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Exploration of community-based rehabilitation for children with neurological impairments following cerebral malaria in Blantyre, Malawi

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"Children with mental or physical disabilities have the right to special care, education and training designed to help them to achieve the greatest possible self-reliance and to lead a full active life in society"

United Nations Convention on the Rights of the Children: Article 23

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Dedication

To ***Victoria****,* ***Tusekile*** *and* ***Tusaiwe,*** *thanks for being there and seeing me through this mission. I owe you more than just this line of words in this document!*

Declaration

I declare that “*Exploration of community-based rehabilitation for children with neurological impairments following cerebral malaria in Blantyre, Malawi*” is my own work, that it has never been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Signed **27 November, 2018**

Sebastian Minongwa Mboma

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Key Words

Cerebral malaria in children
Neurological impairment
Community-based rehabilitation
Experiences
Perceptions
Caregivers
Healthcare providers
Support
Barriers to accessing services
Blantyre, Malawi
Qualitative study

Abbreviation and Acronyms

BMP	Blantyre Malaria Project
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CM	Cerebral Malaria
COM	College of Medicine (Malawi)
COMREC	College of Medicine Research Ethics Committee
COPS	Cognitive Outcomes and Psychiatric Symptoms
CP	Cerebral Palsy
FGD	Focus Group Discussion
ILO	International Labour Organizations
INGO	International Non-Governmental Organization
KI	Key Informant
KII	Key-Informant Interview
MACOHA	Malawi Council for the Handicapped
MPHC	Malawi Population and Housing Census
MRI	Magnetic Resonance Imaging
NGO	Non-Governmental Organization
NI	Neurological impairments
PHC	Primary Health Care
QECH	Queen Elizabeth Central Hospital
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organizations
UNICEF	United Nations Children's Fund
WHO	World Health Organization

Abstract

Background: Cerebral malaria (CM) kills up to 25% of its patients and about one third of its survivors develop neurological impairments (NIs). With advancements in diagnostic and management techniques for CM, more children are likely to survive. The increase in the number of CM survivors may increase the prevalence of children with NIs. In Malawi, rehabilitation for children with NIs is mostly institution-based with erratic community-outreach services, resulting in poor long-term outcomes. To date, community-based rehabilitation (CBR), a comprehensive rehabilitation approach that also addresses socio-economic impact of NIs and may supplement institution-based rehabilitation services, has not been well explored and documented. Presented here are experiences and perceptions on CBR programmes for NIs following CM in Blantyre, Malawi.

Methods: Data for this study were collected through three focus group discussions (FGDs) with primary caregivers of CM survivors and fifteen semi-structured interviews with healthcare workers at Queen Elizabeth Central Hospital (QECH), and key-informants from community-based organizations (CBOs) working with children with disabilities. Data were analyzed using thematic analysis. All interviews and focus group discussions were tape-recorded, transcribed and translated into English.

Findings: Cerebral malaria was found to have impact on its survivors and their respective families for example; behaviour problems in the CM survivors with NIs, stigma and misunderstanding of NIs by community members and health workers, and financial problems of the affected families. Available institution-based rehabilitation services in the district were characterized by challenges such as inadequate expertise in rehabilitation services, unreliable data on NIs, lack of rehabilitation tools and insufficient funding. In addition, the services provided were inequitably distributed and not comprehensive enough to include the socio-economic aspects of rehabilitation. Furthermore, community-outreach rehabilitation services are no longer operational and CBR programmes with its full range of services are not available at all.

Conclusion: Community-based rehabilitation programmes for NIs was found to be important but not available in the district. Rehabilitation services for NIs in Blantyre are still institution-based,

inequitably distributed and often lacking in essential expertise and resources. Community-based rehabilitation programmes for NIs were deemed essential because they were comprehensive in nature and had potential to supplement institution-based rehabilitation services by addressing the social and economic impact of CM-related NIs. It is therefore essential that CBR programmes are instituted again to improve the quality of rehabilitation services for NIs in Blantyre. This should include ensuring availability of reliable epidemiological data on NIs and increasing capacity on rehabilitation through availability of adequate rehabilitation materials and human resources for rehabilitation with desired expertise.

Chapter 1

Introduction

1.0. Background

Plasmodium falciparum malaria remains the major cause of illness and death especially in malaria endemic areas of Sub-Saharan Africa, including Malawi, where over 90% of the cases occur (WHO, 2016a). In 2015 alone, malaria was responsible for over 2 million cases which resulted in about half a million deaths, 70% of which occurred in children aged below 5 years(WHO, 2016a). Cerebral malaria (CM) is the most severe form of *Plasmodium falciparum*. Even with available standard treatment, cerebral malaria has a high case-fatality rate which can reach up to 25% (Dondorp et al., 2010). In addition, up to one third of survivors of CM develop neurological impairments (NIs) (Postels & Birbeck, 2013). Neurological impairments are conditions caused by damage to the nervous system especially the brain and the spinal cord that may result in the loss of some bodily or mental functioning (Davidson & Durkin 2003). Common NIs in CM survivors include cortical blindness, gross and fine motor deficits, ataxia, language regression, epilepsy and behavioral abnormalities (Kawaza et al., 2010).

With advancements in diagnostic and management techniques for CM such as use of malaria retinopathy for diagnosis (Boivin, Vokhiwa, Sikorskii, Magen, & Beare, 2014), Magnetic Resonance Imaging (MRI) for brain scan (Maude et al., 2014), newly developed anti-malaria drugs (Nilsen et al., 2013) and vaccines (WHO 2016b), more children are likely to survive the disease. However, increase in the number of CM survivors may also increase the prevalence of children with resultant NIs (Berry et al., 2012).

Currently, treatment and rehabilitation for children with NIs in Malawi is mostly through institution-based and outreach services. Outreach services refer to the provision of healthcare services by health workers away from the usual facilities in order to ensure access of these services to vulnerable populations such as the poor and those living in hard to reach areas (Roodenbeke, Lucas, Rouzaut, & Bana, 2011).

Although new diagnostic technologies are increasingly becoming available in the country, such as the installation of the MRI machine at Queen Elizabeth Central Hospital (QECH) and use of malaria retinopathy, to a larger extent treatment and rehabilitation for children with NIs are characterized by various barriers which include: shortage of essential drugs, poor quality medical equipment, shortage of trained healthcare professionals (such as physiotherapists and neurologists), and long distances from patients' homes to medical facilities (Munthali, Braathen, Grut, Kamaleri, & Ingstad, 2013). These barriers which are mainly healthcare systems related may negatively impact treatment and rehabilitation outcomes for the affected children. Therefore there is a need to supplement such a struggling healthcare system.

An appropriate response for supporting children with NIs needs to be holistic and sustainable in which the scope of support must go beyond medical rehabilitation. It must also include psychosocial and economic support of the children with NIs and their respective families (Braga, Da Paz, & Ylvisaker, 2005; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Ylvisaker, Jacobs, & Feeney, 2003).

1.1. Problem statement

Malaria transmission in Blantyre, like all parts of Malawi, is all year round but peaks during the hot wet season specifically from November to around May (Kazembe & Mathanga 2016). Every year malaria accounts for over one third of all illnesses in children aged below five in Blantyre District (Kazembe & Mathanga 2016; Roca-Feltrer et al. 2012). In addition, for more than 10 years now, the number of children admitted with CM at QECH malaria research ward has relentlessly not declined (Roca-Feltrer et al., 2012).

In Malawi, the paucity of literature on the burden of NIs in children has incapacitated efforts to scale-up relevant programmes for the affected children and how these programmes could be appropriately designed (Paget, Mahebere-Chirambo, Mallewa, Gladstone, & Chinguo, 2015). To date, most studies in the country have mainly concentrated on the epidemiology of common NIs caused by CM (Birbeck et al. 2010; Boivin et al. 2007; Idro et al. 2010) or on improving institution-based treatment and rehabilitation (Paget et al. 2015), but not on community-based rehabilitation (CBR).

Apart from institution-based and outreach rehabilitation services, children with NIs also need "context-sensitive" and comprehensive rehabilitation support (Ylvisaker et al., 2003:1). This support must be affordable, sustainable and equitably accessible especially by implementing them right in the communities where these children are raised and spend most of their life-time.

To design such an efficient CBR, programme, there is need to seek perceptions and experiences of the primary caregivers of these children with NIs following CM. In addition, there is need for input from healthcare workers who treat these children while admitted at the hospital with cerebral malaria and key-informants from community-based organizations (CBOs) dealing with neurologically impaired children. The purpose of this study was therefore to explore the experiences and perceptions of caregivers, key-informants from CBOs and healthcare providers about CBR services and what was needed by children with NIs following CM in Blantyre, Malawi.

1.2. Study aim and objectives

1.2.1. Aim of the study

The study aimed at exploring perceptions and experiences of CBR for children with NIs following CM, in Blantyre, Malawi.

1.2.2. Objectives of the study

1. To describe rehabilitation services currently provided for children with NIs
2. To explore the participants' experiences and perceptions of existing rehabilitation services for children with NIs.
3. To explore participants' awareness and perceptions about CBR for children with NIs.
4. To explore participants' opinion on what is needed for an effective CBR programme for children with NIs.

1.3. Structure of the thesis

The thesis consists of six chapters. Chapter one sets a background to the burden of malaria-related NIs as a public health problem and presents the purpose and objectives of the study. Chapter two presents evidence from literature on the burden of NIs in children and possible approaches to rehabilitation of these children. It highlights the benefits of CBR and also the challenges faced in its development and implementation. Chapter three describes the study design, methods and tools used in data collection, study population, sampling of participants and how data was analyzed. It also discusses how rigour was maintained and then gives an account of how health research ethics were adhered to. Finally chapter three highlights study limitations how they were dealt with and minimized. Chapter four focuses on study findings, firstly presenting a description of the participants in the study and then findings of the study drawing on the data collected. Chapter five presents a discussion of the findings and relates it to the literature. The final chapter, chapter six, is where conclusions are drawn from the findings of the study and recommendations are made.

Chapter 2

Literature Review

2.0. Introduction

This chapter presents evidence from literature on NIs in children and CBR. The first part of the chapter presents the burden of NIs in children globally, then in Malawi. The chapter then defines rehabilitation and gives a background to rehabilitation. The chapter also presents approaches to rehabilitation as facility-based, community outreach and CBR and how CBR has evolved over the years since its inception. The chapter finally presents perspectives and experiences on CBR from different settings including challenges faced in developing and implementing CBR programmes.

2.1. Neurological impairments in children

Neurological impairments in children include both congenital and acquired health conditions that occur due to insult to the brain or the nervous system and may inhibit normal functioning of cognition, motor, hearing, vision, communication, emotion or behaviour. Available estimates indicate that about 14% of the burden of disease globally is attributed to NIs (Prince et al., 2007). This is likely an underestimation due to inadequate data and failure to fully appreciate the connectedness between mental illness and other health conditions such as malaria especially in resource-poor settings (Prince et al., 2007; Winkler, Mosser, Matuja, & Schmutzhard, 2008). A recent study in Kenya showed that there is a high prevalence rate (24/1000) of NIs at population level in the country (Kawakatsu, Kaneko, Karama, & Honda, 2012). In Malawi, as much as the actual national prevalence of NIs is still not known due to paucity of nation-wide data, results from a recent study conducted in two rural Malawian districts of Thyolo and Ntcheu corroborate with the findings in a Kenyan study showing that the prevalence of NIs is also high in the country (Disability ICfEi, 2014). The study estimated that the prevalence of childhood impairment in Malawi is 17.3 per 1000 children of which, more than half (55%) are NIs (Disability ICfEi, 2014). More specific to malaria, evidence from studies in malaria-endemic settings show that cerebral malaria is the leading cause of NIs especially in children below five years, affecting up to 20% of its survivors (Idro, Marsh, John, & Newton, 2010; Kawaza et al., 2010; Molyneux, Taylor, Wirima, & Borgstein, 1989).

Children with NIs experience a wide range of problems such as spastic paralysis, cognitive impairment, chronic pain, speech impairment, visual impairment, and gastrointestinal and feeding problems (Odding, Roebroeck, & Stam, 2006). Coping with these problems may result in psychological and sociological stress for both affected children and their respective families; as such comprehensive and sustainable support is needed in which psychosocial, communication, and motor domains are well integrated (Nimbalkar, Raithatha, Shah, & Panchal, 2014). The process of providing such support is called rehabilitation.

2.2. Defining Rehabiliataion

The World Health Organization (WHO) recognizes health as a fundamental human right (WHO, 1948), and in its 1978 Alma-Alta Declaration, the WHO advocates that all people must have equitable access to healthcare services (WHO, 1978). To this effect, the WHO adopted Primary Health Care (PHC) as an effective approach for health service delivery with rehabilitation being one of the core strategies for PHC (WHO 2008). The WHO defines rehabilitation as both the provision of measures to achieve optimal physical functioning as well as enabling people with disabilities to socially integrate in order to improve quality of life (WHO 2011). This definition entails that the process of rehabilitation must be comprehensive in its implementation, encompassing all aspects of rehabilitation namely *medical*, *social* and *economic*.

Medical rehabilitation requires clinical identification and management of chronic impairing conditions in order to achieve optimum physical recovery and prevent further impairment (Gutenbrunner, Ward, & Chamberlain, 2018). An example would be diagnosis of epilepsy or spastic cerebral palsy in a CM survivor and provision of appropriate medication and physiotherapy to the patient. Medical rehabilitation is often institution-based as it may require sophisticated equipment and specialized expertise to be executed.

Social rehabilitation is two-fold; one part of it deals with processes that enable individuals to attain functioning ability to fully participate in vital social activities (Portillo & Cowley, 2011). A good example would be inclusion of persons with disabilities to participate in leadership and in decision-making of important matters concerning their respective communities. The other part of social rehabilitation involves improving social environments to promote better participation of persons with disabilities in vital social activities (Portillo & Cowley, 2011). Improving social environments involves both families of persons with disabilities and the entire community. Social rehabilitation is therefore largely community-based as it requires formulation and implementation of rehabilitation programmes right in the communities where persons with disabilities live. Examples in this scenario would be formulation of policies and legislation that protect right of persons with disabilities and advocacy against stigma and discrimination of persons with disabilities.

Lastly, economic rehabilitation refers to empowerment of persons with disabilities to become economically independent so that they can leave independent and meaningful lives (Gokhale, 2001). The process of economic rehabilitation involves imparting of vocational and entrepreneurial skills to persons with disabilities in order for them to get formal employment or be self-employed. Economic rehabilitation may be both institution and community-based; it may range from formal education such as primary schools, secondary schools and tertiary vocational training, to informal trainings in communities where persons with disabilities can learn different forms of craft.

2.3. Approaches to rehabilitation

There are three main approaches to the provision of rehabilitation services namely; *institutional-based rehabilitation approach (IBR), Outreach rehabilitation approach (OR)* and *community-based rehabilitation approach (CBR)* (Jackson 1998; WHO 1994). These approaches are discussed in more detail next.

2.3.1. Institution-based rehabilitation approach

Institution-based rehabilitation refers to medical care and vocational training provided to individuals with disabilities at facilities such as hospitals and special-needs schools (Jackson, 1998). An institution-based approach is essential when specialized rehabilitation services by qualified rehabilitation personnel and provision of rehabilitation equipment is needed. However, it is still perceived as inadequate as it is more focused on individuals with disabilities and gives little consideration to their respective families who are integral to the rehabilitation process of the person with disabilities. In addition, most rehabilitation institutions are often located in cities and other urban centres making access to rehabilitation services inequitable, especially to persons with disabilities living in hard to reach areas far away from urban areas (WHO 1994).

2.3.2. Community-outreach rehabilitation approach

In the community-outreach rehabilitation approach, healthcare workers based at health facilities make deliberate occasional visits to offer medical rehabilitation services to persons with disabilities right in their communities as a relief programme for those living in hard to reach areas and may not be able to afford frequent travels to the health facilities to access rehabilitation services (Rhodes 1996; WHO 1994). Despite the fact that community-outreach rehabilitation service may improve access and delivery of rehabilitation services, it has often been criticized for being too costly to sustain especially in resource-poor settings (WHO 1994).

Having looked at the limitations of both institution-based and community-outreach approaches to rehabilitation, it is apparent that the focus of rehabilitation services must not be perceived narrowly as individual-based which target recipients with disabilities only. Rehabilitation must be embraced as a broader participatory approach in which the individuals with disabilities, their respective families and their communities are involved (WHO 1994). In this regard, rehabilitation services must be brought right into communities where persons with disabilities live. In addition, these services must be kept sustainable by ensuring individuals with disabilities and their respective families are well supported (Saurabh, Prateek, & Jegadeesh, 2015). For example, support can be given through provision of small grants to individuals with disabilities and their families to start up small-scale businesses or equipping individuals with disabilities with vocational skills to initiate income generating activities or getting employed. This perspective of rehabilitation is what has necessitated the conceptualization of CBR.

2.3.3. Community-based rehabilitation approach

In a joint position paper issued by the International Labour Organization (ILO), United Nations Education Science and Cultural Organization (UNESCO) and World Health Organization (WHO) in 1994 and revised in 2004, CBR is defined as a "… strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction and social inclusion for all people with disabilities" (ILO; UNESCO; WHO, 2004). Community-based rehabilitation has two core objectives; firstly CBR aims at equitable provision of health and social services to persons with disabilities in order to realize their full physical and mental potential. The second core objective of CBR is to ensure protection of human rights of persons with disabilities and empowering them to fully participate in socio-economic and developmental activities in the communities where they live (ILO; UNESCO; WHO, 2004).

Community-based rehabilitation is based on five fundamental principles namely; *inclusiveness, participation, self-advocacy, accessibility and sustainability* (ILO; UNESCO; WHO 2004). These principles promote inclusion of persons with disabilities in all developmental programmes in their respective communities and ensure that persons with disabilities have the opportunity to fully participate in decision-making, planning and implementation of such programmes. These principles also strive to advocate for the rights of persons with disabilities and ensure that relevant information is readily available so that they can make informed decisions. In addition, the principles ensure equitable access to socio-economic and health services for persons with disabilities and maintain a sustainable coordination of all stakeholders involved in rehabilitation programmes with Disabled People Organizations (DPOs) taking a central role (ILO; UNESCO; WHO, 2004). In this respect, implementation of CBR therefore is holistic and calls for a concerted effort in which people with disabilities and their respective families, communities, Non-Governmental Organizations (NGOs) and relevant government departments must work together to improve the quality of life for people with disabilities.

The origin of CBR can be traced to around mid-1970s. Initially, CBR was perceived as an outreach strategy to scale-up coverage and accessibility of medical care for persons with disabilities living in hard to reach areas especially in resource-restricted settings; as such, CBR was medical-based in its approach (Evans, Zinkin, Harpham, & Chaudury, 2001; Helander, 2007). From the early 1980s up to late 1990s, CBR broadened its scope to include equalization of opportunities for persons with disabilities through ensuring equitable access to social and economic amenities that are available in the respective communities where they live (Hartley et al; 2009; Finkenflügel et al. 2005). During this period CBR also emphasized empowerment and poverty reduction through provision of programmes aimed at assisting persons with disabilities and their respective families. For example, provision of vocational training for persons with disabilities and disbursement of small business loans or social grants for them and their respective families (Finkenflügel et al. 2005; Hartley et al. 2009).

Since then, CBR has grown beyond medical care provision and empowerment of persons with disabilities. CBR is now widely recognized as human rights-based as it has taken on board social inclusion of all people with disabilities, in which stigmatization of all people with disabilities is condemned and recognize that people with disabilities have the right to be active members of society (WHO 2004).

2.3.3.1. Training and guidelines for community-based rehabilitation

Over the years the WHO has strived to improve the operations of CBR programmes by providing relevant guidance for its practice. To this effect, the WHO published a series of CBR training manuals in 1979, with subsequent revised editions for example in 1980, 1983 and 1989 (Helander; Nelson; Mendis and Goerdt, 1989). What is paramount in these manuals is that the WHO guided CBR implementers at all levels from policy makers to beneficiaries on how CBR programmes must be planned and implemented. The training manuals simplify the rehabilitation process and make it easier to understand even to a lay person (Helander; Nelson; Mendis and Goerdt, 1989).

Following the joint position paper on CBR alluded to earlier, there was a need to standardize CBR implementation across the globe, and therefore the UN agencies, governments, civil societies and DPOs jointly inaugurated and published international guidelines for CBR programmes in 2010 (WHO, 2010a). These guidelines were based on lived experiences and principles of fundamental human rights for persons with disabilities (WHO, 2010a). The guidelines included a matrix that provided a conceptual framework to assist CBR implementers across the globe to choose which components and elements could be implemented depending on their respective needs and resources available (WHO, 2010a).

2.3.3.2. The community-based rehabilitation matrix

The main purpose of the matrix is to provide a visualized framework of CBR strategies to its implementers. The matrix is holistic in nature as it constitutes five essential components that comprehensively define rehabilitation. These five components are; *health, education, livelihood, empowerment* and *social*. Each component is further subdivided into five elements which highlight the actual programmatic areas to be considered when implementing any CBR project. For example if an individual or an organization would like to implement a rehabilitation programme for children with NIs as a result of CM, they must consider health problems that need to be addressed through health promotion in order to prevent new CM cases. Then they have to look into how children who already have NIs should acquire better education so that they grow up to become independent adults. They also need to sensitize the community about social inclusion of people with NIs and how they can become empowered to participate in community development activities. Therefore no single component can be implemented independently, as there is a need to apply the various elements that account for complete rehabilitation. (Refer to figure 1 for a CBR matrix).

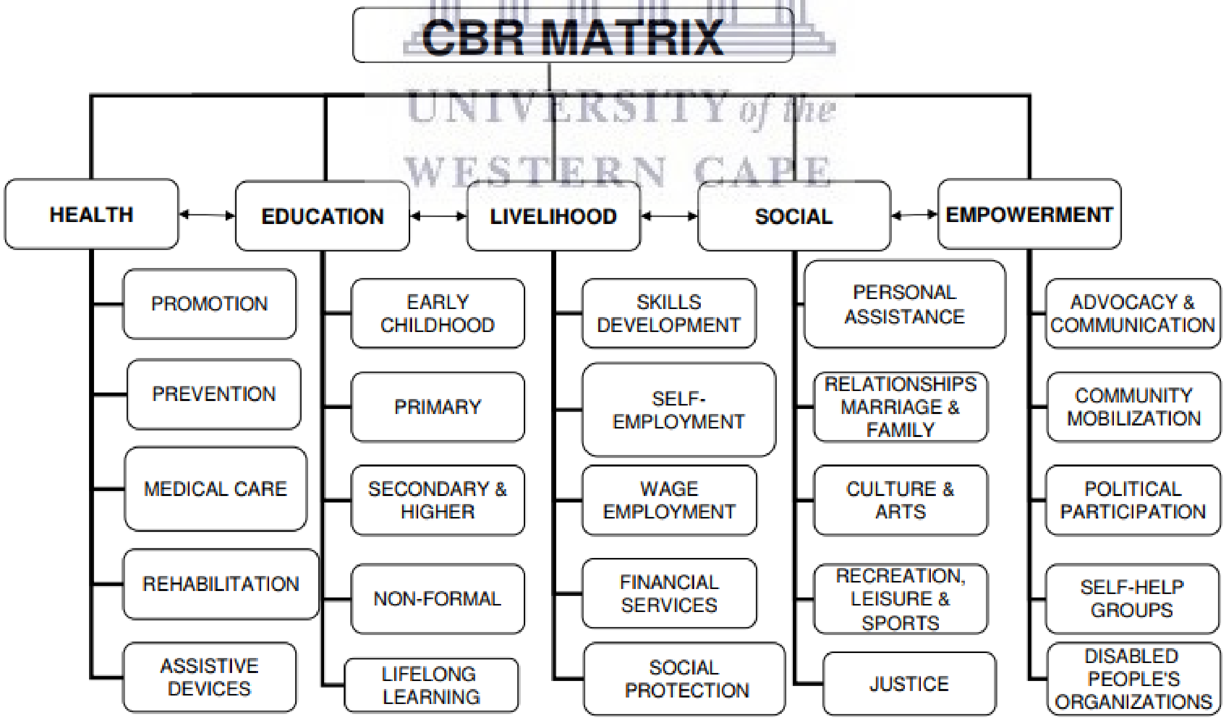

Figure 1: The community-based rehabilitation matrix (Source: WHO 2004:5)

2.3.3.3. Evidence of benefits of community-based rehabilitation

Since its inception, CBR has spread across the regions of the world and to date there are more than 280 CBR programmes in 25 African countries (IDDC, 2012). Generally, the benefits of CBR over the years and across various settings cannot be overemphasized. By placing emphasis on working in the communities and other facilities, CBR programmes have been given credit for bringing healthcare and education services including rehabilitation closer to persons with disabilities. Secondly, CBR programmes have not only empowered and enhanced social inclusion of people with disabilities but has also improved the livelihoods of their respective families and communities in which they live, for example, through provision of financial support and training. Additionally, CBR programmes have been shown to be relatively cost-effective and more sustainable because of the programmes' emphasis on community empowerment and participation (Saurabh et al., 2015).

Evidence from the literature has also revealed that CBR programmes specifically intended for children with NIs have shown increased results in resource-restricted settings similar to Malawi. For example, in Brazil, a randomized-controlled trial revealed that a family-supported intervention for children with traumatic brain injury was more efficacious than a direct clinician-delivered service as children in the family-supported intervention arm had better outcomes than those in the clinician-delivered arm (Braga et al., 2005). In another randomized controlled trial in Bangladesh on alternative modes for service provision for children with cerebral palsy, results showed significant improvement in skills in children with disabilities whose caregivers had assumed a primary role in rehabilitation support following relevant monthly training (McConachie et al., 2000). In a qualitative study aimed at examining the experiences of caregivers of home-based intervention for children with complex communication needs in Kenya, it was revealed that caregivers were able to recognize children's communication strengths. The study also showed that affected children received more psychosocial support from their communities (Gona, Newton, Hartley, & Bunning, 2014).

2.3.3.4. Challenges faced in development and implementation of community-based rehabilitation

There are many challenges that affect development and implementation of CBR programmes but some of these challenges are specific to some settings. However there are four common challenges that have been identified namely: lack of funding for development and implementation of CBR programmes; inadequate human resources and lack of expertise in rehabilitation; unavailability of proper legislative framework to support implementation of CBR programmes; and limited information on disability and CBR (Adaka, Florence, & Ikwem, 2018; Saurabh et al., 2015; WHO, 2011). These challenges are discussed in more detail next.

i. Funding challenges

Financing CBR projects such as purchasing of rehabilitation materials, training of rehabilitation personnel and provision of CBR services to the people with disabilities and their respective families have been cited to be a major stumbling block in the implementation of CBR programmes especially in resource-poor settings (WHO 2011). The main sources of funding for CBR have been through annual budgetary allocation from governments and donations from international NGOs (Hartley et al. 2009). However, experience has shown that most governments fail to fulfill their budgetary obligations for the health sector (OAU, 2001) and hence CBR has similarly suffered inadequate funding for implementation of its projects. Further to this, international NGOs have not been able to sustainably fund CBR. It has been observed that most rehabilitation donors prefer to fund charitable projects more than community development oriented programmes such as CBR because it is easier to evaluate and see the impact of a charitable project even within a short period of time than it is to observe the long-term impact of community development programmes (Adaka et al. 2014).

ii. Inadequate human resources and lack of expertise in rehabilitation

Human resources is a challenge in the development and implementation of CBR in two ways; firstly when there is lack of expertise for rehabilitation in the health personnel working in CBR programmes and secondly, when there is shortage in the number of health personnel with expertise in rehabilitation to meet the required demand for CBR (Adaka et al. 2014). Shortage of human resources for health remains a huge public health problem especially in resource poor-setting (WHO, 2016c) and CBR is more affected as priority in deploying healthcare workers goes to facility-based medical care (Adaka et al. 2014). Evidence from developing countries such as Malawi and Nigeria confirm that human resources for CBR is still a challenge especially due to lack of expertise in rehabilitation and inadequate numbers of trained health personnel to meet the demand (Adaka et al. 2014; Munthali et al. 2013).

iii. Lack of proper implementation of legislation and policies to support community-based rehabilitation programmes

Functional policies and laws on disability and rehabilitation allow effective implementation of CBR programmes (Ndawi, 2000). However experience has shown that in many countries, despite the availability of legislation on disability and rehabilitation, they are yet to be implemented (WHO 2011; Munthali 2011). This has not only exacerbated violation of the rights of the persons with disabilities but also retarded development and implementation of CBR programmes (Ndawi, 2000). For example in Malawi, the *Malawi Constitution, the Disability Act and the Child Care, Protection and Justice Act,* are among many legislations and policies that recognize the rights of persons with disabilities, their protection from discrimination and establishment of relevant rehabilitation programmes. Despite the fact that most of these legislations and policies were formulated some time back, their proper implementation still lags behind as evidenced by the high unmet need for rehabilitation services still prevalent in the country (Munthali et al 2013; Munthali 2011).

iv. Unavailability of reliable information on disability and community-based rehabilitation

The unavailability of reliable information on disability and rehabilitation deters development and implementation of better CBR programmes (Iemmi et al. 2013; WHO 2011). Information about the prevalence of disability and how CBR programmes are being implemented in different settings is important for providing guidance to the development and implementation of more efficient and evidence-based CBR programmes (Adaka et al. 2014). Unfortunately, there is a dearth of such information due to lack of robust research especially in resource-poor settings (WHO 2011) including Malawi (Paget et al., 2015) and this has posed a huge challenge in the development of CBR programmes.

2.4. Conclusion

Having looked at how important rehabilitation is and how CBR can supplement both institutional and outreach rehabilitation approaches, it is important to consider the various factors that may enable applicability of CBR in a Malawian context. The facilitators, benefits and challenges of CBR interventions in different settings have been discussed in this chapter and highlighted the need to gain a deeper understanding of the situation in Blantyre by exploring the perceptions and experiences of implementers and beneficiaries of CBR programmes in Blantye. This understanding is essential in informing the development and implementation of affordable, effective and sustainable programmes in a Malawian setting.

Chapter 3

Methodology

3.0. Introduction

This chapter firstly presents the study aim and objectives. Then a description of the study design which was utilized is given and a justification on why the design was deemed appropriate to achieve the aim and objectives of the study. The chapter also gives description of the study setting then study population and how study participants were selected. Furthermore, the chapter gives an account of the tools that were used for data collection, a description of how data were analyzed, and how rigour was ensured through-out these processes. Thereafter an explanation of how ethics considerations were adhered to is given and finally the limitations related to the study are highlighted.

3.1. Study design

The study sought to explore perceptions and experiences of CBR for children with NIs. Since the study aimed to understand and describe the phenomena being studied deeply as perceived and experienced by participants, an interpretivist research approach was adopted. An interpretivist research approach strives to gain insights of experiences of participants to better understand the reason why participants perceive phenomena the way they do (Atieno, 2009; Lincoln & Guba, 1985). Experiences and perceptions on CBR for children with NIs following CM have not been widely researched in this setting as such there is still limited knowledge about this phenomenon. Within the paradigm of interpretivism, an explorative qualitative design was therefore perceived to be the most appropriate for this study purpose since information about CBR in the study setting remains unknown (Creswell 2013; Robson 2011).

3.2. Description of the study setting

This study was conducted at QECH in Blantyre City and its catchment area within Blantyre District. Nearly all severe malaria cases in Blantyre District are referred to QECH which is also one of the four referral public hospitals in Malawi. Healthcare services in public hospitals in Malawi are free, but mostly characterized by poor quality services due to insufficient supply of essential drugs, unavailability of functional medical equipment and shortage of trained clinical professionals (Munthali et al. 2013). Therefore, most people who can afford to pay out of pocket or are on medical insurance schemes prefer to be treated at private hospitals. The majority of patients who are referred to QECH are the poor from health centres in the city slums and rural areas of Blantyre District, or from secondary level district hospitals in the Southern Region of Malawi (Munthali, 2011). Figure 2 is a map of Blantyre District showing the study site and location of health facilities. QECH is also a teaching hospital and has the expertise to treat children with brain injury and severe neurological problems (Paget et al. 2015). QECH is the only health facility in the country where there is an ongoing Cognitive Outcomes and Psychiatric Symptoms (COPS) prospective cohort study that is aimed at characterizing long term cognitive and psychiatric symptoms following CM in Malawian children aged between 6 months and 18 years. The availability of this cohort provides a suitable platform to interact with caregivers of children that have developed NIs after surviving cerebral malaria. It was for this reason that this current study was nested within this on-going prospective cohort study at QECH. In addition, the setting of the study allowed easy access to healthcare workers who treated cerebral malaria patients during their stay in the hospital.

3.3. Study population

The study population included three groups of participants namely; adult primary caregivers of children who had survived CM, healthcare workers at QECH and Key-informants from CBOs that deal with children with NIs in Blantyre, Malawi.

3.4. Sampling and sample size

The researcher used non-probability purposive sampling as a technique in which he used his judgment to select only those participants with specific characteristics that the study inclusion criteria allowed (Robson 2011). The purposive sampling technique enabled the researcher to ensure variation in terms of gender of the caregivers and the professional specialty, expertise and experience of the healthcare workers and key informants.

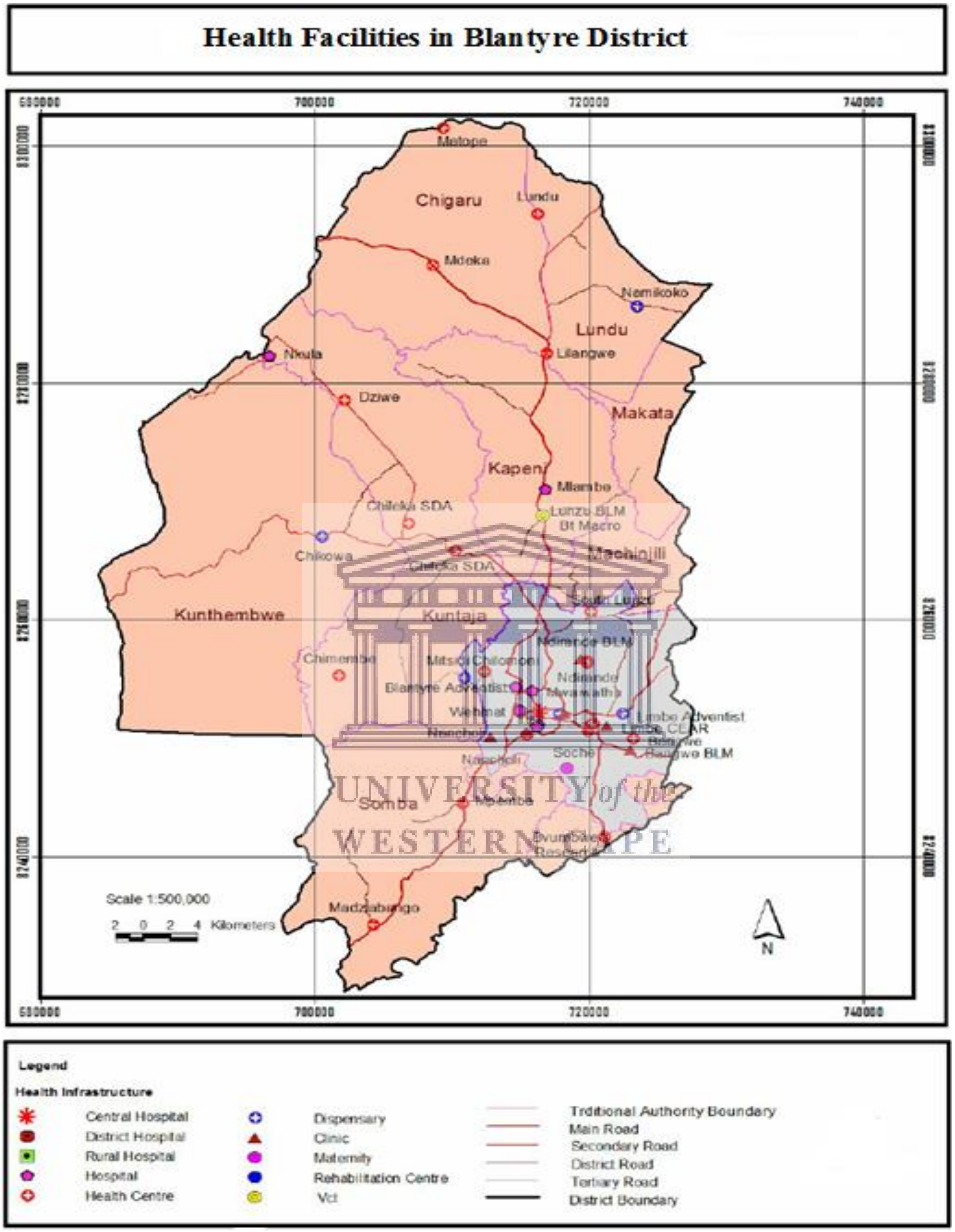

Figure 2: Blantyre District and location of health facilities **(Source:** Moumie Maoulidi, 2015**)**

The following inclusion criteria were used for participants to be sampled:

i. *Caregivers*

- Aged ≥18 years
- Were caregivers of a child who survived CM and is part of the COPS Study at QECH
- Resided in Blantyre

ii. *Healthcare worker*

- Worked in the malaria special care ward at QECH
- Worked on the COPS Study
- Had been working in the malaria research ward for ≥2 years
- Treated, provided physiotherapy or occupation therapy to children with CM during their stay at QECH

iii. *Key-informants*

- Worked with NGOs and/or CBOs that provided rehabilitation services within Blantyre District
- Had worked in rehabilitation for ≥ 2 years

Recruitment of caregivers

Using information from the database of the ongoing prospective COPS cohort, the researcher generated a list of caregivers whose children had survived CM and were known to have developed NIs following the CM episode. From this list, the researcher then knew when these children were scheduled for the COPS study assessment visit. Caregivers of children whose visit dates fell within the current study's data collection period (January to February 2017) were initially recruited. The standard number of participants in a focus group discussion (FGD) is recommended to be between 6 to 12 (Robson 2011); however the number of caregivers who visited the hospital within the study period was not enough. The researcher then endeavored to telephonically contact and recruit caregivers who were eligible for inclusion but their children's assessment visits were not scheduled within the study period. The researcher also made personal visits to the households of other caregivers who could not be contacted by phone to recruit them in order to reach the required numbers for the FGDs. The sample for the FGDs consisted of 23 caregivers. Three FGDs were conducted with FGD 1 having eight participants, FGD 2 having nine participants and FGD 3 having six participants.

Recruitment of healthcare workers

A total of eleven healthcare workers were also purposively selected choosing only healthcare workers who worked in the malaria research ward at QECH and those who conducted assessments in the COPS study for at least two years or more. These healthcare workers were specifically recruited because of their close contact with CM patients during the time they were admitted at the hospital and after they had been discharged. Close interaction with CM survivors gives healthcare workers a rich experience of common NIs associated CM and available rehabilitation services in the district. Eligible healthcare workers especially nurses, doctors, specialists such as pediatric neurologists, clinical officers (a lower cadre from medical doctors who are trained to perform general and some specialized clinical duties such as diagnosis and prescription), physiotherapists, rehabilitation technicians (lower cadre of physiotherapist and occupation therapists who assist in provision of rehabilitation services in health facilities) were recruited.

Recruitment of key-informants

The sample also included four key informants from rehabilitation facilities and CBOs that dealt with children with NIs in Blantyre District. Key informants were community rehabilitation workers who worked with CBOs within Blantyre District and they were specifically recruited because of their experience and expertise in rehabilitation of children including those with NIs as a result of CM. Since the researcher did not know all the rehabilitation facilities and CBOs dealing with NI in children in the district, he used snowball sampling to further recruit key-informants after purposively sampling the first key-informant. Snowball sampling is a sampling technique in which other participants are recruited with assistance from participants already identified and interviewed; this technique is mostly suitable in situations where participants are hard to find (Robson 2011). In order to identify more key informants, the researcher used key informants he had already contacted and interviewed.

After collecting data from this sample, no new information emerged to further illustrate already coded themes and as such the researcher was convinced that information saturation had been reached. Saturation is a point when enough information has been collected such that no new information and no new codes are forthcoming (Fusch & Ness, 2015). Therefore there was no need for further recruitment of participants.

3.5. Data collection methods and tools

Data were collected between 20th January 2017 and 30th February 2017. Almost all the data collection was done in a quiet room at the Malaria Alert Centre (MAC) inside the QECH, except for one which took place at the interviewee's office at the Malawi College of Medicine. All the data were collected by the principal researcher, Mr. Sebastian Mboma except for two semi-structured interviews with healthcare workers. The remaining two semi-structred interviews with healthcare workers were conducted by a colleague, Dr. Kiran Thakur who was principal investigator of a study nested in COPS on evaluation of neurorehabilitation resources for pediatric survivors of CM in Blantyre.

3.5.1. Data collection tools

Data were collected using open-ended semi-structured interview guides. The questions were formulated in line with the research objectives. The researcher ensured that questions were simply phrased and logically arranged so that study participants easily understood them and followed the issues being discussed. The main topics in the interview guides were as follows:

i. *Guide for focus group discussion with primary caregivers of CM survivors with NIs (refer to appendix 13 and 14 for both English and Chichewa versions)*
    - Knowledge and impact of CM
    - Experiences with giving rehabilitation support at home to their children
    - Training received on rehabilitation after discharge from hospital
    - Knowledge of existing/perception on CBR for children with NIs
    - Need and importance of CBR programme for children with NIs?
    - Opinion on how CBR programmes should be implemented

ii. *Guide for semi-structured interviews with healthcare workers (refer to appendix 15 and 16 for both English and Chichewa versions)*

- Training of primary caregivers of CM patients before discharge
- Importance of CBR for children with NIs
- Knowledge of existing CBR for children with NIs
- Opinion about any CBR programmes currently being implemented in the district
- Suggestion on designing and implementation of CBR programmes for children with NIs
- Resources needed for efficient performance of CBR

iii. *Guide for semi-structured interviews with key-informants (refer to appendix 17 and 18 for both English and Chichewa versions)*

- Knowledge of CBR programmes for children with NIs
- Importance of CBR for children with NIs
- Availability of rehabilitation support currently given to children with NIs
- Suggestion on implementation of CBR programmes for children with NIs in terms of capacity, skills and resources.

3.5.2. Data collection methods

Data were collected using semi-structured interviews and Focus Group Discussions (FGDs). A total of 18 data-gathering sessions were completed: three were focus group discussions with primary caregivers, eleven were semi-structured interviews with healthcare workers at QECH and four with key-informants from CBOs. Length of semi-structured interviews ranged between 15 and 25 minutes and the length of FGDs ranged between 30 and 35 minutes. Most interviews were shorter than the standard 45 minutes because participants, for example, healthcare workers and key-informants, had limited time to attend longer interviews since they were on duty. In addition, most caregivers resided in distant remote areas very far from QECH, as such it was important not to keep them for too long as they needed to return home in time. In order to deal with this problem, the researcher made sure that he was precise in his questioning and he tried as much as possible to follow the questions in the interview guide strictly to capture the most relevant information.

i. Semi-structured interviews with healthcare workers

Semi-structured interviews were most suitable for this group of participants due to time constraints and convenience. Due to their busy work schedules it was difficult to gather all health workers together for a FGD as was originally intended. Additionally, IDIs allowed the participants to discuss the topic in a free and insightful manner without interruption and fear of others' perceptions and judgments (Robson 2011). Refer to appendix 14 for the interview guide.

ii. Key-informant interviews with community-based organizations

Key-informants were also interviewed using open-ended semi-structured interview guide in order to gain first-hand information about their perspectives and experiences of rehabilitation in the respective communities where they worked (Robson 2011). Refer to appendix 15 for the key-informant interview guide.

iii. Focus group discussions

The study used FGDs with caregivers of CM survivors with NIs. Focus group discussions allowed for participants to feel comfortable sharing their experiences and perceptions as others in the group had similar experiences. Focus group discussions not only saved time and resources that could have been spent in interviewing each caregiver separately, but also allowed the researcher to collect an extensive amount and range of data from several caregivers at the same time (Robson 2011). Refer to appendix 13 for the FGD interview guide.

All data collected were recorded using an electronic recorder, and then transcribed. All interviews were transcribed by experienced transcribers Sunganani Mtonga and Hendrina Kaliati. Some interviews were conducted in English and others in the vernacular language, Chichewa, depending on the preference of the participants (especially key-informants and healthcare workers). Chichewa is an official language in Malawi and spoken by the majority of the people including the researcher. Interviews done in Chichewa were translated into English by trained linguists Grace Chaika and Bertha Bushiri.

3.6. Data analysis

Thematic analysis approach was used for data analysis (Braun & Clarke 2006). Following this approach, the researcher systematically identified interesting concepts within the dataset, analyzed them to make more meaningful statements (codes and themes) and reported the outcomes. The researcher followed the following steps during data analysis.

i. *Familiarization with the data*

Familiarization is a process in which the researcher thoroughly goes through the details of the data in order to deeply understand its content (Braun & Clarke, 2006). As soon as data collection commenced, the researcher started getting familiar with it by reading and re-reading through the transcripts and re-listening to the original interviews recordings for verification. At this stage, the researcher also took notes on interesting information in the content such as, most commonly said phrases and statements that appeared to respond to the research objectives together with new interesting information emerging from the data.

ii. *Generating codes and themes*

Coding is the process of identifying and labeling concepts in the interview transcripts in order to assign them meanings that have interesting connotations or are relevant to the research questions (Braun & Clarke, 2006). There are two types of coding, *pre-set coding* and *open coding*. *Pre-set* coding occurs when a researcher creates codes in advance before the actual data analysis begins; a researcher then sifts the data during the analysis to find concepts that match the pre-created codes. On the other hand *open coding* occurs when a researcher approaches data with an open mind and takes note of all interesting emergent concepts as the researcher reads through the data and analyzing it (Maguire & Delahunt, 2017). In this study, the researcher used both *pre-set* codes and *open* coding. Some codes were *pre-set* codes prior to the commencement of the actual data analysis, for example *access to rehabilitation services*, and *availability of CBR*, because the researcher was interested in the information which was relevant to the research objectives. However, the researcher was flexible and therefore also used *open* coding looking out for other interesting emergent concepts such as: *worry if child will fully recover* and *failure to work full time to take care of the sick child*. Generated codes were organized and grouped according to their meanings to form sub-themes and themes. Some examples of the codes and themes that were generated in this analysis are illustrated in figure 3.

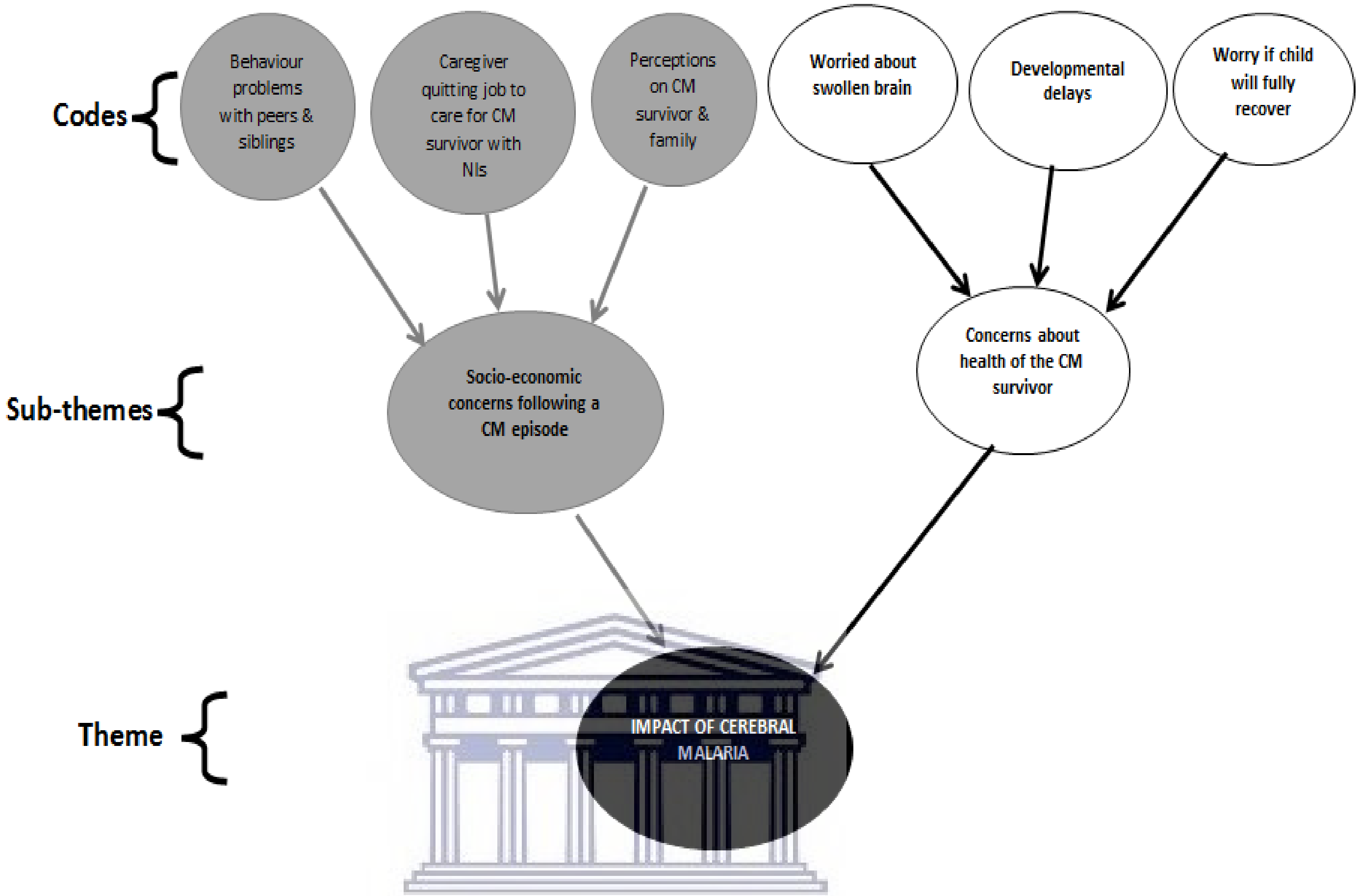

Figure 3: Examples of codes and themes

iii. Reporting the findings

Themes that were in line with the research objectives or highlighted important phenomena about the subject under study were chosen for the final report. Relevant quotations were selected and used as evidence that supported the themes. Participants were assigned alpha-numerical identification codes instead of using their names to ensure anonymity. These identification codes were used together with quotations to support presented themes in the findings section of the report. Refer to table 1 for participants' identification codes.

Table 1: Study participants and their study identification codes

Description of Participants	**Alpha-numerical Code**
Healthcare worker at QECH	
Clinical officer	Clinician 1
Clinical Officer	Clinician 2
Clinical Officer	Clinician 3
Pediatric neurologist	Pediatric neurologist
Ward nurse	Nurse 1
COPS Study nurse	Nurse 2
Physiotherapist	Physiotherapist
Rehabilitation technicians	RT 1
Rehabilitation technicians	RT 2
Rehabilitation technicians	RT 3
Rehabilitation technicians	RT 4
Key informants from CBOs	
Community Rehabilitation Worker	CRW 1
Community Rehabilitation worker	CRW 2
Community Rehabilitation Worker	CRW 3
Community Rehabilitation worker	CRW 4
Primary Caregivers	
Female Caregiver	Female Caregiver
Male Caregiver	Male Caregiver

3.7. Rigour

Rigour in qualitative research refers to strict adherence to research procedures to ensure validity of its findings and reliability of the research methods used (Davies & Dodd, 2002). In this study, the researcher utilized credibility, confirmability and transferability in order to ensure rigour (Lincoln & Guba 1985).

3.7.1. Credibility

Credibility strives to achieve trustworthiness of the findings and to ensure that conclusions are drawn out of accurate findings which are an outcome of reliable and valid research methods (Patton, 1999). The researcher ensured credibility by employing *triangulation* and *peer-debriefing.*

i. Triangulation

Triangulation is the process of data validation which includes incorporation of multiple perspectives of research participants and employing more than one data collection method (Yeasmin & Rahman 2012). Triangulation is important in qualitative research as it increases accuracy of data being collected and makes the study more credible (Creswell & Miller, 2000). The researcher used two types of triangulation; *methods triangulation* and *data source triangulation* (Yeasmin & Rahman 2012).

The researcher used methods triangulation by employing both semi-structured interviews and focus group discussions during data collection. Further to this, the researcher also utilized data source triangulation (Creswell & Miller 2000) through seeking views from multiple sources such as healthcare workers at QECH, key-informants from CBO that deal with rehabilitation of impaired children in Blantyre district and caregivers of CM survivors. By using of these different methods of triangulation, the researcher was able to capture more comprehensive data and gain a deeper understanding of participants’ varied experiences and perceptions about CBR for NIs in CM survivors.

ii. Peer debriefing

Peer debriefing is the process in which the researcher seeks independent advice and opinion from a colleague or other researchers to critique the researcher's ability to adhere to recommended research procedures and maintain its credibility (Creswell & Miller 2000; Robson 2011). In this study, the researcher sought advice on data collection, analysis and documentation from experts in qualitative studies based in the research institution where the researcher works. In addition, since this study was also done for academic purposes, contributions from the thesis supervisor also added value to the quality of the research.

3.7.2. Confirmability

Confirmability is a way of establishing traceable evidence that interpretations are genuinely and accurately drawn from real data and not just mere imaginations of the researcher (Lincoln & Guba, 1982). In order to establish this confirmability, the researcher kept records of all the research activities and his personal reflections through documentation of an audit trail and a reflexive journal (Lincoln & Guba, 1982; Wallendorf & Belk, 1989).

i. Audit trail

An audit trail refers to keeping a traceable account of the research process to help in the validation of how the data were generated and analyzed (Lincoln & Guba, 1982). The researcher kept an audit trail by recording all the activities of this study while carrying out the research. These records act as reference points and evidence that proper procedures in relation to how data were collected and analyzed were strictly followed and adhered to (Creswell & Miller 2000; Robson 2011).

ii. Reflexive journal

Apart from audit trail, the researcher also documented a reflexive journal as a way of ensuring confirmability. A reflexive journal is an assessment of the influence of the investigator's own background, perceptions and interests on the qualitative research process (Krefting 1991). The researcher is a project manager of the COPS cohort study in which this study was nested and that may have had an influence on how he may have interpreted the data. To deal with this situation, the researcher documented how he reflected on the data collected and interpreted the perceptions of participants on CBR for CM survivors with NIs in relation to his own role in the COPS cohort study.

3.7.3. Transferability

Transferability refers to the extent to which findings of a particular study in one setting can be generalized to a similar context in another setting (Robson 2011). The researcher in this study has provided a detailed and rich description of study participants, the study setting and methods used in data collection and analysis to ensure transferability of the findings.

Apart from the above methods, the researcher also verified the information being collected with study participants during and immediately after interviews before they left to ensured accuracy of his understanding of their responses.

3.8. Ethical considerations

i. Ethics approval

Ethics clearance was sought from and granted by The University of the Western Cape Research Biomedical Ethics Committee (ethics reference number: BM/16/4/6) where the investigator in this study is affiliated. Since the study was nested in COPS cohort study which is being conducted at Queen Elizabeth Central Hospital in Malawi, ethics clearance to conduct the study was also sought (through amendment of the COPS main Study protocol, ethics reference number: P.01/08/604) from, and was granted by the Malawi College of Medicine Research Ethics Committee (COMREC) which is also mandated by the Malawi Ministry of Health to give ethical clearance in the country. Refer to appendices 19 and 20 for ethics approval letters of UWC Biomedical Ethics Committee Ethics committee and COMREC respectively.

ii. Informed Consent

The participants were fully informed about the aim of the study, its benefits and risks in order for them to make autonomous informed decisions whether to continue their participation in the study or withdraw. Study information sheets (refer to appendices 1- 4) and consent forms (refer to appendices 5-10) were available in two versions, in English and in the vernacular language, Chichewa. Participants were also informed that participation was voluntary and that they could withdraw whenever they wanted to without any negative consequences to their children receiving rehabilitation and medical care or on being employees of any organization following their decision.

iii. Confidentiality

Since the participants were asked to disclose private information which will be publicly available through publication of the research findings, the researcher reassured the participants that confidentiality will be ensured by concealing their identities in all publications and dissemination of findings from this study; and if necessary only their study codes will be used which will not reveal their identity in any way. The researcher also ensured that data collection venues were secure and private. In addition, participants in the FGDs were required to complete a *confidentiality binding form* to uphold the confidentiality of the discussions by not disclosing the identity of other participants or any aspects of their contributions to anyone outside of the group (refer to appendices 11 and 12 for the confidentiality binding forms).

iv. Risks and benefits

Some of the questions asked during data collection could have provoked emotional distress to some people; this being harmful, and contravening the principle of non-maleficence (Gillon, 1994). The researcher ensured that participants were aware of these risks right at consenting stage. They were assured that they would be referred to the necessary service provider if needed. However, no cases of emotional distress were recorded among participants during the interviews.

3.9. Study limitations

Firstly, only those caregivers of children who were participating in the COPS cohort study were interviewed. A deeper understanding of phenomena being studied could have been attained if other caregivers of children who are not COPS study participants were included in the sample. However, this was not possible due to financial and time constraints. It would have been more costly and time consuming for the researcher to travel into communities in Blantyre and conduct interviews with other caregivers. On the other hand, caregivers in the COPS cohort study were readily accessible to the researcher.

Secondly, the principal researcher in this study is a novice in qualitative research and his limited experience might have compromised the quality of the data collected and credibility of the findings from the study. In order to overcome methodological problems the researcher faced, he utilized *peer-debriefing* (Creswell & Miller 2000; Robson 2011) as described earlier. This enabled him to check if correct methodological aspects of qualitative research were strictly adhered to.

In addition, the researcher is one of the investigators in the COPS cohort study and as such most of the participants, especially primary caregivers of CM survivors and healthcare workers, had already interacted with him several times prior to the interviews. This involvement in the COPS study may have had an impact on their responses to the interview questions, such as caregivers withholding information for fear of compromising the services their children were receiving. To minimize this influence, the researcher assured the participants again about confidentiality with which the information they were giving would be treated. For example, the researcher told the participants that data will be stored on a pass-worded computer and all forms will be kept in locked cabinets in a secure office. Further to this, participants were assured of anonymity whenever the findings of the study would be published or presented anywhere. He also highlighted the importance of the value of their contributions to the purpose of the study and that whatever was discussed during interviews would not compromise any benefits the children in the COPS cohort study were getting.

Lastly, due to time constraints, interviews were shorter than the minimum standard of forty-five minutes. This may have limited the amount of information that would have potentially been collected. However, the researcher ensured that each topic in the research guide was discussed as thoroughly as possible within the available time. In addition since there were multiple sessions with different participants on each type of interviews (FGDs, KIIs and IDIs), it was more likely that the most important and interesting concepts were still captured.

Chapter 4

Findings

4.0. Introduction

This chapter presents findings on data collected from interviews and focus group discussions with study participants. It firstly presents the description of the participants, then the emerging themes. Although the focus of the research was meant to be on CBR, it soon became apparent that there were no CBR services available and therefore much of the data is on rehabilitation services for children with NIs in the district generally. The themes include: (i) implications of cerebral malaria; (ii) challenges related to rehabilitation services in Blantyre (iii) preparing caregivers for caring of CM survivors after hospital discharge; (iv) Unavailability of CBR programmes in Blantyre and (v) Perceived need for CBR programmes in Blantyre. Each theme is described in detail and is supported by quotations from the participants. Lastly the chapter provides a summary of the study findings.

4.1. Description of study participants

A total of 38 participants were interviewed for this study and over two-thirds (25/38) of these participants were females. Out of the 38, 23 were caregivers of CM survivors, 11 were healthcare workers from QECH and 4 were key informants from CBOs which provide institution-based and community outreach rehabilitation services to children with NIs in Blantyre (refer to table 2).

Each of the three FGDs comprised both males and females. In FGD 1 there were three males and five females, in FGD 2, there were four males and five females and in FGD 3 there was only one male and five females. All primary caregivers were parents of the CM survivors except one female in FGD 3 who was an elder sister to the CM survivor.

Table 2: Description of Study Participants and type of interview they participated in

Participant Description	Type of data collection	Male	Female	Total Number
Healthcare workers				
Clinical officers	IDI	2	1	3
Pediatric neurologists	IDI	1	0	1
Nurses	IDI	0	2	2
Physiotherapist	IDI	0	1	1
Rehabilitation technicians	IDI	0	4	4
Total healthcare workers				**11 (29%)**
Key Informants	KII	2	2	**4 (10.5%)**
Primary Caregivers	FGD	8	15	**23 (60.5%)**
Total		13 (34.2%)	25 (65.8%)	**38 (100%)**

4.2. Implications of cerebral malaria on the affected children and their respective families

The impact of cerebral malaria on the health and development of the child and how the impaired child became a burden to concerned families was reported by almost all participants. Most caregivers expressed concerns about the health of their children. Caregivers were worried whether their children will ever fully recover to the way they were before they had cerebral malaria. For example the following concerns were raised by caregivers during the FGDs:

> *"My greatest concern was whether she would get well ever again…"* (Female Caregiver, FGD3)

> *"Aaah when I heard that my child's brain was swollen I was really worried, I kept on thinking about my child that if his brain is swollen like that what will become of him, will*

> *he be able to think normally, will he be able to do things normally?"* (Male Caregiver, FGD2).

Having experienced the impact of cerebral malaria, some caregivers expressed fear about their child falling ill of the same disease again:

> *"When we got discharged from the hospital my big worry was what if my child got ill again…" (*Female Caregiver, FGD1)

> *I'm still afraid what the future holds for this child because of the cerebral malaria she suffered from. I still get worried because every time she has fever, she gets diagnosed with acute malaria …"* (Female Caregiver, FGD2)

Apart from the physical implications, another concern was whether the children would ever be able to catch up with their developmental milestones like their peers. For example, during one of the FGDs some caregivers expressed their concern with regard to this expectation:

> *"I didn't know if she would be able to crawl and play with her friends. Her age mates are in Standard one but she has not yet been enrolled in school because there are so many things that she can't do by herself…"* (Female Caregiver, FGD3)

Lack of understanding of the behaviours related to neurological impairment was perceived to have a negative impact on their education of children with NIs:

> *"…Children who have behavioral problems are not going to school, there is nothing that their parents can do, because if they decide to have them registered at school, the headmaster or the teacher will say, no your child cannot stay with his friends because of his behavioral problems..."* (Nurse 2)

Furthermore, it was observed that taking care of a neurologically impaired child was a big responsibility and possibly a burden to the caregivers:

> *"You know it's difficult to be taking care of a child who has neurological sequelae, or is having consistent convulsions, or they can't sleep at night or are becoming aggressive…"* (Clinician 2)

> *"But the worst of them all are children with brain damage, when these children are in the villages their parents don't know what to do with them, they don't know where else to go with them they just keep them at home maybe waiting for the day when the child is going to die."* (Nurse 2)

Lack of social support from the community seemed to further aggravate this burden of responsibility the caregivers have to endure:

> *"It's really true, just as other people have explained, even in the community where I live, people look at the impairment of my child as a family burden or just as any other disease may affect a family and the community wants nothing to do with it."* (Female caregiver FGD3)

Cerebral malaria also appeared to pose an economic impact on the primary caregivers and their respective families:

> *"It is also scary because sometimes we have to abandon our work which would help us earn something, to take care of the child, we are scared that our child can suddenly get sick just like before and therefore we need to be always available so we could rush to the hospital."* (Male caregiver FGD3)

> *"My mother who works for the Asians even suggested of quitting her job to help me take care of my young sister….I lacked peace of mind because even my own relatives used to mock me; they also suggested that my mother should quit her job so that she could look after the child herself.* (Female caregiver FGD1)

4.3. Challenges to rehabilitation services for children with neurological impairments in Blantyre

Participants in this study reported that rehabilitation services for children with NIs in Blantyre district are largely institution-based and mostly provided by public institutions. However, the provision of these services is marred by a number of challenges as follows:

Long distances to health and education facilities was highlighted as a major barrier to accessing rehabilitation services including special-needs education in Blantyre District:

> *"If you ask them to come to the clinic with the child, it is not easy, they need transportation they use a minibus and they have to carry their child on their back for some distance as such you cannot expect them to come to clinic as regularly as possible."* (Paediatric neurologist)

> *"My child needs to enroll in school this coming academic year but the problem is that there is a long a distance to school. I just wish we could find an organization which could handle children who have suffered from cerebral malaria right in our community."* (Female Caregiver (FGD 3)

The lack of funds to sustain the running of rehabilitation programmes and purchasing of materials and equipment needed for rehabilitation such as educational books and assistive devices was identified as another challenge:

> *"Most of the organizations have stopped offering community rehabilitation I think possibly due to lack of funding to run the services." (*CRW3)

> *"… at first we had some funding to buy assistive device that we were providing such as wheel chairs and corner CP* (*Cerebral Palsy*) *chairs but we no longer have such funding." (*RT1)

Another challenge participants observed was lack of expertise to deal with NIs. The healthcare workers in the study claimed that available training programmes for rehabilitation personnel mostly concentrated on physical disabilities and not behavioural or neurological problems:

> *"Physical disabilities have got experts on how to tackle with them. Behavior problems are different altogether; this is because these behavior problems manifest themselves at home or in school. When a child is taken to hospital, often clinician will brush them off saying you know what, just discipline your child, but the problem may not be a simple discipline problem. Some of these have major behavior problems such that they can be chased away from school, they can't relate with their peers. Unfortunately the training that most clinicians have, I must be honest, is not much in terms of tackling behavior problems."* (Paediatric neurologist)

This lack of expertise was accentuated further in rural community health centres and schools.

> *"They [Healthcare workers in peripheral health centres in the communities] don't have expertise on how to take care of these children with neurological impairments. The child cannot be assessed appropriately, they will just say "We can't do anything, the child is like that, just stay with the child there is nothing that we can do" and the mother or the guardian will just go back home." (*Nurse 2)

> *"…there are* [only] *few health workers who have information about complications of cerebral malaria and these* [neurological] *impairments hence such expertise is not available in the health centres they are only found in big hospitals such as Queen Elizabeth Central Hospital."(*Nurse 2)

A further challenge was lack of adequate numbers of human resources for rehabilitation on behavioural and neurological disabilities to help in scaling-up provision of rehabilitation services into the community, raising the need to train more of such personnel:

> *"…the gap starts from training because you cannot have a community-based rehabilitation programme without skills to support those kids. So we need people to be trained … and be available to the community."* (Paediatric neurologist)

The challenge about the unavailability of reliable epidemiological data on NIs was also raised and the value of such information highlighted:

> *"So what you need is epidemiological data, the kind of data that actually says how much disability is there in Malawi, how much big is this public health problem it. It is only when we do that when we can convince whether be government or non-governmental organizations to think implementation of rehabilitation programmes, but these data are lacking."* (Paediatric neurologist)

4.4. Preparing caregivers for care and rehabilitation at home

The healthcare workers reported that they gave advice to caregivers of CM survivors on how to take care of their children at home and what to look out for after being discharged from hospital.

> *"The moment we have started rehab in the hospital with that child, automatically we start preparing their mother for discharge, so whatever we do we tell them that you must continue to do this at home when they get discharged"* (RT1).

> *"…so first of all we talk to mothers, we advise them that if they see something new in the child's behaviour or health at home, for example child is having convulsions or is having abnormal behavior like excessive fighting with peers, or if they are not doing well at school, they have to understand and support them accordingly."* (Clinician 2)

Caregivers confirmed that they had received some advice from healthcare workers at QECH while still at the hospital on what to expect and how to care for their children at home:

> *"…when the child is getting discharged in the hospital we get relieved of some of the worries because of the pieces of advice given to us by the doctors on how to take care of the child."* (Female caregiver FGD1)

> *"When my child was being discharged from the hospital I was advised that my child should be surrounded by her peers so that she can be encouraged to speak…"* (Female caregiver FGD3)

> *"We were advised that we should engage her in light exercises and that we shouldn't scold her because she understands things differently..."* (Female caregiver FGD3)

However, one interesting observation by one of the healthcare workers was that the type of advice given to caregivers at the time of discharge from hospital was not based on thorough and consistent assessments; as such important pieces of advice might have been left out in some cases. It was emphasized that there is a need to follow-up these children after discharge from hospital in order to pick up some of the complications which may only start after discharge or were just missed at discharge:

> *"But that assessment is not robust, it is not without its flaws. Somebody may consider a child almost back to normal … at that point in time but probably if they will be followed up in the clinic, some of the* [further] *problems will be picked up* [later]*…"* (Paediatric neurologist)

A thorough assessment procedure for children while still in hospital in order to determine if follow-up is needed after a child gets discharged was recommended by the same participant. This implied that such a procedure was not in place:

> *"…what would have been nice is to have a check-list of things; if patients have these things, this is the kind of advice you give them."* (Paediatric neurologist)

4.5. Unavailability of community-based rehabilitation programmes in Blantyre

Most study participants, especially healthcare providers and caregivers confirmed that CBR programmes to supplement institution-based rehabilitation services are not available in Blantyre.

> *"Nope, I do not know any organization that does community-based rehabilitation currently…."* (Paediatric neurologist)

> *"If you are talking about rehabilitation of children that have* [neurological] *impairments because of cerebral malaria, there is no assistance given to them in the community where I live..."* (Female Caregiver FGD 1)

> *"In my community there are no rehabilitation programmes for children that have neurological problems due to malaria…"* (Female Caregiver 3 FGD 3)

Both healthcare workers and community rehabilitation workers however acknowledged that there used to be a number of community outreach rehabilitation programmes in the past in Blantyre, but most of these services were discontinued some time back due to lack of finances to sustain them. Participants revealed that apart from public institutions such as QECH, MACOHA and Kachere Rehabilitation Centre, these community outreach rehabilitation services were also provided by SOS Children's Village and Feed the Children. As a result of the discontinuation of community outreach programmes most community rehabilitation workers have been given institution-based rehabilitation responsibilities. This was confirmed by the paediatric neurologist:

> *"I used to have the pleasure of working with SOS in the past (which provided rehabilitation services)…but apart from that I am not aware of any rehabilitation program…."* (Paediatric neurologist)

4.6. Perceived need and recommendations for community-based rehabilitation for children with neurological impairments

When asked if CBR would be necessary for their children, participants acknowledged that CBR would complement institution-based rehabilitation services of children with NIs especially when they are discharged from hospital since most of these children leave hospital wards when they have not fully recovered or have developed some impairment.

> *"Yes it is very important to follow-up children that had cerebral malaria and have been discharged from hospital ward as this helps in early diagnosis and rehabilitation of any problems that may arise before these problems can reach severe stages. It* [to following-up CM survivors after hospital discharge] *is really important!" (*Female Caregiver, FGD3)

In addition, participants also acknowledged that CBR would provide support to caregivers who often have to be faced with the responsibility of caring for these children alone.

> "*if we can develop rehabilitation centres in the communities so that these kids once they have developed* [neurological] *complications they can be taken care of in those rehabilitations centres. I think that can be a relief to their caregivers who most of their times are busy taking care of these kids alone."* (Clinician 2)

Participants made some suggestions on strategies that would complement institution-based rehabilitation services. Firstly, the need for the creation of caregiver support-groups as a CBR strategy was recommended:

> *"The other thing is also the parents themselves and the caregivers if they meet and share stories on how to manage their kids. Most of these parents there at home are frustrated no-one want listen to them. Exchanging experiences of problems that they are facing sometimes may be important."* (Paediatric neurologist)

The provision of financial and material support to caregivers of children with NIs was seen as important CBR component and the participants made suggestions on how this could be done:

> *"We can put them in groups and give them grants to do businesses that will also encourage their group in participating in activities of their support groups apart from solely getting medical rehabilitation services because they also have social problems."* (CRW3).

> *"…there is that need of giving them different kind of equipment at community level. For example they can put a child on a standing frame and caregivers may be able to do other activities instead of just carrying the child on the back all the time. While on the stand they you can play with other peers while she is seated on a CP* [Cerebral Palsy] *chair or while she is standing on the standing frame. We can also give them supplementary foods."* (CRW 2)

4.7. Summary of findings

Findings from this study reveal that CM brings about adverse health and developmental impact to its survivors and among them are NIs. In addition, CM has socio-economic implication to the families of its survivors especially if they develop NIs. However, up to now there is no up-to-date epidemiological data to measure the burden of NIs in children in Blantyre in particular and in Malawi in general. Furthermore, children with NIs need reliable rehabilitation services with equitable accessibility. However, rehabilitation for NIs in Blantyre is largely institution-based, characterized by acute shortages of rehabilitation materials, human resources and inadequate expertise. Community outreach rehabilitation services in the district have been discontinued and there are no CBR programmes being implemented currently by either government or NGOs to supplement already struggling institution-based rehabilitation services. However, the need to provide rehabilitation services to children with NIs right in their communities and socially and economically support their families is perceived to be great and would be of immense value.

Chapter 5

Discussion

5.0. Introduction

This chapter provides a detailed interpretation of experiences and perceptions of the impact of CM in children. The chapter also discusses challenges being faced in accessing rehabilitation services and how CBR could better supplement institution-based and community-outreach rehabilitation services. Lastly, the chapter discusses a CBR framework and how it could be used to implement rehabilitation services for children with NIs. Some literature used in the discussion may have been primarily meant for rehabilitation in general but they were purposefully selected due to their relevance particularly to CBR activities.

5.1. Impact of cerebral malaria on its survivors and their respective families

Findings from this study highlight the adverse implications CM has on its survivors and their respective families. Experiences of participants in this study show that most children who have suffered from CM experience a variety of adverse neurological disabilities. This finding corroborates with previous studies in Malawi (Birbeck et al. 2010; Boivin et al. 2007; Brim et al. 2017) and Uganda (John et al. 2008) which revealed that children who had survived CM were more likely to develop NIs such as epilepsy, cognitive problems, behavioural problems, and language deficits which delay them from reaching expected developmental milestones.

Apart from the direct adverse impact CM has on its survivors; the findings of this study also indicate that CM indirectly affects caregivers and families of the survivors, especially families of those children who develop NIs. Taking care of children with NIs was reported as a heavy responsibility for the concerned families especially in the absence of reliable rehabilitation services in the community. Similar experiences have also been reported in a previous study done in Malawi by Paget et al. (2015) in which primary caregivers perceived taking care of children with disabilities as a burden and expressed that once you have a neurologically impaired child “it means you are grounded”. Findings in this study further highlight that CM poses an economic burden on the primary caregivers of CM survivors and their respective families. Primary caregivers revealed that taking care of CM survivors with NIs demanded a lot of their time since they have to be available and close to the child all the time; therefore their participation in social and economic activities was limited. This finding corroborates with findings from another qualitative study in Blantyre, Malawi by Mbale et al. (2017), which emphasized that caring for children with NIs had social and financial implications for the concerned families. Another study in India also confirmed that primary caregivers of children with cerebral palsy experienced varied problems which included financial, health and psychosocial problems (Nimbalkar et al. 2014).

5.2. Barriers to rehabilitation for cerebral malaria survivors with neurological impairments

Findings from this study also confirm that there are many challenges facing rehabilitation for CM survivors with NIs in Blantyre which concur with experiences from similar resource-restricted settings such as in India (Kumar & Gupta, 2012), Zambia (Singogo, Mweshi, & Rhoda, 2015) and Kenya (Bunning et al., 2014). The most common challenges include: inequitable access to rehabilitation services; lack of funds and rehabilitation materials to run and sustain rehabilitation services; lack of expertise in NIs; inadequate skilled human resource for neurological rehabilitation; unreliable epidemiological data on NIs to guide successful implementation of relevant rehabilitation programmes for NIs; stigma; and misunderstanding of children with NIs.

5.2.1. Inequitable access to rehabilitation services

Access to health services is a fundamental human right as declared in the UN Universal declaration for human for human rights article 25(1), later affirmed by the Alma Ata Declaration and the United Nations Convention on the Rights of Persons with Disabilities article 9(*a-f*) (UN, 2006; United Nations, 1948; WHO, 1978). However experiences from participants in this study reveal that children with NIs in Blantyre have inequitable access to rehabilitation services. This inequity is due to disproportional distribution of rehabilitation services in the district and inadequate community outreach rehabilitation services to supplement institution-based rehabilitation services.

Experiences from participants in this study have revealed that rehabilitation services for children with NIs are inequitably distributed and still institution-based with most of them located in urban areas which are often very far from where the majority of the patients who need these services reside. As a result, most caregivers have to endure travelling long distances in order to have their children access these rehabilitation services. This experience confirms findings from a previous report on a situation analysis of persons with disabilities in Malawi by Munthali (2011) in which long distances to rehabilitation facilities was cited as one of factors that impeded access to rehabilitation services especially for people living in rural remote areas. In order to improve this current situation in Blantyre, CBR would be the most appropriate approach. According to the joint position paper by ILO, UNESCO and WHO (2004) one of the primary aims of CBR is to ensure adequate access to rehabilitation services and health care for people with disabilities (ILO; UNESCO; WHO, 2004). Evidence has shown that CBR increases access to rehabilitation especially in resource-restricted setting because CBR takes rehabilitation services closer to people (Saurabh et al., 2015).

Apart from disproportional availability of rehabilitation services in Blantyre, experiences of participants in this study, especially rehabilitation technicians and clinicians, revealed that discontinuation of most community-outreach rehabilitation services has exacerbated poor access to rehabilitation services in the district. This finding confirms a previous report which indicated that Blantyre was among the first districts in Malawi to have CBR programmes which were implemented by MACOHA before it spread to other 13 districts in the country (Munthali, 2011). However these CBR programmes were marred with so many limitations; for example their implementation was not stringently based on the WHO definition of CBR (WHO 2004) as such their approach in implementing CBR was not comprehensive enough. The approach did not include social and economic empowerment of the concerned families and promote right of the persons living with disabilities. It was basically a community outreach programme targeting only persons living with physical disabilities at an individual level to provide them with rehabilitation services, vocational training and financial empowerment through provision of loans. The approach also omitted other forms of disabilities such as NIs thereby denying individuals with such conditions access to rehabilitation services (Munthali, 2011; Paget et al., 2015). In addition, these CBR programmes lacked sustainability such that to date, most of the projects that were initiated during that time have been discontinued and no similar programmes have been extended to other parts of the country (Munthali, 2011). In a resource-restricted setting characterized by inequitable access to institution-based rehabilitation services and inadequate reliable supplementary community outreach rehabilitation services, there is need to employ alternative comprehensive, affordable and sustainable approaches to rehabilitation. Therefore CBR becomes the most ideal approach because CBR programmes largely rely on locally available resources and concerted effort from persons with disabilities, family and community members, relevant government departments and NGOs working in different sectors. In addition, CBR programmes go beyond rehabilitation and medical care to include empowerment, inclusiveness and advocating for rights of persons with disabilities (ILO; UNESCO; WHO, 2004). If well implemented CBR programmes can be sustained beyond the funding period and it can bring lasting positive impact to persons with disabilities, their respective families and entire communities (Soji, Kumar, & Varughese, 2016).

5.2.2. Inadequate skilled human resources for rehabilitation of neurodisabilities

Findings from this study have also revealed that human resources for rehabilitation are inadequate both at health facilities and in special needs education institutions. Further to this, there is lack of relative rehabilitation expertise to deal with other forms of disabilities such as NIs as a result diagnosis and management of NIs especially in children remain a huge problem in the district. These findings concur with a report on child neurology services in Africa which indicated that rehabilitation is not only facing acute shortage of essential drugs for neurological conditions but also lack of adequate human resource and capacity to diagnose and manage different neurological conditions especially in children (Wilmshurst et al., 2011). Children with NIs spend most of their time with caregivers and around members of their respective communities therefore employing a community-based approach such as CBR in which primary caregivers and community members are trained to assume some rehabilitative roles would be beneficial especially in a situation where there is scarcity of skilled rehabilitation professionals. For example, experiences from Brazil (Braga et al., 2005), Bangladesh (McConachie et al., 2000) and Kenya (Gona et al., 2014) revealed that the involvement of caregivers and community members, after some training, brought about increased support for children with NIs which resulted in significant improvement in developmental skills in the children. In this respect CBR does not only scale-up rehabilitation services in settings with shortages of skilled human resources but also ensures better rehabilitation outcomes.

5.2.3. Lack of essential rehabilitation resources

The findings of this study show that there is an acute shortage of rehabilitation materials such as: assistive technologies or devices, education materials, medications and funds to run both institution-based and outreach rehabilitation programmes. These findings confirm what was earlier reported by WHO that there is a huge unmet need for assistive devices and technologies especially in poor-resource countries such as Malawi. The report revealed that over 85% of persons with disabilities who need assistive devices or technologies have no access to them (WHO, 2010b).

Despite the fact that both institution-based rehabilitation services and CBR programmes lack rehabilitation materials and funds for smooth running, evidence shows that CBR is relatively affordable and more sustainable because it relies on locally available resources such as community volunteers, simple rehabilitation materials and simple assistive technologies made from cheap locally found materials (Lightfoot, 2016). Evidence also shows that CBR is more sustainable because once rehabilitation skills have been imparted to community members the skills may be internalized and be used even when the trainers have left. These skills may also be passed on to other members of the community and younger generations for continuity. In addition, since assistive rehabilitation devices are made from locally found materials, they may continue to be reproduced when need arises at a lower cost than the original materials (Lightfoot, 2016).

5.2.4. Paucity of reliable data on neurodisabilities to support successful implementation of rehabilitation programmes

This study also confirms that there is lack of reliable epidemiological evidence to measure the burden of NIs in Blantyre. Data from Malawi Population and Housing Census (MPHC) is limited as it does not stratify disabilities by type, age, cause of disability and prevalence by geographical areas. In addition, census is only carried out once in every 10 years, as such much of the changes in the incidence and prevalence rates of disability occurring in between censuses may not be captured (National Statistical Office (NSO) 2008). Similar observation was also made in a situation analysis of persons with disabilities in Malawi by (Munthali, 2011) and in a study by Paget et al. (2015) who also established that there is paucity of epidemiologic data on disabilities in Malawi and recommended for national wide studies to measure prevalence of different types of disabilities. In its 2011 World Report on Disability, the WHO also indicated that data on disability and rehabilitation worldwide is not reliable and often incomplete (WHO 2011). According to findings of this study, lack of epidemiological evidence to show the extent of the burden of NIs in children in Blantyre has retarded efficiency in planning for equitable distribution of rehabilitation services in the district. In the absence of such data there is need to employ alternative measures to ensure that reliable care and rehabilitation for children with NIs is equitably available and CBR is a good example of such alternative measures. Community-based rehabilitation is multi-sectoral as such it creates a good platform to integrate rehabilitation services of children with NIs with other health, social and development activities already taking place in the community without necessarily relying on the availability of new data on the burden of NIs. For example, in a health promotion programme for malaria prevention and treatment under the health component of the CBR matrix, issues of CM and rehabilitation of CM survivors with NIs may be included as part of the activities. Another example would be in a human rights programme under the empowerment components of the CBR matrix, protection of the rights of persons with disabilities may be part of the programme as such children with NIs could benefit from the programme (WHO 2004).

5.2.5. Stigma and misunderstanding of children with neurological impairments as barriers to access of rehabilitation services

This study reveals that there is misunderstanding of behaviours of children with NIs following CM and this has often led to stigma against them and their respective families. This perception is also reported in an earlier study on caregivers' perspective on rehabilitation for children with NIs in Malawi which showed that children with NIs and their families faced stigma from health workers and other families in the community (Paget et al., 2015). Stigma and misunderstanding of behaviours of children with NIs can lead to deprivation of the concerned children of access to institutional-based rehabilitation services and health care especially those offered at local facilities (Henderson et al., 2014). Through its social component, CBR may create a good platform for dealing with stigma, for example, a community human rights committee may be able to advocate for the rights and protection of CM survivors with NIs by lobbying for promotion and implementation of relevant legislation or policies (WHO 2004).

5.3. Community-based rehabilitation as a necessary supplement to institution-based and community-outreach neurorehabilitation services

The evidence discussed above demonstrates that the challenges related to neurorehabilitation services occur largely within in the health system. However, the impact of NIs in children is not only confined to the patients as its impact also poses diverse negative social and economic problems for the primary caregivers of these children and their respective families. A previous study on neurodevelopmental outcomes in Blantyre, Malawi, recommended that caregivers and families members of children with NIs, being their primary contacts, are supposed to be equipped with basic rehabilitation skills and be made financially independent as the most basic fundamental step towards achievement of better neurorehabilitation outcomes (Mbale, Taylor, Brabin, Mallewa, & Gladstone, 2017). However findings from this study show that most caregivers for children with NIs still lack basic rehabilitation skills and also have poor socio-economic status. Therefore to deal with such a multifaceted problem of NIs in children post CM, there is need to employ a comprehensive and a sustainable approach which does not only concentrate on provision of facility-based rehabilitation services, but also addresses social and economic implications of the condition. The WHO has recommended CBR as a strategy to holistically deal with different types of disabilities including NIs. This is because CBR is multi-sectoral in its approach; it includes health, education, livelihoods, empowerment and social components. In this regard, CBR may best supplement institution-based rehabilitation. The framework illustrated in Figure 4, shows how CBR could deal with CM survivors with NIs together with their respective families and communities. The framework has five components namely, health, education, social, empowerment and livelihood which work in collaboration at community level to deal with CM survivors with NIs and their socio-economic environments. Using this CBR framework, may have several advantages as follows:

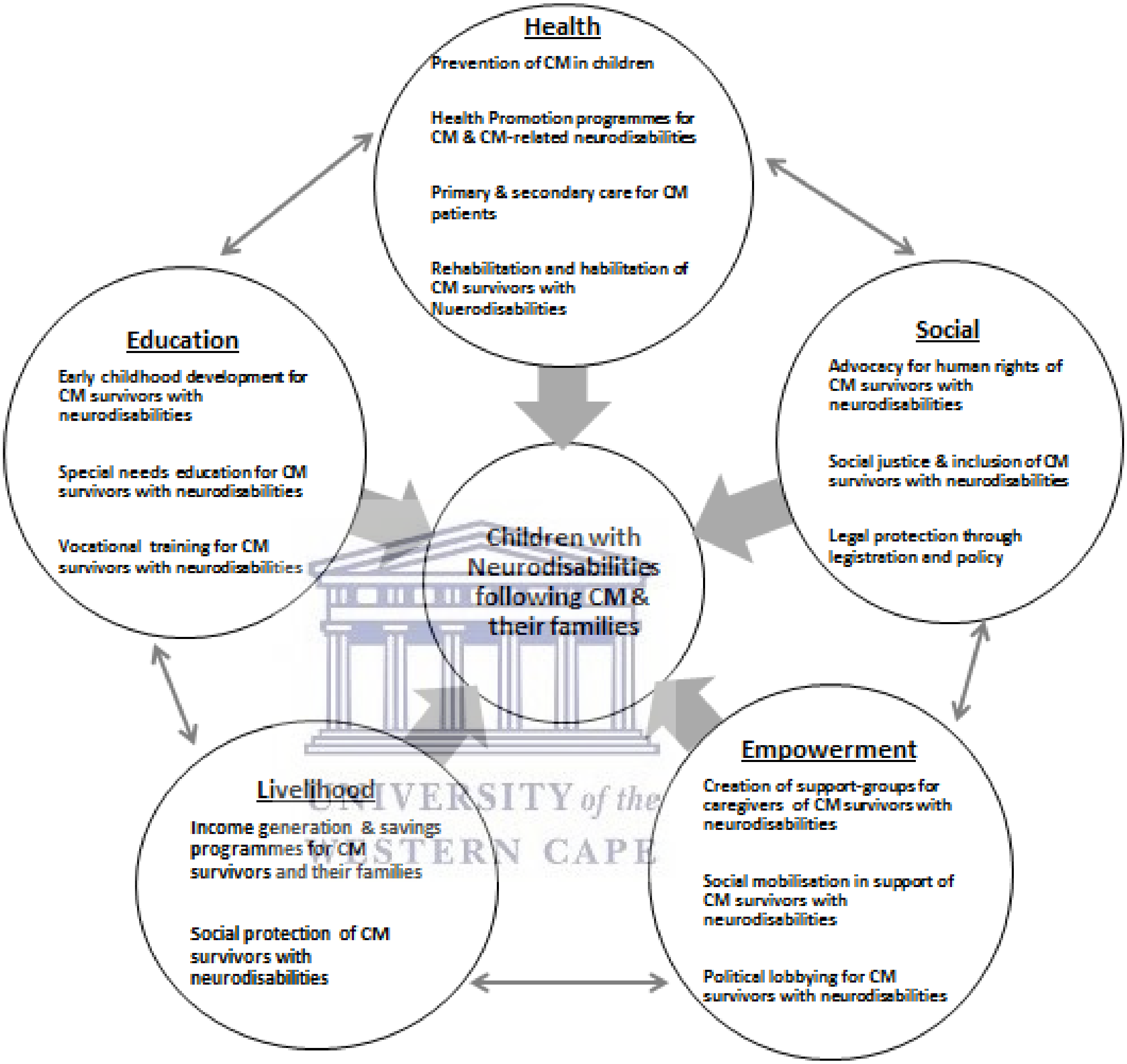

Figure 4: A framework of a comprehensive approach to neurodisabilities in CM survivors using CBR. Adapted from *CBR Matrix* (Source: WHO 2004:5)

i. *Increased access to rehabilitation and healthcare for children with neurological impairments*

Using CBR as illustrated in the framework may bring rehabilitation services closer to the communities where CM survivors with NIs live hence increasing access to the rehabilitation services. For example, one of the main components of CBR is *health*. Under the *health* component many activities on malaria prevention and awareness may be implemented and could include CM prevention, early diagnosis, management, referrals and post CM rehabilitation at community level. As part of the post CM rehabilitation activities, for example, provision of training to local health workers, community volunteers and primary caregivers of CM survivors with NIs on basic rehabilitation skills. Equipping them with rehabilitation skills may make available basic rehabilitation therapy right in the communities where these CM survivors live, thereby reducing frequent long distance travels to the central hospital just for basic rehabilitation services. However, CM survivors with severe NIs needing specialized rehabilitation expertise may however, still be compelled to go to the central hospital where paediatric neurorehabilitation specialists are available. Apart from physical and neurological rehabilitation, CM survivors may often have learning problems (Postels & Birbeck, 2013). In its *education* component of the CBR, some of these problems may be dealt with at community level as well. For example, teachers in local schools may be equipped with basic special-needs education skills so that they are able to deal with some of the learning problems that CM survivors may encounter. These activities must be made available at all education levels such as; early childhood development, primary, secondary and tertiary (vocational training) levels.

ii. *Provision of interventions beyond individual rehabilitation*

Further to increasing access to rehabilitation for CM survivors, the framework illustrates that that CBR is not selectively confined to the individual CM survivor rehabilitation. Its approach is very comprehensive as it also considers the social and economic impact that CM and NIs may have on the primary caregivers of CM survivors, their respective families and communities. In this regard, CBR ensures that the concerned families and communities enjoy a better quality of life and are socially empowered. For example using a collaborative effort of two components of the framework namely *livelihood* and *empowerment*, affected families may be equipped with income-generating skills and are then offered a grant or loan to run their own businesses. Caregivers of CM survivors may also form *support groups* to share experiences of caring for CM survivors and morally support each other. In addition, communities may become better equipped with knowledge to integrate CM survivors with NIs into society and include them in decision-making of social and economic development activities taking place in the community.

iii. Ensures Protection of rights, increased participation and inclusion

Lastly, CBR through its *social* component may encourage social justice and protection of CM survivors with NIs by advocating for formulation, amendments and proper implementation of relevant legislation and policies. For example through formulation of a community human right committee that may ensure that all CM survivors with NIs have access to education and health services as their basic rights (United Nations, 1948). The committee may also conduct advocacy and community mobilization campaign to stop stigma against CM survivors with NIs.

5.4. Summary of the discussion

Cerebral malaria poses a great burden on its survivors, their respective families and communities. Unfortunately the approach used to address the impact of CM in Blantyre is selective in nature as it only concentrates on rehabilitation of disabilities of affected children at an individual level. This approach omits equally important social and economic consequences of CM. In addition, available rehabilitation services in the district are institution-based and are marred with numerous challenges. With regard to the impact CM is imposing on children and their respective families and communities in Blantyre, it appears institution-based rehabilitation and community outreach programmes are not adequate enough. There is need to employ a sustainable and comprehensive approach that looks beyond the rehabilitation of an individual CM survivors. The approach needs to also take into consideration the social and economic impact of the disease. In this regard CBR becomes a more appropriate approach to deal with children with NIs and other CM-related implications.

Chapter 6

Conclusion and Recommendations

6.0. Introduction

In this final chapter, a conclusion is drawn from the findings of the study and recommendations are made.

6.1. Conclusion

This study has been carried out at a time when we are witnessing improvements in diagnosis and management of CM (Burton, 2017) and the resultant decline in CM mortality. However with so many children surviving CM now, there is need to adjust and start focusing our attention on the impact of CM on its survivors and their social and economic environments. Therefore this study unveils deep insights on the challenges being faced by children with NIs due to CM and provides strategies to implement rehabilitation programmes for these NIs and also address the associated socio-economic impact. As recommended by WHO, CBR appears to be an ideal approach to deal with NIs especially in this resource-restricted setting (ILO; UNESCO; WHO, 2004). This is because CBR is affordable, sustainable and comprehensive in its approach. CBR looks at rehabilitation from a PHC (WHO 2008) point of view because it strives to cure and rehabilitate NIs as well as address socio-economic impact associated with these conditions. As much as institution-based rehabilitation remain essential for specialized neurodisability cases (Lightfoot, 2016), however this study concludes that CBR may sustainably offer adequate supplementary rehabilitation strategies for NIs in a comprehensive way and should therefore be implemented.

6.2. Recommendations

In line with the main purpose of this study and in relation to its findings the following recommendations are made:

6.2.1. There is need to greatly improve the practice of community-based rehabilitation in Blantyre and national wide

Having seen the problems facing CBR programmes in this setting, it is evident that there is need to greatly improve the practice of CBR and the following actions are being recommended:

i. Building capacity and increasing the numbers of qualified rehabilitation personnel

The results from this study show that there is acute shortage of personnel trained in NIs rehabilitation in Blantyre and Malawi as a whole. This study therefore recommends establishment of training programmes on NIs and relevant rehabilitation skills to increase the number of rehabilitation personnel in order to meet the demand both at facility and community levels. Further to that, this study recommends that healthcare workers and special-needs teachers must become more versatile by engaging them in robust training programmes that includes neurological impairments. This can be as in-service training for those already employed and through upgrading of the curriculum for the upcoming rehabilitation trainees.

ii. Scaling-up rehabilitation services to ensure equitable access and equitably distribute rehabilitation materials and funds

Evidence from this study reveals that neurorehabilitation in Blantyre District is still institution-based and mostly available in urban areas and that CBR is not available in the district. It is therefore recommended that neurorehabilitation services must be available at all public health facilities including health centres in rural areas. Apart from building capacity as suggested above, there is also a need ensure equitable distribution of funds and availability of essential rehabilitation materials both at health and education facilities.

iii. Establishment of caregiver support-groups

Formulation of support-groups for caregivers of children with NIs must be encouraged. These support groups may not only be a good platform to learn new basic rehabilitation skills from both peers and healthcare workers, but may also bring about an opportunity for caregivers to interact and share experiences and gain moral and emotional support from peers. Using the same platform of support groups, caregivers may also be trained on basic rehabilitation skills by relevant authorities such as healthcare workers and special needs education experts.

iv. Establishment of active engagement of healthcare workers with communities

This study recommends that there should be community engagement programmes in which trained community healthcare workers go into communities and educate them about the different types of disabilities (including neurodisabilities). They should also train caregivers in the community on how to care for their children with disabilities.

v. *Establishment of development programmes*

Social welfare personnel should go into communities and educate them about the rights of the persons with disabilities and how persons with disabilities and their families can be supported and included in social and development activities in their respective communities.

There is also need to establish development programmes that would make concerned families financially independent. For example, provision of loans or small grants to help them start up small-scale businesses. Another example is cash transfers to financially empower families of children with disabilities. This would enable them to afford some of the specialist rehabilitation services that require service fees and equipment because they may not be available in public hospitals.

6.2.2. Advocacy for implementation of policy and legislation that support better practice of community-based rehabilitation

Effective policies and legislation on disability and rehabilitation, may facilitate better implementation of CBR programmes (Ndawi, 2000). However evidence show that despite availability of policies and legislation on disability their implementation continue to remain a problem (Munthali, 2011) there by negatively affecting persons with disabilities including proper implementation of programmes that would benefit them such as CBR. It is therefore recommended that civil society, all relevant government departments and stake-holders participate in lobbying and advocacy for ensuring that available legislation and policies on disability are functional so that all relevant programmes for persons with disabilities including CBR are well supported.

6.2.3. Need for further research to inform better practice and implementation of community-based rehabilitation programmes

The findings of this study reveals that there is paucity of data to inform better practice and implementation of CBR programmes, therefore the following recommendations are made:

i. *Ensuring availability of up-to-date and reliable routine epidemiological data especially on neurological impairments and disability in general*

Continuous capturing and managing of routine data on disability is fundamental in estimating the magnitude of disability as a public health problem. However in Blantyre and Malawi as a whole reliable data on disability is still inadequate. It is against this background that implementation of a robust routine data collection and management system especially on the epidemiology of disability including NIs both at district and national levels is recommended. These data will not only improve availability of reliable estimates of prevalence of NIs, but also provide evidence to inform better implementation of CBR programmes and justify the distribution of the same.

ii. *Need for further research on rehabilitation of cerebral malaria survivors with neurodisabilities after they are discharged from hospital and exploration of better ways to implement community-based rehabilitation*

Despite the fact that some recent new studies have been been abl to characterize neurodisabilities in CM survivors after they have been discharged from hospital (Brim et al., 2017; Langffit et al., 2019), what happens subsequently to the CM survivors who develop these neurodisabilities and their respective families has not been well investigated in this setting. Therefore there is need to further investigate rehabilitation and healthcare for CM survivors with neurodisabilities after they are discharged from hospital and explore the social and economic impact of CM on both its survivors and their respective families. This information will not only improve healthcare for CM survivors but also inform better implementation of responsive community-based rehabilitation activities.

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APPENDICES

Appendix 1

Information Sheet for Healthcare providers and Keyi-Informants for CBOs-English

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INFORMATION SHEET FOR HEALTHCARE PROVIDERS AND KEY-INFORMANTS FOR CBOS-ENGLISH

Project Title:

Exploration of community-based rehabilitation support for children with neurological impairments following cerebral malaria in Blantyre, Malawi

What is this study about?

This is a research project being conducted by Mr. Sebastian Mboma at the University of the Western Cape. We are inviting you to participate in this research project because you are a healthcare provider or you are working in organizations dealing with children with neurological impairment due to cerebral malaria and live in Blantyre.

The purpose of this research project is to learn about availability of community-based rehabilitation support for children with neurological impairments. Based on your experiences and perceptions the researcher will be able to gather information on how better and relevant community-based support for these children can be designed

What will I be asked to do if I agree to participate?

You will be asked to participate in a interview. The interview sessions will be recorded using a voice recorder to assist the researcher recall about every detail that was discussed. The interviews will take about one hour to complete. The interviews will take place in an office in a quiet and confidential environment at Malaria alert Centre inside the Queen Elizabeth Central hospital. We will reimburse the transportation costs you will incur on your way to and from the hospital.

Would my participation in this study be kept confidential?

We will carefully protect your privacy and safeguard confidentiality. You can also stop the interview at any time if you feel that your privacy is not guaranteed. To ensure confidentiality no names will be used in any reporting of the findings from this study, instead we will use identity numbers. Collected data on the forms will be kept in lockable filing cabinets and password-protected computers in the office at Malaria Alert Centre, at Queen Elizabeth Central Hospital.

What are the risks of this research?

The questions are meant to be straightforward but you may find them too personal or distressing. You are free to decline to respond to these or the rest of the questions that you are asked. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort or otherwise during the process of your participation in this study.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help inform designing rehabilitation support and interventions that will help caregivers, families and communities to understand how to take care of children with neurological impairment. You can choose whether you want to take part in our study, or not. Your participation is absolutely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by **Mr. Sebastian Mboma** of the Faculty of Community and Health Sciences, School of Public Health, at the University of the Western Cape with assistance from Blantyre Malaria project. If you have any questions about the study, or would like to know more please contact Mr. Sebastian Mboma at the following phone number **+265999317468,** alternatively you may email him at sebastianmboma@gmail.com**.**

If you have ethical concerns about the study you may contact the Secretariats of the Malawi College of Medicine Research Ethics Committee (COMREC) through phone or writing them a letter.

College of Medicine, 3rd Floor,
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Appendix 2

Information Sheet for Healthcare Providers and Key-Informants from CBOs-Chichewa

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KALATA YOFOTOKOZA TSATANETSATANE WA KAFUKUFUKU YA OGWIRA NTCHITO YA ZAUMOYO NDI MMABUNGWE

Cholinga cha kafukufuku ameneyu ndi chani?

Muli kupepemphedwa kutengapo gawo mu kafukufuku ameneyu chifuwa ndinu mmodzi mwa ogwira ntchito ya zaumoyo, kapenanso ndinu ogwira ntchito ku mabungwe a mmudzi okhudzana ndi ana amene ali ndi mavuto okhudza ubongo mu boma la Blantyre.

Cholinga cha kafukufuku ameneyu tikufuna kudziwa ngati pakadali pano pali chithandizo chochitikira kumudzi chothandiza ana amene ali ndi vuto lokhudza ubongo. Kudzera mu zomwe mumadziwa komanso maganizo anu tiphunzira njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo mmudzi mwawo.

Kodi ndizafunsidwa mafuso otani ndikatengapo mbali mu kafukufuku ameneyu?

Kwa ogwira ntchito ku mabungwe a mmudzi okhudzana ndi ana amene ali ndi mavuto okhudza ubongo mudzapemphedwa kukhala nawo pagulu lomwe lidzfunsidwa mafunso ndi kuzukuta njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo angathandidwire mmudzi mwawo. Kwa ogwira ntchito ku chipatala mudzapemphedwanso kuti panokha muyankhe mafunso okudza njira zabwino za chisamaliro cha kumudzi cha ana amene ali ndi mavuto okhudza ubomngo. Zokambirana zonsezi zidzatepedwa ndicholinga chodzathandiza ochita kafukufukuyu kuti adzakumbukire zonse zonse zommwe zidzakambidwa patsogolo. Zokambiranazi zidzatenga pafupifupi ola limodzi kuti zithe. Kafukufukuyu adzachitikira pa malo opanda phokoso komanso opanda zosokoneza ku ma ofesi a Mlaria Alert Centre mkati mwa chipatala cha Queen Elizabeth. Kwa ogwira ntchito ku mabungwe a mmudzi okhudzana ndi ana amene ali ndi mavuto okhudza ubongo, tidzakubwezerani ndalama yomwe munagwiritsa ntchito kuyendera pobwera ku chipatala,komanso kukupatsani ndalama yoyendera pobwelera kunyumba.

Kodi kutengapo mbali mu kafukufuku ameneyu kudzakhala kwa chinsinsi?

Tidzayesetsa kusunga mwachinsinsi zokhudza kafukufukuyu. muli ndi ufulu osiya kutengapo mbali mu kafukufukuyu ngati mukuona kuti palibe chinsinsi. Pofuna kuonenetsetsa kuti chinsinsi chasungidwa podzaulutsa zotsatila za kafukufukuyu, maina a nthu omwe anatengapo mbali mu kafukufukuyu sadzatchulidwa, mmalo mwake manambala oyimila maina a anthuwa ndi omwe adzagwiritsidwe ntchito. Zonse zomwe zalembedwa pa nthawi ya kafukufukuyu zidzasungidwa mmakabati otsekedwa ndi makiyi komanso makina a computer omwe munthu wadera sangatsegule. Zonsezi zidzasungidwa mu ofesi ku Malaria Alert Centre mkati mwa chipatala cha Queen Elizabeth.

Kodi ndi zoopsa zanji zomwe ndingakumane nazo kamba kolowa mkafukfuku ameneyu?

Mafunso a mkafukufuku ameneyu akuyenera kukhala osavuta, komabe ena mwa anthu amene akutengapo mbali mkafukufukuyu akhoza kuona ngati mafunsowa akulunjika iwowo kapena akhoza kukhumudwa nawo. Muli omasuka kukana kuyankha mafunso oterewa ngakhalenso mafunso onse otsatila. Komabe tizayesetsa kuti zinthu ngati zimenezi zichepe, ndipo tizayesetsa kuti muthandizidwe mwachangu ngati simunasangalitsidwe, mwakhumudwa kapena simukumumva bwino pa nthawi yomwe mukutenga nawo mbali mu kafukufuku ameneyu. Ngati kuli kotheka tizakutumuzani kwa akadaulo oyenera kuti akuthandizeni moyenera.

Kodi phindu la Kafukufuku ameneyu ndi chani?

Phindu la Kafukufuku ameneyu silili lolunjika kwa inu nokha ngati munthu yemwe watengapo mbali mkafukufuku amaneyu. Koma zotsatira za kafukufukuyu zizanthandiza makolo, mabungwe komanso ogwira ntchito za umoyo kupeze njira zoyenera kusamalilira ndi kuthandizira ana amene ali ndi vuto lokhudza ubongo. Muli ndi ufulu kutenga nawo mbali mu kafukufuku ameneyu kapena ayi. Kutenga nawo mbali mkafukufuku ameneyu nkosakakamiza. Kotero kuti mukhoza kukana. Ngati mwasankha kutenga mbali mkafukufuku ameneyu muli ndi ufulu wosiya nthawi ina iliyonse ngati mwafuna kutero. Ngati mwakana kulowa nawo makafukufukuyu kapena mwasiyila panjira, simupatsidwa chilango china chilichonse ndipo mukanali oyenera kupiltiiza kulandila chithanandizo china chiri chonse chomwe mukulandila padali pano kapena mukuyenera kudzalandila mtsogolo.

Kodi ngati ndiri ndi mafunso okhudzana ndi kafukufuku ameneyu ndingamufunse ndani?

Kafukufuku amaneyu akuyendetsedwa ndi a **Sebastian Mboma** a kusukulu ya za umoyo pa University ya Western Cape, ku South Africa, mothandizidwa ndi bungwe la Blantyre Mlaria Project. Ngati muli ndi mafunso kapena mukufuna kudziwa zambiri zokhudzana ndi kafukufuku ameneyu, chonde ayimbileni lamya Sebastian Mboma pa nambala iyi +265999317468 kapena kuwalembela kalata ku email address iyi sebastianmboma@gmail.com. Ngati muli ndi nkhawa zokhudzana ndi kafukufuku ameneyu dziwitsani ma bungwe omwe amaona ngati kafukufuku akuyenda moyenera mosaononga miyoyo kapena chikhalidwe cha anthu a Malawi College of Medicine Research Ethics Committee (COMREC) poyimba lamya pa +265 11871911 kapena kuwalembera kalata pa keyala iyi;

COMREC,
College of Medicine, 3rd Floor
John Chimphwangwi Learning Resource Centre
P/Bag 360, Chichiri, Blantyre, Malawi
email: comrec@medicol.mw.

Komanso mukhoza kuimba lamya kapena kulemba kalata ku School of Public Health:
Head of Department: Prof Helen Schneider,
University of the Western Cape,
Private Bag X17, Bellville 7535,
email:soph-comm@uwc.ac.za
kapena lembani kalata kwa

The Dean of the Faculty of Community and Health Sciences: Prof Jose Frantz
University of the Western Cape
Private Bag X17, Bellville 7535,
email: chs-deansoffice@uwc.ac.za.

Appendix 3

Information Sheet for Caregivers-English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

INFORMATION SHEET FOR CAREGIVERS

Project Title:

Exploration of community-based rehabilitation support for children with neurological impairments following cerebral malaria in Blantyre, Malawi

What is this study about?

This is a research project being conducted by Mr. Sebastian Mboma at the University of the Western Cape. We are inviting you to participate in this research project because you are one of the primary caregivers for children with neurological impairment due to cerebral malaria and live in Blantyre.

The purpose of this research project is to learn about the availability of community-based rehabilitation support for children with neurological impairments. Based on your experiences and perceptions the researcher will be able to gather information on how better and relevant community-based support for these children can be designed and implemented.

What will I be asked to do if I agree to participate?

You will be asked to participate in a focus group discussion with fellow caregivers for children with neurological impairments. The interview sessions will be recorded using a voice recorder to assist the researcher recall about every detail that was discussed. The interviews will take about one hour to complete. The interviews will take place in an office in a quiet and confidential environment at Malaria alert Centre inside the Queen Elizabeth Central hospital. We will give you the transportation costs you will incur on your way to and from the hospital.

Would my participation in this study be kept confidential?

We will carefully protect your privacy and safeguard confidentiality. You can also stop the interview at any time if you feel that your privacy is not guaranteed. To ensure confidentiality no names will be used in any reporting of the findings from this study, instead we will use identity numbers. Collected data on the forms will be kept in lockable filing cabinets and password-protected computers in the office at Malaria Alert Centre, at Queen Elizabeth Central Hospital.

What are the risks of this research?

The questions are meant to be straightforward but some participants may find them too personal or distressing. You are free to decline to respond to these or the rest of the questions that you are asked. We will nevertheless minimize such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help inform designing rehabilitation support and interventions that will help caregivers, families and communities to understand how to take care of children with neurological impairment. You can choose whether you want to take part in our study, or not. Your participation is absolutely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by **Mr Sebastian Mboma** of the Faculty of Community and Health Sciences, School of Public Health, at the University of the Western Cape with assistance from Blantyre Malaria project. If you have any questions about the study, or would like to know more please contact Mr. Sebastian Mboma at the following phone number **+265999317468,** alternatively you may email him at sebastianmboma@gmail.com**.**

If you have ethical concerns about the study you may contact the Secretariats of the Malawi College of Medicine Research Ethics Committee (COMREC) through phone or writing them a letter.

College of Medicine,
3rd Floor, John Chimphwangwi Learning Resource Centre,
P/Bag 360
Chichiri, Blantyre, Malawi
email: comrec@medicol.mw.

Alternatively you may contact: the School of Public Health:
Head of Department: Prof Helen Schneider
University of the Western Cape
Private Bag X17, Bellville 7535
email:soph-comm@uwc.ac.za
or
The Dean of the Faculty of Community and Health Sciences:
Prof Jose Frantz
University of the Western Cape
Private Bag X17, Bellville 7535
email: chs-deansoffice@uwc.ac.za.

Appendix 4
Information Sheet for Caregivers-Chichewa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

KALATA YOFOTOKOZA TSATANETSATANE WA KAFUKUFUKU YA MAKOLO

Cholinga cha kafukufuku ameneyu ndi chani?

Muli kupepemphedwa kutengapo gawo mu kafukufuku ameneyu chifuwa ndinu makolo a ana amene ali ndi mavuto okhudza ubongo mu boma la Blantyre.

Cholinga cha kafukufuku ameneyu tikufuna kudziwa ngati pakadali pano pali chithandizo chochitikira kumudzi chothandiza ana amene ali ndi vuto lokhudza ubongo. Kudzera mu zomwe mumadziwa komanso maganizo anu tiphunzira njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo mmudzi mwawo.

Kodi ndizafunsidwa mafuso otani ndikatengapo mbali mu kafukufuku ameneyu?

Mudzapemphedwa kukhala nawo pagulu lomwe lidzafunsidwa mafunso ndi kuzukuta njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo angathandidwire mmudzi mwawo. Zokambirana zonsezi zidzatepedwa ndicholinga chodzathandiza ochita kafukufukuyu kuti adzakumbukire zonse zonse zommwe zidzakambidwa patsogolo. Zokambiranazi zidzatenga pafupifupi ola limodzi kuti zithe. Kafukufukuyu adzachitikira pa malo opanda phokoso komanso opanda zosokoneza ku ma ofesi a Mlaria Alert Centre mkati mwa chipatala cha Queen Elizabeth. Tidzakubwezerani ndalama yomwe munagwiritsa ntchito kuyendera pobwera ku chipatala,komanso kukupatsani ndalama yoyendera pobwelera kunyumba.

Kodi kutengapo mbali mu kafukufuku ameneyu kudzakhala kwa chinsinsi?

Tidzayesetsa kusunga mwachinsinsi zokhudza kafukufukuyu. muli ndi ufulu osiya kutengapo mbali mu kafukufukuyu ngati mukuona kuti palibe chinsinsi. Pofuna kuonenetsetsa kuti chinsinsi chasungidwa podzaulutsa zotsatila za kafukufukuyu, maina a nthu omwe anatengapo mbali mu kafukufukuyu sadzatchulidwa, mmalo mwake manambala oyimila maina a anthuwa ndi omwe adzagwiritsidwe ntchito. Zonse zomwe zalembedwa pa nthawi ya kafukufukuyu zidzasungidwa mmakabati otsekedwa ndi makiyi komanso makina a computer omwe munthu wadera sangatsegule. Zonsezi zidzasungidwa mu ofesi ku Malaria Alert Centre mkati mwa chipatala cha Queen Elizabeth.

Kodi ndi zoopsa zanji zomwe ndingakumane nazo kamba kolowa mkafukfuku ameneyu?

Mafunso a mkafukufuku ameneyu akuyenera kukhala osavuta, komabe ena mwa anthu amene akutengapo mbali mkafukufukuyu akhoza kuona ngati mafunsowa akulunjika iwowo kapena akhoza kukhumudwa nawo. Muli omasuka kukana kuyankha mafunso oterewa ngakhalenso mafunso onse otsatila. Komabe tizayesetsa kuti zinthu ngati zimenezi zichepe, ndipo tizayesetsa kuti muthandizidwe mwachangu ngati simunasangalitsidwe, mwakhumudwa kapena simukumumva bwino pa nthawi yomwe mukutenga nawo mbali mu kafukufuku ameneyu. Ngati kuli kotheka tizakutumuzani kwa akadaulo oyenera kuti akuthandizeni moyenera.

Kodi phindu la Kafukufuku ameneyu ndi chani?

Phindu la Kafukufuku ameneyu silili lolunjika kwa inu nokha ngati munthu yemwe watengapo mbali mkafukufuku amaneyu. Koma zotsatira za kafukufukuyu zizanthandiza makolo, mabungwe komanso ogwira ntchito za umoyo kuti kupeze njira zoyenera kusamalilira ndi kuthandizira ana amene ali ndi vuto lokhudza ubongo. Muli ndi ufulu kutenga nawo mbali mu kafukufuku ameneyu kapena ayi. Kutenga nawo mbali mkafukufuku ameneyu nkosakakamiza. Kotero kuti mukhoza kukana. Ngati mwasankha kutenga mbali mkafukufuku ameneyu muli ndi ufulu wosiya nthawi ina iliyonse ngati mwafuna kutero. Ngati mwakana kulowa nawo makafukufukuyu kapena mwasiyila panjira, simupatsidwa chilango china chilichonse ndipo mukanali oyenera kupiltiiza kulandila chithanandizo china chiri chonse chomwe mukulandila padali pano kapena mukuyenera kudzalandila mtsogolo.

Kodi ngati ndiri ndi mafunso okhudzana ndi kafukufuku ameneyu ndingamufunse ndani?

Kafukufuku amaneyu akuyendetsedwa ndi a **Sebastian Mboma** a kusukulu ya za umoyo pa University ya Western Cape, ku South Africa, mothandizidwa ndi bungwe la Blantyre Mlaria Project. Ngati muli ndi mafunso kapena mukufuna kudziwa zambiri zokhudzana ndi kafukufuku ameneyu, chonde ayimbileni lamya Sebastian Mboma pa nambala iyi +265999317468 kapena kuwalembela kalata ku email address iyi sebastianmboma@gmail.com. Ngati muli ndi nkhawa zokhudza kafukufuku ameneyu dziwitsani ma bungwe omwe amaona ngati kafukufuku akuyenda moyenera mosaononga miyoyo kapena chikhalidwe cha anthu a Malawi College of Medicine Research Ethics Committee (COMREC) poyimba lamya pa +265 11871911 kapena kuwalembera kalata pa keyala iyi

COMREC,
College of Medicine, 3rd Floor
John Chimphwangwi Learning Resource Centre
P/Bag 360, Chichiri, Blantyre, Malawi
email: comrec@medicol.mw.

Komanso mukhoza kuimba lamya kapena kulemba kalata ku School of Public Health:
Head of Department: Prof Helen Schneider,
University of the Western Cape,
Private Bag X17, Bellville 7535,
Email:soph-comm@uwc.ac.za

kapena lembani kalata kwa
The Dean of the Faculty of Community and Health Sciences: Prof Jose Frantz
University of the Western Cape
Private Bag X17, Bellville 7535,
Email: chs-deansoffice@uwc.ac.za.

Appendix 5

Consent form for Caregivers-English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Consent form for caregivers of children with neurological impairments-English

Introduction

As a caregiver of a child with neurological impairments following cerebral malaria. we would like to ask you questions based on your perceptions and experiences of community based rehabilitation support for your child.

Purpose of the study

The purpose of this study is to learn from your experiences and perceptions as a caregiver about the possibility of having community–based rehabilitation support to help your child improve quicker and cope with social demands of life as s/he grows.

Place of interview and duration

The focus group discussion will take place in an office in a quiet and confidential environment at Blantyre Malaria alert Centre inside the Queen Elizabeth Central hospital.

Confidentiality

All the information we collect from an interview with you will be treated with sensitivity and confidentiality. No names will be included in the data analysis and results of this study or in any communications regarding the study.

Participation in the study

If you are not comfortable with participating in this study, you are free not to do so. If you agree but once we have started the interview and you feel that you no longer would like to continue, you are free to stop participating in the study at any time. This will not affect your child's access to standard treatment or any benefits s/he is currently receiving.

Consenting

I have read or the information about the study has been read to me. I have had the opportunity to ask questions, and my questions have been answered satisfactorily. I understand that the information collected is confidential and I understand that I can withdraw from the study at any time without it affecting access to standard treatment or benefits my child is entitled.

I voluntarily agree to participate in this study.

☐ YES ☐ NO

______________________________	____________________	__________
Name of the Participant	Signature/Thumb Print	Date
______________________________	____________________	__________
Name of the Person requesting consent	Signature	Date

Appendix 6

Consent formfor Caregivers-Chichewa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Kalata ya makolo yovomereza kutenga nawo mbali mkafukufuku

Malonje

Ndinu kholo la mwana amene anadwalapo malungo okhudza ubongo ndipo ali ndi vuto la ubongo. Tikufuna kuti timve maganizo anu komanzo zomwe mukudziwa pa kasamalidwe komanso chithandizo cha ana oterewa chomwe chikuchitikira mmudzi momwe mukukhala.

Cholinga cha kafukufukuyu

Cholinga cha kafukufuku ameneyu tikufuna kudziwa ngati pakadali pano pali chithandizo chochitikira kumudzi chothandiza ana amene ali ndi vuto lokhudza ubongo. Kudzera mu zomwe mumadziwa komanso maganizo anu tiphunzira njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo angathandizidwire mmudzi mwawo kuti akule bwino komanso aphunzire luso losiyanasiyana lofunika pa moyo.

Malo omwe kafukufuku akachitikile komanso nthawi yomwe kafukufukuyu adzatenge

Kafukufukuyu akachitikira muchipinnda mochitilamo misonkhano ku Malaria alert Centre mkati mwachipatala cha Queen Elizabeth komwe kulibe phokoso.

Chinsinsi

Zonse zomwe tizakambirane mkafufukuyu tizazisunga mwa chinsinsi. Maina anthu omwe atengapo mbali mkafukuyu sadzatchulidwa pa nthawi yomwe zotsatila za kafukufuku ameneyu zizaulutsidwe.

Kutengapo mbali mu kafukufukuyu

Ngati simuli osangalatsidwa kutenga mbali mu kafukufuku ameneyu muli ndi ufulu kusatero. Ngati mwasankha kutenga mbali mkafukufuku ameneyu muli ndi ufulu wosiya nthawi ina iliyonse ngati mwafuna kutero. Ngati mwakana kulowa nawo makafukufukuyu kapena mwasiyila panjira, simupatsidwa chilango china chilichonse ndipo mukanali oyenera kupiliza kulandila chithanandizo china chiri chonse chomwe mukulandila padali pano kapena mukuyenera kudzalandila mtsogolo.

Kuvomera kutenga mbali mkafukufuku ameneyu

Ndawerenga kapena andiwerengera zonse zokhudzana ndi kafukufuku ameneyu. Ndinali ndi mwayi ofunsa mafuso ndipo ndakhutilitsidwa ndi mene ndayankhidwila. Ndikumvetsa kuti zomwe tikambirane apa ndi zachinsinsi, ndipo ndikudziwa kuti ndingathe kutuluka mu kafukufuku ameneyu nthawi ina iliyonse opanda kuika pa chiopsezo mwayi olandila chithandizo cha kuchipatala, ngakhalenso chithandizo china chilichonse.

Ndikuvomera mosakakamizidwa kulowa kafukufukuyu

☐ EYA ☐ AYI

__________________________ __________________ ________

Dzina la otenga mbali mkafukufuku Sayini/Chala Tsiku

__________________________ __________________ ________

Dzina la ofunsa Sayini/Chala Tsiku

Appendix 7

Consent form for Healthcare Providers-English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Consent form for healthcare providers -English

Introduction

You are one of the clinical staff members who assess and provide clinical and rehabilitative care to children that have physical and neurological impairments following cerebral malaria, we would like to ask you questions based on your perceptions and experiences about community based rehabilitation support for these children.

Purpose of the study

The purpose of this study is to learn from your experiences and perceptions as a healthcare provider on community–based rehabilitation interventions to help these children improve quicker and cope with social demands of life as they grow.

Place of interview and duration

The interviews will take place in an office in a quiet and confidential environment at Blantyre Malaria alert Centre inside the Queen Elizabeth Central hospital.

Confidentiality

All the information we collect from an interview with you will be treated with sensitivity and confidentiality. No names will be included in the data analysis and results of this study or in any communications regarding the study. .

Participation in the study

If you are not comfortable with participating in this study, you are free not to do so. If you agree to participate, but once we have started the interview and you feel that you no longer would like to continue, you are free to stop participating in the study at any time. This will not affect how people will perceive you at your workplace.

Consenting

I have read the information about the study. I have had the opportunity to ask questions, and my questions have been answered satisfactorily. I understand that the information collected is confidential and I understand that I can withdraw from the study at any time without it affecting my work.

I voluntarily agree to participate in this study.

☐ YES ☐ NO

______________________________	____________________	__________
Name of the Participant	Signature/Thumb Print	Date
______________________________	____________________	__________
Name of the Person requesting consent	Signature	Date

Appendix 8

Consent Form for Healthcare Providers-Chichewa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Kalata ya ogwira ntchito ya zaumoyo yovomereza kutenga nawo mbali mkafukufuku

Malonje

Ndinu mmodzi mwa ogwira ntchito ya za umoyo ndipo mumakumana ndi ana amene anadwalapo malungo okhudza ubongo ndipo pano ali ndi vuto la ubongo. Tikufuna timve maganizo anu komanso zomwe mukudziwa pa kasamalidwe ndi chithandizo cha ana oterewa chomwe chikuchitikira mmidzi momwe amakukhala.

Cholinga cha kafukufukuyu

Cholinga cha kafukufukuyu ndi kufuna kuphunzira kuchokera kwa inu ngati ogwira ntchito ya za umoyo pa maganizo anu ngati kulikotheka kukhazikitsa ndondomeko ya chisamaliro ndi chithandizo cha mmudzi kwa ana amene ali ndi vuto la ubongo. Tikufuna kudziwa ngati pakadali pano pali chithandizo chochitikira kumudzi chothandiza ana amene ali ndi vuto lokhudza ubongo. Kudzera mu zomwe mumadziwa komanso maganizo anu tiphunzira njira zabwino zomwe ndondomeko yothandizira ana amene ali ndi mavuto okhudza ubomngo angathandizidwire mmudzi mwawo kuti akule bwino komanso aphunzire luso losiyanasiyana lofunika pa moyo.

Malo omwe kafukufuku akachitikile komanso nthawi yomwe kafukufukuyu adzatenge

Kafukufukuyu akachitikira muchipinnda mochitilamo misonkhano ku Malaria alert Centre mkati mwachipatala cha Queen Elizabeth komwe kulibe phokoso.

Chinsinsi

Zonse zomwe tizakambirane mkafufukuyu tizazisunga mwa chinsinsi. Maina a anthu omwe atengapo mbali mkafukuyu sadzatchulidwa pa nthawi yomwe zotsatila za kafukufuku ameneyu zizaulutsidwe.

Kutengapo mbali mu kafukufukuyu

Ngati simuli osangalatsidwa kutenga mbali mu kafukufuku ameneyu muli ndi ufulu kusatero. Ngati mwasankha kutenga mbali mkafukufuku ameneyu muli ndi ufulu wosiya nthawi ina iliyonse ngati mwafuna kutero. Ngati mwakana kulowa nawo makafukufukuyu kapena mwasiyila panjira, simupatsidwa chilango china chilichonse ndipo izi sizibweretsa kusintha kulikonse pa momwe anthu amakuonerani kuntchito kwanu

Kuvomera kutenga mbali mkafukufuku ameneyu

Ndawerenga kapena andiwerengera zonse zokhudza ameneyu. Ndinali ndi mwayi ofunsa mafuso ndipo ndakhutilitsidwa ndi mene ndayankhidwila. Ndikumvetsa kuti zomwe tikambirane apa ndi zachinsinsi, ndipo ndikudziwa kuti ndingathe kutuluka mu kafukufuku ameneyu nthawi ina iliyonse ndipo izi sizikhudzana ndi meme anthu amandionera ku ntchito kwanga.

Ndikuvomera mosakakamizidwa kulowa kafukufukuyu

☐ EYA ☐ AYI

______________________________	_________________	________
Dzina la otenga mbali mkafukufuku	Sayini/Chala	Tsiku
______________________________	_________________	________
Dzina la ofunsa	Sayini/Chala	Tsiku

Appendix 9

Consent form for Key Informants from NGOs-English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Consent form for key-informants in community-based organizations -English

Introduction

You are one of the key informants from a community-based organization supporting children who have physical and neurological impairments following cerebral malaria. I would like to ask you questions based on your experiences about how a community-based rehabilitation support for these children is being done in the communities you are working.

Purpose of the study

The purpose of this study is to learn from your experiences and perceptions as a community based rehabilitation support provider in order to help these children improve faster and cope with social demands of life as they grow.

Place of interview and duration

The focus group discussion will take place in an office in a quiet and confidential environment at Blantyre Malaria alert Centre inside the Queen Elizabeth Central hospital.

Confidentiality

All the information we collect from you will be treated with sensitivity and confidentiality. No names will be included in the data analysis and results of this study or in any communications regarding the study.

Participation in the study

If you are not comfortable to participate in this study, you are free not to do so now, and once we have started the interview and you feel that you no longer would like to continue, you are free to stop participating in the study at any time. This will not affect how people will perceive you at your organization.

Consenting

I have read the information about the study. I have had the opportunity to ask questions, and my questions have been answered satisfactorily. I understand that the information collected is confidential and I understand that I can withdraw from the study at any time without it affecting my work.

I voluntarily agree to participate in this study.

☐ YES ☐ NO

______________________ ______________ ________

Name of the Participant Signature/Thumb Print Date

______________________ ______________ ________

Name of the Person requesting consent Signature Date

Appendix 10

Consent form for Key-Informants from NGOs-Chichewa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

UNIVERSITY OF THE WESTERN CAPE

Kalata ya ogwira ntchito mmabungwe othandiza ana omwe ali ndi vuto la ubongo yovomereza kutenga nawo mbali mkafukufuku

Malonje

Ndinu mmodzi mwa ogwira ntchito mmabungwe omwe amathandiza ana omwe ali ndi vulo la ubongo kamba kodwala malungo okhudza ubongo. Mukupemphedwa kuti tikufunseni mafunso okhudza momwe ntchito yosamalira anawa ikuyendera mmadera momwe mukugwira

Cholinga cha kafukufukuyu

Cholinga cha kafukufukuyu ndi kufuna kuphunzira kuchokera kwa inu ngati ogwira ntchito mmabungwe osamalira ana omwe ali ndi vuto la ubongo za momwe ndondomeko ya ntchito yotereyi ingapangidwire komanso momwe ntchitoyi ingakhazikitsiridwe ndicholinga choti tidziwe momwe anawa angathandizidwire mmudzi mwawo kuti akule bwino komanso aphunzire luso losiyanasiyana lofunika pa moyo.

Malo omwe kafukufuku akachitikile komanso nthawi yomwe kafukufukuyu adzatenge

Kafukufukuyu akachitikira muchipinnda mochitilamo misonkhano ku Malaria Alert Centre mkati mwachipatala cha Queen Elizabeth komwe kulibe phokoso.

Chinsinsi

Zonse zomwe tizakambirane mkafufukuyu tizazisunga mwa chinsinsi. Maina a anthu omwe atengapo mbali mkafukuyu sadzatchulidwa pa nthawi yomwe zotsatila za kafukufuku ameneyu zizaulutsidwe.

Kutengapo mbali mu kafukufukuyu

Ngati simuli osangalatsidwa kutenga mbali mu kafukufuku ameneyu muli ndi ufulu kusatero. Ngati mwasankha kutenga mbali mkafukufuku ameneyu muli ndi ufulu wosiya nthawi ina iliyonse ngati mwafuna kutero. Ngati mwakana kulowa nawo makafukufukuyu kapena mwasiyila panjira, simupatsidwa chilango china chilichonse ndipo izi sizibweretsa kusintha kulikonse pa momwe anthu amakuonerani ku bungwe kwanu

Kuvomera kutenga mbali mkafukufuku ameneyu

Ndawerenga kapena andiwerengera zonse zokhudza kafukufuku ameneyu. Ndinali ndi mwayi ofunsa mafuso ndipo ndakhutilitsidwa ndi mene ndayankhidwila. Ndikumvetsa kuti zomwe tikambirane apa ndi zachinsinsi, ndipo ndikudziwa kuti ndingathe kutuluka mu kafukufuku ameneyu nthawi ina iliyonse ndipo izi sizikhudzana ndi meme anthu amandionera ku bungweo kwanga.

Ndikuvomera mosakakamizidwa kulowa kafukufukuyu

☐ EYA ☐ AYI

Dzina la otenga mbali mkafukufuku	Sayini/Chala	Tsiku
Dzina la ofunsa	Sayini/Chala	Tsiku

Appendix 11

FGD Confidentiality Binding Form-English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Title of Research Project:

"Exploration of community-based rehabilitation support for children with neurological impairments following cerebral malaria in Blantyre, Malawi"

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that confidentiality is dependent on participants' in the Focus Group maintaining confidentiality.

I hereby agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name………………………………………..

Participant's signature…………………………………..

Date………………………

Appendix 12

FGD Confidentiality Binding Form-Chichewa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Title of Research Project:

“Exploration of community-based rehabilitation support for children with neurological impairments following cerebral malaria in Blantyre, Malawi”

Zokhudza kafukufukuyu zafotokozedwa mu chilankhulo choti ndimamva bwinobwino. Mafunso omwe ndinali nawo okhudza kafukufuku ameneyu ndayankhidwa bwino lomwe. Ndikumvetsa zomwe ndikuyenera kuchita pamene ndikutengapo mbali mkafukufukuyu ndipo ndavomera kutengapo mbali mukafukufukuyu mwa kufuna kwanga komanso mosakakamizidwa. Ndikudziwa kuti ngati nditangapo mbali dzina langa silizaululidwa ndi ochitiotsa kafukufukuyu. Ndikumvetsa kuti ndikhoza kusiya kutengapo mbali mkafukufukuyu nthawi ina iliyonse yomwe ndafuna opanda kupereka chifukwa chani ndatero, mosaopa kapena kutaya mwayi wa zomwe pakali pano ndikulandila. Ndili omvetsetsa kuti kusunga chinsinsi pamene tikukambirana zokhudza kafukufukuyu kuli mmanja mwa ife amene tikutengapo mbali.

Ndikulonjeza pano kuti ndizasunga mwachinsinsi zones zomwe tikambirane pano, osaulula maina anthu ena amene akutengaponso mbali mkafukufukuyu, ndi zomwe angaanene kwa anthu omwe palibe pa nthawi ya zokambiranazi.
Dzina la otengapo mbali mkafukufuku……………………………………..

Siyini yake/Chala…………………………………..

Tsiku la kafukufuku………………………

APPENDIX 13

INTERVIEW GUIDE FOR CAREGIVERS-ENGLISH

Guide to conducting a Focus Group Discussion with Caregivers

Background

The researcher will explain to caregivers about the purpose of the study and talk about neurological impairments

1. Tell me about your experiences with giving rehabilitation support at home for children with neurological impairments?

Probes

- What do you actually do?
- What challenges do you face?
- How did you learn what to do?

2. Can you explain to us how you came to know how to do rehabilitation support activities?

Probes:

- Any formal or informal training about the rehabilitation support?
- Is there consistence in doing these activities and who monitors this?
- How effective are these activities and how do they monitor change?
- What materials are available to efficiently do these activities?

3. Can you tell us about any rehabilitation support you know of that is currently being given to children with neurological impairments in the homes and community where you live?

4. Can you tell us the need of doing community-based rehabilitation support for children with neurological impairments?

5. What is your opinion about how community-based rehabilitation support may best be done?

   Probe:

   - What do you think still needs to be done?

APPENDIX 14

INTERVIEW GUIDE FOR CAREGIVERS-CHICHEWA

<u>Ndondomeko ya mafunso ofunsidwa pa mchezo ndi makolo a ana amene anadwalapo malungo okhudza ubongo</u>

Opangitsa kafukufuku akuyenera kufotokozera makolo amene akutengapo gawo mu kafukufuku ameneyu cholinga cha kafukufukuyu ndipo awawuzenso za matenda okhudza ubongo omwe amadza kamba ka malungo okhudza ubongo

6. Tatifotokozerani zomwe mukudziwa pa za chisamaliro cha ana amene ali ndi matenda okhudza ubongo kamba ka malungo okhudza ubongo chomwe chikuchitikira pakhomo?

Mafunso otsatira:

- Kweni kweni mumachita bwanji?
- Mavuto omwe mukukumana nawo ndi otani
- Munaphunzira kuti ndondomeko yochitira chithandizochi

7. Tatifotokozereni kuti munadziwa bwanji kuti chisamaliro cha nana amene ali ndi matenda okhudza ubongo kamba ka malungo okhudza obongo chiziyenda chiziyenda motere

Mafunso otsatira:

- Munaphunzitsidwapo za chisamalirochi ndi alangizi kapena adotolo ovomelezeka ndi boma?
- Kodi palindondomeko iliyonse yokhazikika pa momwe mukuyenera kusamalira ana amenewa, ndipo amaonetsetsa kuti ndndomekoyi ikutsatidwa ndi ndani?
- Kodi chisamalirochi ndi chothandiza motani, ndipo alipo yemwe amachita kalondolondo kuti aone ngati chisamalirochi chikuthandiza?
- Pali zipangizo zotani zomwe zimathandizira kuti chisamalirochi chiyende bwino?

8. Tiuzeni za chisamaliro chilichinse chomwe mukudziwa, chomwe chikuchitikira pakhomo kapena mmudzi mwanu pakadali pano chokhudzana ndi ana amene anadwalapo malungo okhudza ubongo ndipo pakadali pano ali ndi matenda okhudza ubongo

9. Mungatiuze ubwino wokhala ndi chisamaliro chochitikira kumudzi chothandiza ana amene ali ndi matenda okhudza ubongo kamba koti anadwalapo malungo okhudza ubongo?

10. Tiuzeni maganizo anu pa momwe mukuonera kuti chisamaliro chochitikira kumudzi cha ana amene ali ndi matenda okhudza ubongo chikuyenera kuyendera?

Mafunso otsatira:

- Mukuona ngati ndi zinthu ziti zomwe zikuyenera kuti zipangidwebe?

APPENDIX 15

INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS-ENGLISH

Demographics and Occupation

ID Number:________

Gender:_____

Age:_____

Cadre in the healthcare provision:_________________

Period of work experience:________

Background

The researcher will explain to healthcare providers about the purpose of study and talk about neurological impairments

1. Do you think it is necessary to have community-based support for children with neurological impairments? Why/why not

2. Can you tell us about any rehabilitation support you know that is currently being given to children with neurological impairments in their homes and communities where they live?

3. What do you think about the way community-based rehabilitation support is being done currently in the area that you work?

4. Is there something more that must be done about community-based rehabilitation support for children with neurological impairments?

Probes:

- Is there requirement for training to for caregivers?
- Is there need for monitoring of these activities, and would be preferred (professional capacity) to do the monitoring?
- What material support would be required for efficient performance?

5. What is your opinion about how community-based rehabilitation support may best be designed and implemented and sustained?

APPENDIX 16

INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS-CHICHEWA

Zokhudza omwe akutengapo mbali mu kafukufukuyu ndi komwe akugwira ntchito ya zaumoyo

Namabala yawo mu kafukufukuiyu:______

Wamkazi/Wamwamuna

Zaka zakubadwa: _______

akugwira ntchito yotani ya zaumoyo:_____________________________

angwira ntchito nthawi yayitali bwanji:_____________________________

Opangitsa kafukufuku akuyenera kufotokozera makolo amene akutengapo gawo mu kafukufuku ameneyu cholinga cha kafukufukuyu ndipo awawuzenso za matenda okhudza ubongo omwe amadza kamba ka malungo okhudza ubongo

1. Kodi mukuona kuti ndikoyenera kukhala ndi ndondomeko yopereka chithandizo cha zaumoyo ndi chisamaliro chochitikira kumudzi chikhudzana ndi ana amene ali ndi matenda okhuza ubongo omwe anadza kamba ka malungo okhudza ubongo?

2. Tiuzeni za chisamaliro komanso chithandizo cha za umoyo chomwe mukudziwa, chomwe chikuchitikira pakhomo kapena mmudzi mwanu pakadali pano chokhudzana ndi ana amene anadwalapo malungo okhudza ubongo ndipo pakadali pano ali ndi matenda okhudza ubongo

3. Tiuzeni maganizo anu pa momwe mukuonera mmene chisamaliro komanso chithandizo cha za umoyo chokhudzana ndi ana amene anadwalapo malungo okhudza ubongo ndipo pakadali pano ali ndi matenda okhudza ubongo chomwe chikuchitikira mu makomo kapena mmidzi

4. Tiuzeni maganizo anu pa momwe mukuonera kuti chisamaliro chochitikira kumudzi cha ana amene ali ndi matenda okhudza ubongo chikuyenera kuyendera?

Mafunso otsatira:

- kodi makolo akuyenera kuphunzitsidwa?
- kodi pakuyenera kukhala kalondolondo wa momwe chithandizo cha umoyo ndi chisamalirochi chikuyenera kuyendera, Amene akuyenera kuchita kalondolondoyu ndi ndani?
- Zipangizo zomwe zikufunika ndi ziti??

5. Parekani maganizo anu pa momwe mukuonera kuti chithandizo cha umoyo komansi chisamaliro cha ana omwe ali ndi matenda a ubongo kamba koti anadwalapo malungo okhudza ubongo chikuyenera kuti chipangidwire komanso kuyendetseredwa?

APPENDIX 17

INTERVIEW GUIDE FOR KEY-INFORMANTS FROM CBOs-CHICHEWA

Background

The researcher will explain to key informants about the purpose of study and talk about neurological impairments

1. What does community-based support for children with neurological impairments mean to you?

2. Do you think it is necessary to have community-based support for children with neurological impairments? why/why not

3. Can you tell us about the kind of rehabilitation support you are currently giving to children with neurological impairments

   Probe:
   - How is it being implemented?
   - Probe: the quality and completeness

4. Is there something more that must be done about community-based rehabilitation support for children with neurological impairments?

   Probes:
   - Is there requirement for training to for caregivers?
   - Is there need for monitoring of these activities, and would be preferred (professional capacity) to do the monitoring?
   - What material support would be required for efficient performance?

5. What is your opinion about how community-based rehabilitation support may best be designed and implemented and sustained?

   Probes:
   - Requirement for training for caregivers or CBO staff
   - Need for monitoring of these activities, and would be preferred (professional capacity) to do the monitoring?
   - Support required for efficient performance and who may provide?

APPENDIX 18

INTERVIEW GUIDE FOR KEY-INFORMANTS FROM CBOs-CHICHWA

Opangitsa kafukufuku akuyenera kufotokozera makolo amene akutengapo gawo mu kafukufuku ameneyu cholinga cha kafukufukuyu ndipo awawuzenso za matenda okhudza ubongo omwe amadza kamba ka malungo okhudza ubongo

1. Kodi mumamvetsa bwanji za chithandizo cha zaumoyo komanso chisamaliro cha kumudzi cha ana amene ali ndi mavuto a ubongo kamba koti anadwalapo malungo okhudza ubongo?

2. Mukuona kuti ndikofunika kukhala ndi chithandizo cha zaumoyo komanso chisamaliro cha kumudzi cha ana amene ali ndi mavuto a ubongo kamba koti anadwalapo malungo okhudza ubongo? Chifukwa ninji?

3. kodi mukudziwapo chani za chisamaliro komanso chithandizo cha za umoyo chomwe mukudziwa, chomwe chikuchitikira pakhomo kapena mmudzi mwanu pakadali pano chokhudzana ndi ana amene anadwalapo malungo okhudza ubongo ndipo pakadali pano ali ndi matenda okhudza ubongo

   - ***Mafunso otsatira:***kodi ndondomekoyi ikukhazikitsidwabwanji?
   - Funso lotsatira: kodi ikukhazikitsiwa moyenera komanso mofikira onse

4. Tiuzeni maganizo anu pa momwe mukuonera kuti chisamaliro chochitikira kumudzi cha ana amene ali ndi matenda okhudza ubongo chikuyenera kuyendera?

   Mafunso otsatira:

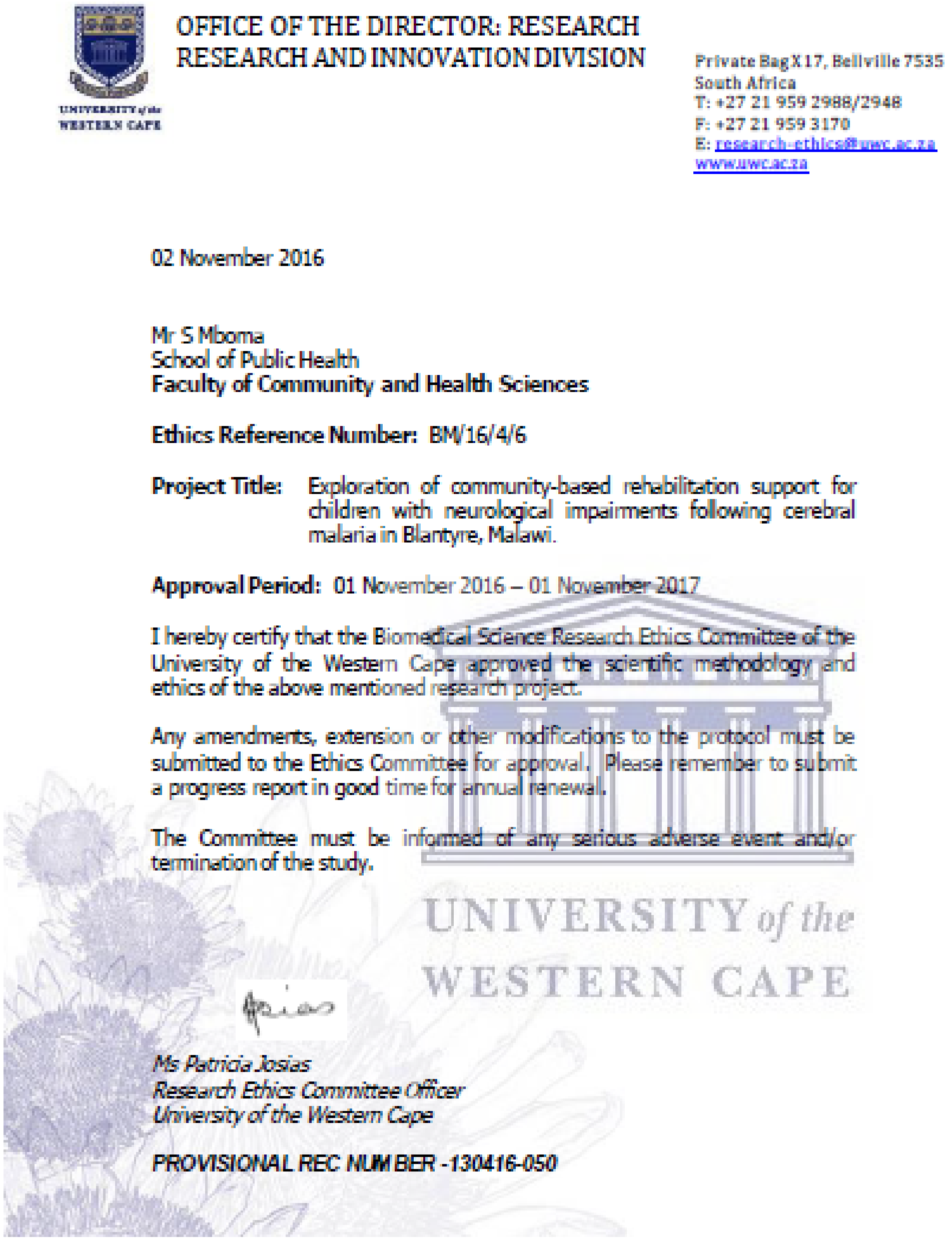
   - kodi makolo akuyenera kuphunzitsidwa?
   - kodi pakuyenera kukhala kalondolondo wa momwe chithandizo cha umoyo ndi chisamalirochi chikuyenera kuyendera, Amene akuyenera kuchita kalondolondoyu ndi ndani?
   - Zipangizo zomwe zikufunika ndi ziti?

5. Parekani maganizo anu pa momwe mukuonera kuti chithandizo cha umoyo komansi chisamaliro cha ana omwe ali ndi matenda a ubongo kamba koti anadwalapo malungo okhudza ubongo chikuyenera kuti chipangidwire komanso kuyendetseredwa?

   Mafunso otsatira:

   - kodi pakufunika maphunziroi kwa makolo a ananwa komanso ogwira nchito mu ma CBO
   - kodi pakuyenera kukhala kalondolondo wa momwe chithandizo cha umoyo ndi chisamalirochi chikuyenera kuyendera, Amene akuyenera kuchita kalondolondoyu ndi ndani?
   - Zipangizo zomwe zikufunika ndi ziti?
   - Chthandizo kuti ntchitoyi iyende bwino, ndipo angamapereke chithandizochi ndi ndani?

APPENDIX 19: UWC Ethics Approval Letter



UNIVERSITY of the WESTERN CAPE

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02 November 2016

Mr S Mboma
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM/16/4/6

Project Title: Exploration of community-based rehabilitation support for children with neurological impairments following cerebral malaria in Blantyre, Malawi.

Approval Period: 01 November 2016 – 01 November 2017

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

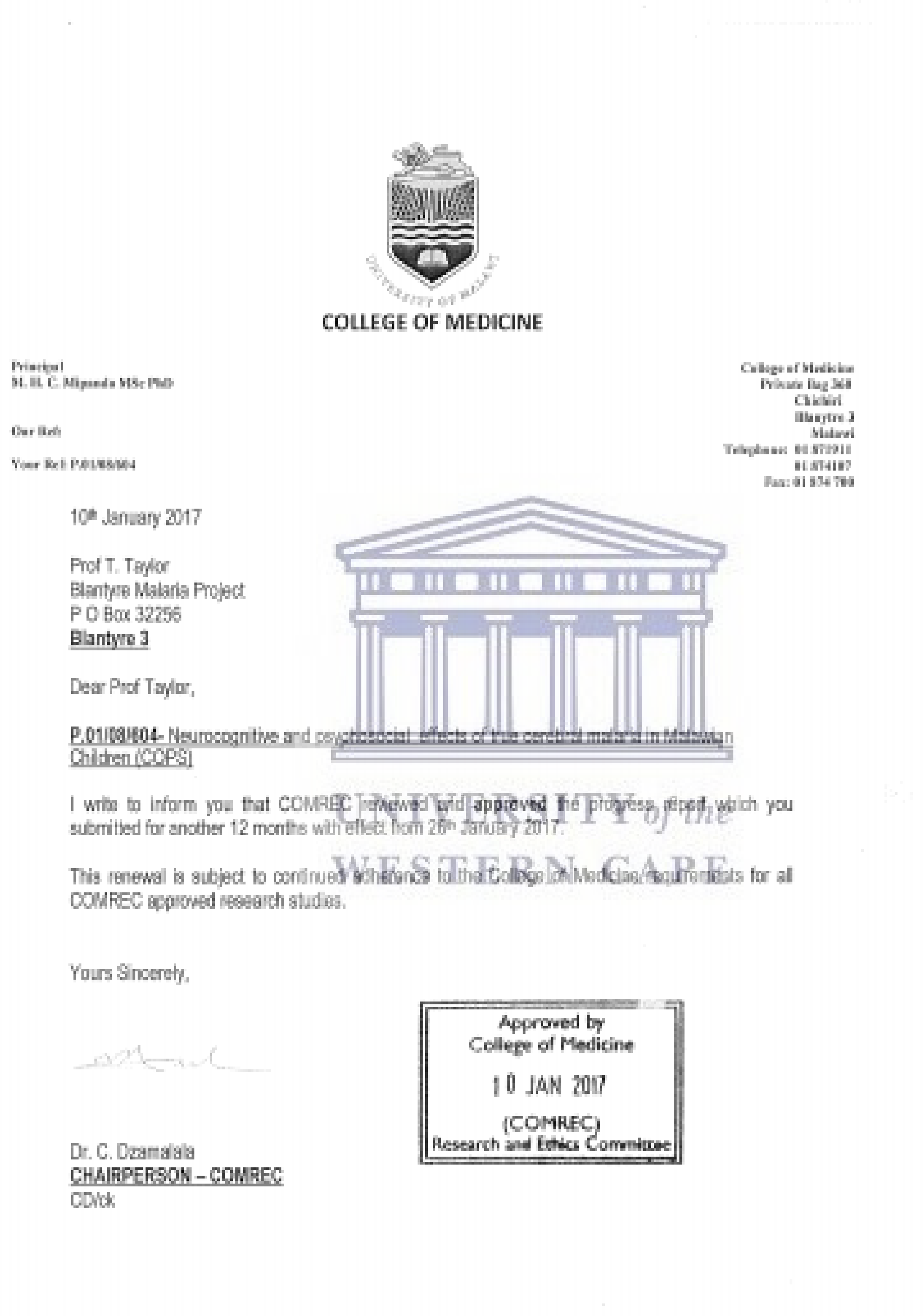
Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER -130416-050

APPENDIX 20: COMREC Ethics Approval Letter



COLLEGE OF MEDICINE

Principal
M. H. C. Mipando MSc PhD

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi
Telephone: 01 871911
01 874107
Fax: 01 874 700

Our Ref:

Your Ref: P.01/08/604

10th January 2017

Prof T. Taylor
Blantyre Malaria Project
P O Box 32256
Blantyre 3

Dear Prof Taylor,

P.01/08/604- Neurocognitive and psychosocial effects of true cerebral malaria in Malawian Children (COPS)

I write to inform you that COMREC renewed and **approved** the progress report which you submitted for another 12 months with effect from 26th January 2017.

This renewal is subject to continued adherence to the College of Medicine requirements for all COMREC approved research studies.

Yours Sincerely,

Approved by
College of Medicine
10 JAN 2017
(COMREC)
Research and Ethics Committee

Dr. C. Dzamalala
CHAIRPERSON – COMREC
CD/ck