Bond, 2004; McLeod, 2011). I therefore paid close attention to specific ethical principles of professional practice stipulated in Bond (2004); Yardley (2011) and McLeod (2011). I began by seeking ethical approval from the University of Manchester’s ethical committee through a written application. My research was then placed under ‘low risk’ and approval granted in writing before embarking on the research process. Immediately approval by the University was granted, I sought for approval from the organisation where the research was carried out through writing as well, which was granted (appendix I).

3.9.1. Informed consent

A number of issues came to play when considering about consent. For instance, I made an endeavour to seek consent from each participant individually at the beginning of the research and before the interview in line with McLeod (2003) and Bond (2004) (see appendix III). To do this I provided my participants with adequate information about the research, detailing my background as a researcher and outlining the reasons for the research (appendix II). I informed them how data would be collected, what would happen to the data collected specifying how I would safeguard their material throughout the research period and what would be involved in the analysis process. I informed them that their data would be used in a thesis anonymously and sought for permission to use their data for any publications if need be. I informed them that I would always safeguard their identity whenever this was done. I also informed them that to
benefit from the study, they would have access to the final anonymous version of the findings from the study.

Consent was sought from the onset and revisited throughout the research process as suggested by West and Byrne (2009), Bond (2004) and McLeod (2011). The participants were informed that they had the freedom to withdraw from the research at any time with no consequences. One participant chose not to take part in the study and the decision was respected. I further utilised counselling skills and was guided by the core conditions of empathy and respect (Rogers, 1961) to honour the decision by the participants throughout the research process.

3.9.2. Confidentiality and anonymity

Researchers should do everything within their ability to maintain confidentiality and the anonymity of participants in a qualitative research study. Anonymity involves protecting information provided by participants in a research in order to safeguard their identity and any identifiable details or issues disclosed (Ritchie, Lewis, Nicholls and Ormston, 2014). According to Saunders, Kitzinger and Kitzinger (2014), anonymity involves keeping participants’ identity secret such that one cannot trace particular information to a particular participant. This resonates with Crow and Wiles (2008) and Orb, Elsenhauer and Wynaden (2001) who assert the importance of anonymity in social research by use of pseudonyms. In this regard, I offered research participant anonymity by ensuring that their identity could not be ascertained and/or any identifiable information could not be linked to them. When recording participants’ data on tapes, I used numbers to label the tapes instead of using participants’ names. Later, I gave them pseudonyms to replace the numbers in order to identify individual participants throughout the study. As IPA focuses on rich individual depictions of experience, pseudonyms were helpful in attaching certain experiences to a particular individual without compromising their identity.

However, as I reflect on anonymity, I realize that I may have provided more limited information than is expected in an IPA study and this may have compromised the representation of participant’s data. A number of participants like their experiences to be fully represented and their voices heard within the professional and academic forum (Smith et al., 2009). I may have over-
emphasized anonymity in the way I over protected participant’s identity and this may have compromised the results. In my view, this was partly because of my position as a mother, who saw the participants as young and in need of protection as well as a professional counsellor who saw my encounter with participants as a confidential one. This may have also come up due to the limited social power of the participants who were young. Young people may be perceived as lacking power while they may see their researcher as an expert or as yielding power (Marshall and Batten, 2004), hence I may have viewed the participants as powerless and in need of protection. This notwithstanding, the potential sensitivity of the topic may have led me to be protective of my participants’ emotions, lest they would have shared issues that would cause distress in them.

Ritchie, Lewis, Nicholls and Ormston (2014) and McLeod (2003) encourage researchers to send parts of anonymised data to participants to check whether they have been represented anonymously in research, in the form of member checking. However, although I presented the data anonymously, I did not present the anonymised data back to participants for confirmation. This would have given them an opportunity to approve the use of anonymised quotations. Therefore, I missed an opportunity to have participants themselves confirm whether the anonymised data presented their views accurately as well as safeguarded their identity. Arising from this I think that future researchers should consider presenting part of anonymised data to participants for confirmation.

Confidentiality on its part involves protecting information provided by participants in research (Bond, 2004; Ritchie, Lewis, Nicholls and Ormston, 2014). In line with this, a number of steps were taken into consideration in order to protect participants’ information from unauthorized disclosure (Bond, 2004) and ensure confidentiality at every stage of the research process. For instance, I recorded the interviews personally and no one had access to the data as a way of ensuring participants’ data was not disclosed. Further, I transcribed the interviews and analysed them personally. During analysis, I used a personal computer that was locked by a password to ensure its security. Paper work has been locked in a room that is only accessible to me to ensure its security to protect participants’ information. Where part of the information has been submitted for assessment for this doctorate, it has been done so anonymously to protect not only participants’ identity but their information as well. Again, as with anonymity, Smith et al, (2009) assert that researchers should weigh between offering total confidentiality and representing
participants’ voices in a research. In their view, offering total confidentiality may compromise participants’ voices; hence researchers are urged to be diligent and balance between the two. In order to maintain the richness of my participants’ voices, I retained gender that was helpful in my discussion but changed other identifiable details to ensure confidentiality. Throughout, I have used the information provided without revealing the full details of who gave what information as well as used the information in themes to allow readers of the research to attach themes to anonymised individuals in order to retain the completeness of the information as well as provide confidentiality. Where I felt that quoting participants word by word would compromise their identity, identifiable information was changed. Orb et al. (2001) assert that absolute confidentiality is difficult to offer in qualitative research. I found this applicable in my research because I found that offering absolute confidentiality limits the extent to which certain description of the experience can be provided in an IPA study, hence the reason I have used a song to highlight some important data that we left out due to confidentiality. This has been done in conformity to presenting participants data as well as abiding by the ethical principle on confidentiality.

3.9.3. Sensitivity of approach

Yardley (2011) highlights the importance of being sensitive to context while doing qualitative research. This involves being sensitive to the cultural context and the research setting. This agrees with Goodley’s (1996) views that doing a study in the field of disability requires sensitivity to participants’ experiences as they are bound to talk about sensitive issues that may affect them emotionally. In line with Goodley’s views (1996), I was sensitive to any signs of distress, I interrupted the interview process in the interest of one participant to find out whether she was still comfortable to proceed with the interview. West and Byrne (2009) urge counselling researchers to be sensitive to the vulnerability of participants and to encourage them to withdraw if they felt uncomfortable. I had measures in place to debrief each participant after the interview. I also put in place a referral system for psychological support paid for in advance to handle any eventualities. However, none of the participants utilised the counselling services I had put in place, except for the debriefing that was done to all at the end of each interview.
3.9.4. Self-care

Dancheve and Ross (2014) and Dickson-Swift, James and Liamputtong (2009) urge qualitative researchers to recognize how they impact on others in the research. They emphasise researcher safety while carrying out research as it will ensure the safety of participants as well. In line with this, I had access to counselling supervision at the same time as academic supervision; my academic supervisors were always available for consultation through Skype and email. I also kept reflecting on the process by jotting in my journal whatever touched on ethics as a way of monitoring my ethical effectiveness throughout the research period (Kasket, 2013). To resolve my emotional issues, I utilised the counselling I had put in place to deal with such issues.

These measures were put in place to ensure that I was emotionally and professionally steady as I worked on the project in line with Smith et al. (2009). I acknowledge that the journey of doing this research had some psychological challenges, which I was able to work through whenever they arose. For instance the sudden loss of my father in-law when I was in the middle of this research prompted me to seek psychological support, which enabled me to work through the loss. Again, I have managed to work through the feelings of loneliness I encountered from time to time as I carried out this study – all these have been made possible due to my degree of sensitivity to self-care. The extract below shares part of what I worked through on this journey.

11th September, 2013.

I have been working on this project for the past three years and I seem to have lost interest. I feel more alone than when I began. I had colleagues and participants to talk with (during the data collection stage). But I think now I am walking on a lonely path (analysing data). My friends seem to be giving way maybe because I have never attended those social gathering for a while. My pastor has been complaining lately about non-attendance of church until she has almost given up on me. I step back for a while and realise that I am dealing with a sensitive topic that has taken a toll on me. I have attended some counselling session lately and thought I had worked through all my issues, but no! I am feeling lonely, because I can’t share my academic woes with non-academics. I will take a nap and focus on tomorrow because it will take care of itself.................
Working through such feelings, which came up during the analysis stage were some of the decisions I made to ensure that I was emotionally sound to carry out this research.

Another ethical issue involved the decision on where to carry out this study. The study took place at venues of participants’ choice. These venues were familiar to participants and guaranteed confidentiality (Bond, 2004). Five interviews took place at a premise identified by a gatekeeper, while one was held in a participant’s home, with the consent of the participants. Both premises were familiar and free from interruption and noise and guaranteed the participants safety. I therefore confirm that throughout the research process, I upheld the ethical principles by ensuring that issues that came up were resolved to ensure the study did not contravene any ethical principle.

3.9.5. **Power Balance while interviewing young people**

Etherington (2008) argues that by viewing our relationship with participants as collaborative rather than the ‘expert knower’, we encourage a sense of power, involvement and agency. I attempted to implement this by putting in measures that showed that I was sensitive to the issues of power throughout. For instance, I considered power issues by stipulating and agreeing over the goals and tasks for the researcher and participant (McLeod, 2003; West and Byrne, 2009) from the start. In line with Cate and Hoots (2000), I worked to develop rapport that would facilitate the participants to share their experiences freely, as well as reminded them about our collaborative involvement that vested power in both the researcher and participants.

However, even though this was done, Smith (2008) challenges researchers on how to ensure this is achieved especially when dealing with participants who may not perceive the situation the way the researcher perceives. Young people may be perceived as lacking power while they may see their researcher as an expert or as yielding power (Marshall and Batten, 2004). If they perceive you as powerful, they may not tell the whole story (Marshall and Batten, 2004). West and Byrne (2009) urge researchers to be highly sensitive to the vulnerability of power imbalances and look for ways to correct the imbalance if they detect it. This is of particular interest where participants are
younger or vulnerable. The fact that I was interviewing young people led me to be careful of how I approached consent. I revisited consent severally in line with West and Byrne (2001), ensuring they consented to what they know. I kept assuring them of their obligation and the freedom to withdraw from the research at any stage.

Another way I dealt with sensitivity or power imbalance was to ensure that I was in constant consultation with my supervisors throughout the research collection period. My academic supervisors were also helpful in providing professional support throughout the data collection period and reminded me of my obligation to honour the participants throughout and avert feeling superior towards my participants. This way I was able to balance power issues as I knew that my role was subordinate to that of the participants’.

From a Kenyan context young people look upon the elderly for direction and guidance hence this may have been an obstacle to the young people who may have been freer to share with a fellow young person. However, I made an effort to ensure that I created a rapport to make them comfortable in the interview (West and Byrne, 2009) before asking them to share their experiences. To do this I used social skills of engaging them prior to the interview just to make them feel comfortable. I also took care of my participants’ age by ensuring that the language used was appropriate to their understanding. Whenever the participant needed clarification I was always ready to provide clarification to them.

3.9.6. Validity and Trustworthiness of the Research

McLeod (2001) addressed the issue of validity in research and argues that qualitative research is more concerned about trustworthiness as opposed to validity that is often acknowledged in quantitative research. Trustworthiness in qualitative research involves a well thought data collection, analysis, and result reporting (Elo et al., 2014). The objective of trustworthiness is based on the principle that the integrity of the findings lies in the data and the researcher’s ability to work with the data in a way that confirms its adequacy (Morrow, 2005; Smith et al., 2009). In order to honour individual instances from participants extracts, or getting back to the ‘things themselves’ as stipulated in Wertz (2005), I have used a number of extracts to give voice to
participants’ experiences. By so doing, the reader is given an opportunity to establish the trustworthiness of the interpretations I made from their lived experiences.

Shenton (2004) highlights some of the strategies of ensuring trustworthiness in qualitative research, such as checking the accuracy of data on the spot, in the course and end of the data dialogues. Smith et al., (2009) highlights Yardley’s (2000) criteria as the most applicable tool to ascertain the trustworthiness of an IPA study. According to Yardley (2000), one has to be (i) sensitive to context, (ii) be committed to rigour, (iii) to transparency and coherence and (iv) to impact and importance. One needs to thoroughly prepare before the study, have advanced skills in data gathering, content analysis, trustworthiness in discussion and reporting of the findings (Elo et al., 2014). In addressing the above and by abiding by McLeod (2011) who reiterates the importance of trustworthiness when carrying out qualitative research I was sensitive to the context. Sensitivity to context involved my awareness of the research area in line with Yardley (2011) which was done by exploring this through chapter two. This sensitivity to context also extended to my awareness of power imbalances within the research and the care taken to recognise and counter balance it. To be committed to rigour, I was careful about the methodology chosen, as I was committed to ensure I had understood its application and to work within my levels of competence when applying it to my research. I also had an in-depth engagement with the data to ensure that the findings were rooted in the data. I further involved my colleagues on the doctorate programme in providing feedback during the research process and utilised feedback from my academic and counselling supervisors as I worked on the research. All these were geared towards ensuring that rigour was applied to my study. In order to both maintain and demonstrate rigour and coherence, I kept an audit trail of the research process, having rooted my analysis within participants’ words throughout. At the same time I have been clear about the methodological decision making processes. Further to this, Danchev and Ross (2014) encourage researchers to keep a reflexive journal where you can reflect more on the process of research. Throughout the research I have been open to these changes and where possible I have acknowledged these through my writing and the journal I maintained. I have also included reflexive sections in chapter three and my concluding chapter where I have been open about my engagement with this study.
Finally impact and importance focuses on the contributions made to knowledge. Regarding impact and importance, I chose a study of importance to the Kenyan context and to ensure that it has achieved its goal I hope to write papers, lead workshops and seminars. I also hope to disseminate the findings through conferences and forums that I will arrange with siblings of children with CP and other disabilities.

As mentioned above, one way I demonstrated trustworthiness was to keep the paper trail in such a way that one can carry out an independent audit to trace the progress and soundness of the study (Smith et al., 2009). To do this I have provided part of the working as an appendix to show some of the steps followed in the analysis. Again, in line with Sanders and Wilkins (2010), I kept a personal research journal where I recorded my progress, difficulties, challenges encountered, surprises, twists and turns of events in order to facilitate self-reflection and self-analysis and to foster new ideas in the research. I did this to demonstrate the rigour and sensitivity applied in the whole process of research as stated by Etherington (2004); Morrow (2005); Finlay (2009); Yardley (2000). Again, my colleagues on the doctorate programme were always helpful in providing feedback during the research that was useful in keeping me on track. My academic and counselling supervisors were always available to offer emotional and professional support. All these were done to ensure that I was sound while working on this research.

3.9.7. Member Checking

To member check is to seek for feedback from the participants about data extracted from their stories (Guba and Lincoln, 1989) as a way of ensuring that their stories are accurately represented in a study. However, Smith (1993) challenges the appropriateness of member checking for researchers using IPA because findings from an IPA research are arrived at after a collaborative engagement between the researcher and participant. The double hermeneutic means that a researcher’s interpretation plays a key role in the construction of the findings. Harpner and Thompson (2012) further challenges member checking as a strategy to validate IPA research due to its interpretative nature. An issue, moreover, is the passage of time between collection and analysis of data. IPA accepts combination of accounts or co-construction through a detailed engagement of data that involves passage of time hence making member checking problematic.
Another factor that led to my rejection of member checking was language as highlighted by Schleiermacher (1998). Language is not static and therefore the same words that were used during the interviews could have different meaning altogether later on for the participant (Schleiermacher, 1998). Schleiermacher (1998) argued that due to researchers using advanced analytical and interpretation skills they are bound to offer perspectives on the text which the author is not aware of. I therefore felt that having subjected participant’s data to an IPA interpretation, the findings would have changed by the time of member checking. As discussed above, a number of measures were put in place to ensure that participant’s accounts were accurately captured and accurately presented. This involved keeping a paper trail as part of the measures put in place to ensure I represented the participants accurately during the analysis. Again my being attentive to professional, academic and peer supervision led me to remaining committed to participant’s data throughout the research process.

### 3.10. Reflexivity

Etherington (2004 p.32) defines reflexivity as “the capacity by the researcher to acknowledge how their experiences and context inform the process and outcomes of inquiry”. More recently Danchev and Ross (2014) defined reflexivity as “the ability to observe, assess and comment on the impact that we have on our research and the impact that the research has on us”. Reflexivity in qualitative research can transform subjectivity from problem to opportunity (Finlay and Gough, 2003). It involves a more dynamic and continuing self-awareness throughout the research process (Finlay and Gough, 2003).

Guba and Lincoln (2008) and Willig (2008), acknowledge that there are two types of reflexivity known as personal or epistemological reflexivity. Personal involves the way our personality shapes the research while epistemological refers to the methodological assumption we make about the acquisition of the world and knowledge. More recently Kasket (2013) has identified to three types of reflexivity identified as personal, methodological and epistemological. Personal reflexivity involves awareness that who you are can influence the research as well as the research affecting
you as an individual, researcher and practitioner. One is therefore open to this changing self throughout the research process and to acknowledge it.

Methodological reflexivity involves an awareness of and a reflection on the way the research was carried out. Danchev and Ross (2014) highlight the importance of being attentive to ethical issues to ensure no harm is caused to self or participants, in keeping with best possible research practice. This may involve all the decisions you made methodologically and how the ethical issues were handled. This part of reflexivity has been undertaken throughout this chapter where I have clearly spelt out all the decisions made about the research throughout this chapter.

Epistemological reflexivity involves a reflection on the assumptions underpinning the chosen methodology which has been also specified in this chapter. My research which involved focusing on people’s personal experiences called for caution especially considering that I was researching on vulnerable people or communities (Langdridge, 2007). I was guided by the principles of IPA and was open to see the world through their perspectives responding more closely to their feelings to ensure that none of them experienced distress as they took part in the research.

Etherington (2004) urges researchers to be open to reflexivity and as one tells his or her story alongside those of other people, one is changed by them. While carrying out this research, I was open to these changes both in my personal and professional life, in order to translate the knowledge acquired into my personal life and professional work.

3.11 My Insider Role

To be an insider researcher refers to when researchers conduct research with a population of which they are also members i.e. sharing the same language, identity, culture or experience (Assellin, 2003). Potentially, this role gives the researcher acceptance by the participants if it is a closed group (Assellin, 2003) hence a greater depth of data is potentially gathered. I was an insider in this research due to having a child with CP and therefore we shared a similar phenomenon of living with someone who has CP. Again, my professional engagement led me to work with young adults who had lived the experience. My insider role gave me a level of acceptance by the young adults, as they knew that I had some contact with the phenomenon
(Asselin, 2003). Whenever I shared something, it seemed to lead me closer to them as they felt freer with me. However, Corbin and Buckle (2009) caution that the insider position can be problematic to the analysis process as the researcher is bound to analyse what he/she may deem relevant to him/herself. In order to deal with these challenges I adopted a reflexive stance of jotting down my conscious fore-knowledge and maintaining a reflexive account of my engagement in order to help ensure that I was not simply imposing my understanding onto the data. As Finlay and Gough (2003) argue, researchers need to use reflexivity to be sensitive to potential issues that may arise in research.

However, defining my position as insider on one level may be viewed as problematic. As much as I was an insider, I am not a sibling to an individual with CP: my positioning as a mother led me potentially to a place myself or be placed within a different standpoint. As discussed earlier, I needed to be aware of age-related power differences within the interview process. On reflection, I wonder whether I am partly insider and partly outsider (Corbin and Buckle, 2009). This was illustrated within one interview when I realised that a participant was struggling to describe what CP was. My position as a mother led me to talk about CP and to explain how it is acquired. At that point in time I realised that I was talking from a frame of reference of a mother and counsellor, than a sibling of a CP individual or indeed researcher. I tend to think that if this study was carried out by a young adult who has a sibling with CP, the findings could have been different hence future research could look at this phenomenon from a sibling’s point of view.

Corbin and Buckle (2009) admits that there are positives and negatives of this role. While the positive involves an acceptance by the closed group who may be open to share their experiences freely with someone who has similar experiences, the negatives may involve role confusion during analysis, where a researcher is bound to interpret what may be of interest to him or herself. In order to mitigate this I used disciplined bracketing to ensure I was not simply imposing meaning, rather that I was identifying meaning clearly present within the data itself.
3.12. Conclusion

The chapter has provided a justification of the methodological choices made. The tools of collecting data and how data was analysed have been provided. Further a discussion of the decisions made throughout the research process and how ethical issues were handled has been enumerated.

The next chapter provides a summary of findings.
CHAPTER 4 - FINDINGS

4. Overview

This chapter presents findings of the study which explored the experiences of young adults who have siblings with Cerebral Palsy, within the Kenyan context.

It begins with providing a detailed description of the experiences that were analysed using an IPA approach presented in a narrative form and provides a conclusion to the findings at the end of this chapter.

4.1 Super-ordinate themes

The overall findings were four themes that emerged that were contributed to by the participants as listed below.

Table 4.1. Superordinate themes

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Theme 1</th>
<th>Theme 2</th>
<th>Theme 3</th>
<th>Theme 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A sense of personal development and reward</td>
<td>Emotional impact</td>
<td>Relationships within the family</td>
<td>Relationships outside the family</td>
</tr>
<tr>
<td>Luunga</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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The study focused on the patterns and connections that were identified within the young people’s accounts after analysing their data using the steps highlighted in chapter three. A number of subthemes contributed to the Super-ordinate themes that are presented in Table 4.2 below.
Table 4.2: A table of super –ordinate themes

| A sense of personal development and reward | • Sense of achievement, satisfaction and concrete reward.  
• Increased understanding and acceptance of the condition.  
• A loving, caring and responsive relationship with their sibling. |
|-------------------------------------------|---------------------------------------------------------------|
| Emotional impact                          | • Feelings of happiness and hopefulness  
• Feelings of anger  
• Feelings of fear  
• Feelings of helplessness and inadequacy  
• A sense of both obligation and responsibility  
• Feeling it is hard and overwhelming |
| Relationships within the family           | • Strengthening of bonds and cohesion  
• Straining relationship and creating division within the family |
| Relationships outside the family          | • Building personal connection outside family  
• Feelings of stigma, non-understanding and lack of acceptance |

In the following section, there is focus on each of the super ordinate themes and the subordinate themes that gave rise to each of them.
4.2 Theme one: A sense of personal development and reward

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<th>A sense of personal development and reward</th>
<th>Sense of achievement, satisfaction and concrete reward.</th>
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<td></td>
<td>Increased understanding and acceptance of the condition.</td>
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<td>A loving, caring and responsive relationship with their sibling.</td>
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Cerebral Palsy (CP) impacted on the young people in this study positively in terms of a sense of development and reward. They demonstrated a sense of achievement, satisfaction and reward. At the same time they felt that they had gained an increased understanding of the condition which led them to accept the condition well and led to their personal development. In their interaction with the siblings, they demonstrated a loving and caring attitude towards their siblings with CP as shall be highlighted in the sub themes below.

4.2.1 A sense of achievement, satisfaction and concrete reward

A sense of achievement, satisfaction and concrete reward came up as one of the effects on the psychological well-being of the young adults in this study.

For instance, in the following extract, Jazala felt some sense of satisfaction in accomplishing a certain task.

"I remember there were moments when I used to take her to the clinic for therapy just me and her alone. So we had to go all the way, carry her, go board a matatu (public transport) up to the stadium... That is about 8 kilometers or so. Cross some roads with her and that time carrying a baby all that way on a dusty.... and by that time I was still in school, I was about sixteen or seventeen years. I was still tiny". Jazala P.178.
This statement by Jazala points to a sense of pride in taking care of his sibling at a tender age, a demonstration of some superhuman effort involved in this role. He talked of how he achieved his goal and felt satisfied when he said that “I felt good because, I managed to take care of her.... I was really happy to have managed to do so” Jazala P.180. He emphasises the fact that "I was still tiny" as stated earlier, to imply that he was carrying out a role that was far above him, at the time, and yet depicting some sense of satisfaction in accomplishing the task. He narrated how he travelled long distances, with his sibling in public transport, carrying his sibling on the back on a dusty road and climbing stairs to a second floor building with his sibling were some of the challenges he experienced when carrying out that particular assignment. However, he went above all odds to ensure this was done and thereby made him feel some sense of satisfaction. His major focus was on accomplishment of this task.

For Khasoa, it was doing things that made the sibling happy that gave her a sense of satisfaction: “I just, for me I usually buy him yoghurt, because he likes drinking yoghurt. So that makes him happy” Khasoa P.335. Again she goes further to say that “Sometimes I play for him music. The one I told you Bongo” Khasoa P.337. Khasoa gained a sense of achievement in doing for her sibling what made him happy. Her satisfaction came from the sibling’s comfort. Earlier on she had talked about the sibling’s love for music in the following extract: , "yeah, sometimes we have fun, we listen to music, he likes bongo( slang for Tanzanian music) music a lot, and also when I feel that he is bored, we just play it just for fun” Khasoa P.278. This was followed by the following words, “It is as if he knows how to sing it, so he makes a lot of noise, but he is not actually singing, just making noise” Khasoa P.280.

Khayecha felt a sense of satisfaction when he forfeited his chance to travel outside the country to help the mother take care of his sibling with CP in the following extract: “Just before she was born I had to go to country x, so my passport came out. So the girl was born before my passport came out. And when I got my passport, Mama couldn’t ... I couldn’t go away from my mama because she was, I am the only boy at home that can help my mama too much, So I had to leave everything to help my parent you see” Khayecha P.503.
He looks at this positively as an opportunity to support her mother in the role and is hopeful the opportunity will come by again:

“Yes I do hope that my opportunity is still around. And I usually don’t give up, even though I have a crippled sister, I usually hope that one day, one time, she is going to be fine and I will get my opportunity” Khayecha P.505.

A concrete reward was identified in Luunga’s account from acquiring a job in the following extract;

“….. And even some time when I was looking for some job; I heard that there was an advertisement. I applied for the job and got it. These are the hopes that I am seeing... I cannot stay at home all the time. I just heard some advertisement that said that they needed someone to do this or that and I got the job” Luunga P.77.

Luunga felt that this was a concrete reward of acquiring a job; she felt that she did not deserve and connects it to taking care of her sibling with CP. She had refused to leave her sibling alone at home and denied herself a chance of going out to look for a job, which she got without struggling.

In turn she attributes this job to a reward for caring for her sibling with CP when she said that:

“there is this company called x, yeah because out there we have many people but I asked God who am I that he chose to go there? I guess just because of taking care of that child” Luunga P.82.

Amidst stiff competition she was selected as a preferred choice. She connects it to caring for her sibling with CP even though those offering the job did not know the role she was playing in her sibling’s life. She goes further to explain how these encounters made her feel in the following extract:

“I felt so happy because I thought maybe if I had left her to go wherever I would have gone, I wouldn’t have gotten that reward and when I took care of her, maybe God said, she has refused to go to search for money to stay with her brother, now I will have to reward her” Luunga P.94.

Another unique experience that acknowledges there were some concrete rewards came from Kubuyo in the following extract as well.
‘yeah, I can remember that one day that thieves had come to steal from my mum and when they saw him, he was just laughing, so they sympathized with him and told mum to move and take the child to hospital”

This experience for Kubuyo was quite different from the others. In his view, the sibling with CP shielded the family from imminent attack by would-be thieves, who left convinced that the family was in more urgent need of medical attention for their sibling with CP. Although this experience did not directly happen to him, the fact that he was part of this family, made him feel that this was a concrete reward, brought about by his sibling’s condition. That is why he remembers it several years later.

Only Manguya is missing out on this theme as he did not mention any rewarding experiences in his account.

4.2.2 Increased understanding and acceptance of the condition

An increased understanding and acceptance of the condition was another important aspect that was identified in five out of six accounts of the young people involved in this study.

Kubuyo’s account demonstrates an increased understanding of the sibling’s condition in the following extract:

"I only came to know about my sibling’s problem when I was in high school. At primary level, I used to wonder why my sibling was not behaving like other siblings, but when I learnt about it in school, I began to understand more about this condition” Kubuyo P.404.

Kubuyo’s understanding of the condition resulted from living with someone with the condition and at the same time learning about the condition in school which led to his growth in perception and that is why he said that “it has really changed the way I see him because I know that he is challenged and I am always ready to support him” Kubuyo P.406.

On her part, Khasoa also showed some growth in understanding when she said the following words:
"when I reached form four, we were learning biology in form four, so we were taught about cerebral palsy children/patients and the way they are mentally ill... and how their brain functions... Then I got to understand everything about him. So from that time, I got to understand the way his condition is and accepted him.... Khasoa P.306.

For Khasoa, having lived with the condition made her understand the condition through experience and later on when she was taught about the same, it increased her level of understanding that led her to accepting the condition of her sibling.

Again, Manguya admitted that he got a deeper understanding of the condition in the following extract:

"I got to understand more about CP and know that there are such conditions and that we must accept people who have such conditions and support them". Manguya P.558.

Having grown up with, and having a practical example of CP, gave him an advantage of increased knowledge on the condition. He not only understood the condition from a theoretical point of view but gained an understanding of the condition and learnt how to relate with others with similar conditions. He admits that clarity about the condition came from counsellors and parents who explained the condition to him in the following extract:

"I got clarity (referring to counsellors) especially when I was young and did not understand it. My parents also explained to me what it was all about" Manguya P.540.

The increased knowledge and understanding led him to teach others about the condition.

Manguya further admitted that; "All of us siblings understand her situation and try to help her cope, play with her and take care of her" Manguya P. 550. Even though Manguya and his siblings had an understanding of the sibling’s condition, he seemed afraid of what would befall his sibling if she ever recovered and how she could recover the lost years:

"I fear whether she would get well. And if she gets well like today, what will happen to her. Will she start school from nursery even if she is grown up? Will she catch up with what she has missed?" P.560.
It meant that he was fearful (skeptic) of seeing an adult sibling involved in childlike tasks. Although Manguya had reported an understanding of the sibling’s condition, this challenges his thought of having understood the condition, as he seems to have a partial understanding of the condition.

Khasoa, Kubuyo and Manguya gained an increased understanding of the condition from their interaction with their siblings with CP and this made it easy for them to understand the condition when they learnt about it in school. Afterwards, it changed their perception as they gained a greater understanding of the condition. A deeper understanding of their siblings’ condition led to a number of them teaching their peers about the condition. An example is Luunga who, though seeming to have had a different view on understanding of the sibling’s condition, and I:

"Mum used to ignore us and never used to say that he is sick or what was wrong with him, sometimes she refused to take him because of the job”. Luunga P.36.

Here, Luunga felt ignored by her mother who should have given her information about the sibling’s condition. However, when she later learnt about the condition in school, she became more knowledgeable about CP. This led to her taking on the role of educating others about the condition in the following extracts:

"We did not know that the child had cerebral palsy…. By the time we brought him here we can see that her legs just started strengthening" Luunga P.70

This is when she came to understand about the condition that she would later teach others.

"I usually tell them [peers in school] even when we are coming to some events in school. I had already taught them and now they were not asking”. Luunga P.72.

This paints a picture that Luunga gained a deeper understanding of the condition by personally experiencing it and started educating others.

Jazala on his part not only gained an understanding of the condition, but also started educating his friends about the condition as well in the following extract.

"They wonder, they sometimes ask what is wrong. And I just explain to them that the condition is called cerebral palsy, whereby the body cannot coordinate with the brain” Jazala P.221.
For him the increased knowledge gave him confidence to educate his friends about CP. These two participants expressed views that echo Manguya’s view, which points to increased knowledge of the condition leading to dissemination of the same.

Khayecha is missing out on this theme as he did not have a clear understanding of CP. When I asked him whether he understood what CP was, he replied that, "may be if you could tell me, I am not that learned” Khayecha P.436. This question was reflected back to the interviewer as he felt he did not have an understanding of the condition. However, although he did not have an understanding of CP as a condition, when describing his sibling condition he seemed to define it when he said that the disease has gone through her muscles in the following extract:

>: “yeah, to my sister, she is unable to walk, you see, I usually tell myself that the disease has gone through her muscles, she can’t walk, she can’t stretch” Khayecha P.475.

Although Khayecha did not have a full understanding of the condition, this description fits a partial explanation of what CP entails.

4.2.3 A loving, caring and responsive relationship with their sibling

Five of the young people in this study also developed, in differing degrees and ways, a loving, caring and responsive attitude towards their sibling with CP. In particular, Luunga, Jazala, Khasoa, Khayecha and Manguya seemed to depict a sense of love, care and responsiveness to their siblings with CP.

Jazala demonstrated love and care by doing certain tasks for his sibling with CP. "At times I stay at home with her, I have to feed her and do everything for her” Jazala P.171. He went further to state that, "they are good moments because she enjoys”. Jazala P.175. He talked about good moments with his sibling that arose from a loving and caring relationship. He also connects with love and care when he said that:

"I will tell them (young people who have siblings with CP) to appreciate the children the way they are. You must first appreciate, accept and love them then you won’t even notice the CP condition, because you will see that they are kind of normal. Sometimes, we even forget that she is a CP
child. Because when you make her feel comfortable, everything flows for her, then she is not that stubborn, she doesn’t feel the challenge.”

He addresses others in reference to his own sibling, whom he feels is not stubborn, and states that by showing appreciation, love and acceptance, it makes his sibling with CP feel less challenged.

For Manguya, responsiveness came from understanding the condition of his sibling in the following extract:

“I got to understand more about CP and know that there is such a condition and that we must accept the people who have such a condition and support them” Manguya P.558.

This is reflected in his words that:

“when she is uncomfortable or crying, I try to make her comfortable, or find out why she is crying and sort the issue out if I can. If she is bored, I try to play with her and talk to her. If I find her jovial, I also play with her to make her even happier” Manguya P.546.

He demonstrated responsiveness by caring and showing love to the sibling with CP and by responding to his sibling’s needs.

On her part, Khasoa talked of how, when she understood her sibling’s condition, she began to treat him with a lot of care:

“I now started treating him in a special way, I knew he had to be fed, changed, cleaned, everything had to be done for him” Khasoa P.301.

She reported that this kind of treatment began after she understood her sibling’s condition. By recognizing that she had to treat the sibling in a special way by responding to his physiological needs, she demonstrated her love, care and responsiveness to the sibling’s condition.

Khayecha points to a caring attitude in the following extract which begins by describing the condition of his sibling with CP:

“So after she was born, mum had never bore a child like that, you see, but after she gave birth or after she was born, two years on, papa died. So when papa died she was being raised by mama. Mama knew that it was a bad disease. She took her to many hospitals. She was then told that they were unable to cure her daughter, she raised her the hard way” Khayecha P.441.
It was this that led him to recognise the importance of developing a loving relationship with his sibling: "As we realized, we decided to give that little child as much love as we could” Khayecha P.442. This came about after understanding the sibling’s condition and he thereafter added that “since then, her response has been good” Khayecha P.443. In his view, loving and caring for his sibling led to a responsive relationship.

Having looked at the sense of personal development and reward in the young adults, I now turn to the emotional impact that the condition had on the non-CP sibling in the next section.

4.3 Theme two: Emotional impact

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<td>2) Feelings of anger</td>
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<td>3) Feelings of fear</td>
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<td>4) Feelings of helplessness and inadequacy</td>
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A range of emotions came up from the accounts of the young adults as a result of having siblings with CP. On one end participants expressed a sense of happiness and feeling hopeful in different ways while on the other hand they expressed feelings of anger and frustration, fear and feelings of helplessness and inadequacy experienced by the young people involved. Some of them identified with more negative emotions while others emphasized their positive emotional responses. For instance most of Khayacha’s emotions pointed to negative emotions whereas most of Jazala’s emotions expressed positive emotions. For others both negative and positive emotions were expressed.

4.3.1 Feelings of happiness and hopefulness

Four of the young people expressed feelings of happiness while five expressed feeling hopeful despite their sibling’s condition. Feelings of happiness and hopefulness were largely associated with particular circumstances or activities in their lives. For instance, Kubuyo talked about feeling
happy whenever he interacted with counsellors during the end of year party in the following extract;

“At x we are supported especially during the end of year party and whenever we have visiting counsellors. I have found such time quite fulfilling as counsellors take care of my emotional challenges and this makes me feel happy” Kubuyo P.408.

From his words it would seem he derived his happiness from being understood by the counsellors who took care of his emotional challenges.

Jazala also demonstrated a sense of happiness. He talked of needing to care for his sibling:

“Yeah at times I stay at home with her. I have to feed her and do everything for her” Jazala P.173. However, he depicts this in a positive way:

“they are good moments because she enjoys and she is not really so stubborn when you do everything for her, she won’t be in the mood of crying all the time, she just feeds well, yeah tries to get her rest watches TV”. Jazala P.175.

His source of happiness came from doing little things for his sibling with CP that made his sibling comfortable and a sense of happiness for him. Another opportunity where Jazala talked about feeling happy was in the following extract;

“we are all jovial about her, we are always happy, we are not sad, we are all happy and... I think that we have some faith that she will someday, she will be okay” Jazala P.215.

He drew his happiness from the fact that he had faith in God that one day his sibling would recover from the condition. This not only point to feelings of happiness but also to his feeling hopeful that his sibling would recover. In his narration, he expressed his frequent experience of happiness: ‘we are always happy’. Again the word ‘happy’ is repeated thrice in a single paragraph to demonstrate how happy he felt.

Khasoa has a different experience from Jazala’s. Her feelings of happiness came from her interaction with her CP sibling, whereby they both enjoyed certain music and had fun together. This is quite pronounced in her narration;

“yeah, sometimes we have fun, we listen to music, he likes bongo(slang for Tanzanian music) music a lot, and when I feel that he is bored, i just play it for him, just to have fun” Khasoa P.278.
Khasoa takes pride in having fun with her sibling with CP which makes both of them happy. This experience had similarities with Manguya’s where happiness came from relating with his sibling with CP whom, he admits, is quite charming. “Sometimes I spent time with her, talk to her, she is very charming” Manguya P.530.

Both Khasoa and Manguya drew their happiness from their interaction with the sibling with CP and the things they did together.

Feeling hopeful was largely experienced by Luunga, Jazala, Kubuyo, Khayecha and Manguya. Luunga in particular was hopeful that her sibling would become a ‘big person’ in society when he grew up: “I hope that when he grows up he will become a big person in society” Luunga P.119. On his part, Jazala was hopeful that his sibling would be able to do certain things he was not able to at the moment in future ”I hope that one day she will walk and talk” Jazala P. 206. They were both hopeful about the future of their sibling with CP and looked beyond the disability in their siblings.

Kubuyo on his part was hopeful that his sibling would be independent in the following extract, “Yes, I hope that one day my sibling will be able to walk, and do everything for himself” Kubuyo P.414. Although different words were used by Manguya, he was also hopeful that his sibling would recover in the following extract, ”All of us siblings understand her situation and try to help her to cope, play with her and take care of her. I hope she gets well” Manguya P.552. Later on in his narration he applied hope when he said the following words “I hope that my CP sister gets well” (Manguya P.568).

Khayecha on his part felt hopeful that he could find a cure for his sibling:

“I hope her condition can be cured and one day someone will come and cure my sister then she will be able to walk, yeah I hope someone will come and help” Khayecha P.472.

Earlier on, Khayecha had said that he was hopeful in the following extract

“As I know, trust me I am not that good and religious, but all I do is just trust. I trust in God, because I am not that learned and religious, I just believe and trust God that my sibling will be fine” Khayecha P 462.
Although these young adults had an understanding about the condition, they were hopeful that their sibling could recover; hence this challenges their knowledge about the condition to some extent.

Khasoa is missing out on this sub-theme as she did not demonstrate any feelings of hopefulness in her accounts. A large portion of her experiences pointed to negative emotional experiences.

4.3.2 Feelings of anger and frustration

Three out of six participants displayed feelings of anger and frustration in their accounts, albeit expressed differently and at differing targets. For instance, Luunga expressed feelings of anger towards her mother for hiding information about the sibling’s condition from her and other family members. She highlighted this when she talked about her mother:

“I think mum knew about it but she did not tell us and we used ask her why she was always taking him to hospital. Mum used to ignore us and never used to say that he was sick or tell us what condition he had. Sometimes she refused to take him because of the job” Luunga P.36.

Here, Luunga’s anger and frustration is directed towards her mother whom she felt knew the sibling’s condition but hid the information from her. Again, this failure to provide her with information about the sibling’s condition led to feelings of anger and frustration not only because of her sibling’s condition but also her mother’s reaction towards her.

Luunga also felt frustrated whenever the sibling with CP kept crying uncontrollably.

“When she is sick, she keeps crying all the time, when you are carrying her. You give her everything that you think she will stop crying but she just keeps on crying. You start wondering what the matter is” Luunga P.55.

This condition of her sibling left her with feelings of anger and frustration because she did not know how to deal with it.

Khayecha’s narration pointed to feelings of anger about his sibling’s condition as demonstrated in his words: “yeah we have lots of stress about her. Sometimes we think of what we should do about her condition, what will make her walk, talk, it just stresses the whole family” Khayecha
He reflects on this when he said the following words. “Because I had never had a sister like that before, it comes to a place where you start questioning why? You start asking yourself why it is only you” Khayecha P.450. This kind of questioning, points to feelings of anger and frustration that his sibling had such a condition. His anger is directed to his sibling’s condition.

Manguya on his part expressed anger as one of the range of emotions towards his sibling’s condition. In his narration, he said that:

“"When I look at her and imagine the kind of life she would have had, I feel bad. And to know there is nothing I can do to help her makes it even worse” Manguya P.534.

He confirms feeling this way in a preceding paragraph when he said that “Just at times feelings depressed about the issue and at times annoyed that it had to happen to her” Manguya P.336. Manguya’s anger is directed towards the sibling’s condition that made him feel angry that her sibling had CP.

### 4.3.3 Feelings of fear

Five out of the six participants expressed some form of fear. Fear of having another person in the family become disabled, fear of having to cope with the future caring roles, fear of giving birth to a child with CP and fear of the unknown were mentioned by the participants as some of the fears they had.

Khasoa, Jazala, Khayecha, Manguya and Kubuyo expressed some form of fear. For instance, Khayecha expressed his fears in the following extract.

“"Yeah I fear, sometimes I feel that the next one is maybe going to be crippled too. Sometimes, I think that someone is going to be crippled afterwards, but I usually take it as God’s will” P.460.

Khayecha seemed afraid of disability occurring again to anyone in his family. When he said that the next one may be disabled, he confirmed his fears about disability recurring in his family again. Whether to himself or a family member, he was afraid of the condition recurring again.

On his part, Jazala feared about future care giving responsibilities when he said the following words; “I have fears because, she is growing and we are all growing and we will, ok someone has
to go his or her own way, make his life or her life. So I always wonder what will become of her. How will she be able to live on her own?"

For Jazala it was the inability in his sibling with CP to live on his own that caused fear in him. He wondered whether the sibling could make it on his own in future. This was confirmed by several unanswered questions he had concerning his sibling’s condition.

Manguya on the other hand had two forms of fear. He feared what would befall his sibling if she recovered and if she could recover the lost years. His experience was unique from others as expressed in the following extract:

"I fear whether she would get well. And if she gets well like today, what will happen to her. Will she start school from nursery even if she is grown up? Will she catch up with what she has missed?" Manguya P.560.

It meant that he was fearful of seeing an adult sibling involved in children’s tasks. His fears mainly consisted of whether the sibling could gain independence and what would happen if she didn’t. Again he feared to give birth to a child with CP in the following account: "Will any of my children have CP?" Manguya P.562.

On the other hand, Khasoa feared about the anticipated responsibility upon her when she was grown up. She said the following concerning her fears:

- "It looks like a very big responsibility especially when I am a grown person. I have my own job. I just usually think about him. How will he be, when I am married maybe. You know he doesn’t look like he will grow taller than he is right now. So I just think that maybe I will find a way out to help him, but I don’t know how?"

She was afraid of the kind of responsibility that would be expected of her in the future when she has other roles like a job and marriage to take care of. She seemed concerned about managing a job and a marriage while at the same time taking care of her sibling with CP in future. Her fears about marriage may be also demonstrated in her words ‘may be’. These words seem to point to uncertainty about whether she would marry or not. Her words also echo Jazala’s words on fear about the future responsibility. They both feared the responsibility expected of them in future.
Kubuyo was also fearful that the sibling with CP could not depend on himself in the following "I fear that he cannot be depended on himself, yeah" Kubuyo P.389.

Although different situations led to feelings of fear, their fear was mainly focused on the future.

4.3.4 Feeling of helplessness and inadequacy

Feelings of helplessness and inadequacy were quite pronounced in most of the young people’s accounts. This came as a result of involvement in the physical comfort of their sibling with CP.

Khayecha’s experience is summed up in the following:

"It is a bigger challenge anyway, it is a big challenge without help, without knowing what to do, without knowing what is the next step she is going to bring (the CP sibling), it is a big challenge... [silence]..." Khayecha P.481.

Here Khayecha connect his sense of helplessness with a lack of support, guidance as to how to respond or knowledge of what the future might bring. He repeats the word 'big challenge’ twice as if to emphasise the size of the challenge. This is further followed by a silence to reflect on the state of helplessness experienced.

Similarly, Manguya expressed feelings of helplessness and inadequacy:

"When I look at her and imagine the kind of life she would have had, and the kind of life she is missing, I feel bad. And to know that there is nothing I can do to help her makes it worse for me". Here, Manguya felt helpless and inadequate when he admitted that there was ‘nothing he would do to help’ his sibling with CP. By looking at his sibling as seriously affected and thinking about what the sibling was missing made him feel helpless.

Jazala, on his part, expressed his sense of the challenge connected to trying to assess her needs and his sense of obligation to respond to them on an ongoing basis:

"I can say that there are challenges of guessing... You have to leave your work and attend to her..... There are just those things you have to do for her which, when she, if she was a normal child she would do for herself" Jazala P.191.
In a short period, Jazala repeats "you have to" ten times to express the numerous demands by his sibling with CP he attended to. He follows this by emphasizing that he felt it was difficult for him through the following words:

"It has been hectic, because at times you are so busy, and she wants to go outside, you just have to attend to her, because you can’t work while she is there crying. So you attend to her first and when you finish you rush and come back to your things – you know at times you want to leave, she starts crying again, she doesn’t want you to leave, so you just have to talk to her well and assure her that you will come back" Jazala P.193.

He seemed lost in the many roles he is required to play at the same time, feeling helpless and inadequate in these roles.

On the other hand, Luunga considered the responsibility of taking care of the sibling as demanding. "We were doing it in the morning, at lunch time and evening. Sometimes we missed our school work so that we can look after him" Luunga P.39. She emphasises the number of times per day, she was expected to attend to the sibling with CP, and considers having to miss out on school work to take care of her sibling, as a state of helplessness as it interfered with her level of concentration. In this, she felt inadequate because she did not have anything else she could do. However, she goes further to reflect on the experience as a burden (her own words). She emphasises that whenever the sibling fell sick, it became difficult to know what to do in such instances:

"When she is sick, she keeps crying, crying all the time, when you are carrying her.... You give her everything that you think will make her stop crying but she just keeps on crying, now that what is this? You start thinking" Luunga P.55.

She felt helpless due to the disappointment she experienced whenever the sibling cried uncontrollably and this is what brought about feelings of helplessness and inadequacy.

4.4 A sense of hardship

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<th>A sense of hardship</th>
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A number of the siblings expressed a sense of hardship in a range of ways. This resulted from their role of being a sibling of an individual with CP that resulted for them in a sense of obligation and responsibility for their sibling with CP.

4.4.1 A sense of both obligation and responsibility

All the young adults in this study undertook a range of duties leading to a sense of hardship that sat alongside a sense of obligation and responsibility. They were involved in taking care of their sibling, for instance feeding, carrying them, attending to their physiological needs, playing with their sibling and doing things that their siblings were not capable of doing. Jazala’s experience seems to sum up the young people’s experiences of their role. Jazala felt trapped in the caring role and relayed his sense of the role’s difficulty:

“There are challenges of guessing, so at times you have to do things for her. You have to leave your work to attend to her. And maybe your work is needed urgently. And maybe she wants to go for a stroll outside. So you have to take the wheelchair as usual. Sometimes you have to model for her using play dough, so you have to model for her. Maybe she is playing with the doll and it falls off. She can’t pick it for herself so you will have to come from where you are and pick it for her. There are those things you have to do for her which, if she was a normal child, she could do herself.”  Jazala P.191.

Jazala felt over-involved in attending to the sibling’s wants like playing, picking up the dough whenever it dropped down, responding to anything she was not capable of doing. Words like “you just have to” are repeated severally to demonstrate the level of responsibility he felt he had to undertake. Again when referring to the wheelchair, he talked about the activity as a usual occurrence. These words point to the fact that Jazala found himself trapped in the caring role, thereby having an obligation and responsibility towards his sibling with CP. At some point he complained about the extra responsibility he took upon himself besides his work. By focusing on his sibling’s inabilities and the role he played to complement their shortcomings, he was pointing to having an obligation and responsibility towards his sibling with CP.
On her part, Khasoa reported that she carried out a number of duties for the sibling like feeding, changing, cleaning as demonstrated in the following extract:

"Now I started treating him [silence] ..... in a special way I knew he had to be fed, he had to be changed, he had to be cleaned, everything had to be done for him” Khasoa P.301.

She goes further to say that:

"Sometimes it is hard for me when, maybe I am having stress because of school, and I have to take care of him at the same time....... it is hard for me to concentrate on my books and him at the same time” Khasoa P.320.

For Khasoa, the heavy workload involved made it difficult for her to concentrate on her studies when the sibling was in need of attention. What was common for the two participants was that the kind of responsibility expected by the sibling with CP, which was quite great and impacted on their work and studies to a large extent.

Luunga, on her part missed school work to look after her sibling with CP. She talked about it in the following extract, “we were doing it in the morning, at lunch time and evening. Even I had our small..... Luunga P.39. It became an obligation and responsibility to ensure her sibling was taken care of even if it meant compromising her school work. In the above statement, she highlights the kind of responsibilities she took upon herself, which were demanding.

Khayecha’s experience differs from the rest of the participants because he lost an opportunity to travel out of the country because he wanted to support his mother whom he felt needed help to take care of his sibling with CP after the death of their father in the following extract:

"Just before she was born I was to go to country x, so my passport came out. So the girl was born before my passport came out. And when I got my passport, mama couldn’t, I wouldn’t go away from my mama because she was..., I am the only boy at home that can help my mama too much. So I had to leave everything to help my parent, you see” Khayecha P.503.

He talked about being the only male sibling that could help the mother to take care of the sibling with CP. This led him to assume a sense of obligation and responsibility on his part as he admits that the other siblings in the family were not helpful in this role.
4.4.2 Feeling it is hard and overwhelming

From their narration, all the participants were involved in the caring role to some extent, some by choice while others due to the enormous demands by the sibling with Cerebral Palsy. They described the responsibility involved as difficult, hectic, demanding and strenuous for them, hence their description of the caring role as a “hard thing to do”.

“At times it is hard to know what she is communicating; at times it is a bit hard. So like you will find her crying and don’t know why she is crying; so actually, getting the actual thing that is making her cry at times is very hard” Jazala P.182.

Jazala later on again said that:

“It has been hectic, because at times you are so busy and she wants to go outside, you just have to attend to her because you can’t work while she is there crying. So you attend to her first and when you finish you rush back to do your things. Sometimes you are very late, so you just have to take your time to talk to her – like five minutes” Jazala P.193.

Jazala found it difficult to carry out his duties whenever the sibling required attention. He therefore prioritized the sibling’s need over his own needs and this affected him due to the extra demands. By stating that, ‘you just have to’ points to feeling trapped in this role.

This was also present in Khayecha’s accounts when he said that

”Mama knew that it was a bad disease. She took her too many hospitals. So she was told your daughter is unable, she raised her the hard way”. Khayecha P.441.

Khayecha talks about the difficulties of raising her sibling as a hard thing. This is also demonstrated in the following extract:

”sometimes mama gets busy, and my brothers are not around. maybe when I am there she tells me not to go to work, to help her, you see, carry my sister around, let her not cry, till mama comes back” Khayecha P.497.

Equally Khayecha’s work is affected because of taking care of his sibling’s needs as the demands seem overwhelming.
Kubuyo, on his part experienced physical hardship differently. He began his narration by stating how difficult the situation was in the following extract:

"Yeah, sometimes he is stressing because you don’t know what he really wants. So he sometimes may want to cry, when he is showing you something, but you really don’t understand him. So you just have to guess. It is really hard". Kubuyo P.372.

Again the disturbance by the sibling with CP, whenever he made noise at night, was experienced by Kubuyo as making it difficult for him to sleep and causing him difficulty or ‘stress’. :

"Mostly at night, sometimes I am actually feeling well and he starts making noise because he is uncomfortable. So you check on him, you make him the way he wants and then go back to sleep and he starts making noise again. So you just get stressed” Kubuyo P.381

For Khasoa, it was difficult especially whenever the sibling cried in the following extract;

"Sometimes it is hard to understand what he wants. May be he has a problem. He may cry, but you may think he is crying out of nothing, but sometimes he is sick. May be he has something in his eyes... so; it is very hard to understand him at that point” Khasoa P.270.

These words are repeated by Khasoa;

"He has a problem with his stomach ... so sometimes it is hard. It is a must you give him some medicine so that he can go to the toilet.....so it is hard for him. So he cries a lot. And maybe you have something to do and he is there crying. It is hard.” Khasoa P.283.

Khasoa experienced both mental and emotional hardship whenever the sibling with CP cried uncontrollably in her narration. "He cries a lot. And maybe you have something to do and then he is crying. It is hard” Khasoa P.283. She went further to describe how difficult it was for her to take care of the sibling and concentrate on her books at the same time:

"It is hard for me when, maybe I am having stress because of school and I have to take care of him at the same time. You know sometimes my mother has a lot of work to do and I have to take care of him and so it is hard for me to concentrate on books and him at the same time” Khasoa P.320.

Khasoa felt the overwhelming demands of the sibling with CP and used the words “it is hard” severally to demonstrate the magnitude of the demands placed upon her by the sibling’s demands.

From Jazala, Khasoa, Kubuyo and Khayecha’s accounts, I can sum up their experiences using their own words that “it is hard”. These words were used severally by these four participants to
emphasize the level of demand upon them by their sibling with CP. Luunga used different words from the four when she said that “it is like a burden” (Luunga P.41) when referring to the demands placed upon her by the sibling with CP. Again, Luunga, when describing her experience, talked about doing physical exercises of massaging the sibling at least three times a day. Having to carry out this obligation at the same time as carrying out other duties of school work made it physically challenging for her. All these are physical hardships that she experienced while taking care of the sibling with CP.

Manguya on his part did not talk about any difficulties. The only possible exception is when he mentioned that he took care of his sibling occasionally:

“Sometimes I spend time with her, take care of her and even talk to her, I also play with her... though times are few” Manguya P.530.

In his narration he does not seem to experience major difficulties involved of caring for his sibling as he only carries out this occasionally.

### 4.5 Theme Three: Relationships within the family

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Another important theme that was identified was its impact on relationships within the family. This was also experienced differently by the participants. To some, they experienced cohesion within the family while others experienced strained relationships which were due to having a sibling with CP. However, there were those who experienced both as highlighted below

#### 4.5.1 Strengthening of bonds and cohesion within the family

Strengthening of bonds and cohesion within the family was experienced by participants in a number of ways. Jazala experienced some increased closeness and cohesion within the family as a
result of having a sibling with CP. The condition had impacted on the entire family to some extent. In his own words Jazala said that:

“Actually it has improved our closeness because we all find ourselves towards her. Everybody is looking at her; nobody wants to hear her cry. Like when somebody hears her cry. Okay all the attention goes to her. Everybody will stop what he or she is doing and maybe find out what is wrong?” Jazala P.198.

This particular child became a centre of attention as most of the family members directed their attention towards her due to her condition. It brought about cohesion and close bonds that Jazala refers to in the above extract.

On her part, Luunga enjoyed close bonds with the sibling with CP. She stated how she relates with the CP sibling as closely as a mother would do in the following extract:

“Okay me I love this child as my own child...even when I am carrying him people say, eh! You have a child...? You know you cannot separate him from me” Luunga P.44.

She felt so close to her sibling with CP and said that no one could separate her from the sibling. She was so comfortable in the sibling’s company such that she did not mind whether the younger siblings helped her or not. She further points to good inter sibling relationship, although again she felt that the other siblings who were younger than her preferred playing with the sibling with CP in the following sentence, “Other siblings like even that child, they play together... even if they go out they go out with him, they don’t leave him” Luunga P.108. In her view the younger siblings only engaged their sibling with play while on her part she remained indoors to care for her sibling with CP. “Me I could say those small siblings like to play. Sometimes we share but me in most cases I love that child. That is the time I like staying around with her” Luunga P.115. She painted a picture of her assuming major responsibility for her sibling’s welfare. Having talked about her special attraction to the sibling with CP, she points to family cohesion where they were comfortable with each other in the family.

Manguya on his part reported that; “All of us siblings understand her condition and try to help her cope, play with her and take care of her”. Manguya stated that there was good inter-sibling
relationship whereby all the siblings attended to the sibling with CP. By admitting that ‘we believe as a family’ in the next paragraph, points to unity and support within the family members. “I believe and we believe as a family that one day she will get well” Manguya P.552.

Support from the family was identified by a number of participants. For instance, Khasoa in her account pointed to this when she said:

, “It has not been easy, but from the support I have been getting from my parents and counsellors, they made it easy for me.” Khasoa P.339.

This meant that she had support from her family members and this is how she may have coped. She described how they used to take care of the sibling with CP, in turns.

Kubuyo also talked about a supportive inter-sibling relationship in the following extract: "Just like the other siblings do help, sometimes you can ask them who knows the problem. One can point at him and say this is it" Kubuyo P.376. This meant that all of them were attentive to the sibling’s needs. However, Khayecha, on his part, had a different experience whereby there seems to be little support in the family with the other sibling preferring to keep their secrets. “Not all the boys say they are going to help him. Everybody hides his-his secrets” Khayecha P.451. Whereas the five participants reported that there were good inter-sibling relationships, his experience differs because he seems to care for the sibling with CP alone as he did not mention the role of other siblings in the family.

4.5.2 Straining relationships and creating divides within the family.

Straining relationship in the family was mentioned by half of the participants in this study. According to Kubuyo, the heavy workload involved in caring for a sibling with CP caused some strained relationship between the siblings as they were caught up in the arguments of who should attend to the sibling with CP. He highlights this in the following extract. Ah! Sometimes it is not all that good because we can start arguing on who should feed him, who to change him and so on. Kubuyo P.399. The workload of caring for the sibling with CP led to frequent arguments among siblings that negatively impacted on his psychological well-being.
For Khasoa, things were different because she did not talk about strained inter-sibling relationship even though she was left alone to take care of the sibling with CP when the other younger siblings went out to play. However, on her part, she felt less loved and ignored by her parents whose concentration was on the sibling with CP. In her view, it was like they loved him more than the rest of the siblings in the following extract:

, “It has not been easy, because most of the concentration was on him. It was like they loved him more than they loved us. And we were always left there alone with the maid so it was hard for us” (Khasoa P.297).

She seems to portray feelings of loneliness and rejection when she talks about “we were always left there alone.” She felt the concentration was on the sibling with CP. However, at some point Khasoa, felt that although her other siblings preferred to play, this did not cause strained relationship among them as she felt the others were too young to take on any caring roles.

Luunga’s experience points to what lack of understanding about the condition caused in her family. She stated that lack of understanding of the condition caused strained relationship within the family which left her feeling angry that her mother hid information about the sibling’s condition from her. In her narration she said that “She was born when I was in school. I think mum knew but she did not tell us... mum used to ignore and never used to say that he is sick or what” Luunga P.36. This is followed by the following words “They used to quarrel and say who will have to take him... now us we wouldn’t understand what was going on” Luunga P.38. However, the relationship improved when all the family members learnt about the condition of their sibling with CP as stated in her own words later; “when we understood the sibling’s condition, we ceased from arguing” Luunga P.104. This experience by Luunga points to what lack of information in her family did to the family members.

4.6 Theme Four: Relationships outside the family

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Relationships outside the family also seemed to have had an influence on the psychological well-being of the young adults in this study. All the participants had different feelings about their neighbours, peers or workmates. There were those who had built personal connections outside the family while others had not. Where they had built such connections, it impacted on them positively while where they were not accepted or understood, they were impacted negatively as demonstrated in the sub-themes below:

4.6.1 Building personal connections outside the family

Four out of six participants experienced the building of positive personal connection outside the family. For instance, Luunga experienced a positive psychological impact whereby she felt she had good connection with her peers in school who were ready to learn from her experiences of growing up with a sibling with CP. This is demonstrated in her words; “I usually tell them even when they were coming to some events in school, and I had already told them. Now they were not asking many questions” Luunga, P.72. Here, Luunga build connection by educating her peers about the sibling’s condition and this led to an acceptance. Her peers, especially those she had already sensitized about the sibling’s condition, seemed to accept her as opposed to those that were not sensitized on the condition.

Kubuyo also felt connected to his friends in the following extract:

“There are some friends who understand ....... For instance, there are those who question whenever I take him to the barber, why I should be taking a grown up to the barber. Yet there are those friends that quite understand and they even accompany me to the barber” Kubuyo P.408.

Although he experienced different forms of treatment from his peers and friends the emphasis here is on those supportive peers whom he felt connected to. This was also demonstrated by Khasoa when she talks about:

“Sometimes.....when I was in primary some of them did not understand, and they did not like the way he was, when mostly he was eating, they would say it is disgusting... so they just, would not support me when I was in primary school. But at least my friends now, they understand [referring to high school friends], Khasoa P.309.
Both Khasoa and Kubuyo’s accounts have similarities because they received different forms of
treatment from friends and peers. However, the fact that there were some friends who were
connected to them positively impacted on their wellbeing.

Manguya’s experience, although different from the two, also demonstrated some form of
connection as well. He preferred keeping to himself as a way of remaining safe from the outside
world and this seemed to have helped him. He admits that he would only share about his sibling’s
condition with a few trusted friends. In his narration, he said that:

“*I don’t tell most of my schoolmates about her except those I trust.  They have been supportive
and understood the condition and this has helped me to feel better*” Manguya P.550

Manguya preferred to confide in a few trusted peers he was connected to about his sibling’s
condition because he felt that they would understand and accept him as opposed to telling those
he felt would not understand him.

4.6.2 Feelings of stigma, non-understanding and lack of acceptance

Feelings of stigma, non-understanding and lack of acceptance by others within the community
were identified in a number of accounts as well. For instance, Jazala is faced with inquisitive peers
when he refers to them as having said that:

“*They do wonder, they sometimes ask what is wrong. And I just explain to them it is called
cerebral palsy…. Yeah they sometimes ask how it comes about. They ask why her?  Why not
another child?  I just tell them some things one does not choose*” Jazala P.221.

Here, Jazala faced a number of questions from his peers who were ignorant about the sibling’s
condition. He, however, took on the role of educating those around him, in order to make them
understand the sibling’s condition and improve their awareness and this changed their attitudes
towards his sibling’s condition.

Khasoa on the other hand felt misunderstood by her neighbours. She pointed to this in the
following extract:

"*I can say about the challenges, like when we brought him (the CP sibling) people say, eh! Where
are you going? Where are you taking this child?  When we carry him they ask that are you going
out or where are you going?  I will go and report you to your mother... when one of our neighbors
came to tell our mum, our mum told them that they are not just going out but taking our child for exercises”. Luunga P: 121.

Luunga felt that neighbours did not understand her. Negative remarks were viewed as unsupportive; citing her relationship with her sibling with CP was viewed as mistreatment, despite her focus on ensuring her sibling was comfortable. The neighbours went ahead and reported her to the mother who confirmed to them otherwise.

Negative attitudes by others left the young adults in this study feeling stigmatised. For instance, Khayecha felt stigmatised by his workmates in the following extract:

“Yeah, sometimes it does affect, sometimes mama gets busy and my brothers are not around. Maybe when I am there she tells me not to go to work to help her, you see, carry my sister around, let her not cry, till mama comes back, you see. We do sometimes, we do quarrel at my job. Sometimes I even my friends run away from me because all the time they see me at home, I am just carrying a cripple you see.” Khayecha P.497.

He emphasises the relationship at work and how his friends keep away from him because of his concentration on taking care of his sibling with CP. This kind of reaction distanced him and led him to prefer staying indoors most of the time.

Luunga, on the other hand, was concerned about people’s reaction to her sibling’s condition when she said the following words, “When others see these children they say this one looks how?” Luunga P.72.

Khasoa reported a different experience when she said the following words:

“Sometime ….. When I was in primary some of my peers did not understand, and they did not like the way he was, mostly when he was eating, they would say it was disgusting, so they just, would not support me when I was in primary. But at least my friends now, they understand” Khasoa P.309.
She spoke about an insensitive peer group in primary school who used negative remarks to refer to her sibling’s condition that left her feeling the impact of her sibling’s label. This kind of negative remarks by Khasoa’s peers affected her psychological well-being in the following account of her experience. “I felt bad; sometimes I even used to cry”. This she followed with remarks that “for those who thought they were so special than others”. Although she admits that people are entitled to their own opinion, this seems to be coping mechanism put in place to deal with those remarks. By referring to her sibling’s behavior as ‘disgusting’, it made her feel stigmatised due to this label by her peers.

Stigmatising remarks were present in the Kubuyo’s words and this was whenever he took his sibling to a barber in the following extract. “There are those who question why I should be taking a grown up to the barber?” Kubuyo P.408. This negative remark that questions why he should be taking his brother to the barber was viewed as insensitive to his feelings.

The absence of stigma was identified in Jazala’s accounts when he said that,

“They do wonder, they sometimes ask, what is wrong? And I just explain to them it is called cerebral palsy, whereby the body cannot coordinate with the brain. Yeah, at times they ask how it comes about. They ask why her? Why not another child? I just tell them that some things one does not choose, they just come. But funnily, they are all interested in her. They always come to visit her. And they are great friends with her. So like even my friend, when my friend comes, the first question is, where is your sister, where is your little sister, I must say hi to her.” Jazala P.221.

Jazala’s response does not point to feeling of stigma but to unanswered questions about the sibling’s condition, which were answered by the kind of information he provided.

Also absent from this theme is Manguya who did not point to feeling stigmatised. However, in the following extract he said that, “I don’t tell most of my schoolmates about her except those that I trust. They have been supportive and understood the condition and this has made me feel better”. Manguya P.550. Although he did not talk about any form of stigma, his narration points to fear of being stigmatised hence the reason he is afraid to tell people whom he does not trust about his sibling’s condition.
4.7 Conclusion

The findings revealed that having a sibling with CP can have an impact on the psychological wellbeing of the non-CP sibling, their role as siblings as well as their personal development. The study has also shown that having a sibling with CP can impact on their relationship with outsiders and the family members either both positively or negatively.

The roles and obligations undertaken by the young adult who have a sibling with CP were brought to the fore through these findings, which revealed that a number of them experienced a sense of physical hardships. Having presented the findings in this chapter, the next section therefore discusses these findings in relation to literature.
CHAPTER 5 – DISCUSSION

5 Introduction

This chapter discusses the findings in the light of relevant literature. The Social Model of Disability (SMD) and the Post traumatic Growth Model (PTG) are the major theoretical frameworks through which the findings are contextualized within the literature.

Findings from this study respond to the research question, “How do young adults experience and understand the impact of growing up with a sibling who has cerebral palsy within the Kenyan context?” The study focused on how young adults who have siblings with CP make sense of their experiences and how it impacts on their psychological well-being. The implications for counselling were also considered.

Overall, the findings revealed that there was a direct impact on the sense of psychological well-being of the participants, both negatively and positively, which has implications for counselling. The young adults experienced feelings of stigma, fear, anger and a sense of responsibility, although this was experienced differently. Some stressed the hardships they experienced while others placed greater emphasis on the rewards. Reported rewards were related to personal development and some concrete rewards while physical hardships were experienced in terms of caring for their siblings with CP and the emotional challenges experienced. The roles they undertook included feeding, dressing, massaging (exercising), taking their sibling to hospital, to church, to the barber and administering drugs occasionally as well as attending to their own school work or employment. Of particular interest is that siblings could be understood as experiencing disability by association (Burke, 2010) – a term that aims to capture the socially disabbling impact of being associated with a disabled individual. Consequently, in my discussion on the social model, the impact of societal attitudes, environmental and organisational barriers (Barnes, 2012; Thomas, 1999; Handicap International, 2005) will be considered in relation to the notion of ‘disability by association’.

To begin with, the findings are discussed in relation to Social Model of Disability.
5.1. The social model of disability

In Chapter two, the Social Model of Disability was defined as “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976, p.14). From this definition, disability is seen as a restriction of activity which excludes people with impairment from enjoying social activities in mainstream society. This definition was coined by disabled people from the UK in particular, arising from their desire to be given equal opportunities to non-disabled people in mainstream social activities. Disabled people felt that they were not disabled by their impairments but rather by society that excluded them from full participation in society; hence disability was seen as a form of social oppression (Barnes, 2012). It was therefore the exclusion through the obstacles or barriers that were placed by society that caused disability (Priestley, 2003). The Social Model of Disability [SMD] thus focuses on attitudinal, environmental and organizational barriers which hinder disabled people in having equal opportunities in terms of education, employment, housing, transport and leisure (Thomas, 1999; Barnes, 2012; Carson, 2009; Priestly, 2009), which I discuss in the following section.

5.1.1. Attitudinal challenges

Attitudinal barriers are seen as disabling not only for disabled people but also to their siblings due to disability by association (Barnes, 2012). In the current study, I identified a number of attitudinal barriers, among them stigma, that negatively impacted on the non-CP siblings. While research studies have shown the presence of some more positive attitudes towards disability in parts of Kenya (e.g. Mugo, Oranga and Singal, 2010: Ogechi and Ruto, 2002), these findings demonstrate the continuation of negative attitudes that might lead to stigmatisation and oppression of disabled people and their families.

5.1.1.1. Stigma

The social model of disability views disability as a source of discrimination and oppression (Thomas, 1999; Waserman et. al., 2005; Thomas, 1999; Priestley, 2003 Barnes, 2012). Discrimination can lead to stigma and vice versa due to negative perceptions that discourage
individuals from social participation (Green, Davis, Karshmer, Marsh and Straight, 2005). In particular, discrimination occurs when stigma interferes with an individual’s ability to participate fully in social and economic life, hence denying one the opportunity to participate in social life. The findings demonstrated evidence of stigmatisation of the participants in the form of labeling, stereotypical views, separation from others and loss of status through the negative remarks by schoolmates neighbours and workmates, which denied young people in this study opportunities to participate in mainstream social activities. This led to some preferring to stay home with their sibling in reaction to their peer’s remarks.

Stigma has been identified as a major factor in many chronic illnesses and disabilities (Gofman, 1963; Senkel and Wong, 2010). It has been reported in families where there is a disabled member and this has been experienced by other family members other than the disabled member. This has been referred to as vicarious stigma (Goffman, 1963; Ostman and Kjelli, 2002). Vicarious stigma or associative stigma involves stigma by virtue of one’s association with a stigmatised individual. It can be argued that the young adults in this study experienced stigma due to their association with a stigmatised individual.

In order to define stigma, Link and Phelan (2001) applied the five components listed below. The first component that involves labeling refers to how human beings are labelled based on their difference, for example, disabled versus non-disabled (Link and Phelan, 2001). The second component involves stereotyping, i.e., the attaching of a range of characteristics, negative or positive, to groupings (Link and Phelan, 2001). The third component involves identifying some groups as ‘other’. It means putting in a demarcation for people that separates them from others, and involves notions of some groups being more ‘human’ than others (Link and Phelan, 2001). The fourth component involves loss of status that leads to unequal opportunity, while the fifth involves all the above four which converge in a power situation that allows stigma to unveil through discrimination that involves denial of access to certain opportunities or rights (Link and Phelan, 2001).

Evidence of stigmatisation of the sibling via the avenue of vicarious trauma or disability by association was evident throughout the study. Kubuyo, for instance, highlighted how his neighbours sarcastically questioned why he was taking his grown up sibling to the barber. These
remarks were perceived as a labeling of his brother, whom they marked as disabled through their questioning and pointed to how they stigmatised him. Khayecha on his part, felt stigmatised by his workmates when they referred to his sibling with CP as a ‘cripple’, a label that he recognised as a stigmatised one, one associated with a ‘less human’, ‘other’ group. Vicarious stigmatisation or disability by association was experienced personally by Khayecha in his sense of rejection. By his workmates running away from him and calling his sibling a ‘cripple’, they were linking him to his sibling and placing his sibling into a category that linked him to undesirable characteristics (Link and Phelan, 2001). He reacted to this by staying at home thus withdrawing and isolating himself from others. This further agrees with the SMD where negative societal perceptions discourage individuals from fully participating in social life (Green et al., 2005).

Khasa on her part experienced vicarious stigma that can be linked to labeling, stereotype and separating as identified by Link and Phelan (2001). Her peers described her sibling’s way of eating as ‘disgusting’ and these remarks affected her. Such behaviours culturally marked both her sibling with CP as inferior and Khasa herself by extension. In her remarks, she highlights how she turned away from ‘those who felt they were more special than others’. By virtue of her association with the sibling with CP, the label led her to feel stigmatised. She thus isolated herself from peers, being denied equal opportunities to participate in mainstream activities. I can argue that the above reactions fitted with Link and Phelan’s (2001) definition of stigma and point to the presence of stigma in the lives of the participants in this study.

These experiences, while pointing to indirect (vicarious) stigma as highlighted by Green, Davis, Karshmer and Straighthow (2005), also demonstrate its potential impact. The young people devised different ways of dealing with stigma, for example, by withdrawing from others and staying at home, thereby not taking on active roles in social life. These kinds of reaction support the social model of disability that views negative attitudes as a barrier not only to disabled people but also their families (Thomas, 1999) in terms of actively participating in mainstream activities. Burke’s (2010) study done in the UK, revealed the presence of some elements of stigma, reflected in family dynamics and social interactions both at home and at societal levels. Barton (1996), also from the UK, further pointed to negative social attitudes directed towards disabled people, which
hindered them from enjoying their rights, thereby causing stigma. Although from different contexts, and done at different times, findings from the current study are in line with those of Burke (2010) and Barton (1996), demonstrating some transferability of findings from the UK context to the Kenyan one.

Research internationally demonstrates not only how the disabled person is stigmatised but the stigmatisation of their siblings and other family members. For instance, findings from a study conducted on Dutch siblings of children with physical disability established that stigmatisation caused distress in the non-disabled child (Waters, Maher and Salmon, 2005). This study also points to how disability by association affects the non-disabled sibling, similar to the current study. Elsewhere, Ostman and Kjellli (2002) in a study that examined the factors influencing stigma by association in the relatives of people with mental illness in a Swedish Multi-Centre study focused on 162 relatives of patients in psychiatric wards to establish their psychological functioning related to stigma. This research, though with a different form of disability, revealed that having an ill relative can cause stigma as demonstrated in eighty three percent of the relatives who had experienced some form of stigma by association. Some of them thought it was better if their patient had died while others experienced suicidal thoughts. The study further revealed that a greater proportion of women had thought that they were better off dead than be associated with the mentally ill person. These studies illustrate potential societal differences in attitudes towards both individual disabilities and disabilities in general. They also point to the possibility of stigmatisation by association as an international experience albeit with differing manifestations.

Literature from a Kenyan context has pointed to continued feelings of stigma among disabled people (GOK, 2003; GOK, 2010; KNCHR, 2014; Kiarie, 2014; Opini, 2012; Gachetha, 2009; Okello, 2009). For instance, KNCHR (2014) reported stigma experienced by visually impaired people. Okello (2009) also provides useful examples where physically disabled women were perceived as a bad omen and therefore men who cohabited with them left very early not to be seen with them. Instances are cited of mothers who bore disabled children being divorced and of families with disabled children locking them indoors (Okello, 2009). Although I studied different forms of disability and the study was a small-scale, highly contextualised one, the findings go some way to confirming this viewpoint, as the siblings’ experience of disability by association point to continuing negative societal attitudes. Overall, while not all participants referred to stigma directly,
the presence of stigmatisation was evident in their accounts. For instance, Manguya in his account said that he does not tell most of his school mates except those he trusted would keep secrets about the condition of his sibling with CP. The desire to keep it to a few trusted friends meant hiding from others what could have been stigmatising for him. These findings support Goffman’s (1963) view that a stigmatised person may prefer to hide some aspects of information from others as a way of dealing with stigma. Their accounts are less easy to reconcile with the more positive picture found within some of the literature related to Kenya. For example, the Kisii and Kalenjin communities are cited as demonstrating positive connotations about disabled people as displayed in their everyday language use (Ruto and Ogechi, 2002). This study demonstrated the possibility of more positive attitudes towards disability within Kenya and indeed the authors argue the prevalence of improved societal attitudes towards disability in modern day Kenya:

‘Modern African societies do not seriously uphold the (sic) traditional beliefs on the causes of disability. With the influence of Christianity, Western education and medicine, the traditional causes of disability are considered archaic and people no longer have any awe over the disabled people’ (Ogechi and Ruto, 2002, p.73)

There is not strong evidence of this in the siblings’ accounts of their lives within Nairobi as this study pointed to the continuation of traditional negative attitudes within the urban context of Nairobi, the capital city. On a positive note, there is some sense here of how individual siblings could respond in a more empowered way to stigmatisation. This may be reflective of family relationships, which in my view were very strong. From an African context, a study by Nartley (2013) focused on the perceptions of stigma on the psychological well-being of siblings of children with intellectual disability in Ghana. The study involved 69 siblings of a brother or sister with ID participated in a correlational survey to assess their psychological well-being. The study revealed that developing a positive relationship among siblings helps maintain the psychological well-being irrespective of the presence of stigma. The study did not reveal the absence of stigma but rather that stigma was lessened where the relationship was positive. There is similar evidence in this study that a strong relationship could potentially help reduce the negative impact of stigma on the wellbeing of individual siblings. For example, Jazala talked about how his family’s closeness and attentiveness to the sibling with CP had helped his family to cope with other challenges. This may explain why even when he was faced with potentially negative questioning, he responded
positively and saw an opportunity to educate others instead of feeling stigmatised. His is an example of a more positive response to potential stigmatisation.

It is evident from the findings that stigma was present as an attitudinal barrier for these siblings due to their association with a disabled sibling. The SMD has therefore been useful in identifying stigma in terms of attitudinal barriers. However, although stigma was evident in the current study, it was not universally or equally experienced. Having looked at the attitudinal challenges, I now focus on environmental and structural challenges in the next section.

5.1.2. Environmental and institutional challenges

The SMD states that individuals are disabled through environmental and institutional challenges that involve financial, physical, political and social elements (Barton, 1993; Oliver, 1995; Priestley, 2003). It is the environmental barriers placed on disabled people that by extension impact on the siblings of disabled people to varying extents.

5.1.2.1. Education

Access to education is an important factor to consider for disabled people and their families. Some participants in this study talked about disruption to their education because of the heavy demands of caring for their sibling with CP. There were a lot of expectations in terms of care such that their education suffered as a result. For instance, Kubuyo narrated how the sibling with CP made noise in the night that often disrupted his sleep. This in turn, impacted negatively on his education in terms of loss of concentration at school. These experiences mirror those reported by Dodd (2004) from the UK, where lack of sleep was identified as a major challenge experienced by non-disabled siblings, due to the noise made by their disabled sibling during the night that disrupted that their sleep.

Additional responsibility in terms of caring disrupted another participant’s school work. She was expected to carry out certain roles that required her attention to a greater extent. Such barriers had an implication on her psychological well-being. However this differs from findings elsewhere where non-disabled siblings are impacted differently due to pressure to perform (Seligman and Darling, 2009). In this context, non-disabled children were expected to perform and achieve what
the child with disability could not. However, participants in this study did not talk of pressure on them to perform but instead highlighted the impact of extra care.

As illustrated, siblings were vicariously impacted by the barriers to accessing education on the part of their siblings with CP. Their siblings’ restricted access to education inevitably meant that the family undertook the major responsibility for their day-to-day care with limited respite. It also led to limited potential for their disabled sibling to subsequently live independently of their family and support themselves financially. This was reflected in part in the siblings’ commonly stated fears for the future, whereby they felt that the siblings with CP would continually depend on them.

Lack of access to education has been identified as one of the barriers faced by young disabled people in Kenya (Mugo et al., 2010). In a study that looked at some of the legislations on disability for young disabled people, Mugo et al. (2010) established that there were gaps in the education system in terms of addressing the issues of young disabled people. For instance, very few young people from rural areas had access to education opportunities (Mugo et al., 2010). This was partly because a number of schools were concentrated in major towns making it difficult for those disabled people who live in rural areas to access education. The study further pointed to lack of schools to cater for hearing and behavioural disabilities that are excluded from mainstream education. In the same context, a number of structural challenges have impacted on disabled learners. Poor infrastructure, few teachers to manage disabled learners, expensive learning materials and equipment are some of the challenges disabled children in Kenya experience (MOE, 2009). Lack of ramps plus the predominance of narrow doors that are not accessible by disabled students (KNCHR, 2014; Opini, 2012) can impact on the non-disabled siblings indirectly due to their association with a disabled sibling. Save for one participant whose sibling attended school, the rest did not mention any of their siblings attending school. In my view this would have a direct impact on the non-CP siblings in terms of respite care.

Another factor that impacts on education for disabled people in Kenya is poverty. The majority of disabled people in Kenya live in abject poverty and as a result has limited access to education (KNBS, 2009; Kamundia 2013). This was highlighted by Kiarie’s (2014) findings that, although physically disabled people received vocational training, they found it difficult to acquire jobs due to
stiff competition with their counterparts who were non-disabled and this left them in a position of dependency.

Generally, the lack of access to education and the consequent lack of access to employment all contribute to dependence of children with CP on their families not only in childhood but into adult life. This position of dependency, as previously noted, is what leads non-disabled siblings to be relied on by their disabled siblings and this can threaten the psychological well-being of siblings who are expected to play significant roles in their sibling’s lives. It appears that some, although not all, siblings adopt or are allotted what might be called caretaker roles either by parents or their others siblings. Where it is allotted rather than chosen, the potential threat to psychological well-being seems increased.

In terms of understanding about cerebral palsy, school seems to have been a major source of understanding of the condition. Non-CP siblings lacked information about the condition until they learnt about it in school. Three participants pointed to school as their major source of information about the condition. The fourth did not have an understanding of CP at the time of interview. Luunga on her part blamed her mother for denying her information about her sibling’s condition until she learnt about it in school. This point to continuing lack of understanding of cerebral palsy amongst the population studied and the impact it has on family members. This confirms findings by Adoyo and Odeny (2015) who looked at challenges experienced by disabled children and established that they lacked information about disability. They acknowledged that children have a right to education and social support from available structures within communities and their parents. This further agrees with Dodd’s (2004) position that emphasised the importance of giving siblings of disabled children information about disability that is appropriate for their age.

5.1.2.2. Access to work (employment)

The SMD identifies lack of access to employment as one of the factors that affects disabled people (Oliver, 1996; Priestley, 2003). As discussed previously, this may result in financial deprivation, hence making disabled people depend on others for survival and depriving them of an opportunity to enjoy their participation in mainstream society (Thomas, 1999). This would impact on the whole family’s economic position and hence the siblings’ standard of living. All the participants who were out of school were in employment, although there were traces of disruption due to caring for their
sibling. Therefore it seems that siblings’ employment position in this study was negatively impacted by their sibling’s physical dependence. For instance, Jazala’s and Khayecha’s employment was disrupted from time to time because of caring for their sibling with CP. Khayecha in particular, highlighted absenteeism as one of the challenges he encountered as a result of caring for his sibling at home. His employment suffered because he frequently stayed at home to take care of his sibling with CP in order for his mother to have time off to attend to other family obligations. Though Khayecha kept his job, this can be challenging in a context where employers who may not understand issues that face the non-CP siblings. Kubuyo’s sibling who was nineteen years could not acquire employment because of his state. This supports the SMD that highlights lack of access to work as one of the challenges for disabled people (Thomas, 1999). Lack of employment has been highlighted in Kenya as a challenge facing disabled people (Kiarie, 2014; Mugo et al., 2010). In particular, Mugo et al. (2010) established lack of employment for young disabled people while Kiarie (2014) confirmed that although people with physical disabilities received vocational training, they found it difficult to acquire jobs due to stiff competition from their non-disabled counterparts. This left them in a position of dependency, and the consequent responsibilities that fell on siblings could negatively impact on their psychological well-being.

5.1.2.3. Financial constraints

The young people’s accounts pointed to limited resources to meet both family obligations and cater for the needs of a disabled sibling. This is particularly prominent in Khasoa’s account when she reported that all the finances were directed towards her sibling with CP. Later on, Khasoa talked of how there was financial stability in her family that resulted from her father acquiring a job that allowed him to cater for the expenses of the sibling with CP. This demonstrates the heavy financial costs involved for families where there is a sibling with CP. These findings are in line with Seligman and Darling’s (2009) view that having a disabled child can cause financial constraints due to the varied needs of a disabled child.

Lack of finance has been a challenge not only for families with a disabled individual but for a large number of Kenyans. Approximately, 46% of Kenyans live below the poverty line (UNICEF, 2015). These figures are higher in rural areas (46.3%) than in urban areas (29%) (Kiriti and Tisdell, 2003). Poverty has been cited as both a cause and a product of disability (Monk and Wee, 2003).
For instance; poverty can lead to too much work, malnutrition and lack of health care (Monk and Wee, 2003). It can also make people rely on traditional treatments that fail. This may lead to diseases that can cause disability. Parents’ failure to take their children for immunisation or medical appointment can also lead to disability (Monk and Wee, 2003) and this has been attributed to poverty among other causes. Conversely, poverty is said to be a product of disability due to the economic burdens on families that ensue.

Whatever the case, these siblings’ experiences need to be understood within this wider environment of potential financial constraint. A report by the African Union of the Blind (2007) pointed to the fact that being rich and disabled means that one has better access to basic human rights while being poor and disabled may mean a deprivation of human rights resulting from your low status in society. Although there is no direct evidence of the status of those involved, there is evidence in the study of financial constraints within the family due to heavy costs of health care. One participant emphasized that the family directed all the resources and concentration to the sibling with CP depriving her of the same. This may speak about the financial constraints that families go through as they allot a larger proportion of their incomes to healthcare for a disabled family member. This supports Makoloo’s (2005) position that a number of Kenyans are constrained due to the heavy demands of medication and other subsistence expenses in families that have a disabled person. In this study, none of the families involved received any financial support from the government which might have supplemented the family income. However, although there are traces of financial constraints, none of the siblings referred to this directly as a major source of difficulty.

5.1.2.4 Access to Transport and Medical facilities

In terms of physical access, the study pointed to a number of barriers in terms of transport and medical facilities. One participant narrated his experience of taking his sibling to clinic at a tender age. He had to use public transport with his sibling with CP which involved carrying his sibling on the back. Although he felt satisfied while carrying out this responsibility, the situation was challenging. This experience not only pointed to the heavy responsibility involved, but to the structural challenges disabled people and their families encounter in the Kenyan context in terms of lack of physical access to transport and medical facilities. Again, there is lack of facilities like
ramps and elevators to be used by disabled people (KNCHR, 2013). Monk and Wee (2010) identified only one district hospital with facilities that cater for disabled people within their location. Again, most transport is inaccessible to disabled people who have either to be carried to board and alight from public vehicles (KNCHR, 2014). Jazala experienced hardship in travelling with his sibling on public transport that did not take care of the needs of his sibling. From a SMD point of view, this environment was not conducive for the role he was playing at a tender age. Khayecha on his part mentioned how he carried his sibling around with peers mocking him for always carrying a cripple. This was a reflection of the fact that he did not have access to mobility aids. This in my view speaks about the challenges faced by these populations from a Kenyan context. Further to this, Kabue (2015) stated that the streets lack adequate pavements and maintained sidewalks to cater for disabled people. These people are exposed to unkempt vegetation that forces them to use road areas that increase their vulnerability. Again, a poor road system has been cited as a major challenge facing disabled people and this has an impact on the non-disabled siblings in terms of facilitating their sibling’s movement (Mukobe, 2013; Kabue, 2015).

In general, a focus on siblings’ experiences through the lenses of the social model of disability and disability by association has brought into focus the number of challenges that siblings encounter as a result of their relationship with a sibling with CP. These are evident in their encounters with peers, colleagues and neighbours. Their views and remarks lead to a sense of stigmatisation in the non-CP siblings. Moreover, lack of welfare provision coupled with the hard economic status of Kenyans pointed to widespread poverty in families of disabled people hence the young adults were impacted economically in terms of lack of resources to meet family financial obligations as well as take care of their sibling’s physical and medical needs. These were institutional barriers identified in the social model of disability. There were also a number of structural challenges ranging from lack of ramps, lifts, proper transport and medical facilities that not only has an impact on disabled sibling but to non-disabled siblings as well as they took on the role of carrying their sibling. The next section focuses on how these attitudinal, institutional or structural converge at the psycho-emotional: hence the next section focuses on psycho-emotional challenges.
5.1.3. Psycho-Emotional Challenges

Thomas (1999) pointed to disability as a factor that undermines the psycho-emotional well-being of an individual. A social relational model of disability emphasises disability as not only focussing on external barriers but also those that operate internally, thereby causing challenges to the psycho-emotional well-being (Thomas, 1999). The SMD, which is an offspring of the social relational model, identifies disability as something that happens as a result of our relationship with a disabling world, which restricts the activities of the people with impairment, thereby interfering with their psycho-emotional well-being (Thomas, 2004). The concept of disability by association points to the vicarious impact on those closely associated with disabled people, in this case, their siblings. I therefore discuss the psycho-emotional status of those involved.

5.1.3.1. Sense of responsibility

A number of the participants confirmed carrying the child around which they found strenuous. Only one participant talked about having access to a wheelchair that he used to take the sibling out. There was pressure to carry out these duties in additional to their daily commitments. This point to the disabling nature of the wider society and how the relatively high demands associated with CP that are thrown back to the family might add to the sense of challenge for the siblings. It also points to the potential relationship between disability and family poverty, either as cause or effect.

The responsibilities undertaken by the young people in this study which involved, dressing, bathing, administering drugs, carrying their sibling around the home, taking their sibling to clinics and exercising their sibling with CP, partly reflects the Kenyan family structure. In Kenya, children are socialised to perform domestic duties even when there is no disabled individual in the family (Skovdal, Campbell and Onyango, 2013; Ekstrand, 1994). Ekstrand (1994) examined children’s perception of child rearing norms and cultural values in Kenya, India and Sweden. This research established that in Kenya, the necessary chores at home were performed by children. These chores in rural settings might involve going to fetch water from the stream, going to fetch firewood and being sent on errands to the market. In urban areas, chores might include administering
drugs, assisting with mobility, bathing, sorting out paper work and paying bills (Ekstrand, 1994). These findings agree with findings from the current study where the young people involved carried out similar chores like administering drugs and assisting with mobility, However, they differ from those identified in Sweden where families are supported by social welfare systems and do not carry out any chores at home (Ekstrand, 1994).

Research from other contexts has also confirmed that siblings can be sometimes pushed to caring roles early in life. For instance, a study by Mophosho et al. (2009) revealed that young children aged 9 to 18 years in South Africa equally undertook chores like feeding, getting juice for the sibling when thirsty, playing with and changing the DVD for their disabled siblings. These findings confirm that the challenges experienced in this study are not unique to the Kenyan situation but a global concern.

Another factor that contributed to the heavy workload was the shift from the extended family structure to the nuclear family within Kenya. Previously, extended families were available to offer such support but a shift in family structure may have led to the sibling taking up more extended care giving roles. This is particularly important considering that the young adults in this study all came from an urban setting where family structures have shifted increasingly from the extended to the nuclear (Mukuria & Korir, 2006; Rombo et al., 2014). There were high expectations of the young people to take care of their sibling with CP that placed a lot of pressure on them and this had a psychological impact. The word ‘it is hard’ was used severally by a number of participants when referring to the amount of physical demands placed upon them due to their sibling’s demands and partly pointed to their emotional status. Although different terminologies were used to express how difficult their role was, it surprised me that a number of the young people in this study talked about physical hardships. The physical demands identified in this study point to constraints which the families with a disabled individual in Kenya go through and are a pointer to the psychological support that families with a disabled person in the Kenyan context may require from professionals in the helping field.

The age of the non-disabled siblings may also have an influence on how they respond to their sibling’s condition (Breslau, 1982). A study by Breslau (1982) examined the effects of birth order and spacing on the psychological functioning of non-disabled siblings and found that younger
female siblings were psychologically better off than older female siblings. This has some relationship with what Luunga experienced as an elder female sibling. She took on more of the caring role than her siblings who were younger than her sibling with CP, and who preferred to play rather than assist in caring. This led to restrictions to her movements and this may have impacted on her psychological wellbeing. A quantitative study by Emerson and Giallo (2014), looked at the differences in the well-being of siblings of children with disabilities compared to those of the typically growing siblings in Australia. It was established that there were differences in the level of their well-being depending on the age of the sibling. Siblings at four to five years of age were at more risk compared to those of six to seven years (Emerson and Giallo, 2014). Although this study looked at younger siblings than those in the current study, it had useful findings relevant to the findings from this study. However, it was difficult to gain a sense of the importance of either birth order or age, as in the current study the majority of the young people were older than their sibling with CP and were themselves young adults. However, future research with Kenya could focus on both younger and older siblings to establish how age impacts on the non-disabled siblings.

Another key area where there was deficiency as pointed out in this study was lack of assistive devices like wheelchairs. As a result, siblings made a large contribution in terms of assisting their sibling in moving around. Khayecha clearly spells this out when he talked about carrying his sibling on his back. This was also prominent in Jazala’s account when he took his sibling to the clinic with no assistive devices to help him carry the sibling with CP. He had to carry the sibling on his back, which, although it is a typical Kenyan way of carrying children, points to lack of assistive devices. Lack of assistive devices is not just a Kenyan issue but also a global concern. WHO (2011) reported about the unmet needs of people requiring assistive devices at international, national and regional levels. Hence, although differently experienced, lack of assistive devices seems to be a global concern.

Moreover, none of the young people talked about direct financial support from the government. Luunga attributed financial stability in her family to her father acquiring a job that led him to cater for the expenses of the sibling with CP. Before her father acquired a job, there were financial constraints, as the mother who was the sole bread winner for the family could not meet the family financial obligation. This led to frequent quarrels in the family which ceased when the family
became financially stable. Again, a developed sense of responsibility can be rooted in an unsure and financially constrained family environment.

Findings from this study have revealed, through the SMD, that there is a connection between a disabling society and the experiences of the young people involved in this study. There is limited evidence of these siblings having access to support services that might have lessened the potentially negative psychological impacts on them and, in particular, the heavy sense of responsibility that can ensue from being obliged to take on major care-taking duties.

5.1.3.2. Fear

Five out of the six participants had experienced some form of fear. This included fear of future care giving, fear of giving birth to a similar child as well as having someone in the family become disabled. They were concerned about what would happen when they are grown and everyone has to go his/her way, make their life, get a job and settle in marriage. They were also concerned about what would befall their sibling with CP when they grew up. This fear points to the impact of disability by association and the more negative aspects of living alongside disability that these siblings have experienced.

A number of studies from different countries show that fear is not simply a Kenyan phenomenon. A range of studies across different regions have found that being a sibling of a disabled person poses fear as one of the psycho-emotional challenges (e.g. Burke, 2010; Connors and Stalker, 2003; Seligman and Darling, 2009; Dodd, 2004 Mophosho et al., 2010; Nartley, 2013). Burke’s (2010) study, for instance, drew from two studies he undertook in the UK, where he looked at the impact of childhood disability on brothers and sisters in the family. The studies utilised both qualitative and quantitative data drawn from 116 families with 344 children where 118 had a disability. The study, which was large scale, revealed that siblings look to the future with fear and uncertainty because of the high level of responsibilities that would befall them. The findings in this study have similarities with those identified by Connors and Stalker (2003) who looked at the views and experiences of disabled children and their siblings. Both studies revealed fear of future care giving roles similar to those expressed in this study. Although participants attached different situations to the feelings of fear, their fear was mainly focused to the future in terms for fear of giving birth to a similar child and to the care giving responsibilities involved for them. It is therefore evident that
fear may be one of the major psychological challenges for siblings of CP within Kenya if these siblings are at all typical. However, it would appear that fear is not only a Kenyan concern but also a global one.

5.1.3.3. Anger

Although expressed differently and at differing targets, feelings of anger were also expressed in this study. In particular, Luunga expressed feelings of anger towards her mother for hiding information about the sibling’s condition from her and other family members. This denial of information for her led to ignorance about the condition that led to feelings of anger. Anger resulted from resentment for being denied information about the sibling’s condition. This finding supports Hames and Apleton’s (2009) views that non-disabled siblings require information about their sibling’s condition. Both Khayecha and Manguya were angry about having a sibling with CP as they questioned why it happened to their siblings but not any other. Anger was also directed to the sibling’s condition and in particular why it happened to them. This finding supports those by Seligman and Darling (2009) written from the US context that focused on how families respond to childhood disability. The study established anger as one of the psychological challenges. However, this differs from findings by Connors and Stalker (2003) where siblings of disabled children did not display anger at all. However, it could be attributed to the fact that they took care of their sibling as a choice but not as an obligation.

Khasoa felt some sense of restriction as a result of her parents’ efforts towards the sibling with CP and this made her feel less loved. She felt that her parents loved the sibling with CP more than they loved her and most of the attention and finances were spent on her. She also felt restricted and that she had missed opportunities that could have been hers if there was no sibling with CP in the family. Restrictions on socialising due the presence of a disabled sibling in the family have also been identified in a number of studies (e.g. Dodd, 2004; Earley et al., 2007; Connors and Stalker, 2003; Burke, 2010). Burke’s (2010) UK study, which involved daily interaction of siblings within and outside the family, revealed that siblings regretted having a disabled sibling. They felt they had limited opportunities to do certain things together as a family because of their disabled sibling. This was because parental attention was focussed on their disabled sibling. The present study therefore reflects wider findings indicating that having a disabled sibling can place restrictions on
the non-disabled siblings, thereby impacting on their psycho-emotional wellbeing, in this case in terms of resentment and anger.

The negative impacts of disability on sibling well-being in these findings therefore mirror findings from other studies elsewhere (e.g. Dodd, 2004; Earley et al., 2007; Connors and Stalker, 2003; Burke, 2010). In different degrees and for differing reasons, participants expressed a sense of difficulty. They did articulate sense of anger, of fear, of at times feeling restricted and overwhelmed by their responsibilities. This was not the whole picture, however. Their experiencing was not wholly negative. Participants were able to identify positive aspects in their lives both in their day-to-day living and in term of longer-term gains. Research has recently shifted into examining potential positive impacts of living alongside disability (Talbot, 2014; Tedeschi and Calhoun, 2004) and this is what I turn to in the next section.

5.2. The Positive aspect of the Siblings experiences

Apart from the challenges identified through the SMD, there were also a number of positive experiences within the young people’s accounts. This shall be discussed using the Post traumatic Growth model that acknowledges that benefits can emerge from a difficult or traumatic situation (Tedeschi and Calhoun, 1995, 1996, 2006). The Post traumatic growth model does not mean the absence of negatives but appreciates that growth can occur as a result of a traumatic experience (Calhoun and Tedeschi, 1999) as it can promise alternative ways of thinking about trauma (Joseph, 2009). Having a sibling with CP is not necessarily traumatic in itself. This study does not depict the siblings as traumatised; rather it paints a picture of ongoing difficulty and challenge. However the model does help bring into focus how positive experiences can go hand in hand with the negative ones. The concept of vicarious post-traumatic growth can also be helpful. This points to how people may have vicarious experiences of post traumatic growth; this occurs in populations not directly suffering but exposed to the suffering of others (Joseph, 2009). Therefore siblings may have developed directly through their own difficulties and indirectly by witnessing the difficulties of others - including their siblings with CP - and how they have found their way through.
Tedeschi and Calhoun (1995) identified growth in three major domains occurring in the aftermath of a traumatic event namely the changed perception, relating with others and philosophy of life. These three areas form the lenses through which findings are discussed.

5.2.1. Changes in Perception

Tedeschi and Calhoun (1996; 2006) identified changes in perception as an area where growth is likely to take place in the aftermath of trauma (Tedeschi and Calhoun, 1996; 2006). Cherwien (2012) examined post traumatic growth in the lives of trauma survivors who had experienced loss of a loved one or chronic or acute illness, or survived violent or abusive crime. Cherwien posits that, for one to experience growth, the individual’s assumptive world must be shattered, forcing them to piece it together in a different manner. During trauma, the assumptive world of an individual is challenged and in order for growth to occur, there should be modification or restructuring of the individual’s assumptive world (Cherwien, 2012; Tedeschi & Calhoun, 2004; 2006). Under this domain therefore, growth occurs when a person has a cognitive engagement with the traumatic event and in the process, tries to repair or reconstruct their understanding of the world (Tedeschi and Calhoun, 1995: 2006). While it can be argued that there is no evidence of trauma or traumatisation in these accounts, there is evidence of challenge and adversity due to their association with a sibling with CP.

Five participants demonstrated a sense of responsibility towards their sibling with CP when responding to their sibling’s physiological needs which they handled with affection. One of the participants demonstrated a sense of responsibility by playing the role of a mother figure to her sibling. In her own words, she confirmed that she treated her sibling with CP as her own child. This was to ensure that her sibling was always comfortable and by so doing she was looking at the positive side of her role. While one participant looked through the sibling’s condition to appreciate what he was able to do, another participant confirmed that by understanding the condition, he had developed an understanding towards his sibling and those in similar conditions.
This agrees with a number of studies which suggest that children who have a disabled sibling tend to develop a positive attitude towards their siblings and others in society (Burke, 2010, Dodd, 2004, Mophosho, et. al., 2010). Findings from this study have similarities with those reported by Dodd (2004), based in the UK. Dodd’s (2004) findings show that brothers or sisters of siblings who have a disability tend to develop positive benefits from the relationship for instance a greater desire to help the sibling with disability. Results were also consistent with findings from a study conducted by Mophosho et al. (2010) in South Africa which looked at the relationship between four adolescent children and their siblings with cerebral palsy and identified a sense of responsibility. Siblings in both studies were helpful to their brothers and sisters with CP as they showed them understanding and a sense of responsibility (Mophosho et al., 2010). These findings are similar to those identified in this study and conform to a notion that positive benefits can result from living with a sibling with disability across different cultural, economic and social contexts.

It is evident that as participants gained an increased understanding of the condition through their interaction with their siblings with CP, it changed their perception. The condition further led them to more self-awareness and to re-organise their priorities. The majority became peer educators at the school and workplace and were more sensitive to their siblings’ and other people’s needs.

5.2.2. Relating with others

Tedeschi and Calhoun (1995: 2006) pointed out that one of the areas where growth can occur in the aftermath of trauma is in relationship with people. Relationships get enhanced as people tend to value their family, friends and develop a greater connection to people in general (Tedeschi and Calhoun, 1995, 2006; Joseph, 2014).

Five participants experienced close relationships within the family as a result of having a sibling with CP. In line with Tedeschi and Calhoun (1996), they came to value their family to a greater extent most probably because of supporting each other within the family unit. In particular, Jazala’s account pointed to increased closeness in the family. He narrated how all attention was drawn towards their sibling with CP. Luunga, Khayecha and Manguya on their part experienced love for the caring role. A more pronounced sense of love for caring came from Luunga who
talked about her love for the sibling with CP as her own child. She felt comfortable staying at home with the sibling and taking on the caring role even when her younger siblings went out to play. She did not complain at all as she seemed to enjoy the role she played. She displayed a sense of excitement as she talked about her love for the sibling with CP as her own child.

Support and closeness in the family became a source of support for them. Khasoa in particular, talked about how the support she received from her family helped her cope with her sibling’s condition. A study conducted by McConnell et al. (2014) to investigate resilience in families raising disabled children established that where families had reasonably good social-ecological resources, outcomes are likely to be good even in the context of extreme stressors. This meant that strengthening of social interaction is an important factor in dealing with traumatic events.

However, positive aspects were less evident in terms of relations to people outside the family. Some participants tended to talk of better relationships more than others. The nature of these relationships outside the family depended on their attitudes towards their sibling with CP. Four of those who experienced personal connection to outsiders did so depending on the positive attitudes they experienced from them. For instance, one participant talked positively about the peers who accompanied him to the barber as being considerate of his condition while another complemented those understanding peers who were considerate of his sibling’s condition. This came with positive feelings while negative attitudes by outsiders tended to evoke negative feelings.

From a negative point of view, one participant felt less valued and ignored by her parents because she perceived that her parents loved the sibling with CP more than they loved her. In her narration she stated how all the attention, concentration and family finances were directed towards her sibling with CP. Her feeling that she had lost her position as a child resonates with Link and Phelan’s arguments concerning the effects of stigmatisation (2001). Negative remarks by peers, workmates and neighbours led to isolation, withdrawal and avoidance in the young adults in a number of ways. In particular, Khayecha’s account points to isolation from workmates because they commented that he was always carrying a cripple. Khasoa completely kept away from those who had made negative remarks about her sibling with CP at school. These findings agree to some extent with those identified by McConnell, Savage and Breitkreuz (2014).
5.2.3. Changes in philosophy of life

Changed philosophy occurs when there is a change of priorities and one accepts things as they are (Tedeschi and Calhoun, 2006). What matters most for the individual changes as one develops increased or greater satisfaction in life.

In this study, a number of things arose for the young adults that led to an increased sense of acceptance and appreciation of aspects of their life. First and foremost, a deeper understanding of the condition led to an acceptance of themselves and what they could do. The limitation in their sibling led them to appreciate doing what their sibling could not do. For example lack of ability in the sibling with CP led to Jazala acknowledging his masculinity as a young person. After the young adults in this study gained an increased understanding of the condition, they became advocates and peer educators to their peers and this brought a sense of satisfaction.

Another aspect that was prominent in this study was spirituality. Spirituality refers to a belief in a power above your existence and a connection to the universal force from above (Connor, Davidson and Lee, 2003). Spirituality can be useful, for instance where it has been used in distressed clients as a coping mechanism and has improved individual’s well-being (Tedeschi and Calhoun, 1996: Cherwien, 2012). Although the participants came from different religious backgrounds, they all made reference to God in their accounts and this surprised me. Reference to God was connected with as a way of accepting the condition of their sibling. They made reference to God in terms of finding hope, meaning and acceptance of their experiences as they saw it as God’s will. These findings conform to the moral model of disability (Goodley, 2011) where disability is connected to having faith in one’s ability to manage the condition. It is also reflective of more traditional Kenyan attitudes connecting disability with divine will.

A number of Kenyans subscribe to one religion and they often turn to God during times of crisis (Mukuria & Korir, 2006). This turning to God during hardships reflects the strong bond that religion creates within the Kenyan society and this may differ from other societies. The findings confirm this by the way young people referred to God severally in their accounts. While religious belief helped in terms of acceptance in terms of God’s will, for two participants disability was spoken of as a gift. This helped them to positively view their lives. Literature within the Kenyan context has
also pointed to the existence of positive cultural views about disability (Gona, Hartley and Newton, 2006; Monk and Wee, 2008; Ogechi and Ruto, 2002). What this demonstrates is how siblings may call on different and at times competing value systems to make sense of their situation, but that religious faith can act as an important source of acceptance and even appreciation.

This tendency of turning to God during a traumatic experience is what Tedeschi and Calhoun (2006) referred to as connecting with spirituality. People not only tend to be more spiritual during trauma but can also reject God altogether (Tedeschi and Calhoun, 1995: 2006). However, none of the participants talked negatively about God as they seemed to find some hope by believing in God. Spiritual belief therefore played a role in their coping to some extent. It would be thus useful for future research to focus on how Religious beliefs can blend with counselling to help support young adults who have a sibling with CP. Although reference to God, sometimes challenged their level of awareness about the condition, it was a coping mechanism that helped them to deal with their immediate feelings.

The PTG has been useful in pointing to the positives in the young adults’ accounts and shown that growing up with a sibling with CP can have its positive rewards.
5.3. Final reflexive statement

In closing, I have sought to provide an overview of the findings and honour the participants’ experiences in composing this song. I composed this song one day as I was working on the data.

"It is hard, it is hard and it is hard for me,
I am mocked; I am laughed at and I am ridiculed,

It is hard
It is hard, it is hard, and it is hard for me.
It is hard in the morning; it is hard in the noontime,

It is hard in the evening; it is hard for me.
I am longing for a day when my sibling will walk, talk, and dance

I am longing, I am longing it is hard for me.
I am lonely on this path, I am lonely, and it is hard for me,
I am looking for a bright day, a time when my sibling will walk.

I am looking for a man, who will understand my plight,
I am looking for a woman, who will understand my plight,
I am waiting; I am waiting, for a bright light in my life,

It is hard, it is hard, and it is hard for me.
I am looking for a culture that will understand my plight,
I am looking for a nation that will understand my plight.

It is lovely; it is worthy to have walked on this path,
It is brighter; it is lighter to have walked on this path.
I am changed by, I am transformed by, I have learnt all along.
I am empathic; I am more tolerant, as I have grown by the day.

I have been changed by the love of my family and friends.

This song was composed as I immersed myself into data and highlights my attempts to capture in poetic form some of the issues that came up in this study. In this song, I represent a number of issues that arose for the young adults. Their psychological and physical challenges led them to the use of words such as "it is hard". These words were referred to severally by a number of participants while describing their different experiences. It was surprising to hear these words
repeated throughout the data by individual young adults who do not have any knowledge of what others went through.

5.4. Conclusion

In response to the research question, a number of issues came up for the young adults who have a sibling with CP. The social model of disability and post traumatic growth model have been important in pointing to these experiences of young adults in this study. This study which explored the experiences of young adults who have a sibling with CP living within Nairobi in Kenya revealed that a number of barriers that have been identified by the SMD still hinder the young adults because of their association with their sibling with CP from fully participating in mainstream activities. There were a number of issues identified in terms of structural and institutional barriers that still pose challenges to this population. These challenges further impact on the psychological well-being of the young people involved through feelings of stigma, anger, fear, a sense of responsibility and restriction from major activities that endanger the psycho-emotional well-being.

The findings have revealed that through the disability by association, non-disabled siblings also experienced feelings similar to those of their siblings. These findings may be valuable for researchers in the field of disability together with professionals working with this population to devise ways of working with young adults who have a sibling with CP. The PTG has also pointed to the potential for more positive experience of living alongside disability.

The next section offers a conclusion, including a critique of the study and makes suggestions for practitioners and trainers. I propose possible ways of mitigating some of the issues identified in this study and make recommendations for future research.
CHAPTER 6 - CONCLUSION

6. Introduction

This chapter provides a conclusion to the study, discusses the original contribution to knowledge, critiques the study and makes recommendations for further research and practice.

Finally it includes a concluding reflexive statement.

Overview of study

The study looked at the lived experiences of young adults who have a sibling with cerebral palsy living in Nairobi, Kenya, in order to explore how they made sense of the experience of growing up with a sibling with CP. The major aim of this research was to establish the impact on the non-CP sibling of growing up with a sibling with CP from the sibling’s point of view and the implications it had for counselling. The findings generated four superordinate themes namely: increased sense of personal development and reward, emotional impact, family relationships and public relations.

The findings revealed that there was a direct impact on sense of psychological well-being both negatively and positively. On one hand, the young adults experienced feelings of stigma, fear about the future, anger and a sense of responsibility. On the other hand they experienced a sense of personal development and some concrete rewards.

6.1. Contribution to knowledge made by this study

The major contribution of this research resides in its highlighting of Kenyan experience and giving voice to Kenyan young people, by pointing to the psychological issues involved for the young adults who have a sibling with CP. Some of the psychological experiences involved were stigma, a sense of responsibility, concern about the future as well as positive growth. Although findings resonate in part with the universal issues involved for siblings of disabled people (Dodd, 2004; Burke, 2010), the unique contribution of this study lies in its context, as it is a pioneering study to explore experiences of young adults who have a sibling with CP within the Kenyan context.
Hart (1998) asserts that one aspect of originality is applying something done in a different country to one’s country. Although a number of studies have been undertaken on this topic, they are very much Western oriented and therefore may not be directly applicable to the Kenyan context. The study therefore is unique to the Kenyan situation and sets the grounds on which other studies can be done from this context. Further, McLeod (2001; 2011) urges researchers to carry out research that can contribute to people’s well-being; my aim was to conduct research that contributes to the wellbeing of young adults who have a sibling with CP. By highlighting their voices as a silent group, this research has contributed to giving the siblings an opportunity not only to have their voices heard by the researcher but by a wider audience.

The study further reflects an understanding that underpins the social model of disability. This highlights the potential importance of the cultural, economic and social contexts in shaping experience and demonstrates how Western research in the area may not be directly transferable to non-Western contexts. However, there seem to be both areas of commonality as well as differences between my research and wider research out there. For instance, stigmatisation has been identified in a number of studies where there is a disabled individual and this study seems to support this theory in relation to the Kenyan context. It adds to Goffman’s (1963) assertion that stigma is a major issue in disabilities.

Furthermore, these findings although from a different background, conform to those by Burke (2010) on disability by association, whereby a non-disabled sibling is affected by the sibling’s condition. In particular, this study, that was undertaken a number of years later in a different location to the study by Burke (2010), has shown similarities in the impact of CP on siblings in terms of the experience of vicarious stigma. This was evident in the way the young adults pointed to negative remarks, sarcastic questioning and negative labeling of their siblings by peers, neighbours or colleagues in the workplace that led to withdrawal from social activities as stated in Green et al. (2005). The study has therefore made a contribution globally by adding its voice on the debate on disability by association through vicarious stigma, hence making a contribution to the pool of knowledge.
Another similarity identified lies in the Posttraumatic growth model. Findings from this research have contributed to debates in the Posttraumatic growth model by the way positive growth was identified in the young people’s accounts. Joseph (2009) pointed to vicarious Posttraumatic growth that can occur in a population that is exposed to trauma by the suffering of others. The young adults were not impacted because they were disabled themselves but due to the condition of their sibling with CP. As they gained a deeper understanding of the condition, this led to a deeper understanding of their issues, an acceptance of themselves and an appreciation of what they could do, which their siblings could not do. Their sibling’s condition became rewarding and a mirror through which they were able to reflect on their positive aspects. In my view therefore, this research has made a contribution by eliciting that a sense of reward and personal development is not necessarily confined to siblings in the west, and that posttraumatic growth may prove to be a more generalisable phenomenon.

However, alongside and within these broad similarities are significant differences in experiences due to cultural, social and economic differences highlighted in the social model of disability. For instance, the study has revealed structural challenges experienced in terms of lack of physical access to transport and medical facilities that impacted negatively on the siblings’ psychological wellbeing. This differs from the West where the social model of disabilities has played a part in encouraging governments to address a number of these structural challenges (Barnes, 2012; Thomas, 1999). The findings have further pointed to high levels of responsibilities that fall on siblings due to the family structure from this context, which differs from the West. Again, the social model identifies lack of access to employment as a factor that affects disabled people (Oliver, 1996; Priestley, 2003). It was evident from the findings that the young adults were impacted economically as they struggled to work at the same time as care for their sibling with CP. Their employment was negatively impacted as a result of their sibling’s dependence on them, something that was not evident in the studies from the West. Due to the need to relieve parents of the burden of care, siblings involved themselves with the heavy responsibility of care giving, which affected their education and/or employment. Conversely, the family played an important role in supporting these siblings, as there were no proper systems in place to provide support within this context.
Aside from this, the study contributed to my growth as a professional counsellor, researcher and mother to a CP child. Through this study, I gained a deeper understanding of the issues involved for my children, clients and myself. Therefore, the study has contributed to my emotional stability, personal growth and professional development. Sanders and Wilkins (2009) urge researchers to carry out research that contributes to the pool of knowledge and advances professionalism, and this has been achieved through this study. Therefore, a major contribution of this study lies in its unique contribution in shining of the light on the Kenyan experience in a field that is dominated by Western research.

6.2. Study limitations

One potential area of criticism relates to sampling. IPA is criticised for its small sample sizes and the consequent lack of ability to generalise from its findings. Moreover, highly pertinent to this study, is its urban context in a country where rural living still dominates and in particular it’s setting within Nairobi, which has its own particular urban characteristics as the capital city of Kenya. The counter argument is that generalisation is not its aim. The desire is to focus in depth on individual experiencing (Smith et al, 2009) in particular contexts. This is a study undertaken in Nairobi and the findings are not presented as directly transferable to other urban centres or rural areas. This study however provides a strong starting-point for wider research within different parts of Kenya.

A related potential critique is that information was not collected at the sampling stage which might have helped contextualization. Details, for instance, on parental occupation/ employment status or tribal background were not collected, detail that might have enriched the discussion of the findings.

A criticism of some of the questions used to guide the semi-structured interviews and more especially after reflecting on the findings is that some had a limitation in terms of the composition. For instance a question that asked them to talk about fear about the future turned out to be suggestive and may have directed the young adults to talk about fear about the future which was one of my themes in this study. However, I have learnt that one has to be aware when designing IPA questions to avoid suggestive questions that can influence the flow of the interview.
On a further note, IPA requires a homogeneous sample (Langridge, 2007; Smith et al., 2009). In this study a number of potential characteristics were not stipulated for inclusion. The study therefore took quite a wide view of homogeneity which reflected in part a wider inclusion criterion, for instance, the Kenyan description of a young person eligible to make their own decisions, which is regarded as being above 18 years but with a higher ceiling. However, as the definition of young adults in Kenya ranges from 18 to 30 years, this definition covered a wide age range in terms of age. I did not specify other potential factors such as gender of sibling with and without CP nor whether older or younger than the sibling, neither did I specify the maximum age of CP sibling, their culture or family size. Therefore it could be argued that my sample contained a level of diversity that impacted on its potential homogeneity.

One reason for my wide inclusion criteria was that, despite having lived with a child with CP for several years and having professional contacts, it was difficult to know whether putting in further inclusion criteria for the sibling with CP would enable me obtain a sufficient number of participants. Conversely, although a representative sample is not aimed for in IPA, it could be argued that a blend of various cultures would have been useful in a country where culture plays an important role.

Despite these potential critiques, I would argue that this study was able to yield meaningful data that may act as a foundation for further research, and that it has illuminated the potential experiences of young adults who have a sibling with CP within the Kenyan context.

A second potential area for critique relates to different viewpoints concerning the value of the insider researcher position. Some commentators stress the positive value of being an insider researcher. Assellin (2003), for instance, highlights the importance of an insider position as being accepted by the research population. IPA argues that an insider position can bring valuable insight into existing ‘horizons of understandings’ within communities. However, it also recognizes the potentially enhanced dangers of imposing one’s understandings onto the data. IPA incorporates the interpretative role of the researcher and urges the researchers to examine their prejudices in order to be fully open to the views of the participants (Finlay 2008; Heidegger, 1927; Gadamer, 1989). IPA is about making sure that you do not simply impose your preconceptions on the data.
but rather that you acknowledge them and reflexivity is regarded as crucial for this purpose. However, despite the checks and balances I put in place, as sole researcher I may have unconsciously imposed my preconceptions at points. For instance, I came to this research anticipating negative psychological challenges due to my previous interaction with young people who have a sibling with CP and this may have influenced how I looked at this study. Moreover as discussed within the study, my insider position was an ambivalent one. This title would lead one to think that I was a young adult who has a sibling with CP and yet my insider position only came because I had some prior knowledge as a mother to a CP child and a counsellor who had dealt with this population. Again my role as a mother could lead me to be tempted to take a role of educating the young adults whenever I realized they did not understand a particular concept, hence my shifting roles within the research encounter may have affected how I was perceived by the participants and the nature of the data produced.

However, as with other IPA studies, as a researcher I do not claim that this study presents objective knowledge. The findings need to be understood as the result of an interpretative process within which the person of the researcher is deeply implicated. Moreover, it is highly contextualized within time and place. It means that if an IPA research is undertaken by others, it could elicit different results depending on the one’s stand point, time, geographical location and other factors.

6.3. Recommendations for further research

As this study forms part of a very small body of research within Kenya, there is significant capacity for further research. Moreover, as these results are not presented as generalisable truths, it is important for future research to take place in order to help to start the building of a more general portrait of experience.

The current study looked at experiences from small sample of young adults who have a sibling with CP within Nairobi. I think it would be valuable for similar qualitative studies to be undertaken in other urban areas to help start to build up a picture of the urban experience across Kenya. It would be useful to discover from a larger population how widespread these experiences are: hence
a quantitative study that can look at the experiences from a larger population may help create a broader brush picture. Moreover, what this study cannot point to is how rural and urban experiences may converge and diverge. Again, qualitative studies could illuminate experiencing within different rural areas and allow the possibility of building a wider picture across different parts of Kenya.

Undertaking the study led to a realisation of the lack of research generally into sibling experience of living with disability within Kenya. Such research is focused largely in the west and is not directly transferable given economic, social and cultural differences. Research into the experience of Kenyan siblings of children with other disabilities would help contextualise the findings of this study.

As I utilised a relatively wide set of criteria for inclusion in the study, I recommend research that focuses in particular on the experiences of, for instance, female siblings, older siblings, siblings from different socio economic groups as research from the west indicates the potential of different experiencing based on gender, family position, socio economic status.

6.4. **Recommendation for practice**

This was an exploratory study and therefore substantial recommendations cannot be made. However, there are potential ways that this study and any that might follow in the area can help to inform practice.

Considering that I will disseminate such findings through conferences and workshops to counsellors, more especially to members of Kenya Counsellors and Psychologist Association, I will sensitize them to the potential negative psychological issues faced by this group such as stigma, fear about the future and anger. From a positive side they should also be open to look at positive growth in the siblings arising from growing up with a sibling with CP.
The young adults in this study talked about lack of information until they learnt about it in school. This point to the potential need for information by this group and therefore it would be useful for professionals dealing with this group to disseminate information to families as soon as a child with CP is diagnosed in order to fill this gap. It is important therefore that this study is made available not just to counsellors but to families and involved professional bodies.

Considering that I will disseminate these findings to the Cerebral Palsy Society of Kenya, it is expected that the management of this organisation can use these findings to publicise the potential issues faced by this group and design ways of addressing these potential issues. This should, I would suggest, incorporate psychological counselling as an intervention for this population that has a number of psychological challenges. Any provision would need to take account of the strained economic circumstances of many such families and the pressures on siblings’ time due to their caring obligations. Any such provision would need to be flexible and low-cost or free.

6.5. Recommendations for training

This study has highlighted the strength of the potential challenges experienced by young adults who have a sibling with CP. It has also pointed to the possibility for potential reward that may be experienced. As such, it could inform counselling training in terms of raising awareness amongst counsellors of the experiences of this group, and help in the development of appropriate ways of working with them.

Results from this study have pointed to the potential importance of adopting a person-centred approach based on the core conditions as an antidote to the isolation and stigmatisation they experience elsewhere. This could alternatively point to the usefulness of a solution-focused approach aimed at helping people capitalise on their resources in order to resolve their problems in living. The findings demonstrate the potential for personal growth in this group and hence this should be borne in mind in any counselling encounter.
On a wider note, this study could contribute to a raised awareness amongst counsellors of the disabling impact of society on the lives of disabled people and their families. It might also simultaneously help as a base for counsellors to explore their own attitudes towards disability.

6.6. A Final reflection

During the introduction, I introduced the role that I would take in this research as an insider and how my role led me to this study. At this stage I am obliged to discuss how this role impacted on me as a researcher and how in turn the research impacted on me. As Etherington (2004) puts forward, we are changed by the results of research as our personhood meets with the research at the same time the research interacts with our personhood. To do this, I have randomly used what I wrote in my reflexive journal to inform what I write here to describe the changes I have encountered in this research journey.

Firstly, my role as insider to this research was complex because of not being a sibling myself. Although I had some prior-knowledge of what happens to young adults who have a sibling with CP. It was not from their point of view but from a professional counsellor’s and mother’s point of view. This notwithstanding, there is some insight I gained from being an insider whereby I was able to reflect on my experiences with clients and my children that led me to a deeper understanding of the issues involved for the population I studied.

Consistent with an IPA research, this study has taught me to be more consistent in writing in my journal for any future project. It has been rewarding to read what I wrote in the journal especially considering the time taken to write this thesis. Had I not been consistent in writing in my journal, I could have lost part of my participants’ views on the way.

I had not anticipated positive changes in the young adults who have a sibling with CP and therefore this study has taught me to be attentive to positive aspects of experience both in my clients, my children and myself.
This study led me to experience some of the emotions that I had bottled up and hence I was able to work through them through counselling, a process which has left me feeling emotionally well. There was some comfort in knowing that my concerns are shared with many people some of them who are younger than myself. Therefore listening to the young adults’ share their experiences led me to deal with my own issues as they arose. My growing interest in this topic was to help me become a better mother and skilled in my field of counselling which I strongly feel I achieved.

On a number of occasions, the research has taught me that as a human being I am vulnerable which can be summarised by the following extract from my journal.

I am feeling anxious, tired, discouraged, a state of almost giving up. But when I remember that the end of the journey is worth waiting for, I get determined to move on. In the morning, I was feeling bad, but this afternoon I am feeling excited and surprised at my findings. I remember my promise to participants that I will disseminate the findings to them and my supervisor’ words that it is injustice to carry out research that cannot contribute to knowledge. What will I share with them if I abandon my study half-way? I get motivated to move on 8th July, 2012.

As I read through my journal, I realised that my research journey had its ups and downs. However, the commitment I had to carry out this study and my passion for the same propelled me to continue with this research.

As I immersed myself into data by reading severally participants data, I felt emotionally affected by the experiences of a young adult whose sibling with CP cannot go to the toilet without taking drugs. I reflected on the challenge to the family of this particular sibling. This led me to think more about my own challenges and I realised it touched on my emotions. I later sought support to deal with my personal issues resulting from this experience.

As Denzin (1989) put forward, research can benefit individuals therapeutically and leave marks that are transformational in their lives hence I was open to this transformation and therapeutic adventure. I can acknowledge that this research has been a learning process as well as a therapeutic one for me.
Again, in line with Etherington’s (2004) view that, research provides an opportunity for growth for the researcher, I have grown both personally and professionally. The journey has been rewarding and challenging to me as a mother, researcher and counsellor. I have been challenged by carrying out this sensitive research that required my attention to distress both in me and my participants. However, my experience as a counsellor on this research journey led me to use counselling skills of empathy which were rewarding to this research.


Appendix A  APPROVAL OF THE INSTITUTION

Tabitha Y. Mukwana
Tel 0721930289

09/12/2011

Dear Madam,

**RE: YOUR RESEARCH STUDY**

We are in receipt of your request to access young adults who have siblings with Cerebral Palsy.

We have no objection to you accessing them and wish to assist you to reach them. We wish you the best in your study which we hope will also help us a society as you establish the relations with the Cerebral Palsy siblings.

Sincerely yours,

Administrator

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Caring for children afflicted by Cerebral Palsy

Executive Committee Members: Mrs. Jardine Mwangela (Chairperson), Purity K. Makori (Secretary), Jackson K. Maina (Treasurer)

Trustees: Prof. Albert Mumma, Dr. Rosalind Reeve, Michael Mwangi
Appendix B

PARTICIPANT INFORMATION SHEET

Dear Participant,

My name is Tabitha Mukhwana; I am undertaking a Professional Doctorate in Counselling at the University of Manchester (United Kingdom).

I intend to carry out a study on “An exploration of experiences of young adults who have a cerebral palsy sibling within Kenyan context”. This study is aimed at exploring the psychological issues in young adults whose sibling have CP. Participants should be aged between 18 to 35 years. This piece of work is for my thesis for the Professional Doctorate in Counselling at the University of Manchester.

I wish to emphasize that it is not a MUST for one to participate in the study if one does not wish to and that will be honoured. Participants will be interviewed on one to one basis. The session takes approximately one and a half hours and will be tape recorded. All information will be treated as confidential.

It is intended that findings will benefit the participants, others whose siblings have CP and professionals dealing with this group to learn from their experiences.

Should any of the participant require further clarification about the study, please do not hesitate to contact me on Tel 0721 930289 or email address t_mukhwana@yahoo.com. The dates for interviews for those who will give consent is from 5th to 10th December, 2011 within CPSK offices, Donholm.

If you are happy to participate please complete and sign the consent form below and return to Cerebral Palsy Society offices, Donholm, Nairobi.

Participant:

I confirm that I have read the above and are willing to take part in the study.

Name ............................................       Sign .................................

Date ..............................................

Signed by  Tabitha Yiswa Mukhwana       Date:  22nd November, 2011
Appendix C

CONSENT FORM

An Exploration of experiences of young adults who have a sibling with Cerebral Palsy within Kenyan context.

If you are happy to participate please complete and sign the consent form below.

Please

Initial

Box

1. I confirm that I have read the attached information sheet on the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that the interviews will be audio/video-recorded.

4. I agree to the use of anonymous quotes.

5. I agree that any data collected may be passed to other researchers.

6. I agree that any data collected may be published in anonymous form in academic books or journals.

I agree to take part in the above project

___________________________ _________________ ________________
Name of participant Date Signature

___________________________ _________________ ________________
Name of participant Date Signature
Appendix D  INTERVIEW GUIDE

An Exploration of experiences of young adults who have a sibling with Cerebral Palsy within Kenyan context.

The following question will be used during the in-depth interview to guide the discussion. The questions may not flow in a systematic way.

As a way of introduction, please may I know your age and highest level of education and/or occupation if any?

It could also be helpful if you let me know the age and sex of your sibling with CP and the size of your family, the gender of the household head and the where you reside.

1. Please tell me about what you understand by Cerebral Palsy
2. Talk briefly about your sibling who has CP.
3. How do you relate with this sibling?
4. Talk about any significant event you have had with this sibling.
5. Tell me any stressful even you have had with your sibling?
6. Talk about how you handled any stressful issue as a result of your sibling with CP.
7. What fears if any, do you have about your future and your sibling’s future?
8. What hopes do you have about your future and the future of your sibling with CP?
9. Have you ever been offered any psychological help as a result of your sibling with CP? If so, talk about it.
10. How do you support your sibling with CP emotionally?
11. What are your comments about this study?

Any additional information, you have freedom to withdraw and to be debriefed at the end of this interview.
<table>
<thead>
<tr>
<th>Original transcript</th>
<th>Initial exploratory notes</th>
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<tbody>
<tr>
<td><strong>Interviewer:</strong> Please tell me what you know about CP?</td>
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| **Participant:** They are kids who are mentally disabled, and they actually, they need our help. So as for me, I take them as normally but I treat them with special care he is special from my other brother. | A mental condition  
People in need of help, attention,  
Special care, treatment  
Different from others who are normal. |
| **Interviewer:** Could you please talk briefly about your sibling that has cerebral palsy? |
| **Participant:** Yah .... and he looks normal to me. But sometimes it is hard to understand what he wants. May be if he has a problem, he can cry but you may be think he is crying out of nothing but sometimes he may be sick yah may be has something in his eyes, I usually don't know so it is very hard to understand him at some point. | A condition that looks normal – sameness  
Hard to understand him  
Cries when he has a problem  
Cries when he is sick  
Difficult to understand him  
It is hard |
| **Interviewer:** Could you talk about how you identify when he requires attention. |
| **Participant:** Sometimes when he pew, he cries a lot, he doesn't stop, so if you want to know, just go and touch him and you will just know that he has pewee. | Inability to understand him  
Communicates through gestures  
Symbolic cry |
| Is there any significant issue you have had with your brother that you may want to talk about? |
| **Participant:** Yeah, sometimes we have fun, we listen to music, he likes bongo (a certain artist) music a lot, and also when I feel he is bored, we just play it. Just to have fun. | Notice sibling’s love for music  
Connects with sibling through music |
| How do you value such moments? |
| **Participant:** It is as if he knows how to sing it so he makes a lot of noise, like he is singing with the rhythm, but his is not actually singing, just making noise.... | Enjoys music |
| Having talked about significant events with your sibling, is there any moments you felt stressed? |
| **Participant:** I mean, he has problems with his stomach he can’t go to the toilet alone, so sometimes it is hard. It is a must you give him some medicine so that he can go to the toilet. The passage for it is so small. So it is hard for him. So he cries a lot. And maybe you have so many things to do and then he is there crying. It is hard. | Medically challenged,  
A medical condition  
"It is hard"  
Inability to concentrate.  
Use of guess work |
| How does that make you feel emotionally? |
| **Participant:** I try to convince myself that he has a problem, so that I don't make him worse from what he is suffering from, so I just try to calm down, because he also has a problem, | Feels for the siblings  
In denial  
He has a problem  
Being calm |
<p>| Being that you understand your sibling’s concern is there any fear you have had about, if any, about the future of your sibling or yourself |
| <strong>Participant:</strong> Sometimes I feel that, I don't | Silence – need for space |</p>
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**your experience of being a sibling of a CP brother?**

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<tr>
<th>Participant: Me - when I reached form three now, we are learning biology in form three, so we were taught about cerebral palsy and the way they are mentally ill. And the way their brain function then I got to understand everything about him. So from that, I got to understand the way he is and accept him.</th>
</tr>
</thead>
</table>
| Learnt about the condition in school  
Deeper understanding  
Acceptance  
Compares with mental illness. |

How did the relationship with your sibling impact on your relationship with others?

<table>
<thead>
<tr>
<th>Participant: Sometimes ..... When I was in primary some of them did not understand, and they did not like the way he was, when mostly when he was eating, they would say it is ‘disgusting’ so they just, would not support me when I was in primary. But at least my friends now, they understand.</th>
</tr>
</thead>
</table>
| Lack of understanding,  
Disgusting,  
Not supportive  
Intolerance, lack of support. |

And ah when they used to say your sibling’s way of eating was disgusting, how did that make you feel?

<table>
<thead>
<tr>
<th>Participant: I felt bad; sometimes I even used to cry. I told my mother told me that, just let them be and to avoid having such friends.</th>
</tr>
</thead>
</table>
| Felt bad, used to cry,  
Feeling alienated,  
Avoidance, advice |

Anything you experienced as a result of that?

<table>
<thead>
<tr>
<th>Participant: Sometimes, for those who thought they were so special than others. And for those who don’t understand people when maybe they are sick, they would think that it is something they wanted for themselves to happen.</th>
</tr>
</thead>
</table>
| Feeling devalued,  
Feeling misunderstood,  
Judgmental, Feelings of anger. |

What was your take on your peers’ remarks?

<table>
<thead>
<tr>
<th>Participant: That they are entitled to what they think, but not to just put all her concentration on the sibling, but to take care of him.</th>
</tr>
</thead>
</table>
| Freedom of expression,  
Less emphasis on negative remarks |

Is there anything else you would like to talk about your experiences of living with a sibling with CP?

<table>
<thead>
<tr>
<th>I would like to ... to learn more about cerebral palsy and just try to find the sort of treatment for him, the way my aunt is doing now. She brings wheelchairs for him from London and he also brings medicine whenever he has a problem and we don’t have such medicine in Kenya..... so we just sent it from far. To help him.</th>
</tr>
</thead>
</table>
| Learn more about CP, finding cure, needing to help, feeling supported,  
The desire to help the sibling. |

You have talked about a number of challenges that you have encountered? Is there any form of support you received for your challenges?

<table>
<thead>
<tr>
<th>Participant: Sometimes it is hard for me when, maybe I am having stress may be because of school, and I have to take care of him at the same time. You know sometimes my mother has a lot of work to do and I have to take care of him and so it is hard for</th>
</tr>
</thead>
</table>
| Pointed to challenges experienced. Changing roles,  
Multiple roles -  
Stressful situation,  
Feeling ‘it is hard’  
Lack of concentration  
Feeling overwhelmed. |
<table>
<thead>
<tr>
<th>Providing care.</th>
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<tbody>
<tr>
<td>Is there any time you have been offered some form of psychological support?</td>
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<tr>
<td><strong>Participant:</strong> Yah, some events for those parties they usually talk about those things. So they counsel us and tell us how to stay with them and how to react to the way they feel and also my mother also encourages me not to be stressful when you have a lot of work just think of him in a way that he needs your help. And that he is not crying just because he wants to cry.</td>
</tr>
</tbody>
</table>
| Experienced psychological support  
Feeling supported emotionally by others.  
Stress management skills taught  
Encouragement from mother |
| When you were supported by counsellors, how did you experience this? |
| **Participant:** Yeah, it helped me because I just got to understand that sometimes, he has a lot of problems. His body is fragile and ah..., you can just hurt just by doing small things to him ..... So whenever my mother handled him, and she fed him, he used to cry, just because he had a wound on his back. But I never knew that he had it. So you just have to be humble when you are dealing with him. |
| Felt supported  
Led to an understanding of the condition  
Fragile, need for special care.  
Increased level of awareness due to handling the sibling. |
| Having noticed your sibling's fragility, how then do you handle him? |
| **Participant:** Sometimes, but that is not all the time, when he looks like that, he is usually sick. When he has flu, so he will just be quiet the whole day. But if you don’t notice it, he will get worse. So that is when he starts crying and you just, may be you have a lot of things to think of. You know you will not concentrate on him and then he starts crying, maybe he is hungry, may be you won't understand him. Anytime his is sick, when he gets worse, that is when you will know, when he has suffered a lot. |
| Affected by sibling's condition  
Inability to concentrate.  
Being responsive to sibling’s needs,  
Special attention required. |
| How do you help your brother when he is emotionally distressed? |
| **Participant:** I just, for me I usually buy him yoghurt, because he likes drinking yoghurt, so that makes him happy. |
| Makes sibling happy by buying him yoghurt |
| Have you also handled him differently during such a moments? |
| **Participant:** Yah, sometimes I play for him music. The one I told you – bongo, and usually this time when my mum told me that he likes some yoghurt, so I usually buy for him yoghurt when he is sad. |
| The desire to make the sibling happy, Connects with the love of music in sibling |
| So if you were to describe your whole journey (yah) with your sibling from the time he was born upto now, what would you say – the walk has been? |
| **Participant:** It has not been easy but from the help and support I have been getting from my parents and the counsellors, they made it easy for me. And now I understand |
| It has 'not been easy',  
Confirms what helped,  
Understanding, need for help.  
Feeling supported. |
<table>
<thead>
<tr>
<th><strong>why he is like that and the kind of help that he needs.</strong></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>Any particular experience you have learnt from your interaction with your sibling that you can tell others?</td>
<td></td>
</tr>
<tr>
<td><strong>Participant:</strong> That he just needs to take care of him and just put himself in her siblings shoes, what if it was him who was like that, how would he have felt being treated like that, and like he is a nobody and nobody cares about him, he would have felt bad. That is why he has to be there for him. You know sometimes they feel lonely and you can’t know, they feel ignored because they can’t do anything without anybody’s help. You just have to be helpful at all times. When you are having good times you have to make him happy. You know he like travelling, so when something like that is said to him, he becomes jovial.</td>
<td><strong>Be caring, be available for them, treat them well, make them happy,</strong></td>
</tr>
<tr>
<td><strong>Attentiveness to siblings emotional needs</strong></td>
<td></td>
</tr>
<tr>
<td>How has been the relationship with other sibling?</td>
<td></td>
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<tr>
<td><strong>Participant:</strong> For me, it is just okey, apart from sometimes in the past, when he was young. He was also disturbing him. When he is told to make him keep quiet, he starts making noise for him but as for now, I see him, he has changed. Now he, from the time he came from school, he started watching some movies that makes him, makes the other sibling happy.</td>
<td><strong>Enjoys good times with other siblings, felt different</strong></td>
</tr>
<tr>
<td>So from the time he was disturbing instead of making him calm, you realize that your other sibling has now known how to treat the Cerebral palsy sibling.</td>
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<tr>
<td>Is there anything that you feel is relevant, maybe just before we close of our session?</td>
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<td><strong>Participant:</strong> I just like to tell the other people that this kind of children really need our help and we should be therefore them and take good care of them. We should not abandon them. You know there are some people who give birth to such kids and they just throw them or they take them to mother Teresa, where they are treated awfully by those people there. That is not good (.</td>
<td><strong>Voicing out for siblings.</strong></td>
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<tr>
<td><strong>The need to take good care,</strong></td>
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<tr>
<td><strong>The need for better treatment,</strong></td>
<td></td>
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<tr>
<td>Original transcript</td>
<td>Emerging themes</td>
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<td>They are kids who are mentally disabled, and they actually, they need our help. So as for me, I take them as normally but I treat them with special care he is special from my other brother.</td>
<td>A desire for attention, attentiveness</td>
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<td>Could you please talk briefly about your sibling that has cerebral palsy?</td>
<td>A sense of helplessness</td>
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<td>Yah .... and he looks normal to me. But sometimes it is hard to understand what he wants. May be if he has a problem, he can cry but you may be think he is crying out of nothing but sometimes he may be sick yah may be has something in his eyes, I usually don’t know so it is very hard to understand him at some point.</td>
<td>Inability to understand the sibling</td>
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<td>Could you talk about how you identify when he requires attention.</td>
<td>Communicates through non-verbal communication, guessing lot.</td>
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<td>Sometimes when he pew, he cries a lot, he doesn’t stop, so if you want to know, just go and touch him and you will just know that he has pewee.</td>
<td>Identifies with sibling’s condition</td>
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<td>Is there any significant issue you have had with your brother that you may want to talk about?</td>
<td>Connection with sibling through music</td>
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<td>Yeah, sometimes we have fun, we listen to music, he likes bongo (a certain artist) music a lot, and also when I feel he is bored, we just play it. Just to have fun.</td>
<td>Special time with sibling, bonding</td>
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<td>How do you value such moments?</td>
<td>Quality time with sibling</td>
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<td>It is as if he knows how to sing it so he makes a lot of noise, like he is singing with the rhythm, but his is not actually singing, just making noise....</td>
<td>Values the time with sibling</td>
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<td>Having talked about significant events with your sibling, is there any moments you felt stressed?</td>
<td>Medical condition, difficult condition, It is hard repeated thrice</td>
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<td>I mean, he has problems with his stomach he can’t go to the toilet alone, so sometimes it is hard. It is a must you give him some medicine so that he can go to the toilet. The passage for it is so small. So it is hard for him. So he cries a lot. And maybe you have so many things to do and then he is there crying. It is hard.</td>
<td>Inability to concentrate</td>
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<td>Sense of physical hardships</td>
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<td>How does that make you feel emotionally?</td>
<td>Empathies with siblings.</td>
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<td>I try to convince myself that he has a problem, so that I don’t make him worse from what he is suffering from, so I just try to calm down, because he also has a problem,</td>
<td>Denied grief</td>
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<td>Connects with siblings problem</td>
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<td>Being that you understand your sibling’s concern is there any fear you have had about, if any, about the future of your sibling or yourself</td>
<td>Inability to respond to question</td>
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<td>Sometimes I feel that, I don’t know actually .... (silence)</td>
<td>Reflects more on fears</td>
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<td>Fear of future responsibility, Lack of sibling independence, Fear of future roles</td>
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<td>Feeling helpless, feelings of anxiety.</td>
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out to help him, but I don’t know how?

Is there anything good you anticipate about the future?

I just hope that, I will be able to get treatment for what he is suffering from. Because I know everything is possible.

Connects with sibling suffering, desire for Cure
Hopeful

Could you talk about your experience of growing up with your sibling since he was diagnosed with this condition?

It has not been easy (lowers voice) - because most of the concentration was on him. And most of the money spent was on his medicine; I have to take care of him. So most of the time our parents, I felt just, they are always thinking about him, and his health. So for us, it was like they loved him more than they loved us at that time. They are always scared, when he cries they think something is wrong so they take him to hospital. And we were always left there alone with the maid so it hard, it was hard for us, so we didn’t understand at that time what was happening to him. So we just took it like that.

Parent pre-occupied with the cp sibling more than her
Feeling less loved
Feeling isolated
Physical hardships
Feeling restricted
Given up
Lack of information about sibling’s condition

At what stage did you come to understand your brother’s condition?

When I reached class eight...... when we started going for those parties, at xxx and I started seeing other kids like him, some were even worse than him, that is when  I started understanding that he had a problem.

Draws comfort from sharing the burden
Comparison
Getting to terms

After you understood your brother’s condition, how did that make you feel?

Yeah after I understood my brother’s condition, I started treating him (silence)... in a special way now, I knew he had to be fed, he had to be changed, he had to be cleaned, everything had to be done for him.

Feeling responsible,
Taking care, treated well, changed perception

You talked about your parent treating your sibling with CP with more affection than you, how did that make you feel?

Ok, they were just taking care of him, the same way they were doing with us. So they could not show more concentrated on him than us.

Equal treatment, attention
No more concentration.

Anything else you would prefer to talk about your experience of being a sibling of a CP brother?

Me - when I reached form three now, we are learning biology in form three, so we were taught about cerebral palsy and the way they are mentally ill. And the way their brain function then I got to understand everything about him. So from that, I got to understand the way he is and accept him.

Felt empowered with knowledge,
Understanding,
Acceptance, changed perception

How did the relationship with your sibling impact on your relationship with others?

Sometimes ..... When I was in primary some of them did not understand, and they did not like the way he was, when mostly when he was eating, they would say it is ‘disgusting’ so they just, would not support me when I was in primary. But at least my friends now, they understand.

Unsupportive peers,
Negative remarks,
Labeling
Feeling misunderstood, negatives

And ah when they used to say your sibling’s way of eating was disgusting, how did that make you feel?

I felt bad; sometimes I even used to cry. I told my

Emotionally withdrawn,
<p>| mother told me that, just let them be and to avoid having such friends. | Emotional distress, Separation, lack of support from peers |
| Anything you experienced as a result of that? | Feeling devalued, Feeling misunderstood, Stereotype remarks |
| Sometimes, for those who thought they were so special than others. And for those who don’t understand people when maybe they are sick, they would think that it is something they wanted for themselves to happen. | |
| What was your take on your peers’ remarks? | Less emphasis on negative peers, Commitment to care, Freedom of expression |
| That they are entitled to what they think, but not to just put all her concentration on the sibling, but to take care of him. | |
| Is there anything else you would like to talk about your experiences of living with a sibling with CP? | Desire to learn more about the condition, Desire to find a cure, Desire to help the sibling with CP |
| I would like to … to learn more about cerebral palsy and just try to find the sort of treatment for him, the way my aunt is doing now. She brings wheelchairs for him from London and he also brings medicine whenever he has a problem and we don’t have such medicine in Kenya….. so we just sent it from far. To help him. | |
| You have talked about a number of challenges that you have encountered? Is there any form of support you received for your challenges? | Physical hardships, Feelings overwhelmed, Lack of concentration, Feeling compelled to care |
| Sometimes it is hard for me when, maybe I am having stress may be because of school, and I have to take care of him at the same time. You know sometimes my mother has a lot of work to do and I have to take care of him and so it is hard for me to concentrate of books and him at the same time. | |
| Is there any time you have been offered some form of psychological support? | Coping with stress, Helpful support, Encouragement from parents and counsellors |
| Yah, some events for those parties they usually talk about those things. So they counsel us and tell us how to stay with them and how to react to the way they feel and also my mother also encourages me not to be stressful when you have a lot of work just think of him in a way that he needs your help. And that he is not crying just because he wants to cry. | |
| When you were supported by counsellors, how did you experience this? | Fragile, Attentiveness, Special attention |
| Yeah, it helped me because I just got to understand that sometimes, he has a lot of problems. His body is fragile and ah…, you can just hurt just by doing small things to him ….. So whenever my mother handled him, and she fed him, he used to cry, just because he had a wound on his back. But I never knew that he had it. So you just have to be humble when you are dealing with him. | |
| Having noticed your sibling’s fragility, how then do you handle him? | Lack of concentration, Empathize with sibling’s condition |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
<td>How do you help your brother when he is emotionally distressed?</td>
<td>I just, for me I usually buy him yoghurt, because he likes drinking yoghurt, so that makes him happy. Notice sibling’s love for yoghurt, connects with sibling’s needs</td>
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<td>Have you also handled him differently during such a moments?</td>
<td>Yoga and music. Have you also handled him differently during such a moments?</td>
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<tr>
<td>It has not been easy but from the help and support I have been getting from my parents and the counsellors, they made it easy for me. And now I understand why he is like that and the kind of help that he needs.</td>
<td>Helpful support. It has not been easy. Physical hardships.</td>
</tr>
<tr>
<td>Any particular experience you have learnt from your interaction with your sibling that you can tell others?</td>
<td>That he just needs to take care of him and just put himself in her siblings shoes, what if it was him who was like that, how would he have felt being treated like that, and like he is a nobody and nobody cares about him, he would have felt bad. That is why he has to be there for him. You know sometimes they feel lonely and you can't know, they feel ignored because they can't do anything without anybody's help. You just have to be helpful at all times. When you are having good times you have to make him happy. You know he like travelling, so when something like that is said to him, he becomes jovial. Being caring, being available for them, treat them well, make them happy, Connects with loneliness, feeling ignored, need for help</td>
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<td>How has been the relationship with other sibling?</td>
<td>For me, it is just okey, apart from sometimes in the past, when he was young. He was also disturbing him. When he is told to make him keep quiet, he starts making noise for him but as for now, I see him, he has changed. Now he, from the time he came from school, he started watching some movies that makes him, makes the other sibling happy. Warm inter sibling relationships Closeness Family support</td>
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<tr>
<td>Is there anything that you feel is relevant, maybe just before we close of our session?</td>
<td>I just like to tell the other people that this kind of children really need our help and we should be therefore them and take good care of them. We should not abandon them. You know there are some people who give birth to such kids and they just throw them or they take them to mother Teresa, where they are treated awfully by those people there. That is not good. Desire for help and support, Need for care, Need for understanding</td>
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## Appendix G  SAMPLE OF CLUSTERED THEMES

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<th><strong>A sense of personal development and reward</strong></th>
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<td>Sense of achievement, satisfaction and concrete reward.</td>
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<tr>
<td>Increased understanding and acceptance of the condition.</td>
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<tr>
<td>A loving, caring and responsive relationship with their sibling.</td>
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<td>Feelings of anger</td>
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<td>Feelings of fear</td>
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<tr>
<td>Feelings of helplessness and inadequacy</td>
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<tr>
<td>A sense of both obligation and responsibility</td>
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<td>Feeling it is hard and overwhelming</td>
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<td>Straining relationship and creating division within the family</td>
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<td>Family arguments and disagreements</td>
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<td>An understanding and accepting society</td>
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<tr>
<td>Feelings of stigma, non-understanding and lack of acceptance</td>
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