



**EXPERIENCES OF CAREGIVERS ON HEALTHCARE AND  
PSYCHOSOCIAL SERVICES AVAILABLE FOR CEREBRAL PALSY  
CHILDREN IN MANGOCHI DISTRICT**

**CHEER PROJECT, MICRO RESEARCH COHORT 2, GROUP 5**

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## Executive summary

**Study type:** This was a cross sectional phenomenological qualitative study

**Problem:** Children with Cerebral Palsy (CP) require multidisciplinary and holistic care in order to comprehensively manage their medical needs as well as maximize their developmental and educational potential<sup>1</sup>. In addition, many children with Cerebral Palsy have complex limitations in self-care functions which renders them completely reliant on their caregivers<sup>2</sup>. The provision of such care may therefore be detrimental and stressful to both the physical health and the psychological well-being of parents of children with Cerebral Palsy<sup>3</sup>. Exploring experiences of caregivers on healthcare and psychosocial services available for children with Cerebral Palsy is key in addressing gaps existing in provision of quality health care and psychosocial services both at community and hospital settings.

**Methodology:** The study utilized qualitative research design which was cross sectional and phenomenological in nature. The study was conducted at Mangochi District Hospital and targeted caregivers of children with Cerebral Palsy. The duration of the study was 10 months; between December 2021 to September 2022. Convenient sampling was used with a sample size of 12 caregivers. Data collection was done using face to face in depth interviews with the aid of interview guide. Tape recorder was used and the information provided by the participants was transcribed. Data was presented in themes and subthemes.

**Study findings:** The findings of the study showed that majority of participants reported that their children received good physiotherapy services, health care workers were friendly and welcoming and they had short waiting time to receive the services.

However, some of the participants received inadequate information related to etiology of CP, prognosis of CP, alternative treatments and on child care at home. There was also lack of follow up of CP children and lack of home visits by health care workers. Majority of participants received informal psychosocial support from their relatives and friends. However, majority of formal psychosocial services were lacking for example there was lack of counselling services, no visits by counsellors or social workers, unavailability of support groups and lack of assistive devices at home. Challenges which caregivers encountered were related to financial support resulting in their inability to meet basic needs for CP children and transport challenges to take their children to the hospital for monthly physiotherapy services.

**Recommendations:** The study recommends that health care workers should be trained in order to provide evidence based CP information and psychosocial counselling services. CP children and their caregivers should also be followed up by community health care workers for support and continuity of services. There is need to engage non-governmental organization existing within Mangochi district to support caregivers in terms of basic needs and psychosocial support. All in all, there is need for multisectoral collaboration in order to manage CP children comprehensively.

**Dissemination of results:** The study findings has been sent to COMREC, has been disseminated at RDC conference and will be disseminated at MOH conference and other upcoming national and international conferences, stakeholder and professional review meetings, seminars. Soft copies of research documents have been made available to Ministry of Health, Kamuzu University of Health Sciences and Mangochi DHO. The study findings will also be published in paediatric journals

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## List of abbreviations and acronyms

CHEER: Capacity Building for Health Profession Education and Research

COMREC: College of Medicine Research and Ethics Committee

CP: Cerebral Palsy

HMIS: Health Management Information System

ICF: International Classification of Functioning Disability and Health

KUHES: Kamuzu University of Health Sciences

MoH: Ministry of Health

RDC: Research Dissemination Conference

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## CHAPTER 1

### 1.1. Background

Globally the prevalence of Cerebral Palsy (CP) is 1 to nearly 4 per 1,000 children.<sup>4</sup> The prevalence of CP in African countries is higher than in Western countries.<sup>4</sup> In Africa, the prevalence of CP varies widely from country to country from approximately 2 to 10 per 1000 children.<sup>1</sup> In Malawi, CP is a major disabling condition among children.<sup>5</sup> According to 2021 HMIS data there are 6,149 children below the age of 15 years of age with CP attending physiotherapy.<sup>6</sup> Further 23% of children with neurological problems in Malawi have Cerebral Palsy.<sup>7</sup> In Mangochi there are 462 children aged 0-15 years who have Cerebral Palsy attending physiotherapy.<sup>6</sup>

There are three approaches to healthcare service delivery for children with cerebral palsy that includes family-centred care, the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) and collaborative community-based primary care.<sup>8</sup> Family-centred care focuses on family strengths and promotes mutual respect and information sharing between families and healthcare providers.<sup>8</sup> This approach aims at enabling and empowering parents in the healthcare management of their child. Healthcare providers work in a collaborative partnership with families, involve the family in the development and evaluation of services for their child, and provide flexible services to meet the specific needs of each family.<sup>8</sup>

The second health care service delivery approach is the ICF which is a framework that considers the multidimensional interactions between an individual's health, functioning, participation and the social and environmental context of their life.<sup>8</sup> Collaborative community-based primary care is the third approach to healthcare service delivery for

children with cerebral palsy that advocates for all primary and preventative healthcare services for the child and their family to be delivered in the community by a general or specialist physician in collaboration with other health service providers.<sup>8</sup>

Despite the theoretical change toward a family centered health care service delivery approach, parents of children with CP continue to experience dissatisfaction with their children's care.<sup>8</sup> Limited access to health care facilities and specialists, as well as a lack of adaptive equipment such as wheelchairs and other ambulation aids, contributes to the treatment gap for children with CP.<sup>1</sup> Some of the caregivers reported failure of health care workers to disclose information about the disability of their child.<sup>9</sup> High levels of social stigma towards children with neurologic disorders were reported as reasons for families failing to seek treatment even when it was available<sup>1</sup>.

The ability of many families to adjust and cope with disabilities is determined by the availability and quality of support they receive.<sup>9</sup> Researchers who investigated the lived experiences of parents of children with disabilities has revealed the role of social support in improving the livelihood of parents of children with disability by strengthening their coping abilities.<sup>9</sup> Therefore, a need to conduct a study on the experiences of caregivers on health care services for children with CP both at community and hospital level in order to explore more on the type of services the children with CP and their families receive. This will be a prerequisite for improvements in health care provision for CP children at all levels.

Children with CP require multidisciplinary and holistic care in order to comprehensively manage their medical needs as well as maximize their developmental and educational potential.<sup>1</sup> A systematic review on CP in Africa revealed that parents of children with

Cerebral Palsy reported that community-based rehabilitation programs were effective in increasing access to education and assistive devices,<sup>1</sup> however none of these studies exploring the experiences of caregivers on the availability of community services for CP children have been conducted in Malawi.

Many children with Cerebral Palsy may have complex limitations in self-care functions which renders them completely reliant on their caregivers.<sup>2</sup> The provision of such care may be detrimental and stressful to both the physical health and the psychological well-being of parents of children with Cerebral Palsy.<sup>3</sup> Therefore, there is need to learn from the caregivers on the availability of psychosocial services as they care for children with Cerebral Palsy.

There are few studies published that focus on the experience of caregivers on the availability of services for children with CP whilst most studies are grounded more on biomedical approach with the aim of fixing impairment and achieving normality<sup>10</sup>. This study will therefore help to address this information gap. This study therefore aims at exploring experiences of caregivers on services available for children with CP in order to understand services that are available and those that are lacking in Malawi setting.

## 1.2. Rationale/justification for the study

Majority of research studies for CP in Africa have focused on prevalence, etiology, classification, treatment and management, and comorbidities with many gaps in the literature related to lack of qualitative studies exploring experiences of care givers on services for CP children.

There is also lack of studies addressing access to resources and barriers to care. This study will therefore help to address this gap by providing information related to experiences of caregivers on services related to CP.

The findings of the study may also help to identify the gaps on availability of health services, community services and psychosocial services available for children with CP and discover the experiences caregivers related to these services. This information will provide more knowledge in identification of existing gaps in service provision hence it will help to improve quality service delivery and guide in policy formulation to ensure provision of multidisciplinary and holistic care.

### 1.3. Objectives of study

#### Broad objective:

To explore experiences of caregivers on health care and psychosocial services available for children with CP in Mangochi district

#### Specific objectives:

- i. To understand experiences of caregivers on hospital services for children with CP
- ii. To find out experiences of caregivers on community health services for children with CP
- iii. To learn experiences of caregivers on the availability of psychosocial services

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1. Introduction

This section discusses studies that have been conducted in relation to experiences of caregivers on health care services for children with Cerebral Palsy. However, there is limited information related to the topic because more studies have concentrated on the prevalence of Cerebral Palsy and biomedical approaches in managing the condition. The review of literature was guided by the objectives for the study and it mainly focused on the experiences of caregivers on hospital services for children with CP, caregiver's experiences on community health services and caregiver's experiences on the availability of psychosocial services for CP children and their families.

Literature review has been done through rigorous search from books and internet journals. Internet search engines includes; the Google Scholar, WHO website, Research gate, Science Direct and Bio Medical Central.

The key words that have been used during the literature search are; Cerebral Palsy, caregivers, experiences, health care services and psychosocial support.

#### 2.2. Experiences of caregivers on hospital services for children with CP

An explorative phenomenological qualitative study was conducted in Namibia on experiences of mothers of children born with Cerebral Palsy.<sup>2</sup> The study participants were 12 mothers of children under 14 years who were born with cerebral palsy who were admitted in the hospital and those who brought their children for follow up at Intermediate Hospital Oshakati in Oshana region in Namibia. Mothers interviewed in the study had mixed perception regarding the quality of information and service they received from

health care services. Some of the mothers appreciated the service they received from health care professionals, however, majority of mothers were furious about health care workers' failure to disclose the condition of their children as well as failure to give as much information about the condition. Some mothers were not informed about the congenital disorder of their child immediately after birth. They discovered the disability themselves at a later stage, this created a feeling of shame and disappointment to mothers as they expected health care professionals to inform them about the congenital abnormality of their child.<sup>2</sup>

Similarly, Hayles et al conducted a qualitative exploratory study on parents' experiences of health care for their children with Cerebral Palsy in Australia.<sup>8</sup> Thirteen (13) parents of children with CP aged less than 17 years old participated in the study. The study revealed that although some parents received some information from health care workers, the information provided was not comprehensive nor ongoing. Parents described that they received information and guidance from other parents at opportunistic moments or from the Internet. Navigating the systems was also made more difficult by onerous paperwork, limited eligibility criteria, and stretched services which limited access to services. Although parents were eventually able to access the care that was needed, knowing where to go or who to contact was a challenge for almost all parents. Parents described health care for their child with CP as an ongoing cycle of dealing with one issue after another, with the needs of the child and family constantly changing or evolving. The needs of the child and their family changed as a result of increases in the child's functional abilities or size, increases in the child's independence and participation in health care decisions and processes, or in response to the changing demands in life such as school attendance and

social acceptance. Parents in the study learnt of their child's needs in two ways, thus through experience and through receiving information and guidance. However, parents also reported that learning through experience created uncertainty. Parents preferred learning about their child's needs through receiving information and guidance in an anticipatory way. Parents considered that the information they did receive from health professionals and health care providers was often received by chance. This means that information that the parents received from health care providers was not planned and was just given to parents by chance. However, most parents described that having links with other parents, or a social network of parents and carers, was a powerful method for information sharing and problem solving. This study therefore reveals that there was little information that the caregivers received from health care workers about the condition and services available for CP children.<sup>8</sup>

Another study was conducted in Alexandria, Egypt on quality of care provided to children with Cerebral Palsy.<sup>10</sup> The study used a quantitative approach and it recruited 88 parents and caregivers of children with cerebral palsy attending services at Alexandria University Children's Hospital. Fifteen paediatric neurology residents and the Head of the Paediatric Neurology Unit also participated in the study. Caregivers were asked general question about their overall satisfaction with the services provided at the hospital for the CP children. In addition, a structured client satisfaction questionnaire consisting of 8 items was used to assess their degree of satisfaction with specific aspects of the services that included waiting time, waiting area, availability of facilities, number of days the services are available, cost of services, time allowed to discuss problems with care providers and the adequacy of the explanation received. The study found out that only 37% of mothers were

satisfied with the services provided at the hospital for their children; 2% were unsatisfied and 61% were uncertain. Satisfaction was particularly low for waiting time, waiting area and availability of required facilities for their child's care. About two thirds of the mothers (64%) were satisfied with the cost of services. Only 28% were satisfied with the amount of explanation received about their child. This show that caregivers are given little information pertaining to the child's condition and prognosis and this affected the quality of service which CP children received.<sup>10</sup>

According to a study done in Zambia on challenges experienced by mothers caring for children with cerebral palsy it was found that mothers caring for children with cerebral palsy experiences several challenges with the health care system that included lack of provision of assistive devices, attitudes of health care professionals and a lack or provision of transport. Some of the mothers reported that health care professionals were unhelpful and disrespectful.<sup>11</sup>

### 2.3. Experiences of caregivers on community health services for CP children

In India a qualitative study was done on the burden of caregivers of children with Cerebral Palsy.<sup>12</sup> Ten mothers of children with Cerebral Palsy participated in the study. Mothers expressed a high level of motivation and awareness about caregiving for a child with disabilities, however there was lack of knowledge about options for caregiving, support systems, and other social welfare schemes was a major contributor to stress. Caregivers perceived a sense of discrimination and isolation from the community. They felt unable to participate in community events, celebrations or festivals. The caregivers were blamed for the condition of their child. They also felt that the community members spoke behind their backs about their child's condition. Mothers reported lack of support groups and



information support; they complained that government does not organize any support groups of parents with disabilities and do not disseminate any information related to the welfare measures provided for such children. This is a major stressor as the caregivers do not know where to go and what help to seek. Caregivers reported high health-related expenses, especially expenses related to traveling to a health facility for physiotherapy for the child. They felt that there were no buffers to meet these expenses. They recommended that the social welfare policies of the government must cover at least some of these health care-related expenses.<sup>12</sup>

#### 2.4. Experiences of caregivers on psychosocial support and services

A qualitative study was conducted in Namibia on experiences of mothers of children born with Cerebral Palsy.<sup>2</sup> The study revealed that mothers endured emotional and psychological challenges when raising a child born with cerebral; Mothers were shocked, worried and were in the state of disbelief when they learnt about the condition of their children. They felt guilty about the child's disability and blamed themselves as the reason for the disability of their children. Some of the mothers felt bitter in their hearts and showed signs of very low self-esteem and physically cried when they reflect on and see their children with congenital disorders. Mothers were also traumatized by family members and spouses who failed to accept the child with cerebral palsy. On social support services existing outside the family; mothers mentioned receiving support from Faith Based Organizations including pastors, fellow parents of children with CP and assistance from a formal institution such the hospital.<sup>2</sup>

Similarly, mothers in Zambia expressed experienced lack of support from family, friends and community members.<sup>11</sup> This resulted in them being socially isolated which was partly

as a result of fear amongst mothers that people would not accept their children or blame them for the condition of the children. According to the mothers they were blamed for the child's condition by husbands, family, friends, and community members. The interviews revealed that some of the mothers were in conflict with their spouses because of having a child with CP and some of them were divorced as a result.<sup>11</sup> This was mainly because of a lack of acceptance of the child and embarrassment, especially by the male spouses, as well as influence from relatives, poor spousal support and poor coping mechanisms. The study found that managing the chronic health problems of a child with CP along with coping with the demands of everyday life can have a detrimental effect on both the physical and psychological well-being of parents and caregivers.<sup>11</sup> The mothers taking care for children with CP have psychosocial issues that require psychosocial support from family and community members in order to promote their wellbeing.

Another study was conducted in Nigeria on psychosocial problems among mothers of children with Cerebral Palsy.<sup>13</sup> The study revealed that mothers experienced several problems while caring for the child with CP. One of the problems experienced was the over dependence of the children on the mothers due to the inability of the children to attain successive developmental milestones which if attained would have reduced the extent of dependence of the children.<sup>13</sup> The overdependence of the child also restricts the movement of the mothers hence they cannot maintain a regular job nor manage their businesses. Inability to work reduces their capacity to earn a living leading to reduced financial resources. The overdependence of a child with CP also induces a lot of stress on the caregivers. They have insufficient time for other chores, responsibilities and isolation from community activities because of time spent attending to the child at home. This stress may

lead to poor quality of sleep with attendant result of day time dysfunctioning. Invariably, resulted in reduced quality of life of the parents. This raises concern in regard to providing support for the parents of children with CP to alleviate the overdependence and stress. Many caregivers of children with CP have expressed a need for someone to stand in for them to have a chance to do other duties. The study recommended provision of continuous support to caregivers through interventions, which may help to improve quality of life and assist caregivers to deal with the different stressors attendant on caring for a child with CP. Employing sufficient community health workers in the community health centres may also help in reducing the stress parents undergo in bringing their children to the hospital. These community health workers can conduct treatment sessions in their homes or nearby community which the parents will appreciate.<sup>13</sup>

## 2.5. Conclusion

The literature review has shown that several studies have been conducted related to experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children. The literature review has revealed that caregivers were given inadequate information related to CP and some caregivers discovered the disability themselves at a later stage, which created a feeling of shame and disappointment as they expected health care professionals to inform them about the congenital abnormality of their child. Caregivers complained that the information provided by health care workers was not comprehensive nor ongoing. Caregivers also experienced several challenges with the health care system that included lack of provision of assistive devices, attitudes of health care professionals and a lack or provision of transport. On social support services existing outside the family; caregivers received support from Faith Based Organizations including pastors, fellow parents of children with CP and assistance from a formal institution such the hospital.

## CHAPTER 3

### METHODOLOGY

#### 3.1. Type of study

The study utilized cross sectional descriptive phenomenological approach.

#### 3.2. Study place

The study was conducted at Mangochi District Hospital which is a government institution located in southern part of Malawi. This hospital serves as a referral facility for all children with Cerebral Palsy within Mangochi district. Children with cerebral Palsy also visit the hospital on a monthly basis for medical and physiotherapy services.

#### 3.3. Study population

The population for the study were caregivers of children with Cerebral Palsy attending physiotherapy and medical services with their children at Mangochi district Hospital. The caregivers were chosen for the study because they were involved in day to day care of CP children and they accompany these children during the provision of health and social services.

#### 3.4. Study period

The study was conducted between January 2022 and November 2022.

*Table 1: Gantt chart of study period*

<b>ACTIVITY</b>	<b>JAN 2022</b>	<b>MAR 2022</b>	<b>MAY 2022</b>	<b>JUNE 2022</b>	<b>JULY 2022</b>	<b>SEPT 2022</b>	<b>OCT 2022</b>	<b>NOV 2022</b>
Proposal writing								
Pretesting of data collection tool								
Data collection								
Data translation and analysis								
Report writing and submission								
Dissemination of results								

### 3.5. Sample size and sampling technique

The researchers recruited a sample of 12 participants. The sample size selection was supported by Boddy<sup>14</sup> who stated that samples of 12 may be useful as a guide in designing qualitative research, with practical research illustrating that samples of 12 may be cases where data saturation occurs<sup>14</sup>. Guest, Bunce, and Johnson,<sup>15</sup> also operationalized saturation and made evidence-based recommendations regarding non probabilistic sample sizes for interviews<sup>15</sup>. Based on the data set, they found that saturation occurred within the first twelve interviews. However, during data collection of this study data saturation

occurred at 12<sup>th</sup> participant. Data saturation means sampling to the point at which no new information is obtained and redundancy is achieved.<sup>16</sup> A convenience sampling technique was used for this study. Caretakers of children with CP who will be readily available for services at Mangochi District Hospital were recruited for the study.

### Inclusion criteria

The study included:

- Parents and guardians of children with Cerebral Palsy of any age
- Parents or guardians with children with CP who were in a stable state (not requiring emergency care)
- Parents who attended routine medical visit with their children at the hospital
- Guardians or parents who participates in the care of the child at home

### Exclusion criteria

The exclusion criteria for those who did not participate in the study included:

- Parents or guardians who had hearing or speaking disability
- Parents or guardians whose children were critically ill

### 3.6. Data collection procedures

Data collection was done using face to face in depth interviews with the aid of a semi-structured interview guide that was developed by researchers (refer to Appendix 2A). Tape recorder was used during the interviews and the information provided by the guardian was transcribed after the interview. The semi structured interview guide had two sections; Section A which contained demographic data of the participants and Section B which contained open ended questions that allowed participants to express their experiences. The questions focused on experiences of caregivers on hospital services for children with CP,

caregiver's experiences on community health services for CP children and on the availability of psychosocial services for CP children. In order to facilitate communication, the guide was formulated both in English and Chichewa (Refer to Appendix 2A and 2B).

To ensure data trustworthiness the researchers conducted interviews with all the participants using the same interview guide. The interview guide was pretested on 3 caregivers of children with CP at Mangochi District Hospital to ensure that the interview guide had the required information that needed to be obtained from the participants. After pretesting, the interview guide was modified. Expert review process was done whereby the research supervisors, research mentors and other paediatric doctors and nurses were consulted to review the interview guide before the data collection and review data analysis findings. Finally, triangulation was done thus cross-checking data from multiple sources to search for regularities in the research data. These measures were made in order to ensure that the collected data was authentic and truthful so that results should be trusted by all.

### 3.7. Data management/analysis

To ensure anonymity participant's names were written on the questionnaire, instead number codes were used. Tape recorder was kept safe in a locked drawer. Data recorded in tape recorders was also kept in laptops and locked with password for safety and privacy. Interview guide papers were kept in a locked drawer for safe keeping and maintenance of participant's privacy and confidentiality.

Data obtained from the participants was analyzed using thematic content analysis. The analysis followed the following steps as outlined by Creswell <sup>17</sup>. Firstly, the data was organized by transcribing the interviews, thus the researchers listened to the tapes to become immersed in the data, tape-recorded interviews was then transcribed word for word

then entered and stored in a word document. Secondly, data was organized and was divided into meaningful analytical units. Organized data was then coded by being assigned and grouped into codes. Coding helped the researchers in the generation of themes and subthemes which was presented as findings in the study.

### 3.8. Presentation of results

The results from the interview was presented using themes and subthemes.

### 3.9. Dissemination of findings

The study findings were disseminated to COMREC, stakeholders and health professionals through review meetings, seminars, national and international conferences. Soft copies of the study were also shared with Ministry of Health, Kamuzu University of Health Sciences and Mangochi DHO. The study findings will also be published in paediatric journals.

### 3.10. Ethical consideration

The proposal was submitted for ethical review and approval at College of Medicine Research Ethics Committee (COMREC) to ensure that patient's rights are protected. Permission to conduct the research was sought from the District Health Office ethical committee, they were notified about the study and permission to conduct the study was obtained.

The details for the study that include the purpose, procedure, risks and benefits was explained to the caregivers who met the inclusion criteria in the local language (Chichewa).

After giving the information about the study, participants were allowed to make an informed choice of whether to participate in the study or not. Participants who consented



to participate in the study signed the consent form by either thumbprint or signature. Participant's right to information, confidentiality, anonymity and privacy were respected. Participants were also informed that they were allowed to ask questions and had the right to participate voluntarily and could withdraw at any point and this would not affect their access to care (See appendices A, B, C and D for consent forms in English and Chichewa respectively). To ensure confidentiality, participants' identity was not disclosed and number codes were used on the interview guides. Only the researchers and mentors had access to the information.

### 3.11. Possible constraints

The study was conducted at one site only due to limited time and funding of the study programme. The findings might therefore not give a general representation of experiences which caregivers of CP children have on health care and psychosocial services.

## CHAPTER 4

### PRESENTATION OF FINDINGS

#### 4.1. Introduction

This chapter presents findings of the study on the experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children at Mangochi district hospital. The study findings are presented in consistency with the study objectives and themes that has been developed.

#### 4.2. Demographic data

All 12 participants were females, 10 were biological mothers of children with CP. One participant was an aunt for the child whose mother passed away when he was young and the other participant was a grandmother. Eight (8) of the caregivers were young mothers within the ages of 20 to 25 years old, 3 caregivers were between 26 to 30 years old and one caregiver was 38 years old. Ten (10) participants were married, one was single and one was divorced. On education level, 7 participants were primary school leavers, 4 were secondary school leavers and one did not attend any school. Nine (9) participants were not working and were depending on their spouses and relatives for support. Two participants were self-employed and one was working temporarily. Table 1 summarizes the characteristics of the participants who took part in this study.

**Table 1: Demographic data of participants (caregivers of children with CP children)**

<b>Category</b>	<b>Characteristics</b>	<b>Frequency (N=12)</b>
<b>Gender</b>	Female	12
	Male	0
<b>Age</b>	20 – 25	8
	26 – 30	3
	31 – 35	0
	36 - 40	1
<b>Level of education</b>	Tertiary	0
	Secondary	4
	Primary	7
	No education	1
<b>Employment</b>	Temporally employment	1
	Self employed	2
	Unemployed	9
<b>Marital status</b>	Single	1
	Married	10
	Divorced	1
<b>Relationship of caregiver to child</b>	Mother	10
	Aunt	1
	Grandmother	1

Based on the findings of the study, five main themes were generated as shown in Table 2.

**Table 2: Themes and subthemes**

<b>Themes</b>	<b>Subthemes</b>	<b>Codes</b>
<b>Experiences before diagnosis</b>	During birth	Prolonged labour, prematurity, difficult delivery
	After birth	Jaundice, convulsions, body weakness, poor neck control, delayed developmental milestones
<b>Experiences of CP management at hospital setting</b>	Good client reception	Short waiting time, friendliness of health care workers, good satisfaction of services
	Inadequate information on CP	Lack of information on etiology, prognosis and management, inadequate health information on home care Informal support
	Lack of comprehensive management	Lack of psychosocial counsellors, prosthetic, lack of medications and other services, disintegrated care
<b>Experiences of CP management at community setting</b>	Availability of informal support networks	Family and friends and religious leaders
	Inadequate formal support networks	Few NGOs, lack of psychosocial counsellors, lack of visits from HSAs, lack of follow up
<b>Needs of caregivers of children with CP</b>	Basic needs	
	Rehabilitation equipment	
	Home visits	Lack of home visits by health care workers

Themes	Subthemes	Code
<b>Challenges encountered by caregivers with CP children</b>	Financial challenges	Lack of transport for travelling to and from the hospital
	Long distance	Missing monthly appointments
	Lack of prosthetics and play materials	
	Lack of special learning facilities	

#### 4.3. Experiences before diagnosis

##### 4.3.1 Experiences during birth

One of the participants reported that she had prolonged labour and difficult delivery and the child was born prematurely. Another participant reported that her child did not cry at birth and some children developed asphyxia soon after birth.

Participant MH06 noticed that the child the child was doing things differently as compared to children of his age group. She explained

*“I noticed that the child was doing things different compared to other children of her age, the child was weak and was not able to sit. The problem started during her birth, she did not cry soon after birth and the child had problems with breathing after birth.”*

Participant MH10 narrated that:

*“The child was born prematurely at 7 months, I also had prolonged labour which lasted for 3 days and when the child was born she had asphyxia and the child was admitted at nursery for 1 week the child also developed jaundice. The child did not cry at birth up until I was discharged. I was doing Kangaroo mother care to the child for 2 months at home but still the child was not crying. After 2 months I went back to the hospital for review and the doctors told me that the child has problems in his brain”*

#### 4.3.2 Experiences after birth

Four (4) participants sought medical help after noticing that their children were not able to sit on their own, their bodies were weak, had poor neck control and convulsions, strange cry and had delayed developmental milestones as compared to children of their age group

Participant MH11 narrated that her child was not breathing properly soon after birth:

*“The child was not breathing properly soon after birth and the child was taken for resuscitation and given oxygen, she stayed there for some minutes. During the night I noticed strange cry and abnormal neck stretching, I told the nurse about it and the nurse gave her an injection and the child slept well up until we were discharged. At home, the problem started again, the child was having twitching and strange cry every day, every morning and evening, her body was also hot. One day I noticed that the child was weak and flabby and I went to the hospital with her and I was referred to physiotherapy.”*

Participant MH12 also narrated:

*“I discovered that the child had problems related to the brain soon after the child was born, she did not cry soon after birth and the child went to nursery and was on oxygen for one week. After discharge the child was having convulsions. When the child was 6 months old, I went with the child for review to the hospital where I was told that the child has problems related to the brain.”*

Participant MH09 explained that she took her child for physiotherapy after discovering that the child was not able to sit and had poor neck control

She explained:

*“When the child reached 4 months, she was not able to sit and her body was weak, I took the child for physiotherapy. When the child reached 8 months her neck was not strong, when I carried her or put her on my back she had poor neck control, she was still not able to sit on her own and she was just sleeping. I started visiting physiotherapy when she was 4 months up until now the child is 1 year and 11 months”.*

Participant MH11 explained that the child had convulsions (twitching), fever and was weak and this prompted her to seek medical helps

*“The child was not breathing properly soon after birth and the child was taken for resuscitation and given oxygen, then we were discharged. At home, the problem started again, the child was having twitching and strange cry every day, every morning and evening, her body was also hot. One day I noticed that the child was weak and flabby and I went to the hospital with her and I was referred to physiotherapy”*

#### 4.4. Experiences of CP management at hospital setting

##### 4.4.1 Good client reception

Short waiting time, friendliness of health care workers, good satisfaction of services

Four (4) participants reported that they were received well by the health care workers at physiotherapy clinic. The participants said that health care workers are friendly, good and they welcome children and caregivers well.

Participant MH02 narrated:

*“They receive me well, they help the child in good time and I go back home in good time.”*

Participant MH05 said that:

*“The health workers are very welcoming.”*

Participant MH06 and MH09 respectively reported that:

*“They welcome me well, they are friendly and good.”*

*“They receive us well, they are welcoming and friendly”*

Six (6) caregivers reported that they waited between 10 minutes to 30 minutes for their children to receive physiotherapy services.

Participant MH02 narrated:

*“I stay at physiotherapy for a maximum of 30 minutes; I go back home before 12 o'clock.”*

Participant MH05 stated:

*“I wait for about 10 minutes before my child is assisted.”*

Participant MH06 narrated:

*“They assist the child in less than 1 hour, I do not wait for long for the child to be assisted.”*

Participant MH08 stated:

*“We do not take long to be assisted by the health care workers, when we are many they put us in different beds and they help us well.”*

Participant M10 narrated:

*“I do not wait for long, this is because children are given different dates of appointments therefore there are few children to be seen during the review dates.”*

Participant MH01 said that she does not wait on the queue when accessing medical services for the child.

*“I was told by one of the doctors that I should not wait on the queue, I should just go with the child to treatment room. so, I don’t wait on the queue. They gave me a card to show to clinicians so that I can go inside and be treated immediately.”*

Four (4) participants were satisfied with the care their children receive at physiotherapy clinic because their children were improving. However, 2 participants were not satisfied with the services because their children were not improving.

Some of the participants who were satisfied with the care narrated that:

Participant MH06:

*“Yes I am satisfied with physiotherapy services, the child has improved, the child is able to sit and able to eat properly.”*



Participant MH03:

*“Yes I am satisfied with the care, at first the child was not sitting properly and had poor muscle control, but after starting physiotherapy and home exercise, the child has good head control, the child is able to turn the head, hold the breast and is able to sit. We are seeing great improvement in the child.”*

Participant MH04:

*“Yes, am satisfied with the services that the child receives.”*

Participant MH10 was satisfied with the care, however wanted more assistance and information related to how can the child improve for the better

She narrated:

*“Yes, I am satisfied but I think the child is not changing interms of his back, I feel that the clinician who reviews and assists the child should tell me how should we make his back again.”*

Few participants were not satisfied with the health services their children received.

They narrated:

Participant MH01:

*“No, am not satisfied because the child is not improving despite taking the child to hospital for so long.”*

Participant MH11 narrated:

*“I am somehow not satisfied because this is the third year I have been taking the child for physiotherapy but his body is still weak.”*

#### 4.4.2 Inadequate information on CP

Majority of participants reported that there were not provided with adequate information related to etiology of CP, prognosis and management and they received inadequate information on home care for their children.

Majority of caregivers were told information about Cerebral Palsy by the clinicians. However, some of the caregivers were given inadequate information and there was delayed information giving. 3 participants reported given information from clinician, 1 reported not got information from clinician

Participant MH04 narrated:

*“I discovered that the child had problems related to the brain after the clinician at physiotherapy told me. I was told that the child was born preterm therefore he also has problems related to the bones, he has weak bones and has problems with sitting”*

Participant MH05 narrated:

*“When the child was 6 months old he could not sit and the doctor told us that the child has problems related to the brain.”*

Participant MH02 narrated:

*“I learnt that the child had CP at the hospital it was the clinician who told me. I was visiting the hospital frequently but I was not told anything about the child up until on 20th May 2022 when the child was 1-year-old.”*

Participant MH01 expressed concerns about the need for more information about CP:

*“I wish that they should have given me information on whether the child’s condition will improve or whether he will be healed.”*

#### ***4.5.1. Information on prognosis of the condition***

The caregivers were told that their children's condition will improve depending on their efforts and consistency on physiotherapy visits and home exercises. However, some were told that prognosis depends on the child's condition, some children will get cured completely whilst others will not.

Three (3) participants were told that their children's condition will improve depending on their efforts and consistency on physiotherapy visits and home exercises. while 2 participants were told that prognosis depends on the child's condition, some children will get cured completely whilst others will not.

Participant MH04 narrated:

*"I was told that if I bring the child to physiotherapy and if I support the child at home the child can be able to do other things on his own like sitting. I am seeing some improvements in the child after doing exercises at home, the child is able to sit on his own for some time."*

Participant MH06 narrated:

*"I was told that other children get better and cured whilst others do not get cured"*

Participants MH08 narrated:

*"I was told that if I will be helping the child sit and stretch his legs, he will improve. But I have never been told if the child has started improving"*

Participants MH10 narrated:

*"I was told that the child might get better but it depends on my efforts if I do the stretching exercises at home. It also depends on God's will for the child to heal"*

Participant MH05 narrated:

*“We were told that the only cure is physiotherapy, there is no specific medication to cure CP, they said that maybe in future the child will get better”.*

#### ***4.5.2. Home care information received by caregivers for children with Cerebral Palsy***

Majority of caregivers were taught on how to do stretching exercises for their children and help them achieve developmental milestones for example supporting the child to sit, crawl and stand.<sup>4</sup> Participant were told to buy chairs for supporting the children to sit

ParticipantMH01 stated:

*“They encourage me to be doing exercises to the child. They also advise me to buy chair for the child so that she can be sitting well. At first I noticed that the child was improving he was able to sit but now he is not.*

Participant MH03 explained:

*“I was told that I should be doing exercises to the child at home, I should use the chair or put the child at the corner of the house so that the child should be able to sit.”*

Participant MH09

*“They told me to be doing exercises to the child at home. They taught me on how to do stretching exercises to the child, how to help the child crawl They also told me to help her touch things using her hands.”*

Participant MH11

*“I was told that I should be doing stretching exercises to the child. I dug a small hole which the child sits on it. Sometimes I put the child at a corner with the aid of the blanket for support so that the child can sit and stand.”*

#### **4.5.3. Additional information caregivers wanted to know about Cerebral Palsy**

4 participants wanted to get more information from the health care workers related to reasons their children were having CP, prognosis of the condition and how to take care of children at home.

Participant MH04 narrated:

*“I wanted to know what has made the child have this condition.”*

Participant MH01 stated:

*“I wish that they should have given me information on whether the child’s condition will improve or whether he will be healed.”*

Participant MH05 narrated:

*“I wanted to know more if the child will be completely cured.”*

Participant MH12 narrated:

*“I wish I could get more information on how I can take care of the child. The health workers should teach us on how we can take care of children with CP and they should demonstrate on how we should take care for children with CP”.*

#### **4.6. Hospital services for Cerebral Palsy**

Majority of children with CP visits physiotherapy services only. Some children were visiting Nutritional rehabilitation units and underfive clinics for growth monitoring and treatment of medical conditions and other were visiting pharmacy to receive medications for epilepsy. Three (3) participants visited physiotherapy services only. Some participants were visiting nutritional rehabilitation units and underfive clinics for nutrition supplements, growth monitoring and treatment of medical conditions and others were visiting pharmacy to receive medications for epilepsy.

Participant MH04 narrated:

*“I take the child to physiotherapy then to Nutrition Rehabilitation Unit to receive nutrition supplements (chiponde), sometimes when the child is sick I take the child to underfive clinic*

*to be seen by the doctor. At physiotherapy they stretch the child's legs and hands, then the child is put on the chair and is supported to stands on the board."*

Participant MH05 narrated:

*"They take care of the child well, the child's hands and legs are stretched and she is taught how to stand and walk. There is improvement in child's condition because at first the child was not able to turn his head and body but now he is able to turn and he is able to crawl. The child is also given antiepileptic medication at the pharmacy of which he takes 2 tablets everyday"*

Participant MH10 narrated that the child is given play materials at the physiotherapy department

*"Apart from physiotherapy, the child is give play materials to play with."*

Participant MH10 also narrated about the stretching exercises that the child is done during physiotherapy

*"When I go to physiotherapy they welcome me and check the health passport of the child, then the child is put on the bed, I help the child to sit and I stretch the joints of the child ten times. I also do these exercises at home three times a day, in the morning, afternoon and evening."*

Participant MH02 narrated that she also visits underfive clinic with the child apart from physiotherapy:

*"I take my children to under five clinics for growth monitoring then I go to physiotherapy."*

Participant MH06 narrated that:

*"When the child is sick I take the child to underfive OPD clinic".*

#### ***4.6.1. Understanding the rationale for provision of physiotherapy services***

Majority of participants understood the rationale for provision of physiotherapy services for their children.

Participant MH03 narrated:

*“Yes, I understand why they perform the exercises to the child, they want the back of the child to be normal and straight. They do this whilst the child is young so that when the child grows she should have a normal growth.”.*

Participant MH05 stated

*“Yes, I do understand that the child receives treatment according to the problem that the child has. I understand that the child is done physiotherapy so that he should do other activities independently, they help him to hold things which he does not hold by himself”.*

Participant MH04 narrated

*“Yes, I do understand, the child is assisted with physiotherapy because he has weak bones. They teach us to do the exercises so that we can continue doing the stretching exercises at home”.*

#### ***4.6.2. Lack of psychosocial services at the hospital***

Majority of participants reported lack of psychosocial services at the hospital for example there is no counselling services and social support services in terms of provision of support devices to help CP children with standing, walking and sitting. The participants also reported that they have never met a social worker, counsellor or a clergy.

Participant MH02 narrated:

*“I do not receive any psychological support at the hospital.”*

Participant MH03 narrated

*“We do not receive any psychological support at the hospital, children only receive physiotherapy services.”*

#### **4.6.6. Additional health care services needed by caregivers of children with CP**

Majority of participants wished that their children should be done further investigations and surgical procedures, some requested for Beit cure services.

Participant MH03 narrated:

*“My wish is that the child should have further investigations; I want my child to be done X- ray so that I should exactly be told what the child’s problem is. We requested that the child should have an X ray but that was not done. They just said the child has a problem but they did not specifically say what the child’s problem is. They just said the child was born with this problem.”*

Participant MH06 stated:

*“I asked the doctor if the child should be done surgical operation for her to be normal and the doctor told me that it is not possible”*

Participant MH05 narrated:

*“I have heard that there are specialists who visit the hospital and when people frequently visits the hospital for physiotherapy with their children they are sent to Zomba or Blantyre for treatment and the child improves for the better.”*

Participant MH07 narrated:

*“My only worry is on the child’s condition, I wish there was cure for the child, I was told that it is not possible for the him to get cured. I asked if the child can go to Beit Cure but I was told that Beit Cure treats children with other conditions but not children with problems related to the brain. The child can only be treated if he has brain lesion”*

Participant MH02 narrated:

*“I asked the doctor about the child’s problems if the child has any other problems apart from the brain problem, maybe the child can be seen by other specialists to review the child on other body areas for example the back and the legs. I heard that other specialists visit the hospital to review children for example orthopaedic doctors, I wish my child can be reviewed by the orthopaedic doctor so that he can be assisted comprehensively.”*



Participant MH01 narrated:

*“We want the child to be done further investigations so that we can exactly know the problem that the child has”*

Participant MH05 and MH06 expressed their need to be given advise and health education related to child care.

Participant MH05 narrated:

*“I would have loved if the health workers could have been giving us advise and health education on how to best take care of the child with CP”*

Participant MH06 explained:

*“It can be good if you will be providing advice to us so that we can know what we are supposed to do to the child and what we are not supposed to do”*

Participant MH02 also expressed the need for health workers to tell the caregivers their names

She stated:

*“We need to know names of the health workers, the health workers taking care of children should be the same, I am willing to do anything I am advised by the health workers”*

#### 4.7. Home care for the child with CP

Majority of caregivers reported that they were able to take care of their children at home. They provided their children with basic care for example feeding, bathing and elimination.

Participant MH01 narrated:

*“The child does not sit so I help her sit, she does not feed on her own sometimes she refuses food so I feed her, I use cup to make her take tea or water and I feed her with hands for other food. She is able to eat with my help and she swallows properly”*

Participant MH02 explained:

*“I help the child to sit and stand, sometimes I take the pail and put the child inside the pail to help the child stand with support. The child is 1 year and 6 months and I feed the child using spoon, he sometimes feed on his own small portions but food falls down. He eats sweets and Kamba puffs on his own, for nsima he does not eat on his own, he tries to take nsima but he fails to put it on his mouth it falls down. I bath him three times a day. He uses pampers. He plays with his friends well though he cannot do some of the things”*

Participant MH07 narrated:

*“In the morning I give her food, then later I bath her and put her down so that she can play. If the child has passed stools I remove the nappies and wash her. I also make sure that her clothes are clean”*

Participant MH09 said:

*“I mostly do piece work which helps me buy food, soap and clothes for the child. I feed, bath the child and wash clothes for the child”*

Participant MH04 narrated:

*“I use spoon to feed the child, the child eats porridge mixed with groundnut flour, sometimes soya porridge alternating with chiponde, sometimes when I have money I buy milk for the child sometimes supershake. Soon after eating I put the child on my lap so that he can eliminate. I use the chair that I borrowed from my friend to help the child sit so that he can be chatting with his friends”*

#### **4.7.1. Who taught caregivers on child care**

Caregivers were taught by health workers and their mothers on how to take care of their children.

Participant MH01 narrated

*“I was taught by the health care worker at the Nutrition Rehabilitation Unit on how to feed the child. The child was admitted last year with malnutrition and anaemia and that was the time that I was taught on how to feed the child. I was taught that I should give the child six food groups”*

Participant MH02 said:

*“Health workers from the hospital at physiotherapy department taught me to do these activities”*

Participant MH03 explained:

*“We were taught at the underfive on exclusive breastfeeding and on feeding the child porridge”*

Participant MH11 narrated:

*“I was taught at Mtanga Health centre by people from a certain organization”*

Participants MH05 and MH07 were taught child care by their mothers

Participant MH05 said:

*“My mother taught me on how to care for the child in terms of feeding and bathing her”*

Participant MH07:

*“My mother taught me to do the exercises for the child”*

However, some of the participants were not taught by anyone on child care.

Participant MH09 narrated:

*“Nobody has taught me how to do these activities, I just felt that I have to do basic things for the child like feeding and bathing the child”*

Participant MH04 narrated:

*“Nobody has taught me on how to take care of the child”*

Participant MH06:

*“Nobody has taught me on how to take care of the child, I was just observing her behaviours and assume that the child needs care for example elimination”*

Participant MH08:

*“Nobody has taught me to do this it’s just my personal intuition”*

#### 4.8. Education for CP children

Majority of caregivers reported that their children had not yet started school. Majority of children were young to start school as reported by the participants.

Participant MH01 said:

*“My child is 1 year and 2 months; she has not yet started school”*

03: Not yet the child is still young she is 7 months

Participant MH06 narrated:

*“The child has not yet started school I am waiting for her to be 2 years old so that she can start nursery school”*

Participant MH07 narrated:

*“The child does not go to school because he is small”*

Participant MH09 explained:

*“She has not yet started going to school but I teach her at home on how to speak, walk and chat with friends”*

#### 4.9. Challenges encountered by caregivers during child care

Caregivers reported several challenges related to child care. These challenges included; lack of food for their children, transport challenges, children crying uncontrollably and challenges related to basic care.

Some caregivers reported that children cry continuously and uncontrollably

Participant MH01 said:

*“The child sometimes cries continuously but now the condition has improved with medication the crying episodes has reduced”*

Participant MH05 explained:

*“The child gets sick sometimes he has fever so I take him to hospital, sometimes he cries continuously”*

Some caregivers reported having challenges in providing food for the child

Participant MH04 explained:

*“I have challenges to find the required food stuff for the child, I wish there was someone to help me buy the food stuff for the child”*

Participant MH07 said:

*“I have challenges with providing food and soap for the child. I only give porridge to the child because I cannot afford to buy other food stuff for the child”*

Participant MH10 explained:

*“The child is selective when it comes to food, he eats soft food easily compared to nsima, so sometimes when I do not have the food he wants he just feed a little”*

Participant MH11 explained:

*“The child has difficulties in feeding, the child does not swallow normally and sometimes doesn't drink water properly, he spills the water. The child also cries frequently. Sometimes the child seems to be confused”*

Participant MH02 narrated:

*“The child is able to eat available family food. Sometimes when we do not have food I just give him breast milk”*

Some participants reported having challenges with child care

Participant MH12 narrated:

*“Sometimes when I am bathing the child, when I haven’t positioned her well, water gets into her mouth and she develops shortness of breath”*

Participant MH08 explained:

*“At home I do not work properly, the child wants to be at my back each and every time because she cries when she is left on the floor, we cannot move the mattress from the bedroom to outside”*

Participant MH09 expressed her challenges related to lack of transport money to take the child to hospital for review. She explained:

*“I have transport challenges, when I have no money I find it hard to take the child for physiotherapy to the hospital”*

#### 4.10. Community support networks for CP children and their caregivers

##### **4.10.1. Family members**

Majority of caregivers reported that they were supported by their family members in taking care of their children in terms of helping them with basic child care and providing them with financial support

Participant MH01 narrated:

*“My mother and my husband helps me in taking care of the child. They feed the child, bath her, dresses her and help her sit”*

Participant MH03 explained:

*“My grandmother helps me with taking care of the child and with some exercises for the child. My sister in law helps me in taking care of the child and she also takes the child to the hospital sometimes. My grandmother gave the child traditional medicine and there is an improvement after she was given the medicine, she also encouraged us to be visiting the hospital”*

Participant MH07 explained:

*“My mother and grandmother assists me with the care of the child. My relatives assist me in terms of providing transport money for the hospital visits, they also give me money to buy food and soap for the child”*

One participant (participant MH02) who had various sources of support narrated:

*“My child received K15,000 three times from a certain organization. I get support from my sister, my sister in law and my father in law. My sister is in South Africa, she sometimes sends me money to buy food for the child, sometimes she sends me clothes. My sister in law take care of the child”*

Participant MH10 gets support from her church members. She reported:

*“I get support from the church, they counsel me and encourage me to pray hard so that the child should get better, they also encourage me to follow the advice that I get from the hospital”*

However, some participants reported that they do not receive support from anyone

Participant MH08 narrated:

*“I do everything for the child. No one helps me with child care”*

Participant MH04

*“Nobody helps me take care of the child”*

Participant MH10

*“No one supports me with child care”*

#### ***4.10.2. Support from non-governmental organizations***

Some participants reported that there were non-governmental organizations that came to their community teaching them on child care for CP children. Some organizations offered financial support to young children.

Participant MH11 narrated

*“I was told the HSA who stays at Chimwala to go to Mtanga health centre where people from a certain organization taught me and other mothers with CP children on child care, but they only came twice”*

Participant MH02 stated:

*“Here we do not have any organization that helps children but from where I was staying in my home village, children who were younger less than 2 years, their mothers were receiving K15,000 to buy food stuff for children. I am not sure if this happens here”*

Participant MH04 explained:

*“I once heard of an organization which came in our area and it was helping young children I do not know what they were doing. I did not participate in that organization”*

Participant MH07 narrated:

*“There are organizations in my area, but I do not receive support, others they receive bicycles and others are supported monthly. I feel that my child is not assisted because they do not know that I have a child with this condition”*

However, majority of participants reported that there were no organizations within their community that offered them with support

Participant MH01 narrated:

*“There are no organizations in my area”*



#### **4.10.3. Caregiver's interaction with social workers or counsellors**

All caregivers reported that they have never been visited by the social workers.

Participants MH07 and MH10 narrated:

*Participant MH07: "I have never been visited by the social worker"*

*Participant MH10: "I have never been visited by the social worker at home"*

One participant reported to have met the counsellor

Participant MH05 stated:

*"Yes, I met the counsellor at my area, I met her on the way home and it was once, she encouraged me that I should take care of my child and love him so that they should always be happy and not sad and depressed. I do not know her name but she works here at the hospital"*

#### **4.10.4. Caregivers interaction with religious leaders**

Some participants reported that they have met pastors and sheiks for spiritual support and healing prayers for their children

Participant MH01 stated:

*"I went to a pastor twice with the child for healing prayers and spiritual encouragement"*

Participant MH05 stated:

*"I once went to the Sheik who was giving me the medication to give the child"*

Participant MH06 narrated:

*"I go to the pastor for healing prayers of the child"*

#### **4.10.5. Lack of support groups for caregivers**

None of the caregivers had ever participated in the support groups.

Participant MH01 narrated:

*"No I have never participated in any support group"*

Participant MH03 stated:

*“No I have never participated in any social group that deals with CP children, we only have women groups that encourages each other on family planning and nutrition for children on 6 food groups”*

Participant MH05 narrated:

*“No, I have never participated or heard about any social groups for caregivers for children with CP”*

#### ***4.10.6. Lack of home visits by health care workers***

Less than half of participants have been visited by the Health surveillance assistant (HSA). None has been visited by health care workers at physiotherapy clinic. Some of the reasons that the participants gave for the home visit was not related to provision of support related to child's CP condition but it was related to routine HSAs visit in the communities

Participant MH03 narrated:

*“The Health surveillance assistant (HSA) visits us for other things not related to the child health welfare but for other hygienic education for example how we should take care of our toilets. The HSA also teaches us about exclusive breastfeeding”*

Participant MH09 narrated:

*“The Health surveillance assistant (HSA) sometimes visits me. She gives me health education on how to prepare nutritious food for the child, and I should take good care of the child”*

Participant MH02 explained:

*“The child was once visited by health workers who gave the child polio vaccine during the polio immunization campaign”*

One Participant MH09 was visited by HSA specifically on issues related to the child's condition. She explained:

*“Yes, I have been visited by the health worker who stays at Chimwala. She told me to go to Mtanga health centre. People from a certain organization taught me and other mothers with CP children on child care, but they only came twice”*

However, more than half of the participants have never been visited by the health care worker

Participant MH01 narrated:

*“They have never visited me in my home but during the immunizations they ask me about the child condition and her wellbeing”*

Participant MH04 narrated:

*“Nobody visits the child at home”*

Participant MH05 narrated:

*“There is no one who visits us at home”*

Participant MH08 narrated:

*“I have never been visited by anyone*

#### ***4.10.7. Caregivers recommendations on who should do home visits***

Majority of caregivers recommended that healthcare workers from physiotherapy clinic should visit them atleast once a month. Some caregivers recommended Health surveillance assistant within their community to visit them for physiotherapy and to review their children

Participant MH01 said:

*“Any health worker can visit me more especially the Health surveillance assistant”*

Participant MH02 narrated:

*“Most of the times when we go to the hospital we are seen by different workers but there is one health worker who treats my child well, I would like that lady to treat and see my child. I do not know her name, the child gets well with the health worker but when the child is treated by other health workers he cries and feels uncomfortable. There are other health workers who are fast and some are slower”*

Participant MH03 explained:

*“We want the health workers (HSAs) who give us health education at underfive clinic to be coming and visit us in our home so that they can see how the child is growing and improving, we want them to encourage us that the child is growing well and advise us properly on how to take care of the child. We want them to be coming once or twice in a month so that we can be encouraged by them”*

Participant MH04 narrated:

*“I wish health workers from physiotherapy could visit me once a week so that they can be reviewing the child and see if am taking care of the child properly”*

Participant MH05 narrated:

*“I would want the health workers from physiotherapy clinic to visit me atleast daily so that they should be doing physiotherapy”*

Participant MH06 explained:

*“I would wish different organization visits us, and health workers who are on pension can visit the child, at least once in a month and they can coordinate with health workers at physiotherapy. It may be hard for health workers at physiotherapy to visit me because they are also busy at the hospital assisting other sick people”*

Participant MH08 explained:

*“I would like the health workers at the physiotherapy clinic to visit me, atleast twice a month and they should support me with pampers and chairs for the child”*

Participant MH10 said:

*“I would like health workers from the physiotherapy clinic to visit me at home so that they can see how I am taking care of the child and check if the child is improving or not”*

Participant MH11 narrated:

*“I would like Health workers from physiotherapy to visit me so that they should taught and remind me on child care. They should be giving us money to buy food for the child support. Children with CP needs frequent and special diet”*

Participant MH12 explained:

*“Health workers from physiotherapy should visit us twice a month and they should bring play materials and food stuff for example Likuni phala”*

#### 4.11. Support services requested by caregivers

Caregivers had different needs on support services. Some of the caregivers requested financial and material support to carter for transport, food, pampers/drypers, mattresses, bikes and recreation materials for their children.

Participant MH01 narrated:

*“I pay a lot of money (K3,000) for transport when taking my child to hospital for physiotherapy service. I pay K1,500 when coming to the hospital and K1,500 when returning back home. I would appreciate if they could be giving us transport money”*

Participant MH12 explained:

*“I need assistance with transport money and on child care for example giving us football, dolls and bicycles to assist the child with recreation”*

Participant MH04 who takes care of her late sister's child requested food support. She narrated:

*“The child does not breastfeed so I have challenges in obtaining food for the child. I need support to buy some food stuff for the child for example milk and porridge”*

Participant MH04 also expressed need for medication at the hospital

*“The child has a chronic ear problem, when he is seen by the health workers he is not given any ear medicine because it is out of stock, so I wish that the ear medication should be available at the hospital”*

Participant MH05, MH06 and MH07 requested bikes to help their children in walking. they narrated:

Participant MH05:

*“I want the child to have a chance of getting a bike which can help him with walking, his friends can help him walk him through and play. I also want the child to have the play materials”*

Participant MH06:

*“I would want my child to have devices which helps in balancing the child when he stands, there are bicycles which have baskets and children are placed inside those baskets. I have never seen the bikes here at the hospital, people buy them from people who come from South Africa”*

Participant MH07:

*“I would love if they would provide us with a bike so that the child should be able to walk using the bike”*

Participant MH09:

*“I need my child to have a bike with wheels so that the child should be able to walk with the aid of that bike”*

Participant MH02 narrated:

*“I was also told to find a small plastic bike with tyres so that the child can stand and walk with the aid of that bike but the bike is expensive and I cannot afford it. The child does not take long to walk with the aid of that bike. At first it was K26,000 but I do not know the price recently. The bikes are from Tanzania”*

Participant MH08 narrated:

*“There is need for more play materials for children so that when more children have come for review they should play with the materials. We also need mattresses and pampers for children, chairs for children to sit at home we cannot manage to buy the chairs because they are expensive”*

Some participants requested for financial support in order to meet their children's needs

Participant MH07 narrated:

*“The child needs to be assisted financially for example providing us with money so that we can use it to buy required stuff for the child”*

Participant MH09 said:

*“I feel that the social organizations should also be involved in caring for the child, they should give me money to take care of my needs and the child's needs”*

## CHAPTER 5

### DISCUSSION OF FINDINGS

#### 5.1. Introduction

This chapter will discuss on the findings related to experiences of caregivers of CP children. The discussion will focus on the demographic characteristics of the participants, experiences of caregivers related to the diagnosis of their children, information of CP that caregivers had, experiences on health care and social services for CP children and challenges faced by caregivers during care of children with Cerebral Palsy

#### 5.2. Demographic characteristics of caregivers

This study found that all caregivers of children with CP were women, mostly young mothers between ages of 20 and 30. Majority of caregivers had poor socioeconomic status; they were not working, were primary school leavers and were depending on their relatives and spouses for support. Poor socioeconomic status affected their way of finding food and other resources for their children and they also had transport challenges to ferry their children to hospital during monthly medical reviews. These findings are similar with Pfeifer<sup>18</sup> who found that most caregivers of children with CP were young mothers and did not have paid jobs despite their families' low income. Chiluba<sup>19</sup> also noticed that majority of participants (92%) in his study were women, these women were also caregivers of children with CP. Mothers and women in general tend to assume the responsibility of caring for children with CP, forgoing other occupational roles.



### 5.3. Experiences of caregivers on CP diagnosis of their children

The findings for this study reflects on the risk factors and complications that might have contributed to the development of Cerebral Palsy in children. Some of the caregivers experienced difficult delivery, prolonged labour during intrapartum period. Some of the caregivers reported that their children were born prematurely, did not cry at birth, had asphyxia and some developed jaundice soon after birth. The current findings for the study shows that both perinatal factors and maternal factors contributed to the development of CP in children.

These findings are supported by systematic review finding done in Africa and Malawi inclusive, which stated that most common reported etiologies identified in African cohorts were birth asphyxia, kernicterus, and neonatal infections, with prematurity or low birth weight identified as a major etiology in only 2 studies.<sup>1</sup> Similarly, another study found that perinatal asphyxia is the most common history finding in Cerebral Palsy cases, followed by seizures during infancy, pathological jaundice, neonatal sepsis and history of neonatal intensive care unit admission.<sup>20</sup>

According to Chen,<sup>21</sup> the risk factors of cerebral palsy are complex and diverse and has a long time span which can occur before, during and after birth. These risk factors affect each other and form an intertwined network, leading to the occurrence of diseases. In their study, they identified gestational hypertension, preterm birth, premature rupture of membranes, and emergency cesarean section as risk factors for Cerebral Palsy in children.

Most participants sought medical help after noticing that their children were not able to sit on their own, their bodies were weak, had convulsions, strange cry and had delayed developmental milestones as compared to children of their age group. These findings are

consistent with the associated impairments of Cerebral that include history of recurrent seizures, disturbances of sensation, perception, cognition, communication, behavior and other secondary musculoskeletal problems.<sup>20</sup>

#### 5.4. Caregivers information related to Cerebral Palsy

This study found that majority of caregivers were told about Cerebral Palsy by the clinicians. However, some of the caregivers were given inadequate information related to prognosis, child care and alternative investigations and treatments available for children with CP. In a similar study, participants expressed the need to receive information that should be focused on the child's health condition, available healthcare facilities and what government support is available and how to access it.<sup>22</sup> In terms of the child's health condition, participants wanted to know more about CP, its prognosis, if its curable and treatments available.<sup>22</sup> Similarly, Palisano<sup>23</sup> found that parents expressed needs for information related to child condition, behaviour, and how to explain the child's health condition to others, information on available and future services, community resources and supports. This suggests that the services received did not meet all of the families' information needs. Caregivers often lack knowledge about CP hence need for improvement in their knowledge about CP to empower them in providing the needed care for their children with confidence, and to improve the health condition and quality of life of their CP children.<sup>23</sup>

Information is one vital need for caregivers. Due to lack of knowledge, caregivers may lack clear understanding of CP and might have fear of unknown. Their lack of knowledge about CP and the lack of information on community resources available for them and their children may make them feel isolated and stigmatized which might lead into depression.<sup>24</sup>

A clear diagnosis is very important for caregivers with CP children to help them understand their children's problems, plan for the future, and improve their health outcomes.<sup>25</sup> Magnetic Resonance Imaging (MRI) scan or Computerized Tomography (CT) scan are often used in the diagnosis of CP.<sup>25</sup> The findings of these scans may help to identify brain injuries or problems in brain development.<sup>25</sup> However, these investigations were not done for CP children in Mangochi.

According to Amasri<sup>26</sup>, the need for information is continuous throughout childhood and adolescence but the specific types of information needs may differ based on child/youth age and family dynamics. For instance, families of pre-school age children might need information about the diagnosis, prognosis and available services.<sup>26</sup> Families of children in primary school might express needs for information about environmental adaptation and assistive devices, while families of adolescents might request information on resources and supports for post-secondary education and employment.<sup>26</sup> Service providers are encouraged to partner with families to identify their information needs and apply information within the context of their children's condition.<sup>23,26</sup>

## 5.5. Health care services for children with Cerebral Palsy

### ***5.5.1. Cerebral Palsy services offered at the hospital***

Participants reported that physiotherapy was the main service which children with CP sought at Mangochi district hospital. Children were scheduled to attend the physiotherapy clinic once every month and they were seen by the physiotherapy clinicians and assistants. Health centres were not providing physiotherapy services and some of the participants travelled long distances to reach to the district hospital for physiotherapy.

Few participants who had children with other medical problems for example malnutrition, ear problems and other minor illnesses reported that they were also seen by other health care workers in nutrition rehabilitation unit and Outpatient department for treatment within the district hospital.

At physiotherapy department, the health care workers examined children's ability to move and hold things and exercises were also done. Physiotherapy aims to improve independence of the affected child. Its ultimate goal is to recover adaptive functions and to improve postural control, locomotion and manipulation.<sup>27</sup> Physical therapy is also important because it promotes mobility, improves stamina and endurance, and reduces the risk of contractures and deformities in children with CP.<sup>28</sup>

The current study also finds out that the Health care workers at physiotherapy department were friendly and received them well at physiotherapy clinic. This is similar to study findings by Nimbalkar<sup>29</sup> who find out that participants perceived that their child's physiotherapists were well behaved and cooperative and contrary to the current study participants reported that the physiotherapists often provided emotional support as well as occasional consultation on the phone was given as well.<sup>29</sup>

According to Auwal et al<sup>30</sup> encouragements from the therapists are needed in order to boost the morale of the caregivers. When health care workers are friendly, the caregivers are free to open up and share their problems and feelings related to child care and they can be assisted accordingly.

Majority of caregivers waited for less than 30 minutes for their children to receive physiotherapy services and they spent less time during physiotherapy. On the contrary participants in India, felt disappointed when the doctor (physiotherapist) spent a lesser amount of time with their children, since they had travelled long distances and faced multiple difficulties in bringing the child to the hospital.<sup>29</sup> They expected the physiotherapist to spend at least 40 minutes with the child during each session. They believed that compliance with doctor's instructions for exercise proved to be better than with the parents' instructions alone. When health care workers spend more time with the children and caregivers during the physiotherapy sessions they provide open interaction and allows caregivers to share their challenges encountered during care of child with CP. Providing adequate time to interact with caregivers and their children also allows the health care workers to observe the physical therapy that parents do at home and they can demonstrate and provide guidance on proper physical therapy techniques. Therefore, health care workers should provide adequate time for managing the child as well as the family to promote family centered care.

#### ***5.5.2. Caregivers satisfaction with the health care services***

The current study found that majority of caregivers were satisfied with the care their children received at physiotherapy clinic, they had short waiting time and the health care workers were friendly and received them well at physiotherapy clinic. They were satisfied because their children were improving.

However, few participants were not satisfied with the hospital services because their children were not improving. Similarly, caregivers of CP children in India felt satisfied when the child demonstrated improvement after receiving treatment from the physiotherapist.<sup>29</sup> In another study, the positive responses provided by the caregivers regarding physiotherapy were only related to the improvement of the child's functional status<sup>19</sup>. According to Abdullahi et al<sup>30</sup>, improvement in the child's condition during the rehabilitation program is one of the most important facilitators that motivate the caregivers to put more effort in the rehabilitation of their children with CP.

The current study findings are also consistent with study findings in Zambia which found that more than half (60%) of the caregivers were very satisfied and rated the physiotherapy services as excellent whilst 36% of the participants were moderately satisfied and rated the services as good.<sup>19</sup> On contrary, Khalil et al<sup>10</sup> study found that less than half of the caregivers (37%) were satisfied with the services provided at the hospital for their children. The mothers' satisfaction was very low for the waiting time and waiting areas as well as the availability of required facilities for their child's care. Moreover, they were dissatisfied with the amount of explanation they received about their child.<sup>10</sup>

Iannelli et al<sup>31</sup> found that parents of children with CP were significantly less satisfied with the inpatient care as compared with parents of children without a disability. They were unsatisfied with poor communication by health-care staff, skill and knowledge gaps in regard to the management of disabilities and lack/shortage of appropriate equipment in the hospital for patients with complex disabilities.<sup>31</sup>

The current study also found that caregivers were given inadequate information by health care worker. According to these findings, there is need to ensure caregivers satisfaction in order to improve quality of care provided to CP children. There is need to equip health care workers with adequate knowledge of CP and other disabilities so that they are able to understand the special needs of the children. Simple strategies, such as improving communication between staff and parents/patients, should also be implemented to ensure adequate care in the hospital.

Understanding patient and caregiver's experiences of health care are important for delivering improvements in quality and outcome of health care services. Caregivers satisfaction with the care provided to their children is one of the outcome measures commonly used to assess the quality of health care Hayles.<sup>10</sup>

The exploration of experiences of health care for children with Cerebral Palsy and their families is congruent with the principles of family-centred care, and reflects the importance of parents and families in the health care of children as is promoted in clinical practices in order to improve satisfaction of care in this population.<sup>10</sup>

### **5.5.3. Lack of psychosocial services at the hospital**

Majority of participants reported lack of psychosocial services at the hospital for example there were no counselling services and social support services in terms of provision of supportive devices to help CP children with standing, walking and sitting. The participants also reported that they had never met a social worker, counsellor or a clergy. These findings are similar with Pfeifer study in which caregivers' reported that rehabilitation professionals did not provide social support which to mothers caring for CP children.<sup>18</sup>

According to Basaran<sup>27</sup>, caring for a child with impairment often causes detrimental effect on caregivers' mental health. The disabled children may have some limitations that require long-term care that exceeds the usual needs of a normal developing child.<sup>27</sup> Meeting the needs of children with CP and providing them care can generate a certain level of stress in parents that may include tense family relations and social isolation due to CP children's limited mobility, which can be either minimized or aggravated depending on the family's social, emotional and financial resources.<sup>18</sup>

Primary caregiver may experience several psychosocial problems that may be detrimental to both their physical and mental health resulting in poorer quality of life and consequently this may affect their ability to provide the vital care requirements to the child.<sup>27</sup>

Consideration of the mental health of caregivers is important to achieve the best results in rehabilitation programs for CP children. Healthcare professionals must focus on how the caregiver can be supported to reduce stress and burnout. The caregiver interventions such as counseling and relaxation techniques may enable caregivers to adopt healthier lifestyles for themselves and their disabled child. Therefore, social support and different coping strategies should be developed in the context of family-centered services to respond caregivers' special needs and to buffer parents from the stress of having a child with CP.<sup>27</sup>

#### **5.5.4. Services requested by caregivers of children with CP**

Majority of participants wished that their children could be done further investigations and surgical procedures, some requested for Beit cure services. Some participants suggested that it will be good if the hospital could be providing them with supportive devices and play materials for children for example the wheel chairs, bikes and toys.



Shortage of adaptive devices for example wheel chairs which would assist caregivers in carrying for their children were also mentioned in a study conducted by Diseko<sup>3</sup> as a challenge for caregivers.

Most of the mothers reported that they would want the government to provide more equipment to the hospital, provide more awareness on the condition and employ competent doctors. Other mothers reported that they want the hospitals to give them drugs that would help the child.<sup>13</sup>

Challenges that mothers experienced with the health care system included a lack of provision of assistive devices, attitudes of health care professionals and a lack or provision of transport as is illustrated in the quotations below. One of the mothers found health care professionals unhelpful and disrespectful.<sup>11</sup>

## 5.6. Community support networks for CP children and their caregivers

### ***5.6.1. Availability of informal support***

The findings from this study revealed that majority of caregivers received informal support from their family members that included their parents, spouses and inlaws. Caregivers received support from family members related to basic care of their children, they also received psychological and financial support. Some participants reported that they had met pastors and sheiks for spiritual support and healing prayers for their children. However, one caregiver reported that she received no support at all. These findings are similar to a study done in Nigeria which found that majority of parents reported that they received financial and moral support in the form of advice and prayers.<sup>13</sup>

However, Ogunlana<sup>13</sup> also found that some mothers received insufficient support. It is evident that caregivers' who are adequately supported, have less caregiver burden and greater well-being than those who are less supported.<sup>32</sup>

According to Abdullahi et al<sup>30</sup>, help from family members can help reduce stress for the caregivers; and make them recharge and prepare to look after their children. The presence of social support, such as family and friends, may be an effective buffer to mitigate stress in caregivers.<sup>18</sup> Therefore, provision of social support including formal and informal social support can ameliorate the adversity, physiological and psychological afflictions experienced through parenting of children with CP.<sup>13</sup>

#### ***5.6.2. Inadequate formal support networks in the community***

The study found that less than half of participants had been visited by the Health surveillance assistant (HSA) for other community routine visits other than provision of support related to child's CP condition. None of the participants had been visited by health care workers from the physiotherapy clinic nor social workers. Only one participant met the counsellor. Less than half of the participants had access to non-governmental organizations for financial support and some were taught on child care specifically for CP children. The study also found that there were no support groups for caregivers of CP children in the communities. These findings are similar with study done by Egilson<sup>28</sup> who found that access to occupational therapists was less and seldom available in local communities outside of the capital area.

Study findings from South Africa conducted in semi-rural community clinics involving the interaction between multidisciplinary team (occupational therapist, physiotherapist, speech and language therapist) and children with CP and their caregivers revealed that caregivers of children with CP needed financial and emotional support.<sup>33</sup> By adopting a decentralised community, the study found that services were accessible, there was improved social support and improved the outcomes of a rehabilitation intervention programme compared with an institutional based health setting.<sup>33</sup>

Support groups on the other hand, are designed specifically to offer a means of social support for members and to enhance their coping skills.<sup>18</sup> Support groups also help caregivers by offering the best way to promote safe, timely, and effective care for their children.<sup>34</sup> In addition to formal knowledge, sharing experiences in support groups also enables caregivers to gain practical knowledge and skills for the day-to-day management of their CCP.<sup>34,35</sup> Caregivers feel confused with their children's condition, such as the type of CP or severity of motor impairments. This may increase their level of stress and lead to decreased level of satisfaction.<sup>18</sup> Support groups may help to reduce the isolation and stress experienced by the members, allow for both giving and receiving emotional support.<sup>35</sup> Therefore, caregivers also need psychological support through participation in support groups to decrease their stress.<sup>34,36</sup>

All in all, lack of resources, transport limitations and psychosocial challenges that comes with taking care of CP children pose a challenge to caregivers and their families. Community-based interventions therefore promote family involvement, provide psychosocial support, provides home and community support and improve social functioning and self-esteem.

### **5.6.3. Caregivers suggestions for home based care support**

Majority of caregivers recommended that healthcare workers from physiotherapy clinic should visit them at least once a month. Some caregivers recommended Health surveillance assistant within their community to visit them for physiotherapy and to review their children. These findings are similar with study by Egilson<sup>28</sup> in which the participants wanted CP rehabilitation services to be available in their local community to reduce transportation costs, reduce pressure on the family life, and increase the amount of time the children had to engage with their peers. The participants suggested that the physical therapy should be part of local health clinic services, while others mentioned that there should be therapy centres near their neighbourhoods.<sup>28</sup>

Similarly, in Zambia more than half of caregivers (76.0%) responded positively to the importance of having community support workers. Caregivers complained that bringing the patient to the hospital was a very tough thing to do physically and financially. They, for this reason, emphasized that they needed to have community health workers conducting treatment sessions in their homes.<sup>19</sup>

To sum it up, the current study has emphasized the need for community health workers and physiotherapists to visit CP children and their caregivers in their homes for encouragements, counselling, education on child care and physiotherapy sessions. The community visits will also curb the transport challenges hence reducing transport costs and preventing the caregivers and CP children from travelling long distances for management.

### 5.7. Challenges faced by caregivers during care of children with Cerebral Palsy

The findings of this study established that most caregivers experienced challenges in meeting the basic needs of their children due to lack of finances. They reported having inadequate food, clothes, diapers and playing materials. These findings are consistent with reports from several studies that stated financial challenges among caregivers of children with cerebral palsy impeded meeting necessities like food, clothes, diapers and high hospital and transport fees.<sup>30,37</sup> Study conducted by Nuri<sup>22</sup> also noted that families encountered additional financial expenses for a child with CP, beyond what they would typically pay for their children without CP. Financial needs were specifically linked to access to general medical services, rehabilitation services and purchase of assistive devices for the child with CP.

Nketsia et al <sup>38</sup> also found that caregivers of children with Cerebral Palsy in Ghana complained about the non-availability and high cost of equipment, especially wheelchairs and standing frames for their children as major challenges. Caregivers for children with Cerebral Palsy in Ghana also complained about the inaccessibility of specialist clinics as some travelled long distances to the hospitals about transportation costs to the facility whilst others complained about the frustrations they go through at the hospital.<sup>38</sup>

Some of the countries may provide some financial support for individuals with disabilities and their caregivers to decrease the effect of financial challenges. This financial support may be provided through social support services from governmental agencies.<sup>23,39</sup>

CP is a long-term condition that requires long-term care which requires more financial resources. Consequently, cost of care can add more strain to the caregivers and constrain their ability to afford services for their children.

In the current study, none of the caregivers reported sending their children to school. This is similar to study conducted by Nimbalkar et al<sup>29</sup> who found that participants reported lack of special training facilities for their children which was the main reason for their children not attending school. Nketsia et al<sup>38</sup> also reported that participants in his study encountered difficulties in searching for suitable day care and educational facilities for their children with CP. Many participants reported that mainstream schools were unable to meet the special educational needs of their children as they were constantly denied admission.<sup>38</sup> In Malawi there are few schools which assists children with special needs, therefore there is need to establish these schools to promote education of children with special needs.

## 6.0. Strength of the study

The study used qualitative methods in order to collect rich information related to experiences of caregivers of children with CP. The study also enquired from caregivers all aspects of child care and needs in order to establish gaps related to comprehensive management of CP children.

## 7.0. Study limitations

- The study was conducted in one health facility which would limit generalization of findings to the whole population of children in Malawi.
- The researchers are also aware that participants' responses might have been limited. This therefore calls for more studies to unearth other issues that might not have been covered by this study.

## 8.0. Recommendations

The findings for the study had established experiences and challenges encountered by caregivers when caring for the children with CP.

- There are gaps related to information which caregivers had related to CP, therefore there is need to provide adequate and focused information to caregivers related to general information about CP, home management and physical exercises and other relevant topics. This can be done by training health care workers to be competent and knowledgeable in providing current and evidence based CP information.
- The study also found that caregivers were not provided with psychosocial and counselling services. Health care workers, social workers, health surveillance assistants and counsellors should therefore be trained on provision of psychosocial support services to caregivers of children with CP

- There is also need to establish support groups for caregivers so that they may support and learn from each other on how to take care of children with CP.
- There is need for multidisciplinary team approach in the management of children of CP. Different sectors within the district should collaborate for example Ministry of health, Ministry of Education and social welfare and other stakeholders existing within the district in order to provide comprehensive services to meet the special education needs, health and psychosocial needs of children with CP and their caregivers.
- The study established that there is lack of follow up of children and their caregivers in the community. Follow up can be done by community health care workers HSAs and others who are available within the community. The health care workers working at the district hospital can also conduct supportive supervision related to home based care for children with CP.
- The study findings also established that the district hospital is the only facility that conduct routine physiotherapy services for CP children, this affected caregivers because they travelled long distances to the facility and some missed the appointment dates. To make the services accessible and easy to reach, the services should be offered at health centre level. Health centre staff should be equipped with knowledge and skills on physiotherapy and psychosocial services.
- Caregivers also complained of financial challenges in meeting needs for their children therefore there is need to engage non-governmental organization existing within Mangochi district to support caregivers in terms of basic needs for their children for example provision of food, drypers and walking aids.



- There is need to link caregivers with Non-governmental organizations that can provide finances for establishment of small scale businesses for caregivers to support their children with daily basic needs.

## 9.0. Future research

It was noted that there are more children with CP in Mangochi district. There is need to conduct research to discover risk factors associated with CP in the district in order to find interventions to reduce CP cases in children.

There is also need to conduct a study involving health care workers working with children with CP to discover their experiences and challenges related to services they provide.

There is need to explore on the availability of national policies and guidelines for comprehensive management of children with Cerebral Palsy

## 10.0. Conclusion

The purpose of the study was to explore experiences of caregivers on health care and psychosocial services available for children with Cerebral Palsy in Mangochi district. The findings of the study showed that majority of participants reported that their children received good physiotherapy services, health care workers were friendly and welcoming and they had short waiting time to receive the services. However, some of the participants received inadequate information related to etiology of CP, prognosis of CP, alternative treatments and on child care at home. There was also lack of follow up of CP children and lack of home visits by health care workers. Majority of participants received informal psychosocial support from their relatives and friends. Majority of formal psychosocial services were lacking for example there was lack of counselling services, no visits by

counsellors or social workers, unavailability of support groups and lack of assistive devices at home. Challenges which caregivers encountered were related to finances support resulting in their inability to meet basic needs for CP children and transport challenges to take their children to hospital for monthly physiotherapy services.

The study recommends that health care workers should be trained in order to provide evidence based CP information and psychosocial counselling services. CP children and their caregivers should also be followed up by community health care workers for support and continuity of services. There is need to engage non-governmental organization existing within Mangochi district to support caregivers in terms of basic needs and psychosocial support. All in all, there is need for multisectoral collaboration in order to manage CP children comprehensively. Finally, there is need to conduct research in order to explore on the availability of national policies and guidelines for comprehensive management of children with Cerebral Palsy.

## 11.0. Requirements and Justification

### **Study requirements**

#### **Human resource**

- 4 data collectors and 2 data translators

#### **Material resource**

- 4 GB Flash Disk for keeping and transferring recordings
- Tape recorder for recording
- Batteries for tape recorder
- Hard covers, pens and pencils for transcribing data from participants
- Airtime for communication with supervisor
- Personal Protective Equipment for participants and researchers protection from COVID virus
- COM Research Administration Fee

#### **Justification**

It is a requirement for the ethics committee that is going to review and approve this protocol for administrative purposes.

Accommodation and transport costs for researchers who stays outside and far from Mangochi district hospital.

Compensation to the participants

## Budgetary estimates

Table 1 budgetary estimates

ITEM	UNIT COST	TOTAL COST
4 GB Flash Disc	K6,000	K6,000
Tape recorder	K15,000	K15,000
Batteries for digital recorder	K5,000	K5,000
Printing and binding costs for proposal	K40,000	K40,000
Hard covers, pens, pencils	K10,000	K10,000
Printing Interview guides	K3,000	K3,000
Airtime for communication with supervisor	K10,000 each *4 people	K40,000
Compensation to qualitative participants K3000 per person	K3,000 x 15	K45,000
PPEs (masks, sanitizers)		K10,000
Allowances for data collectors	K47,000*4*2 days	K376,000
Data translators	K47,000*2*3 days	K282,000
Accommodation and Transport costs		K200,000
COMREC administration fee		K125,000
10% contingency		K116,000
10% KUHES fees		K128,000
<b>Grand Total</b>		<b>K1,401,000</b>

## 12.0. References

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## 13.0. Appendices

### Appendix 1A: Participant Information Sheet

Experiences of caregivers on health care and psychological services available for Cerebral Palsy children in Mangochi District Hospital

Kamuzu University of Health Sciences

***Please read the information below and sign the form next page if you are taking part in this study***

We are nurses and clinicians working at Mangochi district hospital and we are conducting a study under CHEER project. This study will be conducted at Mangochi district hospital. You are therefore being invited to take part in this study. The study has been approved by the Research and Ethics Committees of Kamuzu University of Health Sciences. Before you decide to participate in the study, it is important to understand why the research is being conducted and what will involve. Please ask if there is anything that is not clear or if you would like more information. Participation is voluntary.

#### **What is the purpose of the study?**

The purpose of the study is to explore on experiences of caregivers on health care and psychosocial services available for Cerebral Palsy children. The study findings may guide health planners on planning interventions towards improving health care and psychosocial services for children with Cerebral Palsy

**Do I have to take part?**

Participation in this study is voluntary. You are free to take part or not or to withdraw at any time you feel like without giving reasons. Your refusal to take part in the study will not affect the quality of health care your child is going to receive in any way. If you agree to take part, you will be asked to sign a consent form. Information about you will be confidential and no one will identify who answered the questions. No names will be written on the interview guide, instead, code number will be used.

**What do I expect as a participant?**

You will be asked some questions related to your experiences on hospital services for children with CP, your experiences on community health services and on the availability of psychosocial services for CP children. Your responses will be documented on the interview sheet and recorded on the tape recorder to avoid missing information. You will be required to answer the questions truthfully and it will take approximately less than 1 hour.

**What are the possible risks for taking part?**

There are no known risks associated with this study.

**What are the possible benefits?**

There are no immediate benefits to you. Findings of the study may help to improve health and social services, information, education and communication related to management of Cerebral Palsy in children.

At the end of the interview you will receive K3, 000 as a compensation for sacrificing your time to participate in this interview.

**Who do I contact for further information?**

If you would like more information or have any queries about the study, contact the Principal Investigator, Mrs Felistas Chiundira, Kamuzu University of Health Sciences, Private Bag 360, Blantyre 3. Cell phone number: 0999317298

**Who do I contact when I feel that my rights have been abused during the study?**

If you feel that your rights were abused or if there was no confidentiality during the study please contact COMREC chairperson, Kamuzu University of Health Sciences, Private Bag 360, Blantyre 3. Cell phone number: 0888118993 .

### Participant consent form

1. I have read (or have had another person read to me) the attached information sheet for this study and have understood the purpose of the study and the problems involved. Yes/No
2. I agree to voluntarily participate in the study and provide answers to the best of my knowledge. I understand that I am free to withdraw from the study any time and this will not influence anything. Yes/No
3. I know that I am not going to have any injury or harm during the research process. The information that I will give to the researcher should not be used against me in future. Yes/No
4. I understand that the information I give will be kept confidentially and will only be accessed by the researcher or those people directly concerned with this study. Yes/No
5. I understand that I will not benefit financially. Yes/No
6. I know how to contact the researcher if I need to. Yes/No

I voluntarily agree to take part. Yes/No

Participant's name	Signature/Thumb print	Date
.....		

Witness name	Signature	Date
.....		

Name of interviewer	Signature	Date
.....		

***THANK YOU FOR TAKING PART IN THIS STUDY***

## Appendix 1B: Kalata Yofotokozera Zakafukufuku

**Kafukufuku wofuna kudziwa zinthu zomwe oyang'anira ana a ulumali wa mubongo amakumana nazo pomwe akulandira thandizo ku chipatala, kumene akuchokera kapena kukhala ndi chisamaliro cha moyo wawo**

Ife ndife anamwino ndi madokotala ogwira ntchito pachipatala chachikulu cha Mangochi ndipo tikupanga kafukufuku motsogozedwa ndi pulojekiti ya CHEER. Kafukufukuyu adzichitikira pa chipatala chomwe chino cha Mangochi. Muli kupephedwa kutenga nawo mbali mu kafukufukuyi. Kafukufukuyu wavomelezedwa ndi akomiti yoona za kafukufuku ya sukulu ya ukachenjede ya madokotala ndiponso anamwino. Mukuyenera kumvetsetsa cholinga cha kafukufukuyu musanapange chisankho cholowa nawo. Ngati chilipo china chomwe simunamvetse chokhudzana ndi kafukufuku ameneyu, mutha kufunsa. Kutenga nawo mbali pa kafukufuku ameneyu ndi kosaumiriza ayi.

### **Kodi cholinga cha kafukufukuyu nchiani?**

Cholinga chakafukufukuyu ndikufuna kudziwa zinthu zomwe anthu oyang'anira ana a ulumali wa mubongo amakumana nazo pomwe akulandira chithandizo ku chipatala, kumene akuchokera kapena kukhala ndi chisamaliro cha moyo wawo.

Pali chikhulupiliro choti zotsatira za kafukufukuyu zidzathandiza akulu a zaumoyo kupeza njira zina zopititsa patsogolo ntchito zosamalira ana a ulumali wa mu ubongo



**Kodi ndingatenge nawo mbali pakafukufuku uyu?**

Ndikufuna kwanu kusankha kutenga nawo mbali mukafukufuyu kapena ayi. Muli ndi ufulu kufuna kusiya nthawi imene mukufuna ndipo izi sizizaletsa mwana wanu kulandira thandizo.

Mayankho anu azasungidwa mwachinsinsi ndipo dzina lanu silizalembedwa pena paliponse chifukwa tizagwiritsa ntchito ma nambala. Mapepala onse azaotchedwa pomaliza pakafukufuku ameneyu.

**Kodi chidzachitike ndi chiyani ngati nditenge nawo mbali?**

Mukavomereza kutenga nawo mbali mukafukufukuyu mudzafunsidwa mafunso okhuzana ndi maganizo anu pa chithandizo chaku chipatala chomwe mwana wanu amalandira, komanso chithandizo chomwe inu ndi mwana wanu mumalandira kumudzi kapena komwe mukukhala, mudzafunsidwanso zinthu zina zokhudza chithandizo kumoyo watsiku ndi tsiku wa mwana wanu kuwonjezera pa chithandizo chimene mumapeza ku chipatala. Mukupemphedwa kuyankha mafunsowa malinga ndi momwe mukudziwira ndi mowona mtima ndipo mafunsowa adzatenga nthawi pafupifupi ola limodzi.

**Kodi zovuta zimene zingaoneke potenga nawo mbali ndi ziti?**

Palibe zovuta zodziwika mukatenga nawo mbali mukafukufukuyu.

**Kodi phindu lake nchiani?**

Sikuti pali phindu lina lapadera mukatenga nawo mbali. Pali chikhulupiliro choti zotsatira zakafukufukuyu zidzathandiza kupeza njira zina zothandizira ana omwe ali ndi vuto la

ulumali wa ku ubongo komanso zidzathandiza kupeza njira zofalitsira mauthenga okhudza vutoli.

Kafukufuku adzakupatsani chindapusa cha K3,000 pa nthawi yanu imene mwagwiritsa ntchito kutengera ndi malamulo a bungwe loyendetsa kafukufuku la COMREC.

**Ndingamupeze ndani ndikafuna kumva zambiri?**

Ngati mukufuna kudziwa zambiri za kafukufuku ameneyu kapena muli ndi mafunso, mutha kulankhulana ndi Mrs Felistas Chiundira wotsogolera kafukufukuyi, Keyala; Kamuzu University of Health Sciences, Private Bag 360, Blantyre 3. Nambala ya foni: 0999317298

**Patapezeka kuti ufulu wanga waphwanyidwa ndingamupeze ndani**

Ngati mukuona kuti ufulu wanu waphwanyidwa nthawi yakafukufuku, kapena sanakusungireni chinsisi mutha kulankhulana ndi mkulu woona za kafukufuku ku COMREC pa nambala iyi 0888118993. Keyala Kamuzu University of Health Sciences, Private Bag 360, Blantyre 3.

## Kalata ya chivomerezo yolowera mu kafukufuku

Onetsetsani kuti mwawerenga ndi kumvetsetsa zakafukufuku ameneyu musanasayinire

1. Ndawerenga (kapena wina wandiwerengera) kalata yolongosola za kafukufuku ali pamwambayu ndipo ndamvetsa cholinga cha kafukufukuyu ndizovuta zake.  
Inde/Ayi
2. Ndavomereza kutengapo mbali pa kafukufukuyu mosaumirizidwa ndi kufunsidwa mafunso amukafukufukuyu. Ndamvetsa kuti ndili ndi ufulu kusiya nthawi ina ili yonse. Inde/Ayi
3. Ndikuziwa kuti sindiyenera kuvulala kapena kupeza vuto munthawi ya kafukufukuyi, ndipo zomwe ndingayankhule kapena kupereka mukafukufukuyu sizidzanditembenukira. Inde/Ayi
4. Ndikumvetsa kuti zonse zomwe zamukafukufukuyu zidasungidwa mwachinsinsi ndikugwiritsidwa ntchito ndiopanga kafukufukuyi kapena okhuzidwa ndi kafukufukuyi. Inde/Ayi
5. Ndamvetsetsa kuti palibepo phindu la ndalama potenga nawo mbali mukafukufuku ameneyu. Inde/Ayi
6. Ndikudziwa mmene ndikapezere opanga kafukufukuyu ngati ndikofunika kutero  
Inde/Ayi

Ine ndikuvomeleza kutenga nawo mbali mukafukufukuyu. Inde/Ayi

Dzina la otenga mbali

Chizindikiro

Tsiku

.....

Dzina la mboni

Chitsindikizo/Saini

Tsiku

.....

.

Dzina la opanga kafukufuku

Chitsindikizo

Tsiku

.....

*Zikomo potenga nawo mbali pa kafukufuku ameneyu*

## Appendix 2A: Interview guide

### Experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children in Mangochi district

**Participant's ID number:**

**Interviewer:**

**Date of interview:**

Section A- Demographic data		
A1	How old are you?	15-20yrs.....1 21-30yrs.....2 31-40yrs.....3 Over 40.....4
A2	What is your marital status?	Married.....1 Single.....2 Divorced.....3 Widow.....4
A3	What is your denomination?	Roman catholic.....1 C.C.A.P.....2 Islam.....3 Jehovah's witness.....4 Seventh day Adventist.....5 Church of Christ.....6 Assemblies of God.....7 Other Pentecostal churches.....8

		Other (specify).....9
A4	What is your education level	Primary .....1 Secondary.....2 College.....3 None.....4
A5	What kind of work do you do?	Employed.....1 Self employed.....2 None.....3 Other .....4
A6	What kind of work does your husband do?	Employed.....1 Self employed.....2 None.....3 Other.....4
A7	How related are you to the child?	Parent.....1 Sibling.....2 Grandparent.....3 Aunt/uncle.....4 Other.....5

## **Section B: Experiences of care givers on health care services, community and psychosocial services**

### **I. Experiences of caregivers on hospital services for children with CP**

#### **1. How did you discover that the child had CP?**

##### *Probes*

- What prompted you to seek treatment
- Who told you first about the diagnosis of the child

#### **2. What information were you given about this condition?**

##### *Probes*

- What information were you told on prognosis, management
- What type of information were you told about home care for child with CP

#### **3. What other information did you wish you could get?**

#### **4. How are you treated when you bring your child for review or physiotherapy or any other treatment?**

##### *Probes*

- How do health care workers receive you during care of the child? (Are they friendly and welcoming )
- How long do you wait before your child is attended to?

#### **5. What kind of health care services do your child get when you visit the hospital**

*Probes*

- Are you satisfied with the health services provided to the child?
  - Do you understand the reason why the child is getting such care?
  - How many places within the facility do you visit to get treatment for the child
6. Do you always honor the appointment dates?
  7. If no why?
  8. What type of psychological support do you receive at the hospital?

*Probes*

- Have you ever met a counsellor, pastor/sheik or social worker at the hospital?
7. How can the existing health care services available for children with Cerebral Palsy be improved?
  8. Do you need other health care services apart from the ones that the child is getting?

**II. Experiences of caregivers on community health services for children with CP**

1. Who visits you and the child in your home for support?

*Probe*

- Have you ever been visited by the Health surveillance assistant (HSA) or any health worker personnel?
2. If yes what type of support do you get from such visits?
  3. How do you manage daily tasks (such as feeding, bathing, use of toilet, play and using the toilet)?



*Probe*

- Who has taught you to do these activities?
  - Who helps you on these activities?
4. What are the challenges that you meet as you take care of the child?
  5. Which health care worker would you wish to visit you in your home?

*Probe*

- For what support and how frequently
6. How can the psychosocial services for caregivers of children with Cerebral Palsy be improved?

**III. Experiences of caregivers on the availability of psychosocial services**

1. What formal support systems and organizations are available to you?

*Probe*

- Have you ever been visited by a social worker?
  - Have you ever participated in support groups for caregivers with CP children?
  - Have you ever been visited by any organization that supports children with CP?
2. If yes, what type of support have you received from the formal support system?
  3. What informal support networks have helped you through tough times?

*Probe*

- Do you get support from your friends, family, church members

4. If yes, what type of support do you get from them?
5. How can the psychosocial services available to caregivers of children with Cerebral Palsy be improved?
6. Do your child go to school or is s/he being visited by a teacher?
- 7.

Do you have other information or issue related to the discussion that we should discuss?

*Thank you for participating, this marks the end of our interview*

## Appendix 2B: Kalata ya Mafunso

**Zinthu zomwe oyang'anira ana a ulumali wa mubongo amakumana nazo pomwe akulandira thandizo ku chipatala, kumene akuchokera kapena kukhala ndi chisamaliro cha moyo wawo**

<b>Gawo loyamba: Mbiri ya munthu</b>		
<b>A1</b>	Zaka zanu zobadwa nzingati?	15 -20yrs.....1  21-30yrs.....2  31-40.....3  Zopitilira.....4
	Muli pa banja?	Eya .....1  Ayi .....2  Banja linatha.....3  Amuna/akazi anamwalira.....4
	Ndinu a Chipembezo chanji	Katorika .....1  C.C.A.P.....2  Chisilamu.....3  Mboni .....4

		SDA.....5  Assemblies church.....,6  Mipingo ina.....7
<b>A4</b>	Maphunziro munafika nawo pati?	Pulayimale.....1  Sekondale.....2  Ukachenjede.....3  Palibe .....4
<b>A5</b>	Mumagwira ntchito?	Eya .....1  Ayi.....2
	Ngati eya mumagwira ntchito yanji?	Yolembedwa.....1  Yodzilemba.....2
	Amuna anu amagwira ntchito yanji?	Yolembedwa.....1  Yodzilemba.....2
	Pali ubale wanji ndi mwana?	Kholo.....1  Agogo.....2  Ena.....3

**Gawo lachiwiri: Zinthu zomwe oyang'anira ana a ulumali wa mubongo amakumana nazo pomwe akulandira thandizo ku chipatala, kumene akuchokera kapena kukhala ndi chisamaliro cha moyo wawo**

**1. Maganizo anu pazomwe mumakumana nazo pomwe mukulandira chithandizo cha mwana wanu kuchipatala**

a) Kodi munamuzindikira bwanji mwana kuti ali ndi vuto la mu ubongo?

*Fufuzani zambiri*

- Chinakupangitsani ndi chani kuti mufune thandizo la ku chipatala?
- Kodi ndi ndani anakuuzani za vuto la mwanayu poyambirira penipeni?
- Kodi ndi uthenga wanji omwe munauzidwa pokhudzana ndi vuto la mwanayu?
- Kodi munauzidwa uthenga wanji okhudzana ndi machilitso a matenda a mwanayu?

b) Ndi uthenga wanji umene munakafunitsitsa mutauzidwa okhudza chisamaliro cha matenda a mwanayu?

c) Kodi mumathandizidwa motani mukapita ndi mwana ku mafizo kapena pamene mukudzakumanaso ndi a dotolo?

*Fufuzani zambiri*

- Kodi mumalandiridwa motani ndi anthu ogwira ntchito kuchipatala mukabwera ndi mwanayu?
- Mumadikira nthawi yaitali bwanji panzere musanaonedwe ndi a dotolo?

d) Ndi chisamaliro chanji chomwe mumalandira mukapita ndi mwana ku chipatala?

*Fufuzani zambiri*

- Kodi mumakhala okhutitsidwa ndi chisamaliro chimene mwana amalandira kuchipatala?
- Kodi ndinu omvetsa chifukwa chomwe mwanayu amalandilira chithandizo chimenechi?
- Mumayenda malo angati pachipatala mukamalandira chithandizo chamwanayu?
- Kodi nthawi zonse mumabwera kuchipatala kuzakumana ndi adotolo pa tsiku limene mwapatsidwa?

a. Eya

b. Ayi

- Ngati ayi perekani zifukwa

e) Ndi uphungu wanji wa mmalingaliro umene mumalandira mukapita kuchipatala

➤ Munayamba mwakumanapo ndi aphungu, alangizi, abusa kapena oona zachisamaliro chamwanayu?

f) Mukuona ngati ndi malo ake ati amene akufunika kukonzedwa pachisamaliro cha mwana kuchipatala?

g) Kodi mumafuna chithandizo china cha kuchipatala kupatula chimene mwana amalandira pakadali pano?

**2. Maganizo anu pazomwe mumakumana nazo komwe mukuchokera kapena kukhala pa zokhudza chithandizo cha inu ndi mwana wanu**

a) Kodi ndi ndani amakuyenderani kunyumba pokhudza chisamaliro cha mwana?

*Fufuzani*

- Munayamba mwayenderedwapo ndi a zaumoyo kapena aliyese ogwira ntchito ku chipatala?

a. Eya

b. Ayi

b) Ngati eya ndi chithandizo chanji chimene munalandira?

c) Mumakwanitsa bwanji kumusamalira mwana (pomudyetsa, kumusambitsa, kupita naye kuchimbudzi komaso posewera)?

*Fufuzani*

- Anakuphunzitsani ndani kupanga zimenezi?
- Amakuthandizani ndani kupanga zimenezi?

d) Kodi ndi mavuto anji amene mumakumana nawo pomuthandiza mwanayu?

e) Ndi ogwira ntchito akuchipatala ati amene mumafuna atamazamuyendera mwanayu?

*Fufuzani*

- Mukufuna atamakuyenderani kangati ndipo azibwera ndi chithandizo chanji?

f) Kodi tingapange bwanji kuti tipititse patsogolo chithandizo cha mwanayu kumbali ya uphungu, maganizo a ungwirowo ndi chisamaliro cha tsiku ndi tsiku?

**3. Maganizo anu pazomwe mumakumana nazo zokhudza chisamaliro cha moyo wawo**

a) Ndi chithandizo chanji cha mabungwe chimene muli nacho kudera kwanu?

*Fufuzani*

- Kodi munayenderedwapo ndi alangizi a zachisamaliro cha anthu kudera kwanu?
- Munayamba mwatengapo mbali mmagulu amene amakambirana zokhudza matenda amwanayu?
- Munayamba mwayenderedwapo ndi amabungwe amene amathandiza ana amene ali ndi vuto la ulumali wa mu ubongo?

b) Ngati eya, anakupatsanipo chithandizo chanji?

c) Kodi ndi chisamaliro china chiti kupatula cha amabungwe ndi a chipatala chimene munalandirapo?

*Fufuzani*

- Mumathandizidwako ndi anzanu, akumpingo kapena achibale anu?

d) Ngati munathandizidwako ndi chithandizo chanji chimene munalandira?

e) Kodi mwana wanu amalandira maphunziro ku sukulu kapena pakhomu pano?

Kodi pali mafunso kapena zina zoti mungaonjezere kupatula zomwe takambirana apazi?

**Zikomo potenga nawo mbali mu kafukufuku, kucheza kwathu kwathera pamenepa**



## Activity scoring for investigators

Activity	Responsible individuals	Members contribution
		0%
Proposal writing	All members	15
Developing data collection tool	Matenje and Chiundira	10
Finalizing, editing and sending to supervisor and COMREC	Chiundira and Kawonga	10
Follow up on research finances with CHEER project	Matenje and Manongá	10
Data collection	Masese, Matenje and Chiundira	10
Data analysis	Chiundira and Masese	15
Report writing	All members	10
Research publication	Chiundira and Matenje	10
Research dissemination	All members	10



FROM: Felistas Chiundira

TO: Chairman College of Medicine Research Ethics Committee,  
Kamuzu University of Health Sciences, Private Bag 360, Blantyre 3

DATE: 04/02/2022

Dear Sir,

**RE: Submission for Ethics Review – Experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children in Mangochi district**

Children with Cerebral Palsy require multidisciplinary and holistic care in order to comprehensively manage their medical needs as well as maximize their developmental and educational potential. However, it has been observed that there are gaps to provision of quality services to these children. There is inadequate information related to experiences of care givers on healthcare and psychosocial services available for children with Cerebral Palsy children which this research seeks to explore.

Therefore, **I write to seek permission to conduct a cross sectional qualitative study on Experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children in Mangochi district.**

Please find the attached documents for COMREC's consideration for ethical review and approval: these includes; study protocol, Curricula vitae of Investigators and Support letter from the Director

of Health and Social services for Mangochi district. **Letters of support from CHEER project has already been sent to COMREC by the project coordinator.**

Do not hesitate to contact me should you require any further information regarding this study.

Yours Sincerely,



Felistas Chiundira- Principal Investigator; Kamuzu University of Health Sciences:

[fchiundira@kuhes.ac.mw](mailto:fchiundira@kuhes.ac.mw)

Telephone: 01 594 030

Fax: 01 594 757



*In reply please quote Ref. No.....*

MANGOCHI DISTRICT COUNCIL  
PRIVATE BAG  
MANGOCHI

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*All correspondence should be addressed to*

District Commissioner

25<sup>th</sup> January, 2022

### **The Chairperson**

College of Medicine Research and Ethics Committee  
Kamuzu College of Health Sciences Private Bag  
360  
Chichiri, Blantyre 3.

Dear Sir,

#### **LETTER OF SUPPORT FOR THE RESEARCH PROJECT: "EXPERIENCES OF CAREGIVERS ON HEALTH CARE AND PSYCHOSOCIAL SERVICES AVAILABLE FOR CELEBRAL PALSY CHILDREN IN MANGOCHI DISTRICT".**

I write to express our district's support to Group 5 Micro-Research Project (CHEER Supported), who are applying to COMREC for consideration for the above titled research project to be conducted in Mangochi District.

Should there be any need, please do not hesitate to contact me through the details above.

Yours faithfully,

A handwritten signature in black ink, appearing to read "Chimwemwe Thambo".

**Dr. Chimwemwe Thambo**

**For: DIRECTOR OF HEALTH AND SOCIAL SERVICES**

24<sup>th</sup> Jan 2022

From: Theme Lead CHEER District Learning Platform.

To: The KUHREC Administrator

Re: Micro Research Project proposals 2021 Cohort

Good day Madam

Micro Research is a theme under the Capacity building for Health Professional Education and Research (CHEER) project sponsored by NIH. We are currently submitting five research project proposals for your review and comments. The proposals are as follows:

1. Factors Influencing Covid19 Vaccine Uptake Among Rural Adult Population In Mangochi District, Malawi.
2. Experiences Of Caregivers On Healthcare And Psychosocial Services Available For Cerebral Palsy Children In Mangochi District
3. Knowledge, Attitudes and Practices of Covid 19 Preventive Measures among Hypertension Patients at Monkey Bay Community Hospital
4. Investigating Knowledge And Determinants And Birth Preparedness Among Pregnant Women In Mangochi District.

We will be grateful for your assistance

Kind regards

Maureen Maleta



## CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.02/22/3586 - Experiences of caregivers on healthcare and psychosocial services available for Cerebral Palsy children in Mangochi district, version 1.0 by Felistas Chiundira

On 13-Apr-22

*As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC some of which are indicated on the next page for your study*

Prof. E. Umar -Chairperson (COMREC)

13-Apr-22

Date

Approved by  
College of Medicine

13-Apr-2022

(COMREC)  
Research and Ethics Committee