



Kamuzu College of Nursing

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH HYDROCEPHALUS AT QUEEN
ELIZABETH CENTRAL HOSPITAL

MASTER OF SCIENCE (CHILD HEALTH NURSING) THESIS

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SUBMITTED TO THE FACULTY OF NURSING IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR A DEGREE OF MASTER OF SCIENCE IN CHILD HEALTH
NURSING

APRIL 2018

Declaration

I, Cynthia Chidziwisano, hereby declare that this thesis on experiences of caregivers of children with hydrocephalus at Queen Elizabeth Central Hospital is entirely my work. This thesis has not been presented for any award at any university within or outside Africa. All the sources of information quoted in the thesis has been acknowledged and added to the list of references.

Cynthia Chidziwisano

Legal full name

Signature

Date

Certificate of Approval

The undersigned approve that this thesis represents the students own work and has not been presented anywhere else in or outside Africa.

Signature _____ Date _____

Dr. Mercy Pindani, PhD

Main supervisor

Dedication

The thesis is dedicated to my Husband Kondwani for his untiring support and my children Joshua and Angel.

Acknowledgements

I thank the Lord for seeing me through my Master of Science in Child Health Nursing studies and during the write up of this thesis. My vote of thanks should go to the following for helping me in various ways:

- Elma scholarship fund through Kamuzu College of Nursing.
- Dr Mercy Pindani and Tiwonge Munkhondya my research supervisors for their support and encouragement.
- Dr Elizabeth Glaser and Chimwemwe Kwanjo Banda for their support.
- Mr Constantine Chaima for his untiring support.
- Mrs Diana Kafotokoza for her support.
- My husband Mr Kondwani Regison Chidziwisano for his support during my studies.

Abstract

Background: The impairment of cortical connectivity involving the afferent and efferent pathways in hydrocephalus usually leads to cortical pathway dysfunction. Consequently, in most of the affected children the dysfunction is permanent causing both motor and cognitive deficits and behavioral difficulties. This causes the affected child to entirely depend on the caregiver for all daily functions. Therefore parents are responsible for helping the child in all the activities of daily living. Understanding parents' experiences has the potential to improve parent–professional collaboration and the management of the child's condition.

Aim: To explore parents' experiences of living with a child with hydrocephalus and their responsibility of having to care for a growing child who is entirely dependent on them.

Design and methods: A descriptive qualitative method was undertaken, and twenty caregivers were interviewed using an in depth interview guide.

Findings: Six themes were identified; strange illness, financial constraint, work overload, social stigmatization and support system. The identified themes were all from the parent's verbalized experiences, the caregivers referred to hydrocephalus as a strange disease which they have never heard or seen. Financial constraint is a major challenge arising from their failure to work or do business and from frequent hospitalization. Social stigmatization was another major challenge which was deterring the caregivers from participating in important community events. Furthermore support system involved the support the caregivers received from their friends and relatives, health professionals and the organizations.

Conclusion: Therefore, caregivers of children with such a condition must cope tremendous emotional, physical and economic burdens, although in the course of this, they gain a vast experience on care management approaches of the affected child. Therefore collaboration

with parents requires health professionals to listen to parents' concerns and value their experiences.

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List of Abbreviations

CNW	:	Chatinkha Nursery Ward
COMREC	:	College of Medicine Research and Ethics Committee
CPC	:	Choroid Plexus Cauterization
CPD	:	Continuing Professional Development
CSF	:	Cerebral Spinal Fluid
ETV	:	Endoscopic Third Ventriculostomy
GST	:	General Systems Theory
HCW	:	Health care workers
HMIS	:	Health Management Information System
ICP	:	Increased Intracranial Pressure
IFSBH	:	International Federation of Spina Bifida and Hydrocephalus
KCH	:	Kamuzu Central Hospital
KCN	:	Kamuzu College of Nursing
MDHS	:	Malawi Demography Health Survey
PONW	:	Paediatric Orthopedic and Neuro Ward
QECH	:	Queen Elizabeth Central Hospital
SHIP	:	Spina Bifida Hydrocephalus Interdisciplinary Program
UNICEF	:	United Nation Children Fund

USA : United States of America

VPS : Ventricular Peritoneal Shunt

WHO : World Health Organization

Definition of Terms

Caregiver:	The one who cares for and contributes the benefits of Medical and economic resources to a child.
Child:	Any person aged below the age of 18.
Communication:	The giving and exchange of information, ideas or feelings.
Health information:	Involves information concerning child's medical diagnosis, treatment, any investigation/procedures, care of the child throughout the disease process and the possible outcome or complications that can arise
Health information giving:	The act of conveying health information to caregivers
Infant:	Child aged from zero to twelve months old.

CHAPTER 1

Introduction and Background

Introduction

Hydrocephalus is a condition in which the brain has an abnormal buildup of cerebral spinal fluid (CSF), due to congenital or acquired factors that prevent the large intracranial sinuses in the brain from absorbing the CSF (Cartwright & Wallace, 2010). Consequently the accumulation of CSF, coupled with dilatation of ventricles (areas of the brain that have fluid) causes enlargement of infant's head size, increased intracranial pressure (ICP) (a rise in pressure around the brain) and death if untreated (Cartwright & Wallace, 2010) (Cestari, Carvalho, & Barbosa, 2013a) (Warf, 2011). Hydrocephalus may occur as an isolated condition or with other neurological conditions, but its treatment requires a lifelong medical and surgical care (Cartwright & Wallace, 2010).

In recent studies done by (Warf, 2011) (Kamalo, 2013) the child with hydrocephalus who has had a Ventricular peritoneal shunt (VPS) may require shunt revision due to shunt failure, infection and even due to normal growth of the child. As a result the child has frequent hospital admissions that may be emotionally tiring and draining for both the child and caregiver. Similarly, (Cartwright & Wallace, 2010) explains that ICP in both shunted or non-shunted hydrocephalus cases may affect the metabolism and maturation of the brain, causing irreversible brain damage, which affect normal brain development.

Additionally (Eskandari, Mcallister, Monfils, & Way, 2018) indicate that the cortical connectivity involving the afferent and efferent pathways, is usually impaired in hydrocephalus, leading to cortical pathway dysfunction. Consequently, if the dysfunction is permanent the child

will have both motor and cognitive deficits and behavioral difficulties (Warf, 2011). This causes the affected child to entirely depend on the caregiver for all daily functions.

(Cartwright & Wallace, 2010) indicate that frequent shunt revisions and ICP, causes precocious puberty (onset of puberty 1-2 years earlier than usual), hence early pregnancies.

(Warf, 2011) (Paget, Mallewa, Chinguo, Mahebere-Chirambo, & Gladstone, 2016a) in their studies, mention the economic impact incurred through the transport cost and food cost, arising from the frequent hospital admissions and reviews.

Therefore, this qualitative study seeks to explore the experiences of the caregivers of the children with hydrocephalus, aged from 2 to 10years. The caregivers experience will be studied concentrating on the aspects of their knowledge and practices, their challenges, and their support system.

Background

Globally, hydrocephalus is one of the common birth defects, occurring in one out of 1,000 live births (Cartwright & Wallace, 2010). (Esaml, 2012) indicate that 70-90% of all children with spina bifida develop hydrocephalus during the first two years of life.

Hydrocephalus and spina bifida affect 1 and 3 per 1,000 infants, often resulting in severe disabilities (Esaml, 2012). In Sub Saharan Africa over 375, 000 cases are reported annually (Warf, 2011). Developing countries have high burden of pediatric hydrocephalus cases due to high birthrates, neonatal infections, malnutrition, infectious diseases, maternal and perinatal risk factors and education gaps (Warf, 2011)

(Kamalo, 2013) explains that VP shunts were being inserted in affected children since the year 1991, but the etiology and the number of cases were never known until 2003. Additionally, in unpublished reports by (Kaunda, 2016) it is indicated that Malawi before the year 2003, had

no identified hydrocephalus cases. This was as a result of the parents hiding their affected children until they died, they did this because such children were culturally unaccepted. Parents started bringing their affected children to the hospital after IFSBH through their trained nurses intensified national awareness campaigns. Kamalo indicates that in 2005, QECH had 223 cases in two years, while unpublished data by Kaunda, (2016) indicates a total of 660 surgeries in the years 2015 and 2016. Nationally, unpublished data by Kaunda, indicates that 1,000 new cases have been reported indicating a rise of the condition compared to previous data.

There are three surgical approaches being used in Malawi and these are; Ventricular peritoneal shunt (VPS), Endoscopic third ventriculostomy (ETV) and ETV-Choroid plexus cauterization (CPC) (Kamalo, 2013) Shunt involves the placement of a tube from the ventricles (fluid filled space of the brain), to another body cavity where it can be drained, mostly the peritoneal cavity. While ETV is used to divert CSF through bypassing an obstruction to its normal absorption region the subarachnoid space (Cartwright & Wallace, 2010) Finally, ETV-CPC is when a soft neuro endoscope is used to seal the choroid plexus in both lateral ventricles, so that they stop producing CSF (Kamalo, 2013)

At the Queen Elizabeth central hospital (QECH), children with hydrocephalus are admitted at the pediatric department; Chatinkha nursery ward (CNW), Pediatric orthopedic and Neuro ward (PONW), Pediatric nursery ward (PNW) and are reviewed following discharge at the Under-five neuro clinic. Recent unpublished data by (Chapweteka, 2017) indicates that the hospital has an annual turn up of about 600 children with hydrocephalus. There is a 20% shunt revision rate and a death rate of 4%, this data shows that unlike in the past when the death rate was over 50%, current surgical interventions have prolonged the lives of these children (Kamalo,

2013) Current unpublished data by Kaunda, (2017) explains that most of these children are surviving to adulthood, although a large percentage still depend completely on their caregivers.

International Federation of Spina Bifida and Hydrocephalus (IFSBH)- Spina Bifida Hydrocephalus Interdisciplinary Program passport (SHIP) for caregivers, offers an overview of the child's condition, enabling the specialists managing the child to have coordinated multidisciplinary approach (IFSBH, 2013). This passport is kept by the care giver and is brought to each hospital visit, and also used for home visits. Additionally, the passport recommends that the dates of assessment be kept, date of birth, location, when and where the problem started, the head circumference and the child's mental development, if normal or delayed. The passport also recommends an overview of topics of which caregivers of children with hydrocephalus should be informed. These topics include the condition of the child and degree of risks, the next step in treatment, cost of available resources, measuring head circumference, signs of high blood pressure, skin care, deformity and occupational and physiotherapy.

The IFSBH- SHIP caregiver's passport is provided to caregivers of children with spina bifida and hydrocephalus at QECH and Malawi in general. However there is not much data regarding caregiver's knowledge and practices on some of the recommended topics like; ICP, head circumference measurement and steps in treatment. In line with this, a study conducted in England by (Smith, Cheater, & Bekker, 2013) indicates that parents perceived that their expertise was not always valued by the health professionals, or used to inform clinical decisions, even though they were able to recognize illness symptoms suggestive of shunt malfunction. As a result, parents went on to ask that health professionals listen to their concerns and value their experiences. Because Parents can recognize illness symptoms suggestive of shunt malfunction, they should be involved in nursing children with hydrocephalus. Collaboration with parents

requires health professionals to listen to parents' concerns and value their experiences and expertise (Relkin, 2013).

Children with congenital or acquired hydrocephalus need prompt treatment to reduce brain damage from increased intracranial pressure (Dupepe et al., 2016). Unpublished data collected in Blantyre QECH, by Kaunda, 2016 has reported that some caregivers with children with hydrocephalus have had experience where they have had to wait for the children to turn 6 months, before the service providers could refer them to a tertiary hospital for shunt insertion. Others have stayed home hoping that the fontanelle would close, all these end up delaying the management of the child. Consequently this causes brain damage, thus the children are left with developmental deficiencies, leading to dependency on the caregiver. In a related study by (Dupepe et al., 2016) it was discovered that early shunt insertion yields better results in hydrocephalus management, reducing the risk of further brain damage. The occupational and physiotherapy team also manages the child's developmental needs and provide the child with assistive devices to assist in mobility and comfort of the child. They also provide wheelchairs and corner chairs, to support the rapidly growing head of the child.

Kaunda, (2016) in her unpublished study, indicates that currently Malawi has teenagers and adults who have had the condition from infancy. The country has a total of 700 to 750 survivors of children with hydrocephalus and spina bifida, the QECH neuro team interacts with the survivors on the IFBSH international day hosted at QECH annually.

Unpublished data by Solomon and (Kaunda, 2016) explains that the management of choice for children with hydrocephalus at QECH is ETV, VPS is being avoided because of its high infection rate. Pre-operatively a septic check is done for all children which include malaria parasite, level of hemoglobin and CSF analysis. Broad spectrum antibiotics like ceftriaxone

100mg/kg are given to clear infection before surgery, also given post operatively depending on the patient's condition. Ventricular tapping, head circumference measurement and ICP are done by both the nursing and medical team.

Problem Statement

Hydrocephalus is one of neural disabilities affecting many children attending Queen Elizabeth Central Hospital. It is documented that QECH admits 600 children with hydrocephalus annually and these children require repeated surgical interventions of Shunt insertion, revision and ETV (Kamalo, 2013). Children with hydrocephalus have developmental delay, cognitive and motor deficiencies due to brain damage (Cartwright & Wallace, 2010). In line with this, the cognitive and motor deficiencies result in potentially life long disabilities and continued dependence on caregivers for all aspects of daily life.

Therefore caregivers of children with such conditions must cope tremendous emotional, physical and economic burdens and may benefit from supports both within their community and from the health system. One important aspect of health system support for caregivers is education and supports specifically focused on the unique challenges of hydrocephalus. Yet such access to such educational resources may be lacking or in other situation be in English, while most caregivers only speak English. The International Federation for Spina bifida and Hydrocephalus (IFBSH) has a health passport for caregivers of children with SB and Hydrocephalus, "the Spina bifida Hydrocephalus Interdisciplinary Program (SHIP) passport", however this resource is entirely in English.

According to (Paget et al., 2016) attending to the elimination, feeding and emotional needs of the child with neural disability such as hydrocephalous causes stress and burn out in the caregiver. The frequent hospital admissions, transport costs and the cost of caring for the child

with neural disability also lead to financial burden to the caregiver. However, the experiences of the caregivers for children with hydrocephalus at QECH have not been previously investigated.

Broad Objective

To explore the experiences of caregivers for children with hydrocephalus at Queen Elizabeth central Hospital.

Specific objectives.

1. To describe the caregivers understanding of hydrocephalus.
2. To describe caregivers practices in the provision of care to children with hydrocephalus.
3. To explore challenges faced by the caregivers of children suffering from hydrocephalus.
4. To determine the support needed by caregivers of children suffering from hydrocephalus.

Significance of the Study

Caregivers of children with hydrocephalus play an important role in the management of these children. Understanding the experiences of these caregivers is therefore important for the improvement of nursing care to the patients and enhancing the relationship between the caregivers and the nurses. This will be as a result of the caregiver's expression of the challenges that they encounter as they care for the children with hydrocephalus, hence the nurses will understand and support them as necessary. Therefore the nurses and caregivers interaction will be improved, resulting in improved care to the child with hydrocephalus. Additionally, the study will establish what really happens on the ground, so that the knowledge gained will form base for further studies in the same field (Smith, Cheater and Bekker, 2013).

Constraints of the Study

The study's results will apply to QECH setting, because it will only be conducted at the named hospital, it will only be conducted at the named hospital due to inadequate funds.

Dissemination of the Results

Dissemination will be through publishing the study in peer reviewed journals. A study report will be given to the QECH hospital director, head of paediatric department and COMREC. A copy of the dissertation will be submitted to University of Malawi offices in Zomba, and Kamuzu College of Nursing's (KCN) library. Study findings will also be presented to academic staff at KCN during research seminars and to QECH pediatric department.

CHAPTER 2

Literature Review

Introduction

Global, regional and national literature of experiences of caregivers of children with hydrocephalus, from nursing journals and full-text research reports were reviewed. The search engines used were Google Chrome and Google Scholar. The following electronic data bases were used to identify articles for review; Full Free PDF for free scientific publications; HINARI, EBSCO, JSTOR and Pub med/MEDLINE. The American Psychological Association (APA) citation and format style has been used in this document. The major searching words used were, caregivers experience, hydrocephalus caregivers, support caregivers, congenital abnormalities caregivers and caregivers experience challenges on the aspect of their knowledge, practices, challenges and the support that they receive.

Hydrocephalus is a long term condition which influences the family, due to the frequent hospitalizations, surgical procedures and cognitive and motor impairment it causes on the child (Cestari et al., 2013a). Living with a child with hydrocephalus causes the parents and guardians to not only to rely on the health professionals, but also for them to take up the responsibility of caring for the child in and out of the hospital. Consequently, because of the demands of the disease process, like shunt insertion surgery, shunt malfunction and cognitive impairment, the child's parents or guardian take up the challenging obligation of becoming a caregiver, on top of the normal parenting duties (Smith, Cheater, & Hilary, 2015). This literature review covers the aspects of the caregiver's knowledge, practices, challenges and the support that they receive.

This literature review will not discuss the experience of service providers or the experience of

the child with hydrocephalus in detail, although they will be mentioned a number of times because they influence the caregivers experience.

Caregivers Understanding of Hydrocephalus

In this objective research articles pertaining to the caregivers understanding of hydrocephalus are reviewed. (Smith, 2010) discovered that the main source of information of caregivers pertaining to the child's condition is the health care workers. This is as a result of the frequent contact that is there between the care givers and HCW, while admitted in the hospital. There is contact when the HCW are; giving medication to the child, sending the child for a certain procedure, giving health education and attending to the caregiver's complaints and concerns. In all these situations the care giver gains knowledge from the information being provided. Additionally, the care givers depend on the health HCW to inform them about the child's health condition, and clearly explain to the caregivers their role in the provision of care to their child with hydrocephalus.

In another study by (Oliveria, Pereira, & Freitas, 2010), they explained that the more the number of years that the caregivers had been to school, the more the knowledge on the hydrocephalus condition. This is true because a caregiver who has had formal education would have the knowhow of seeking for more information on their child's condition, and would most likely use the available resources to get more information, unlike a caregiver from the village who had not gone to school, everything may sound new and strange, and the service provider may need some time to explain and make clear the information being provided. (Smith et al., 2013) indicated that caregivers who have had an education seek to understand the knowledge and skills pertaining to the hydrocephalus condition so that they are able to note any deviations from the normal, unlike their counterparts with little or no education. Similarly, (Animasahun,

Kehinde, Falase, Odusanya, & Njokanma, 2015) indicated that a high socioeconomic status, was found to have positive influence on the caregiver's knowledge of the condition of their child, because they have access to the internet and other social media for information. As a result this helps the caregivers be able to balance their activities easily, without facing a lot of disruption in their lives normal activities.

In addition, caregivers integrate their information on normal child development, and prior child illness episodes to be able to detect any changes in shunt functioning that might require health professional attention (Oliveria et al., 2010) This experience helps the caregiver be able to identify deviation from the normal like in the case where the child has ICP. (IFSBH, 2013) explained that most caregivers usually hunger for information specifically related to their child's condition, and in their report, they indicate that caregivers can find information from fellow caregivers association and through the utilization of the booklet provided to all caregivers of children with spina bifida and hydrocephalus. Caregivers support groups, are important because each one of the caregivers shares their experience and knowledge of expertise, eventually all the group members benefit from this through gaining new knowledge.

According to (Hudepohl, Robins, & King, 2013), caregiver's expertise and confidence in the provision of care to the child with hydrocephalus is important, because this helps prevent anxiety in both the caregiver and the child. In addition, (John, Ram, Sundarmurthy, Rathod, & Rathod, 2016) explained that caregiver's realization that they have a child with disability, influences their health seeking behavior, this is in response to the society which at times victimizes the disabled population. (John et al., 2016), continued to say that health seeking behavior of caregivers with children with hydrocephalus is influenced by the society they live in, their cultural practices and beliefs. If the society believes that there is hope for the child with

disability, the caregiver will be encouraged to seek help, if the society believes otherwise, then the child with hydrocephalus will be a taboo, and may be hidden from the critical eye of the society.

(Kazui et al., 2016) reported that caregivers are influenced to seek for health care, when they have knowledge of how shunt helps in reducing increased intracranial pressure, thus reducing cognitive impairment, knowing how much a burden it is to care for the child with extreme cognitive impairment. Another important aspect of loading the caregiver with knowledge is through use of awareness campaigns. In line with this, awareness campaigns for both caregivers and service providers have proved to mold positive health seeking practices, disregarding level of education (Cartwright & Wallace, 2010).

Caregivers Practices in the Provision of care to Children with Hydrocephalus

This objectives reviews literature of articles that discuss the caregivers practices as they provide care to their children who are affected by hydrocephalus. (Smith et al., 2013) in their study indicated that the international health policy, has declared that patients with chronic illness, should take part in planning about their health management. Additionally, (Smith et al., 2015) reported that in the case where the patient is a child, the caregiver becomes the one to takes part in decision making concerning the child's health care plan, together with the HCW. This may be considered with caution, while considering the fact that caregivers are usually stressed due to the disease condition of their children, and this may affect their thoughts, hence affect their decisions. Similarly, Smith (2010) explained that a good parent-professional teamwork, makes it easy to identify shunt malfunction. When there is good teamwork, parent's gain the skills and knowledge on the child's health condition, and are able to differentiate between normal childhood ailments from an illness arising from shunt problems.

In a related study (Bannink, Idro, & Van Hove, 2016) indicate that caregivers are affected by the HCW's negativity towards the hydrocephalus condition, like frequent hospital admission, thus creating practices which affects health seeking behaviors and care practice. Furthermore, caregiver's decision to seek health professional's care, is influenced by the calculated desire to strike a balance between managing the child with the hydrocephalus condition, and meeting the essentials of the rest of the family (Smith et al., 2013). When caregivers fear the HCWs', it may be difficult for them to rush to the hospital at the sign of deviation from normal of the child with hydrocephalus. A good collaboration of the caregivers and the HCWs' create a good hospital environment which is welcoming and makes it easy for the caregivers to bring the child to the hospital when need arises.

Recent studies have discovered that caregivers are discouraged to take part in the care of their children because HCW's do not regard as important their expertise (Cartwright and Wallace, 2010; IFSBH, 2013). Consequently the care givers are sent out of the picture if they question or disagree to a health care plan of their child. Eventually this affects the caregiver's implementation of their expertise and may choose not to tell of significant changes in the patient's condition as they may feel that their opinion does not matter.

Challenges Faced by the Caregivers of Children Suffering from Hydrocephalus

In this objective, recent research articles concerning the challenges that the caregivers of children with hydrocephalus experience have been reviewed. Studies have found that caring for a child affected by hydrocephalus leads to stress and anxiety, and other psychological disorders like insomnia (Kulkarni, 2016). In a related study, (Morgado & Figaji, 2014) indicated that the caregivers stress is increased if the child has episodes of seizures, as there is concern of child survival chances and risk of brain damage, thus cognitive and motor impairment. Stress affects

the caregivers eating habits, social interaction and all important aspects of the individual are affected by stress, thus making the caregiver counterproductive.

(Gurol, 2015) found that the other challenge that causes stress among caregivers is the issue about hydrocephalus condition developing in utero or a few days or months after birth. Usually the child is small and has to be hospitalized frequently, while frequently undergoing through several surgical procedures, which occurs because of shunt malfunction or failure. (Kulkarni, 2010) explained that parental concern comes in because of the demanding care for the child and the eventful health pathway, which eventually affect the caregiver psychologically. Furthermore the caregivers' worry about what would happen in the future of the child with hydrocephalus.

The caregivers also have problems pertaining to transportation to and from the hospitals they have to source for funds to be able to pay for the fare, this makes them have a strain in the finances (Gurol, 2015) (Paget et al., 2016). In a related study by (Kulkarni, 2010) it was discovered that caregivers worry about the attention the child with hydrocephalus requires often consuming all their time, including time to go to work or other income generating activities. Financial constraint is a concern of care givers of children with chronic conditions, transport is one of the ways that money is spent, although food, shelter and money to buy airtime and other essential hospital needs are also major ways that money is spent, which could otherwise been kept for other use.

Consequently Kulkarni, 2010 explained that the caregivers fail to take care of themselves, fail to do household chores and duties and have no time for social activities and interactions, and fail to take care of the other children that they have (Paget et al., 2016) It was discovered that the pressure arising from the special care demands of this child, causes

depression and burnout in most mothers (Paget et al., 2016). In addition, the burden of care and the unmet expectation of the child getting better, can lead the caregivers to give-up, thus depression and breakdown (Kulkarni, 2016). As a result this has caused a risk for neglect, as the caregiver no longer has the energy to care for the child adequately, and in a study done by (Paget et al., 2016) child abuse has been reported. Compared to other disease related effects, the cognitive impairment is one of the major factors that causes stress on the caregiver of the child with hydrocephalus. This is because the child entirely depends on the caregiver (Kazui et al., 2016)

(Kazui et al., 2016) explained that the other aspect that causes challenge on the care giver is the negative cultural beliefs and practice. In some communities having a child with hydrocephalus may be considered a taboo, and thus social neglect. Consequently this causes pressure on the caregiver, as they become divided on the health professional's opinion on hope for the child and the society's demand that the child be abandoned. Cultural beliefs also have influence on the caregiver's willingness to spend on the overall care of the child and even the special education of the child (Vinchon, Rekate, & Kulkarni, 2012). (Gurol, 2015) indicated that some care givers had expressed concern about the time requirement and the stress that erupts from caring for the child caused marital problems such as separation and divorce.

Support Needed by Caregivers of Children Suffering from Hydrocephalus

(Anderson, Dumont, Jacobs, & Azzaria, 2008), reported that lack of adequate preparation and support of a caregiver is a major threat to the child with hydrocephalus. Research has shown that caregivers are considered as secondary patients needing support and protection to their health as they provide care. In addition, caregivers are considered as workers providing care without payment and need to be trained to gain the skills and knowledge as regards to caring for

a child with hydrocephalus. This support to be rendered to caregivers, could be teaching, psychological, hands on, caregiving partner and financial support (Masthoff, 2016).

Caregivers have expressed lack of support from the service providers, who they claim do not take into consideration their expertise and experience in the care of the child with hydrocephalus (Smith et al., 2013). In a study by (Gurol, 2015), it was reported that teaching caregivers helps them to have realistic expectations of their child's illness and to cope up with the diagnosis. According to (Norkett, McLone, & Bowman, 2016) it was found that service provider need to offer support to the caregivers, right from the time a diagnosis is made, through explaining the disease condition, treatment schedules and what to expect.

The service providers working with children affected by hydrocephalus do offer support to the caregivers, even though some caregivers still feel that they are not supported as desired. Service providers support the care givers through encouraging words, helping them use their phones in case of emergencies and providing donations of clothes and other important accessories that the caregivers may need to make their hospital stay comfortable. They place the patients with the same condition in the same room for admission, so that they can keep each other company and encourage each other not to give up. And as they see others being discharged with the same condition they get encouraged. (Abhaya, Kulkarni, Cochrane, & Shams, 2008) reported that the support to caregivers is mainly handed by nurses who conduct training session for them, and help them plan their care and personal plan so that they don't crash with the patient's care program or schedule

Positive cultural practices have been discovered to reduce caregiver's stress, because those surrounding help in caring for the child, and therefore the caregiver is not left alone (Lee et al., 2011). In line with this, (Norkett et al., 2016) indicate that caregivers need social support,

through the provision of encouraging information that makes the caregiver feel a sense of belonging and not isolated as they care for the child with hydrocephalus. (Smith et al., 2013), it has been noted that there is a need a focal person who the caregivers could contact while at home, especially a nurse.

Similarly, in a study done by (Kahle, Kulkarni, Limbrick, & Warf, 2016), caregivers explained that they require to be supported by friends, relatives, family, fellow caregivers and support group, even after normal working hours. It has been reported that caregivers complained that the service providers lack time to give the required vital information to them and intentionally make it impossible to create good relationship with the caregiver (Smith et al., 2013). The service providers need to be responsive to the caregivers' questions about their child's condition such as how the child is fairing and the general prognosis of the child. This gives caregivers a sense of being assisted and supported (Johnson, Dudgeon, Kuehn, & Walker, 2007).

(Kulkarni, 2016) observed that having another person to take of the child and allows the caregiver to go out and relax is another aspect that a caregiver value as a sense of being supported. (Bannink, Stroeken, Idro, & Hove, 2015) also noted that this helps to reduce stigmatization and allows them to attend to personal matters as well as support gatherings. Other family member need to also offer themselves to care for the child so that the main care giver can have time to do other things. Similarly, (Thwala, Ntinda, & Hlanze, 2015) reported that caregivers experience both psychological and physical stress because of the endless special care they provide to the child. He added that a multidisciplinary support approach by the service providers is recommended.

Another support intervention that has been studied as helpful is individual approach and counselling which helps improve the caregiver's welfare. This is opposed to group approach which improves the caregiver's knowledge on when to seek for health professional intervention as they provide care to the child (Piškur et al., 2012). It is recommended that the individual support intervention provided to the caregivers should last for 7 months. Individual support allows the caregiver to explain even the intimate details which would be difficult in the case of group counselling. The service providers should always attempt to find a private room so that individual counselling can be achieved. This requires that there should be follow up visits and counselling sessions, which are costly and almost nonexistent. Furthermore, friendly phone calls, and home visits are supportive especially to the caregivers who, fail to gain control over their situation (Cestari, Carvalho, & Barbosa, 2013).

CHAPTER 3

Methodology

Introduction

Methodology is a descriptive guideline of how the research is to be carried out, it defines the mode of data collection, how the results are to be presented and the general presentation of the study (Burns & Grove, 2009). In line with this, the chapter explains the details of the study methods and design; place; population; sample size and sampling methods; recruitment criteria; data collection procedure, data management, analysis and trustworthiness.

Study Design

This study will employ a descriptive qualitative design in order to explore the experiences of caregivers of children with hydrocephalus at QECH. This is because Qualitative research aims at providing an in depth and interpreted understanding of the social world of research participants; by learning about the sense they make of their social and material circumstances, their experiences, perspectives and histories (Ritchie, Lewis, Nicholls, & Ormston, 2014) In this study the use of qualitative approach will provide an opportunity for a systemic in-depth, evaluation of a question that may not be easily answered through quantitative methods.

Study Setting

The study will be conducted at QECH paediatric department; Paediatric orthopaedic and Neuro ward (PONW) and Under-5 neuro clinic. **This is because the hospital is a major referral hospital receiving more than 500 children with hydrocephalus annually.** The hospital admits patients from all over Malawi and neighbouring countries such as Mozambique.

Therefore this will enable the researcher to get information from caregivers with different backgrounds and social economic status.

Study Population

The study population will be care givers of children with hydrocephalus at the QECH paediatric department ward; namely Paediatric Orthopedic and Neuro Ward (PONW) and under-5 neuro clinic. These service care points, the PONW and under-5 neuro clinic provide care to children with hydrocephalus.

Sample Size

The sample size for this study will be 30 participants. The guiding principle will be data saturation, and saturation is reached easily if participant are good informants and are able to reflect on their experiences and communicate effectively (Ritchie et al., 2014). It is hoped that the caregivers of the children with hydrocephalus aged above 2 years will have adequate experience to be interviewed and reflect their experiences effectively.

Sampling Method

Non probability sampling methods is a sampling techniques in which samples are selected based on the subjective judgment of the researcher, rather than random selection like in probability sampling techniques. In this technique the odds of any member being selected for a sample cannot be calculated. Purposive sampling method which is one of the five types of nonprobability sampling method will be used in this study. Purposive sampling method is a non-probability sample that is selected based on characteristics of a population and the objective of the study. The participants selected have particular features, like being a caregiver of a child with hydrocephalus admitted in PONW which will enable detailed exploration and understanding of the central themes and questions which the researcher wishes to study (Ritchie et al., 2014).

Inclusion and Exclusion Criteria.

The caregivers of children with hydrocephalus aged two to ten years old will be included, and these children will be the ones admitted at the PONW, or attending the under-5 neuro clinic. While exclusion criteria will be those caregivers whose children with hydrocephalus are less than 2 years old, and above 10 years old, critically ill, child in theatre or less than 24 hours post operatively. Those whose children are not at the under-5 neuro clinic or admitted PONW will not be included. Interviews will be conducted, in the afternoon hours after the ward rounds and neuro clinic reviews. The nurse in charge will be asked to explain to the participants the ongoing study, and the caregivers will be handed over to the researcher for interviews.

Data Collection Instrument

(Polit & Beck, 2014) indicate that semi structured interview guide are used when the researcher has broad questions that must be addressed in an interview. Using a topic or interview guide helps to ensure that all those interviewed have equal opportunities to provide information, and are assessed consistently. The researcher will develop a semi-structured interview guide **(Appendix 3A & 3B)** from the specific objectives and theoretical framework, which are the knowledge and practices, the challenges and the support system to the caregivers. The interview guide **(Appendix 3A & 3B)** is useful for getting the story behind a participants experiences. Additionally the interview questions can pursue in depth information around a topic, and can be used to further investigate their responses through use of open ended questions.

Data Collection Process

Recruitment of participants will be done in the PONW and the Under-5 neuro clinic. The participants will be given detailed written information **(Appendix 1A & 1B)** about the study and the consent **(Appendix 2A & 2B)** form to read, understand and sign to indicate their willingness

to participate. A private room in the wards will be used for interviews, and Chichewa language will be the only language used. The interview will last maximum **45 minutes**, so that the caregivers can go back to attend to their children.

Data Management

Data management will follow four steps, namely creating data, organizing the data, accessing the data, looking after and sharing the data. To accomplish this, consent forms, letters to different departments and the tool will be formulated and kept ready and safe. All the files in the computer will be named according to content, to avoid a mix up of information. Finally all the data will have a back- up, and all the data files and a recorder will be kept in a locked safe, access will be denied to others except for the researcher and the allocated supervisors. The electronic data will be kept in the researcher's computer with a private password.

Data Analysis

Data will be analyzed manually and through thematic data analysis in which the themes will be recorded within the data. Themes are patterns across data sets that are important to the description of a phenomenon and are associated to a specific research question. Thematic analysis is simple to use and it allows for flexibility in the researchers choice of theoretical framework. Some other methods of analysis are closely tied to specific theories, but thematic analysis can be used with any theory the researcher chooses. Therefore thematic analysis allows for rich, detailed and complex description of the data.

Trustworthiness

It is the truth or accuracy of a claim (Burns & Grove, 2009) and involves the opportunity to reflect and comment on their story and retold by the narrative researcher. A framework with

four criteria of developing trustworthiness will be used, these are credibility, dependability, confirmability and transferability (Polit & Beck, 2010).

Credibility.

This is when the context description is meaningful, true, convincing and makes sense (Miles, Huberman, & Saldana, 2014). This will be achieved through accurate conclusions and explanations for incoherent explanation will be offered for questionable responses. The participants will be allowed to refuse to participate and to only participate willingly.

Dependability.

To achieve dependability of the data, the researcher will only interview the caregivers who fall under inclusion and exclusion criteria described above. This will ensure that if other researchers repeat the work, similar results will be obtained (Polit & Beck, 2010). These processes include; the research methods, detailed collection of data and analysis of the study. The researcher will have a log book of the steps and the decisions (including rationale for decisions) that the researcher have followed during the project, from the start of research project to reporting of the findings which are called audit and decision trails. The written report will also provide thorough understanding of the methods employed in the study.

Confirmability.

In this study, confirmability will be achieved by recording all the words spoken by participants and the researcher during in-depth interview in order to distinguish the participant's data from interviewer's view. The researcher will act as an active listener and facilitator to allow participants to give detailed information of their experience.

Transferability.

Transferability is when the reader of the research study would be able to transfer findings to other contexts (Miles et al., 2014). This will be achieved through keeping field notes with information of the time, settings and cultural beliefs of the study population, this data will be included in the contextual background of the study. Consequently this will guide other researchers to sufficiently compare with other samples, if they have similar contextual background information.

Ethical Consideration

Ethically there will be no physical, emotional or social harm and there will be no monetary benefits for the participants. Additionally, the participant's participation will help to improve the patients care of children with hydrocephalus (Polit & Beck, 2010). Voluntary participation will be observed and informed consent will be obtained from the participants involved. Privacy and confidentiality will be observed and data that will be collected will be kept in locked lockers and the computer used will have a password. Anonymity will also be observed because the participants will not be linked to the information that they will provide (Polit & Beck). The consent will be obtained through verbal and written signature. Ethical approval to conduct this study will be obtained from the College of Medicine Research and Ethics Committee (COMREC) through Kamuzu College of Nursing, and permission from QECH hospital Director and head of Pediatric department through letters will be sought.

Study Limitations

The study will only be conducted at QECH as such results cannot be generalized. Another major limiting factor is the study time and financial constraints. Since the research is being conducted in partial fulfillment of the award of a Master of Science degree in Child health

Nursing, it has to be finalized within a specified period of time hence it is not easy to include other facilities.

Dissemination of Study Results

Study findings will be presented to academic staff at Kamuzu College of Nursing (KCN) during research seminars and QECH paediatric department during Journal club and **Continuous Professional Development (CPD) meetings in addition to a written report.** A copy of the thesis will be placed in KCN library. Other copies will be sent to Ministry of Health and QECH paediatric department. The results will be published in Nursing Journals and will be disseminated at conferences both locally as well as internationally.

CHAPTER 4

Presentation of Findings

Introduction

This chapter presents the findings of the study conducted in Blantyre. The aim of the study was to explore the experiences of caregivers of children with hydrocephalus at Queen Elizabeth central hospital (QECH). The specific objectives of the study were: describe the caregivers understanding of hydrocephalus, describe caregiver's practices in the provision of care to children with hydrocephalus, explore challenges faced by the caregivers of children suffering from hydrocephalus and determine the support needed by caregivers of children suffering from hydrocephalus.

The process of data analysis was done through the application of thematic data analysis. First, the researcher read and reread all the participants' interview guides and listened to the recorded interviews. Next, the researcher transcribed the data collected from the interviews. Meanings were formulated from the significant statements and codes were generated, and these codes evolve into categories and eventually into themes. The researcher wrote an exhaustive description of the caregiver's experience, from which the essential structure of the phenomena was formulated (Vaismoradi, Turunen, & Bondas, 2013).

The findings are in two sections. The first part contains demographic characteristics of the 20 caregivers who participated in the study at the pediatric neuro ward and under-five neuro clinic at QECH. The demographic characteristics also contain information on caregiver's children with hydrocephalus ranged from 2 to 12 years old. The second part presents the analysis of qualitative data which was derived from one to one in-depth interviews with participants using semi-structured interview guides.

Demographic Data

Table 1.1 shows the demographic characteristics of the caregivers and affected children. The table presents the demographic characteristics of total of twenty (20) caregivers and children with hydrocephalus with an age range of 2-12 years old.

Table 1: Demographic Characteristics (Caregiver and Affected child)

Characteristics (Caregiver)	n	Characteristics (Child)	n
Age		Age of child with hydrocephalus	
20 years or less	2	24-59 months	11
21-34	10	5-10 years	7
35-44	6	11-12 years	2
45-54	1		
Unknown	1		
Marital Status		Age of child at first hydrocephalus diagnosis	
Married	14	0-28 days	4
Separated	2	1-6 months	11
Widowed	3	7-12 months	2
Divorced	1	1-5 years	3
Educational level			
Primary	9	Number of children with Hydrocephalus and	
Secondary	9	spina bifida (SB	
Tertiary	1	Hydrocephalus only	2
None	1	Hydrocephalus and SB	2
Religion			
Roman Catholic	3		
CCAP	4		
SDA	1		
Other	12		
Occupation			
Small business	3		
Farmer	6		
Unemployed	11		
Nationality			
Malawian	19		
DRC	1		
Tribe			
Chewa	4		
Lomwe	9		
Mang'anja	1		
Ngoni	3		
Sena	2		
Other	1		
Relationship to child			
Mother	19		
Grandmother	1		

Table 2: Findings Pronoun interpretation

Pronoun	Number of caregivers
Some	5-8
Another	1
Most	15 and above
Other	5-8
All	20
Majority	18
A few	1-4
Almost	17

Qualitative Data

The qualitative data was analysed using thematic analysis (TA) which was described in chapter three. The interview results are presented in six main themes and seven sub themes that emerged from the caregiver's responses and these were: (1) Strange illness (2) Social stigmatization (3) Disability burden (4) Work overload; activities of daily living, infection prevention and psychological care (5) Financial constraint; frequent hospitalization (6) Support system; relatives and friends, health professionals and organizations. The themes have been described in the sections that follow, and direct quotes from caregivers have been used to illustrate what was actually said.

Theme 1: Strange Illness

This theme addresses the study objective on caregivers understanding of hydrocephalus. Caregivers were assessed on their experience regarding their understanding of hydrocephalus. Some of the caregivers verbalized that the disease condition was new to them, and at first they thought that the increased child's head would be cured using traditional home remedies. Caregiver # 10 explained:

“At first I did not know the disease. I knew about the usual headache known by our parents and grandparents. That they would do traditional medicine and the problem would end. But the condition that my child has, I did not know. I first heard about it in 2007 when my child was brought to the hospital”.

Some caregivers responded to say that antenatal scanning helped them to accept the child's condition with ease. Caregiver # 5 explained:

“My child's condition was discovered during an antenatal visit, it was shocking to me that my child would be born with a lifelong condition. It was good that I knew before the

child was born, but still more I had concerns on how the child was going to be like with the problem that he had”.

Another caregiver who had scanning done during antenatal visit was shocked at the revelation that the child that was being expected would be born with hydrocephalus. Caregiver # 14 explained:

“When they told me after the scanning that my child was going to be born with hydrocephalus and spina bifida, I was shocked. This was because I had a good appetite and was able to eat foods like vegetables rich in folic acid”.

Another caregiver associates diarrhea to the disease condition. Caregiver # 2 explained:

“I don’t know what causes the disease, but we notice that diarrhea was the first problem that the child had before the head started to increase in size”.

Some caregivers explained that they don’t know what causes hydrocephalus and worry because the condition is new and has no known cure. Caregiver # 15 explained that:

“I get stressed up when I spend time thinking and asking myself about what really happened for the child to be found with this problem because my child was well when he was born”

Caregiver # 20 explained:

“Before people used to say that this illness has come as a strange illness and cannot be cured, but right now it is curable.

Caregiver # 1 explained:

“I have never seen or heard about this condition when my child first had it we were all in a state of shock”.

Another caregiver associated the hydrocephalus condition with witchcraft. Caregiver # 17 responded:

“At first I didn’t know the disease. I knew hydrocephalus when my child started suffering from the condition. We thought that the child had been bewitched”.

Theme 2: Social Stigmatization

The study objective that is being addressed by the theme of social stigmatization is the one on challenges faced by caregivers of children with hydrocephalus. Some caregivers also explained that they felt socially stigmatized when they had to do piece work to get some money, they are forced to leave the child with hydrocephalus alone at home. “This is because the child usually weighs heavy because of the head size, and some employers were usually not comfortable to have the mother come along with her sick child”. In other cases the caregivers also mentioned that people actually socially segregated them, when they see the caregiver passing with her child, they would stop talking and all look at her with her child. Caregiver # 6 explained:

“When you live in a community there are usually development activities and we are expected to go and help but I fail to attend to such functions because the work being done there is tough mostly and I may not manage to work with the child at my back. In the end I stay at home, I even stopped attending funeral ceremonies. This is because every time I went to a funeral and took my child, people would pinch each other and this gave me pressure. My child should not suffer at the mercy of people and so I just stayed home.

And if I do not attend funerals people normally do not even ask because they understand my situation”.

Some caregivers had to bear the insult and claims that tell that such a child born with hydrocephalus can only be a result of witchcraft practices and traditional rituals by the parents. Caregiver # 17 explained that:

“They may say that such children don’t live long, and such children are born because of the witchcraft practices of their parents, it’s like they are for ritual practices. But I don’t even pay attention to them because I know my hands are clean and I don’t practice such traditional witchcraft rituals and practices. In fact I was encouraged when I was admitted here, to find a ward full of children with a similar condition”.

Another caregiver explained that she has not experienced any social stigmatization from the time her baby was born and diagnosed with hydrocephalus. Caregiver # 4 explained:

“Nobody ever told me to my face anything that made me feel socially isolated because of my child’s condition. They would never do it, maybe they talk bad things about my child behind my back, but not in my face. After all why would they do it, I never planned to have a child with hydrocephalus”

Theme 3: Disability Burden

The theme on disability burden addresses the study objective of caregiver’s challenges. The caregivers were assessed on their experienced problems as they care for their children with hydrocephalus. Some caregivers explained that children with hydrocephalus were particularly very selective in their food choices. Caregiver # 13 explained:

“The problem are the financial issues, this child chooses his food so much, and without money it is difficult and causes me psychological torture. For me to care for him the way he wants”.

Some caregivers complained of lack of assistive equipment like wheelchair, corner chair or walker, the government hospital could not support all the needy patients. This forced some caregivers to buy the assistive device for their children. Caregiver # 5 explained:

“I don’t have a corner chair, am yet to solicit one. A friend taught me to place a child at a corner and place blankets, but still more not very comfortable for the child, indeed a corner chair is ideal and very important, but to have it locally made would cost me 5,000 kwacha”.

Most of the caregivers responded to say that they were finding it hard to care for their children with hydrocephalus, and be able to sustain a business or be employed. Caregiver # 12 explained:

“The other thing is I cannot work anymore because in the end the child misses out on important things like physiotherapy, which is vital for him to prevent stiff limbs”.

Another caregiver explained that because of the child’s condition, government schools cannot manage to meet the special needs of the child with hydrocephalus. And therefore the caregiver is forced to take the child to a private school, and unfortunately these schools intentionally raise the fees higher than the standard to bar the child from attending. Caregiver # 12 responded:

“Another issue is a teacher cannot manage to be changing the child when he soiled himself, and so I am forced to make sure that the child passes stools before going to

school, and it is not easy. And some schools to avoid issues with a child with hydrocephalus, they just raise the fees so as to bar us from taking our child there”.

Theme 4: Work Overload

The theme of work overload addresses the study objective on the caregivers experienced challenges. The caregivers were asked to explain the problems that they face as they care for the child with hydrocephalus.

Activities of daily living.

Most of the caregivers indicated that taking care of the children with hydrocephalus required their commitment more than they did while taking care of the other children who did not have hydrocephalus. This is because unlike the other children who were normal, the children with hydrocephalus required that the parents should assist them with activities of daily living, infection prevention and psychological care. Additionally the parents needed to specifically see to it that the children were having play time. Otherwise the children would feel isolated and would have an unstimulated mind, which is detrimental to mental and physical wellbeing.

Caregiver # 10 responded that:

“In the morning my 9 year old son wakes up earlier than myself, I help him wash his face and if there is sun, I put him outside to bask in the sunshine. Then I prepare soya porridge for him to eat for breakfast, after eating I bath him and take him to school. He carries along with him, toys and playing materials, at 12 noon I go and get him, prepare food and feed him. Porridge or rice I have to feed him as he cannot manage to feed himself, but nsima, bread and even a banana with help he manages to feed himself”.

Another caregiver with a nine year old daughter explains on the care that she gives to her child, different from the care she gives to her other children who are even younger than the affected child. The caregiver # 9 explained:

“I make porridge for her, by around 7 am, he loves porridge. I feed and bath her in the early morning hours. In fact I feed her because for her to feed herself she takes too long to eat. And I always feel that she may end up hungry, while food is available. So if she insists on feeding herself she feeds herself the remaining food. Afternoon the same and night the same. If she wets or soils herself I make sure that I have changed her nappy, I intentionally stop doing other things so that I care for her”.

Another caregiver also described that physiotherapy is vital for her daughter, being a child with both hydrocephalus and spina bifida. Caregiver # 14 explained:

“When I wake up in the morning, I do clean intermittent catheterization (CIC) on my child, because she has spina bifida. Then I bath her, then I feed her porridge, after porridge I do physiotherapy exercise on her. I exercise her hands, her legs and toes to prevent stiffening of limbs”.

Another caregiver narrated how her life suddenly came to a stop when her child was diagnosed with the condition. She explained that all she did the whole day was take care of the child. Caregiver # 2 explained:

“When its morning, I take the child and put him to sleep close to where I am working as I cook porridge along. Then I wake him up, and take warm water and bath him, after that the clothes that he was wearing in bed, I take them off and put them in a tin. After that I bath him and I finish, then I wipe him and then apply oil on him, after this I feed him

porridge and then I take water and clean him up and carry him at my back. Then if I become tired but the child is not yet asleep, I carry him in my hands and most of the household chores it's my child who does them. Mostly I don't do household chores, I fail to work around the house with this child, I just stay. Mostly I am busy taking care of my child with hydrocephalus".

Another caregiver explained the care that is given to a 12 year child with hydrocephalus in a whole new perspective, where by on top of feeding and changing nappies, she also keeps turning him as he sleeps to prevent pressure sores of the head. Caregiver # 20 explained that:

"We need to continuously check on him because we need to see if he is wet or not so that we can change him fast. This is because if we don't change him, he will be wet for long and this can cause pressure sore in the long run. Even when sleeping we need to be checking on him and turn him on the other side after some time, he may get pressure sores. When feeding him feed him with care because some food may not go straight into his stomach like for normal person, and he may choke on it".

Other caregivers mentioned on the fact that having a wheelchair or a corner chair is vital in keeping the child in a sitting posture, otherwise the child will always be in sleeping position. Others mentioned that even though they did not have a corner chair, a mountain of blankets arranged at a corner of a room, serve a similar purpose. Caregiver # 6 explained:

"I cook porridge, and then place water for bathing on the fire as I feed the child the porridge. Afterwards I bath him, he has a corner chair, and so I take him and help him sit on the chair. When I see that he is tired I take him and carry him at the back, and once my back is tired I put him to sleep".

Some caregiver's expressed their worry about the future of the child the challenge of having a growing child who is totally dependent on the caregiver, and what does the future hold for the child in this state. Caregiver # 12 responded:

"The work that I do for this child is a lot because he does not say that he wants to go to the toilet, at times he tries to crawl but fails. So I have to carry him the whole day every time he needs to bath or use the toilet. In my heart I always worry if my child will ever walk again, it is my desire to see him walk".

Another caregiver explained that she was fine taking care of her three year old child, and does not feel overworked. Caregiver # 4 responded: *"No I am fine if I wanted to do piece work or business I would do it".*

Most of the caregivers responded that they would make sure that after nappy change, they wash their hands. The use of mosquito nets was also mentioned to prevent malaria, and keeping the utensils clean to prevent diarrhea. Another practice was the cutting of grass to be short and clearing the bushes around the home. Keeping the play area of the child with hydrocephalus clean was also mentioned. Caregiver # 6 explained:

"I use mosquito net, keep compound with cut grass not keeping stagnant water. Cleaning utensils to prevent diarrhea, sweeping the house, and when the child soils his nappy, change and wash hands. And another important practice is to keep food clean and safe".

Infection prevention.

Another group of caregivers mentioned that keeping the child's utensils and all other necessary equipment private also was very important in preventing infection during child care.

Caregiver # 11 explained that:

“The way I practice infection prevention for my son is that he has his own plates and they are always kept clean. His drinking water is kept in a 5 litre bottle, and we put water guard”.

Another caregiver emphasized the fact that she monitors the cleanliness state of the children coming to play with her children. Caregiver # 19 responds:

“I make sure that where she sits it should be clean so that there are no bad things that the child can use to hurt herself. Also at times when her friends, even though I am a needy woman, but if her friends look dirty and I ask them to leave. So that they can have a bath first and change clothes, because otherwise they may infect my already suffering child with flu and cough”.

Psychological care.

All the caregivers n=20 responded by saying that encouraging their child with hydrocephalus required that the caregiver should speak to child with love and gently. The caregivers also mentioned that they sent the child to school so as to interact with his or her friend. Almost all the caregivers encouraged their sick child that they would get well and all will be well. Caregiver # 12 explains:

“I send him to school for him to see that he is not different from his friends. I speak to him nicely, I don’t reprimand him, and sometimes I encourage him when he fails. I encourage him that one day he will be able to walk”.

Other caregivers also mentioned that they encourage the child spiritually, the caregivers tell the children that God cares and that he would heal them. Caregiver # 9 responded:

“I encourage him a lot because I notice that whenever I am stressed and sad, he also becomes sad. And when he is sad he has convulsions, so because of this when I am sad I try not to show that I am sad. I show him love so that he should not be sad like me so I

play with him. We received dolls from white people at Thyolo, so I put them close to him so that he can play with them. I also bought a radio, because he likes to listen to Christian programs and music”.

Theme 5: Financial Constraint

The theme of financial constraint is derived for the study objective on the experienced challenges of the caregiver. The caregivers were assessed on the problems that they face as they care for the children with hydrocephalus. Majority of the caregivers faced financial challenges, they complained that they could barely meet the daily needs and food for the affected children. Most of the financial constraint arose from the frequent hospitalization, the disability burden and caregivers work overload. Some caregivers verbalized that the children with hydrocephalus were particularly very selective in their food choices. Caregiver # 13 explained:

“The problem are the financial issues, this child chooses his food so much, and without money it is difficult and causes me psychological torture. For me to care for him the way he wants”.

Frequent hospitalization.

Some caregivers verbalized that the children with hydrocephalus were frequently hospitalized because of frequent illness. Caregiver # 16 responded:

“The child frequently gets sick, another challenge is a lack of food and clothes for the child. We do casual labor to find money to look after the child. When I go to do piece work, I leave the child at home alone”.

Another caregiver explained that her child needed to have frequent reviews and admissions because of hydrocephalus, and this has therefore led to financial constraints.

Caregiver # 18 responded:

“This year alone we have been admitted five times. At first he had shortness of breath. The second time we went home and he started convulsing, and we were admitted again. Then we stayed at home for three weeks and were admitted again. After this we stayed home for two weeks and were admitted for the fourth time with convulsions. And now is the fifth time, I am spending a lot of money to support myself during these admissions, including the transport fare from home”.

Some caregivers explained that they also spend a lot of money on the transport and fee for physiotherapy services. Caregiver # 1 explained:

“But while at Zomba they also suggested that we go to Sue Rider, where children with disability are seen and physiotherapy is offered. So we went to sue rider and they said that we will be paying for each visit”.

Another caregiver responded to say that she and her husband were financially stable and had not been experiencing any financial hardship. Caregiver # 7 explained:

“My husband works and is able to meet the family financial needs, we only have one child, and so the family needs are not much”

Theme 6: Support System

This theme addresses the study objective on the caregiver’s support that they need as they care for the child with hydrocephalus.

Relatives and friends.

The majority of caregivers verbalized that their relatives and friends supported them and were not complaining. Caregiver # 20 responded that: *“My sister is my major source of support, she receives money from her husband in South Africa for her and the 4 children. So she supports me, in fact all my relatives support me very much”*.

Another caregiver mentioned that she lacked support from her relatives and friends, organization and the hospital. Caregiver # 9 responded:

“Lack of transport to enable me to come for reviews in time, and also his clothes are now small. I also don’t have a house to live in. where I live now, a kind person just allowed us to live there, so we really don’t have a proper home to live. The friends and relatives when I go to them for help, I really get disappointed with the way they respond to me. Like when I come here, I just call that I am admitted, but none of them has ever followed me to visit the child”.

Some of the caregivers appreciated the effort that their friends and relatives put in helping them care for their children with hydrocephalus. Caregiver # 12 explained: *“They helped me look after the child, sometimes they take him for a walk. The relatives of both sides do this and I really felt that they are very supportive to me”*.

A few caregivers expressed dissatisfaction with their relatives and friends that did not support them, and they felt that they are alone with their affected child. Caregiver # 17 explained:

“They don’t encourage me they don’t even come and see me here at the hospital, even when I complain about transport issues they don’t even care to help me. My husband

does not care about the disease, he is in fact just goes around with different women, since I had this child”.

Health professionals.

Almost all the caregivers responded that the health workers in one way or the other, played an important role in supporting the caregivers caring for children with hydrocephalus.

Caregiver # 1 explained:

“They say that children should eat a balanced diet, when sick we should take him to the hospital, also take the child to school, if possible. They also advise us to take the children for physiotherapy, told us of children with hydrocephalus who are now able to walk”.

Only a few caregivers complained that they felt that the health care workers were not being helpful. Caregiver # 7 explains:

“There is no help as I have already explained, but now the only help I have is the nurse, he is from my country DRC. He has encouraged me to take the child to the hospital, from the day he met my child, he has always encouraged me to take the child to the hospital, and not keep her indoors”.

Another caregiver also responded that she can barely appreciate the work done by the health care workers, because they don’t even handle her as a human being with feelings when they are helping her sick child. Caregiver # 19 explained:

“I should say the truth the hospital barely assists me in the side of support, they never take time to counsel or encourage us in any way never. All they do is just do their work, this other time they put shunt twice and it failed both times. After all this bad experience, nobody has encouraged me in any way about my child condition. They just said that the

child should receive antibiotics for 14 days then will go back to theatre, for another shunt. After all they find any fluid in the child head. And As if I should abscond, after all from 2013 to date my child's head remains the same. I ask myself if I go home will her child grow bigger if they don't operate on her. If they put the shunt what's the use, she has been put shunts before what benefit is this operation going to serve. This is going to be the 5th operation, scars in the head all over. But my concern is if I leave and my child gets sick they may not help me again here".

Organizations.

Majority of the caregivers, verbalized that there was no organization that had helped them with the care of their children with hydrocephalus. In fact another caregiver mentioned that she desired that these organization should help by building a special school for children with hydrocephalus. Caregiver # 10 explained:

"Help is there except for transport as I already mentioned. At the hospital when we have a meeting in October annual meeting, people have complained that we need a special school for our children. Because children would come from all around, our children cannot learn together with a normal child, it is like he is escorting his friends just wasting time. Taking them to government school is not real, this would give us hope to know that my child is genuinely progressing well academically".

Whereas the rest of the caregivers responded to say that specific organization were very helpful with the care of their child with hydrocephalus. Some explained that the organizations have been helping with child physiotherapy sessions, donation of wheelchairs and giving health education to caregivers of children with hydrocephalus.

Caregiver # 17 explained: *“Sue rider they help with physiotherapy and teach us how to do physiotherapy on the child at home, we go to Kanako, they do physiotherapy every Saturday”*.

Most of the caregivers complained about school, it is not easy especially when the child is growing up. It is very difficult to find a good school which ready to accommodate a child with disability, and change their nappies and attend to the child’s basic needs like feeding. Caregiver # 10 explained: *“I don’t have hope that my child will continue with school. He cannot go to a government school because he may only be interested in playing while his friends are learning. It always feels like he is just escorting his friends to learn while he plays”*.

Summary

This chapter has presented the study findings, in line with the four study objectives namely to; describe the caregiver’s understanding of hydrocephalus, describe caregiver’s practices in the provision of care to children with hydrocephalus, explore challenges faced by the caregivers of children suffering from hydrocephalus and determine the support needed by caregivers of children suffering from hydrocephalus. Five themes were identified and their findings have been given namely: (1) Strange illness (2) Social stigmatization (3) Disability burden (4) Work overload (5) Financial constraint (6) Support system. Quotes of the exact words used by the caregivers during interviews have been used to back up the meaning of results.

CHAPTER 5

Discussion of findings

Introduction

This chapter presents the discussion of findings of the study which was aimed at exploring the experiences of caregivers of children with hydrocephalus at Queen Elizabeth Central Hospital. The discussion includes how the study relates to other research findings. The findings have been discussed consistent with the six themes which were derived from the study objectives. The study objectives were to: describe the caregiver's understanding of hydrocephalus; describe the caregiver's practices in the provision of care to children with hydrocephalus; explore challenges faced by the caregivers of children suffering from hydrocephalus; and determine the support needed by caregivers of children suffering from hydrocephalus.

The findings that will be discussed are according to the following major and sub themes that emerged from the analysis of findings: strange illness; social stigmatization; disability burden; work overload: activities of daily living, infection prevention and psychological care; financial constraint: frequent hospitalization; support system; relatives and friends, health professionals and organizations. Demographic information is incorporated in the discussion. Recommendations, areas that need further research and limitations of the study are also discussed in this chapter.

Demographic Data

Age of the caregivers.

The study findings on demographic data revealed that all the 20 caregivers were aged from 18 years and above, for the researcher it was ethically right to interview the mothers.

The Convention on the Rights of children, refers to all persons below the age of 18 as children (Ozer et al., 2014). The availability of matured caregivers is beneficial because psychologically they are stable. Consequently this is an advantage because taking care for the child with serious illness can have negative psychological effects on the caregiver, due to stress resulting from worry of the child's health and future (Kulkarni, 2016). Therefore a psychologically matured caregiver can better handle the stress that comes with caring for a chronically ill child.

Gender of the participants and their relationship with children.

The findings show that all the caregivers were females family members, majority were mothers to the affected children while one was a grandmother. Having mothers as caregivers to the children is calming to the children because most children feel safe and are calmer when their mother is taking care of them. Additionally culturally most caregivers to hospitalized children are females, even though they may get some assistance in caring for the hospitalized children from fathers, grandparents and other relatives (Paget, Mallewa, Chinguo, Mahebere-Chirambo, & Gladstone, 2016b). Contrary to the current research results, a study done in United kingdom, on the parents experience of living with a child affected by hydrocephalus, and their collaboration with the health professionals in diagnosing shunt malfunction; revealed that there were more fathers than mothers caring for the hospitalized children (Smith, 2010b).

Age of child at first hydrocephalus diagnosis.

The findings also revealed that majority of the children developed hydrocephalus when they were below 1 year old. As a result the children were presenting with noticeably, large heads, because the skull bones had not matured and fused. In a related study, the findings reveal that frequently continuing macrocephaly is usually seen in children who develop hydrocephalus while they are below 2 years (Kahle et al., 2016a). From these findings the young infants should

have their head circumference measurement done during their scheduled under five clinics and during the time that they are brought to the hospital for treatment. This is necessary because studies show that children born with chiari malformation type II usually present with hydrocephalus in young infancy, between 2 to 3 months up to 2 years, rarely seen in newborn babies (Yusuf et al., 2017) (Jones & Weerakkody, 2017). Therefore head circumference measurement will help to detect hydrocephalus in these children at its early stage. Young infants who have been diagnosed with meningitis should be thoroughly screened for hydrocephalus as meningitis is a major risk factor for this condition. A research study done in Turkey shows that bacterial infection like meningitis, due to the inflammatory process causes accumulation of CSF therefore hydrocephalus (Garoo, 2018).

Number of children with hydrocephalus and spinabifida

From the study results it is seen that some children who had hydrocephalus also had spina bifida. It is a common occurrence to have children with spina bifida developing hydrocephalus. At Queen Elizabeth central hospital, the study site children with hydrocephalus and those with spina bifida used to be in the same ward for care. The trend was changed four years ago when those with spina bifida were considered surgical patients, and so therefore their care was shifted to surgical unit. Research studies have found that 95% of children born with open myelomeningocele develop hydrocephalus. Therefore chiari malformation type II should be suspected in children born with spina bifida (Norkett et al., 2016). Similarly as already mentioned, this kind of malformation definitely leads to development of hydrocephalus, therefore it would be efficient and logical to cooperatively manage these two conditions in-one setting, to assure early screening, identification and management of hydrocephalus.

Strange Illness

Most of the caregivers expressed their great concern that hydrocephalus is a strange illness, and it was a shock to them to learn that their child was affected by this condition. Having a child with a strange condition especially in the rural setting, is mostly associated with witchcraft practice and usually comes as a cultural shock too (Groce & Mcgeown², 2013) (Metzler, 2013). In fact because of the strange perception of the disease the child is delayed in going to the hospital to receive treatment. This is because the first option is to take the child to the traditional healers, instead of rushing the child to the hospital. As a result there is usually delay for the child from receiving the early- recommended surgical management for the disease. Additionally it becomes difficult for the caregiver to follow up on treatment because they may get discouraging remarks from those surrounding them, to whom the disease is also a strange illness. In a related study done in Uganda and Tanzania, results showed that the recent growing urbanization has exposed a great link between witchcraft and disability, and an attempt by concerned governments to address the misconception (Groce & Mcgeown², 2013). In a related study done in United Kingdom (UK) that caregivers were filled with worry when their children were diagnosed with hydrocephalus, considering the difficult step of fitting in the child with the challenges accompanied by the condition to fit in the family system, and so the caregivers were filled with doubt about the future progress of the child (Smith Joanna, Cheater Francine, & Bekker Hilary, 2015) (Gurol, Erdem, & Tasbai, 2015).

Social Stigmatization

The caregivers expressed their concern on social stigmatization because of the kind of treatment they receive when they go out to do part time jobs. The employers are usually never comfortable to have a woman wash her clothes with a child with hydrocephalus. At community

functions people stop doing their things and just stare at the caregiver and the affected child that they have carried. Additionally some community members accuse them of having used the child for witchcraft rituals. Eventually this may cause the caregiver not be able to go to work or business eventually causing economic constraint. Some caregivers verbalized that their community members have excused them from doing or participating in community activities understanding the burden that they have of caring for the affected child. This is encouraging because it shows that there are some communities that are considerate of the tough experience that the caregiver of the child with hydrocephalus goes through. Some caregivers have been left by their husband, refusing to take care of the child with hydrocephalus. This leads to stress in the caregiver. A caregiver on the current study was abandoned by her husband after she delivered a baby with hydrocephalus. This is similar to a research done in Uganda where findings revealed that women who had delivered children with hydrocephalus and spinabifidawere being abandoned by their husbands (Bannink & Idro, 2013) In a research study done in Uganda, the case is quite extreme in comparison to the Malawian cases, as the community literally stays away from the child to avoid being infected(Bannink & Idro, 2013). The current study case is different, caregivers have not experienced complete expulsion from the community.

Social stigmatization causes the caregiver to eventually rush to the witchdoctor for child treatment or in other cases the caregivers hide the child in the house. Consequently this causes the child to be delayed in receiving emergency surgical intervention. Causing delays in hydrocephalus management, which leads to complications like extreme brain damage, which may cause extreme neurological deficit and disability. The results of the current study showed that children were being taken to school together with their friends, where as those in the

northern region of Uganda, literally stayed out of school (Kahle, Kulkarni, Limbrick, & Warf, 2016b) .

Disability Burden

Having a child affected by hydrocephalus brings in various experiences that indirectly cause financial strain on them. Some caregivers complained that the children with hydrocephalus are particularly choosy and selective with their food selection in an extreme manner. The caregiver actually is forced to buy food outside their budget to meet the child's food demands. This is a great concern because if the children are not eating adequately the caregivers fear for possible malnutrition a complication that is not rare in hydrocephalus. Additionally malnutrition makes management of hydrocephalus difficult because a malnourished hydrocephalic child cannot go through the surgical shunt or ETV management.. And this prolongs the child's hospital stay because the child is firstly moved to a nutrition ward for nutrition rehabilitation, which usually takes long for the child to recover. And then after nutritional rehabilitation is when they are moved back to neurosurgical ward for neurosurgical management.

Different from the current study results, study results from a London study revealed that children with picky and choosy eating habits are associated with anxiety and other psychological issues (Zucker, 2015). This could be true because children with hydrocephalus meet a lot of social stigmatisation, which could cause anxiety and feelings of isolation and being inferior. Therefore psychological care through encouraging and comforting words is vital, of which all the study results revealed that all the caregivers were making it a habit to say encouraging words to the children that all shall be well.

The other burden that caregivers complained about was family dysfunction, it was discovered that some husband had abandoned their families after the birth of a child with

hydrocephalus. In a related study done in Mexico, the results showed that child disability had a great impact on the caregivers life, of which family dysfunction was one of the two greatest impact coming second to caregiver depression (Fernanda et al., 2016). Therefore health care professionals should include assessment of burden in caregivers' as they provide care to the children with hydrocephalus.

Work Overload

The study results revealed that the caregivers experience burden of work as they care for the child with hydrocephalus as a result this bars them from being able to do a business or seek employment to earn a living this is another contributing factor to financial constraint. In a related study, it was found that children with severe disability depend largely on their caregiver, therefore the affected family's are supported financially in high income countries to help them in adjusting their life after the birth of a child with such a disability (Bannink et al., 2016). It was also revealed that some caregivers expressed that taking care of the affected child demands a lot, and makes the caregiver feel like they no longer exist for themselves but rather its like the whole day is spent on caring for the child, unable even to participate in social events. As a result this is a cause of stress for the caregivers therefore it is a concern because a stressed caregiver may not be a good co-worker to the health professionals in the care of the child with hydrocephalus. Similarly a study done in Blantyre on the rehabilitation of children with neurodisability, the caregivers expressed a sense of feeling grounded by the care burden (Paget et al., 2016b). The feeling that the caregiver cannot freely move about doing what she likes makes the caregiver feel like they are in an enclosed space that they cannot leave. The stress that the caregiver goes through can lead to neglect and abuse of the child.

Financial Constraint

Frequent hospitalization.

For almost all the caregivers financial struggles are one of the toughest challenges that they face. Mostly the children affected by hydrocephalus are frequently admitted for surgical procedures, and their hospital stays are prolonged as a result of pre or postoperative management. The study results revealed that the caregivers were admitted for management of infected or failed shunt or ETV. Usually hospital admissions demanded a lot of financial input by the caregiver and family as a whole. In a related study done in United States of America (USA), it was found that hospital admissions for a child suffering from hydrocephalus is one of the most expensive, this is because of the chronic nature of the disease and the frequent and numerous surgical procedures performed costing millions and requiring funding (Tamara D. Simon et al., 2008) (Simon et al., 2008).

Additionally though the hospital services are free, facilities cannot afford to cover for all of the caregivers and patient's needs. The cost of accessing health care included transport from the health centres, to the district hospitals, and then to Queen Elizabeth central hospital and back again. These children travel from different districts all over Malawi and even Mozambique to receive care at Queen Elizabeth central hospital, the fees can be substantial. Caregivers require food, bedding or lodging when attending to the child at the hospital, in addition if a husband or any other female relative comes to help-these other guardians also require funds to cover travel, food and lodging.

Support System

The results of the study revealed that most of the caregivers were appreciating the support that their family, friends and health professionals were offering in their care for the children with hydrocephalus. This is encouraging to the caregivers who are usually going through stress and pressure due to the workload that they have to endure as they care for their child. And the stress coming in because of the frequent hospitalization and financial constraint that most of them experience. These results differ from the ones obtained in the study done in USA where parents verbalised their concerns saying that they felt that the health professionals were sidelining them and not taking their contribution seriously. The parents also explained that the health professionals did not have good interpersonal relationships with them and never shared important information with them (Smith Joanna, Cheater Francine, & Bekker Hilary, 2013).

The results also revealed that most of the caregivers were concerned that the organizations were not doing much to support their children with hydrocephalus. Most supportive organization help in providing nutrition such as porridge flour for the affected children as most the caregivers are struggling financially. They also at times provide transport fare for the caregivers to take the children for review at the central hospital, which is very far from most of the affected childrens. By assisting caregivers in managing their affected children, they also help in linking the families in forming support groups, which they fund, and eventually build support to the caregivers of the affected children. The support organization also help in sensitization and awareness campaign, of which the health professionals themselves may not widely reach the communities as much as a support organization would. This is also seen in the Ugandan scenario in the result of the study done where support organizations helped in awareness campaign (Bannink et al., 2015). Sensitizing the masses will reduce social

stigmatization, and will also combat delay in seeking medical attention once a child is suspected of developing hydrocephalus.

Additionally the caregivers also expressed their need for a special school for children with hydrocephalus. The caregivers were concerned that their children merely were escorting their friends to school to learn. This is because with the teaching approach that is offered in almost all the government and private schools, there is no approach fit to cater for children with hydrocephalus. Additionally the available schools do not have the facilities or the manpower to change diapers and assist in mobility of the children with hydrocephalus, the assistive devices like the corner chairs, walkers and others. The study results differ from results of several recent studies which have found that inclusive learning where by the children with disability learning with those of normal stream should be encouraged, rather than learning where by the children with disability are taught separate from the normal children (Minou, 2011) (Veen, Smeets, & Derriks, 2010). Support organizations, parents and NGO's must work with the government to provide adequate facilities and resources to support an inclusive learning environment for the children with hydrocephalus and other disabilities.

Conclusion

In conclusion the findings of this study revealed that the experiences of caregivers of children with hydrocephalus is vast, and there is a lot that the caregivers go through. Taking care of a child with hydrocephalus is hard work and requires a lot of support to be rendered to the caregivers. In fact it is important the family members, health professionals and the community at large be involved in the support of the caregivers as they care for the affected child. These caregivers go through financial challenges, work overload, social stigmatization just to mention the most critical. If left without support the caregivers would barely manage to provide

appropriate care for their children. There is need for more comprehensive support for neurosurgical patients and their families.

Recommendations

The finding of this study revealed that hydrocephalus was referred to as a strange illness by the caregivers and their relatives. Caregivers' beliefs related to this strange disease, attributing it to witchcraft or other causes-delays the time to treatment in the affected child, as caregivers expend traditional treatment methods before taking the child for proper medical and surgical attention. Consequently these delays contribute to increased brain damage in the affected child, and at times unnecessary and avoidable deaths. In line with this the health professionals and relevant support organisations should sensitize the community on hydrocephalus and its management. In a related study done in Uganda, it was found that negative approaches, opinions and practices usually hinder treatment for children with hydrocephalus (Bannink et al., 2015). Therefore community and health centre based sensitization and education on the signs and symptoms of hydrocephalus with linkages to accurate diagnosis and treatment can result in improved outcomes for the affected children (Bannink et al., 2015).

The study findings further show that the caregivers feel overwhelmed by the physical, financial and emotional drain of meeting the intensive care needs of a child with hydrocephalus. Because of a lack of wheelchair, walker, and other assistive devices, most caregivers report carrying a child on their back while performing daily activities. Over time, caregivers experience increasing physical strain while carrying their aging growing child. Therefore the neurosurgical team should include provision of resources to obtain assistive devices as part of their core programs. This is because mobility challenge is a major setback in the case of the children with hydrocephalus. Adults with disability greatly benefit from the use of assistive devices to help

them participate in daily activities; but unfortunately assistive devices have been underutilized in children despite evidence that the devices improve the quality of life of the affected child improving their ability to perform daily activities (Henderson, Skelton, & Rosenbaum, 2008). Therefore the child should be evaluated by the physio and occupational therapy on recommendations for appropriate assistive devices, families should be provided with such devices for the affected child with training on their usage and follow up on to monitor changing needs as the child grows and develops.

The caregivers verbalized a need for a special school for children with hydrocephalus to be established and structures built. They explained their concern that the children affected by hydrocephalus had special learning needs, which teachers at the normal schools were not able to provide. These children require special learning approach methods and facilities, which would be provided in a well setup human resource to care for the affected children. This is contrary to the UN for rights of the child (1989) which declared that the education approach for children with disabilities be changed from special approach to inclusive approach (Minou, 2011).

Therefore in line with the UN for child rights, Policy makers should reinforce that schools should be established in line with the rights of the child requirements; in which inclusive learning approach is established. This inclusive approach prepares the child with disability and the child without disability for living with diverse individuals (Al Hout, 2017) (Mattingly & Suubi, 2015). Additionally this approach will cut down the cost of setting up private institutions for children affected with hydrocephalus, and reduce social stigmatization.

Areas that need Further Study

The study identified the gaps that need to be addressed through further studies as follows:

- The nurses experience of parental participation in the care of children with hydrocephalus.
- Intervention study on short term solutions for a successful establishment of inclusive learning.
- Intervention study on how caregivers' participation can be implemented at QECH.
- Factors that hinder inclusive learning approach in primary schools in Blantyre.
- Predictors of health professionals' information sharing to caregivers of children with hydrocephalus in health care setting.
- Neurosurgical care management outcome among children with hydrocephalus at QECH.
- VP Shunt and ETV management, a comparative study of child survival and functionality.

Limitations of the Study

The study was done at one setting which is QECH, which is a large tertiary and can only apply to that setting. Health professionals experiences with caregivers were not sought views regarding their experiences with caregivers experiences were not sought. This is a potentially significant gap as information from nurses and other professional service providers would have enriched the findings and conclusions of the study. Seeking nurses views would have enriched the findings and conclusion of the study.

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APPENDICES

Appendix 1A: Caregivers Information Letter

Section A: Participants Information

Dear participants

My name is Cynthia Chidziwisano and I am currently registered as a student at University of Malawi, Kamuzu College of Nursing for Master of Science degree in Child Health. I am conducting a research project on “The experiences of caregivers of children with hydrocephalus at Queen Elizabeth Central Hospital.” and I write this letter to ask you to participate in the study mentioned above. **The aim of the study is to describe the knowledge, practices, challenges and to determine the support needed by the caregivers caring for children with hydrocephalus.** The study will explore the experiences of those caregivers with hospitalized children, and those attending the under-five neuro clinic at QECH.

Participation in the study is entirely voluntary. You may choose to participate or withdraw from the study at any time, which will not have any effects on the services that you are receiving from the health care providers in this hospital. Furthermore, the study does not have any foreseeable physical harm (risks); however in cases of any emotional or psychological harm you will be counselled accordingly or you may forward your concern and complaints to the researcher at Kamuzu College of Nursing.

Please note that there will be no financial benefits for participating in the study. However, exploring the experiences of caregivers of children with hydrocephalus will assist in responding to caregivers’ needs and guide health professionals to render support to caregivers of children with hydrocephalus, in the hospital and at the under-five neuro clinic. No reports in this study will identify you in any way and results of the study will be given to you should you so wish.

Should you agree to participate, I will ask you to sign a consent form or put a finger print on the space provided to indicate that you have accepted to be interviewed. It is anticipated that the interview **will take 45 minutes**. The interview will be conducted at a time that is most suitable and convenient to you in a quiet environment to avoid any disturbances.

You may wish to know that this study has been reviewed by College of Medicine Research and Ethics Committee (COMREC), which is a board that ensures the protection of research subjects in Malawi.

Thank you for taking time to read this information letter.

Should you require any further information regarding the study or your rights as study participant you are free to contact me, or my research supervisor or COMREC.

Cynthia Chidziwisano (Mrs.),

University of Malawi,

Kamuzu College of Nursing,

Post Office Box 415,

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Tiwonge munkhondya,

University of Malawi

Kamuzu College of Nursing

Post Office Box 415,

BLANTYRE

0999468842

The chairperson,

COMREC Secretariat,

P/Bag 360,

Chichiri,

BLANTYRE

Or you may call on 01989766.

Appendix 1 B: Caregivers Information Letter (Chichewa Version)

Kalata yofotokoza za kafukufuku

Wokondedwa

Ndine Cynthia Chidziwisano, wophunzira zaunamwino kusukulu yaukachenjede ya Malawi ku Kamuzu Koleji, amene ndikuphunzira zokhudza umoyo waana ndipo ndikupanga kafukufuku wokhuza maganizo amakolo ndi zomwe amakumana nazo pa chisamaliro cha mwana wavuto yodzaza madzi m'mutu pa chipatala cha QECH.

Ndalemba chikalatachi ndi cholinga chofuna kukupemphani kuti mutengepo mbali polowa nawo mukafukufukuyu. **Cholinga cha kafukufukuyu ndi kusathula maganizo amakolo pa zimene amadziwa, komanso chisamaliro, zovuta komanso chithandizo ndi chilimbikitso chimene amalandira posamalira mwana wavutoli.** Izi zizathandiza ogwira ntchito kuchipatala kugwira bwino ntchito yawo ndi makolo pomwe akuyanganira mwana amene ali ndi vuto lodzaza madzi m'mutu.

Dziwani kuti simukukakamizidwa kutengapo mbali komanso muli ndiufulu ngati mukufuna kusiya nthawi imene mungafune popanda vuto lina lililonse ndipo muli omasuka kufunsa mafunso alionse okhudza kafukufukuyu. Mukuyeneranso kudziwa kuti mayankho anu adzasungidwa mwachinsisi ndipo sizizadziwika kuti anayankha mafunsowa ndindani chifukwa mayina anu sadzayikidwa pamapepala a mafunso m'malo mwake tizagwiritsa ntchito manambala. Dziwaninso kuti palibe chiopsezo china chili chonse pakafukufukuyi.

Ngati mwavomereza kutengapo mbali pakafukufukuyi muzapemphedwa kusayina fomu kapena kusindikiza chala chanu ndiponso kuyankhapo mafunso **kwanthawi ya mphindi 45.** Ngati pangakhale mafunso kapena nkhawa ina ili yonse yokhudzana ndikafukufukuyu khalani omasuka ndikubweretsa madandaulo anu kwa wapampando, COMREC P/Bag 360, Chichiri, Blantyre 3 kapena muyimbire telefoni pa nambala iyi 01989766.

Cynthia Chidziwisano (Mrs.),

University of Malawi,

Kamuzu College of Nursing,

Post Office Box 415,

BLANTYRE

0888537873/ phiri2016cynthia@kcn.unima.mw

Tiwonge munkhondya,

University of Malawi

Kamuzu College of Nursing

Post Office Box 415,

BLANTYRE

0999468842

The chairperson,

COMREC Secretariat,

P/Bag 360,

Chichiri,

BLANTYRE

Kapena muwapeze pa nambala ya lamya iyi 01989766.

Appendix 2A: Caregivers Consent Form

PLEASE READ AND SIGN THE FORM IF YOU ARE TAKING PART IN THIS STUDY

I..... (Name/ Thumb Print), voluntarily give permission to participate in the study.

I have read or have had another person **read to me and understood the content of** the information letter and I have been given the opportunity to ask questions, where deemed necessary, about the study.

I understand that the information I give will be kept confidential and will only be accessed by the researcher and/or those people who are directly concerned with the study

I know that I do not have to suffer any injury or harm during the research process and the information that I will give to the researcher will not be used against me in future.

.....

.....

Participant's Signature

Date

.....

.....

Researcher's Signature

Date

Should you have any further inquiries please contact: The Chairperson, COMREC Secretariat
P/Bag 360, Chichiri, Blantyre 3 or you may call on 01989766.

Appendix 2B: Caregivers Consent Form (Chichewa version)

Kalata yachivomerezo ya Chichewa.

Sayinani dzina lanu kapena sindikizani chala chanu pamalo omwe apelekedwawa ngati mwavomereza kutengapo mbali pakafukufukuyu.

Ine..... (Dzina)/ Sindikizani chala) ndavomera ndikupeleka chilolezo mosaumilizidwa kutengapo mbali pakafukufuku, kufunsidwa mafunso ndikuyankha mafunsowo mmene ndingadziwire nditatha kuwerenga/ kuwerengeredwa ndikumvesetsa kalata yolongosola zakafukufukuyu, cholinga chake ndi zovuta zake.

Ndamvesetsanso kuti ndili ndiufulu wosiya nthawi ina iliyonse popanda chifukwa ndipo kuti izi sizizasokoneza chithandizo ndikulandira. Ndamvesetsanso kuti zonse zomwe nditayankhule kapena kupereka mukafukufukuyu zizasungidwa mwachinsinsi ndiponso kuti palibe phindu la ndalama lililonse. Ndauzidwanso m'mene ndingapezere opanga kafukufukuyi ngati kuli kofunika kutero.

.....

.....

Dzina la otengambali

Tsiku

.....

.....

Mwini kafukufuku

Tsiku

Ngati pangakhale mafunso kapena nkhwana iliyonse yokhudzana ndikafukufukuyu khalani omasuka ndikubweretsa madandaulo anu kwa **wapampando wa COMREC** pa telefoni nambala iyi 01989766.

Appendix 3A: In depth interview guide: Question for Caregivers

Section A: Demographic data

In this section you will be asked about your personal information

A1. Age

What is your age?

Below 19 years 1

20 to 25 years 2

26 to 35 years 3

35 to 45 years 4

Above 46 years 5

A2. Educational level

What is the highest level of education that you have attained?

Standard 1-5 1

Standard 6-8 2

Form 1-2 (JCE) 3

FORM 3-4 (MSCE) 4

Tertiary education 5

A3. Marital status

What is your current marital status?

Married 1

Divorced 2

Widowed 3

Separated 4

Single 5

Other 6

A4. What tribe do you belong to?

Chewa 1

Lomwe 2

Ngoni 3

Sena 4

Tumbuka 5

Yao 6

Other 7

A5. Which denomination do you belong to?

CCAP 1

Roman Catholic 2

SDA 3

Islam 4

Pentecost 5

None 6

Other 7

A6. Employment status

Unemployed 1

Farmer 2

Employed: Professional 3

Unprofessional 4

Other specify 5

A7. How many children do you have?

1-3 1

4-6 2

7-10 3

Their ages

0-1 1

2-5 2

6-12 3

13 above.....4

Age of the child with hydrocephalus

Age of child at diagnosis of hydrocephalus

Section B: In-depth interview guide

B1. Tell me all that you know about this disease called hydrocephalus which your child has.

Probes

Causes of hydrocephalus

Signs and symptoms

Management of the condition

Complications of this condition

Instructions to be followed

What is your source of information?

When the information was provided to you?

How has the information helped you?

B2. Can you explain to me the care that you provide to your child?

What comfort and support do you provide to your child with hydrocephalus?

Probes

How do you;

Feed the child

Practice Infection prevention

Provide psychological care to the child

What are the treatment and drugs that you give to your child?

B3. Explain what problems you face as you provide care to your child?

Probes

Perception

Lack of support

Lack of equipment

Too much work

Social stigma

Explain how these challenges have affected the care that you give to your child?

How do you deal with the challenges?

B4. Can you explain to me how the following groups have supported you in the provision of care to this child?

Health care workers

Relatives and friends

Organisations

Explain any other support that you would have loved to receive but you are not receiving currently?

Probes

Counselling and psychological support

Assistive equipment such as wheelchair

Appendix 3B: In depth interview guide: Question for Caregivers (Chichewa version)

Section A: Demographic data (Chichewa version)

Mu chigawo choyamba tikufunsani zokhudza moyo wanu

A1. Zaka

Kodi muli ndi zaka zingati?

14- 19 1

20 - 25 2

26 - 35 3

35 - 45 4

46 kupita m'tsogolo 5

A2. sukulu

Kodi munalekeza pati ndi sukulu yanu?

Pulaimale 1-5 1

Pulaimale 6-8 2

Sekondale 1-2 (JCE) 3

Sekondale 3-4 (MSCE) 4

Kuposera sekondale 5

A3. Banja

Kodi inuyo?

Ndiri pa banja 1

Banja linatha 2

Namfedwa 3

Tinanyanyalitsana 4

Sindili pa banja 5

Zina 6

A4. Kodi ndinu wa mtundu wanji?

Chewa 1

Lomwe 2

Ngoni 3

Sena 4

Tumbuka 5

Yao 6

Zina 7

A5. Kodi ndinu wa chipembezo chanji?

CCAP	1
Katolika	2
SDA	3
Msilamu	4
Pentecost	5
zina	6
Other	7

A6. Ntchito

Sindigwira ntchito	1
Mulimi	2
Yolembedwa: Yaukatswiri	3
Yopanda ukatswiri	4
Zina nenani	5

A7. Muli ndi ana angati?

1-3 1

4-6 2

7-10 3

Ali ndi zaka zingati?

0-1 1

2-5 2

6-12 3

13 ndi kupitirira.....4

Mwana wanu amene akudwalayu ali ndi zaka zingati?

Munadziwa za matendawa mwana wanu ali ndi zaka zingati?

Section B: In-depth interview guide (Chichewa version)

B1. Fotokozani zimene mumadziwa za matenda amene mwana wanuyu ali nawo

Mafunso otsatira

Zoyambitsa vutoli

zizindikiro

chithandizo

zovuta zokudza ndi vutoli

malangizo oyenera kutsatiridwa

kodi mumamvera kuti zokhudza vutoli?

Kodi uthengawu munaumva liti?

Kodi uthengawu wakuthandizani bwanji?

B2. Tafotokozani m'mene mumamusamalira mwana wanu?

Kodi mwanayu mumamulimbikitsa bwanji?

Mafunso otsatira

Kodi mumatani;

Podyetsa mwanayu

Kuti mupewe kutenga kapena kupatsira mwana mwatenda

Kuti mumulimbikitse mwanayu m'maganizo

Kodi ndi mankhwala anji amene mumamupatsa mwanayu?

B3. Kodi mumakumana ndi zovuta zANJI pomusamalira mwanayu?

Mafunso otsatira

Malingaliro anu

Kusowa chilimbikitso

Kusowa zipangizo

Kuchuluka kwa ntchito

kusalidwa

kodi zovutazi zimasokoneza bwanji chisamaliro chanu pa mwana wanu?

Kodi mumathana nawo bwanji mavuto amenewa?

B4. Fotokozani m'mene magulu awa amakulimbikitsani pa chisamalitro cha mwana wanu?

Kuchipatala

Abale ndi anzanu

Mabungwe

Fotokozani ngati pali chisamaliro chimene mumafuna mutamalandira koma simulandira?

Mafunso otsatira

Maphunziro achilimbikitso

Zipangizo zogwiritsa ntchito, ngati **njinga ya odwara**