UNIVERSITY OF EDUCATION, WINNEBA

# HEALTHCARE SEEKING BEHAVIOURS OF PARENTS WHO HAVE CHILDREN WITH DISABILITIES AT UNIVERSITY PRACTICE INCLUSIVE BASIC SCHOOL, SOUTH CAMPUS AND REV. FR. JOHN MEMORIAL SCHOOL, WINNEBA

PRISCILLA DEEDE HAMMOND

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A THESIS IN THE DEPARTMENT OF SPECIAL EDUCATION, FACULTY OF EDUCATIONAL STUDIES, SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES, UNIVERSITY OF EDUCATION, WINNEBA IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF THE MASTER OF PHILOSOPHY (SPECIAL EDUCATION) DEGREE

JULY, 2018

# DECLARATION

## Student's Declaration

I, PRISCILLA DEEDE HAMMOND, declare that this thesis, with the exception of quotations and references contained in published works which have all been identified and duly acknowledged, is entirely my own original work, and that it has not been submitted, either in part or whole, for another degree elsewhere.

SIGNATURE: ………………………………

DATE: ……………………………………

## Supervisor's Declaration

I hereby declare that the preparation and presentation of this work was supervised in accordance with the guidelines for supervision of thesis as laid down by the University of Education, Winneba.

Name of Supervisor: DR. YAW NYADU OFFEI

SIGNATURE: …………………………………

DATE ………………………………………….

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# DEDICATION

I dedicate this work to my dear husband Mr. John Hammond and my three lovely daughters, Queen Elizabeth, Adelaide and Joni Hammond for their love and support throughout my career especially, this Thesis.

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# ABBREVIATIONS

| | |
|---|---|
| ADHD | Attention Deficit and Hyperactivity Disorder |
| ADA | Americans with Disability Act |
| CDCP | Centre for Disease Control and Prevention |
| GHDS | Ghana Human Development Scale |
| GSS | Ghana Statistical Service |
| ICF | International Classification of Functioning |
| MoH | Ministry of Health |
| NAD | Norweigian Association of the Disabled |
| NHIS | National Health Interview Survey |
| PT | Parent |
| STDs | Sexually Transmitted Diseases |
| STIs | Sexually Transmitted Infections |
| UN | United Nations |
| UNCRPD | United Nations Convention of the Rights of Persons with Disabilities |
| UNICEF | United Nations International Children"s Emergency Fund |
| WHO | World Health Organization |

# ABSTRACT

The purpose of the study was to explore healthcare seeking behaviours of parents who have children with disabilities in University Practice Inclusive Basic School and Rev, Fr, John Memorial School both in Winneba. A case study design was adopted where the researcher used a qualitative approach such as semi-structured interview guide to gather data for the study. Data from participants were analysed using thematic analytical approach. The results revealed that some of the parents after the first diagnosis by health professionals consulted a spiritualist or herbalist for help. Some parents also revealed that they buy over the counter medications when their children with disabilities fall sick whilst others maintained that the hospital was their first point of call when their child was sick. Also, some parents stated that their responses to their children‟s healthcare depended on the severity of the sickness. The results also revealed that availability and accessibility to healthcare services, stigmatization as well as socio-cultural factors influenced parents in seeking healthcare services for their children with disabilities. Also, the study revealed that acceptance by society, expansion of resources, training of health professionals and support for parents were ways that could be adopted to improve healthcare seeking behaviours of parents The study recommends that Ministry of Gender, Children and Social Protection and the Social Welfare Department to provide health education for parents who have children with disabilities on how to seek healthcare services for their children and also educate them on them on that factors that influence these parent‟s healthcare seeking behaviours.

# CHAPTER ONE

# INTRODUCTION

## 1.0 Background to the study

Globally, the population of persons with disabilities is increasing at a faster rate. According to the World Health Organization [WHO] (2005), there are approximately 650 million people living with disabilities worldwide and an estimated 200 million of these are children. The WHO found that 80% of the estimated number reside in low-income and middle-income countries including Ghana asserted that this group of is highly susceptible to the risk of missing out on essential health services and rehabilitation opportunities. In order to ensure equity in human rights, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), highlighted the rights of individuals with disabilities and sets out a code of implementation in countries that have endorsed the agreement, including Ghana. According to Geldof (2016), UNCRPD underscores that disability is not a health issue that needs to be treated, but persons with disabilities have the right to health services, including rehabilitation services required to manage disability-related health issues. Ghana ratified UNCRPD in the year 2012, having adopted a national Disability Act in 2006 (Enable UN, 2006). This means that the Ghanaian government is obliged to offer quality rehabilitation services to children with disabilities. Despite efforts to scale up these services to meet this obligation, the current capacity is insufficient (Buor, 2004; Kuyini, Alhassan & Mahama, 2011).

There are a number of estimations on the prevalence of children with disabilities in Ghana. According to Ghana Statistical Service (2013), the 2010 population and housing census reported an estimated one to two percent (1-2%) of young people in Ghana as having a disability, while UNICEF (2008) reported that approximately 22%

of all children aged 2-9 years could be at risk of having a disability. In Ghana, Oti-Boadi (2016) indicated that based on the 2010 population census data, about 737,743 (3% of the population) live with disability. These reports, therefore, suggest a slightly higher prevalence rates amongst children.

Raising children with disability creates enormous psychological challenges often expressed as depression, anxiety and somatic symptoms for parents (Norlin & Broberg, 2013). Several studies have found that having a child with disability is unequivocally associated with personal and financial adjustments and adaptation to the new role of meeting the unique needs of the child (Olsson & Hwang, 2008; Oti-Boadi, 2017). In the case of parents, the birth of a child with disability or the discovery that a child has a disability, becomes an intense and traumatic event. Parents also have to deal with daily demands of care giving including feeding, bathing, dressing the child, toilet training and child behavioural problems (Tomanik, Harris, & Hawkins, 2004). Most parents also express concerns about how their children will function independently or who will take care of the child when they are no more. This, to a larger extent, may cause some parents to react to the child"s situation in an emotionally and physiologically negative way.

According to Smith (2002) parents who have children with disabilities experience greater stress and a larger number of care giving challenges such as health problems, greater feelings of restriction and higher levels of parental depression than parents who have children without disabilities. Some families experience difficulties in financial assistance and inadequate support from the members of their extended family and communities. Families of children with disabilities face both the normal pressures and tensions of family life and, in addition, adjustments to the presence of the child with a disability. Such families usually require assistance in order to reorganize their lives towards positive adaptation. According to Abosi (2001), Ghanaians, like many others of different cultures in the past, looked at disability as a curse from the gods and as a sign of bad omen. Abosi further stated that most of these negative attitudes are more of misconceptions that stem from the lack of proper understanding of disabilities, and how they affect the functioning of the affected individuals. As a result, negative attitudes tend to constitute stumbling blocks towards the total acceptance of the disabled. Bender (2008), stated that a disability may generally be defined as a condition which may restrict a person"s mental, sensory or mobility functions to undertake or perform a task in the same way as a person who does not have a disability. According to Geldof (2016), it is also estimated that the prevalence of child disability will even increase in low and middle income countries, such as Ghana, in the years 2012-2022.

In this world, not many people realize how difficult it is to be a parent until they themselves become a parent. According to Thwala, Ntinda and Hlanzi (2015), it is even more difficult to be a parent of a child with disability. The frustration that parents who have children with disabilities experience could make them distant themselves from participating in educational decisions when their children enter school. Raising a child with disability requires strength and flexibility, because the child has special needs in addition to the regular needs of all children. Parents can find themselves overwhelmed by various medical, care giving, and educational responsibilities. Beresford, Rabiee, and Sloper (2007), stated that no matter how severe the special needs of the child is, the parents are inevitably affected in one way or the other. It is believed that most of such parents are affected emotionally. Parents often struggle with guilt; they feel as though they somehow caused the child to have the disability, whether from genetics, alcohol use, stress or other logical or illogical reasons. This guilt can harm the parent"s emotional health if it is not dealt with. Some parents experience spiritual crisis or blame the other parent for not giving the support which is needed. Additionally, most parents have aspirations for their children from the time of birth, and can experience severe disappointment that the child will not meet those aspirations due to the disability. In order for these parents to cope with this experience, they must deal with the "death" of the perfect child who existed in their minds and learn to love and accept the child they have. They have to stop feeling ashamed or embarrassed that their child is intellectually disabled. Smith (2002) concured with Blachar and Bakar (2007) that even after diagnosis; parents often face a whole gamut of emotions before they can grapple effectively with the stark truth that their child has a disability.

According to Beresford et al. (2007), parents of children with disabilities suffer from exhaustion and stress due to the degree of the amount of care their child needs. Feeding, clothing, bathing and diapering an infant is much easier physically than in doing the same tasks for someone who is school-going age. Having a child with disability can also place immense economic stress on the child"s parents, because raising a child with disability may be more expensive than raising a child without disabilities. Expenses may arise from medical equipment and supplies such as wheel chairs, hearing aid, medical care, care-giving expenses, private education, learning equipment or tutoring. Parents who have children with disabilities also have to deal with complex issues related to the child"s education. Close parental contact with the school system is vital in order for the child to receive a proper education. Parents must collaborate with teachers in order for their child"s education to be effective. Teachers and parents have to be partners in the education of the child with disability (Smith, 2002). Thwala & Simelane (2010) asserted that parents and other caregivers are an integral part of their children"s education. For this reason, they must be involved in making educational decisions affecting their children from initial planning to implementation.

Parents who have children with disabilities experience challenges, which may lead them to make mistakes in the upbringing of their children, and which can result in learning difficulties and other problems. They need to be motivated to become involved in the education of their children. Parents play a greater role in the education of their children because they know their children better and are able to inform teachers about their learning problems. They can help teachers to better understand their children"s behaviours, and they can also contribute to the design and implementation of joint learning support strategies for their children (Lewis & Doorlag, 2006).

In the broad sense, healthcare seeking behaviour includes all behaviours associated with establishing and maintaining a healthy physical and mental state, behaviours that deal with any digression from the healthy state and reducing impact and progression of an illness (Shaikh & Hatcher, 2005). According to Ogunlesi and Olanrewaju (2010), the healthcare seeking behaviour of a community determines how they use health services. Utilization of health facilities can be influenced by the cost of services, distance to health facilities, cultural beliefs, and level of education and health facility inadequacies. Healthcare seeking behaviour also determines how health services are used, and in turn, the health outcomes of that population. Katung (2001) contended that factors that determine health behaviour may be physical, socio-economic, cultural or political. Indeed, the utilization of a health care system may depend on educational levels, economic factors, cultural beliefs and practices. Other factors include environmental conditions, socio-demographic factors, knowledge about the facilities, gender issues, political environment, and the healthcare system itself.

Organization of the health care system is a key determinant for healthcare seeking behaviour. Also, attitudes or behaviours of community members and that of the healthcare professionals sometimes contribute negatively to healthcare seeking behaviours amongst parents. In developing countries such as Ghana, parents who have children with disabilities face many challenges when it comes to seeking healthcare services, because of the disability their children have. The type of disability of the child, the stigma associated with having such a child, the stress involved in caring for the child, the cost involved and even proximity of healthcare facilities all come together to influence parents" behaviour.

## 1.1 Statement of the problem

The concept of healthcare seeking behaviours has evolved with time. Today, it has become a tool for understanding how people engage with healthcare systems in their respective socio-cultural, economic and demographic circumstances. All these behaviours can be classified at various institutional levels; family, community, health care services and the state. In places where health care systems are considered expensive with a wide range of public and private health care services providers, understanding healthcare seeking behaviours of different groups of people is important to combat negative behaviours people have towards seeking healthcare. Despite considerable literature on health seeking behaviour of parents of children with malaria, fevers, and tuberculosis in sub-Saharan Africa, health seeking behaviour for disability is hardly investigated (Geldof, 2016).

Persons with disabilities are treated differently from all other persons in many countries including Ghana (Ambikile & Outwater, 2012; Avoke, 2002). This in effect, can influence the way parents seek healthcare services for their children who have disabilities. Studies on the accessibility of biomedical healthcare in Ghana revealed that people with disabilities face significant barriers when accessing biomedical health care services. Among these barriers include finance, negative attitudes of healthcare personnel, lack of knowledge about treatment options and stigmatisation (Avoke, 2002; Mensah, 2015).

Geldof (2016), conducted a case study of health seeking behaviour of caregivers of children with disabilities in two communities in Ashanti Region in Ghana. In the study, four individual cases were presented, which found that primary caregivers (parents, aunts, uncles, grandparents) were the main people who took responsibilities in the healthcare seeking process, because they could identify with the child‟s disability and consequently play an active role in seeking health care. It however appears that in Ghana, few studies have been carried out on healthcare seeking behaviours of people in general but it seems no such study has been conducted solely on parents who have children with disabilities to be specific and in the Effutu Municipality to be precise. This prompted the researcher to conduct the current study.

### 1.2 Purpose of the study

The purpose of the study was to explore healthcare seeking behaviours of parents who have children with disabilities.

## 1.3 Research objectives

The following specific objectives guided the study:

- To explore what healthcare seeking behaviours do parents who have children with disabilities have.
- To examine the factors that influence the behaviours of parents in seeking healthcare services for their children with disabilities.
- To determine what strategies can be adopted to support parents to improve on their healthcare seeking behaviours.

## 1.4 Research questions

The study was guided by the following research questions:

1. What healthcare seeking behaviours do parents who have children with disabilities exhibit?
2. What factors influence how parents who have children with disabilities behave in seeking healthcare services for their children with disabilities?
3. What strategies can be adapted to parents to improve on their healthcare seeking behaviours?

### 1.5 Significance of the study

The result of the study would help in revealing what healthcare seeking behaviours parents who have children with disabilities have. This would enable the various healthcare centres find means of guiding parents on their healthcare seeking behaviours. In addition, the result of the study would help in identifying what factors influence parents who have children with disabilities to behave in seeking healthcare services for their children with disabilities. This would also enable the healthcare authorities find means of identifying those factors in order to educate parents on them. Also, the result of the study would help in finding strategies that can be adopted to support parents to improve on their healthcare seeking behaviour. This would also enable the healthcare centres to find ways of adopting effective strategies to support parents to improve on their healthcare seeking behaviours. Finally, the result of the study would add to the existing literature for any researcher interested in similar studies.

### 1.6 Delimitation of the study

There are many issues that affect parents who have children with disabilities. However, this study focused on only healthcare seeking behaviours of parents who have children with disabilities.

### 1.7 Organisation of the study

This study was organized into six chapters. Chapter one presents the background to the study, statement of the problem, purpose of the study, objectives of the study, research questions, significance of the study, limitations and delimitations of the study, organisation of the study and operational definition of terms.

Chapter two deals with literature review, that is, the review of relevant literature on topics related to subject under study. Chapter three presents the methodology employed in the study. This details research design, the researcher"s methodological position, research setting, population, sample and sampling techniques, research instruments, trustworthiness, pre-testing, data collection procedures, data analysis procedures, and ethical consideration**.**

Chapter four focuses on the report and analysis results of the study while chapter five captures the discussion of the findings. Chapter six also presents a summary of findings, conclusion and recommendations based on the findings of the study.

## 1.8 Operational definition of terms

**Healthcare seeking behaviour:** is the time difference a parent of a child with disability spends between the onset of an illness of his or her child and getting in contact with a healthcare professional, the type of healthcare provider the parent will seek help from and how compliant the parent is with the recommended treatment (Siddiqui, Sohag & Siddiqui, 2014).

**Parent:** a mother, father or guardian of a child with disability (Ceka & Murati, 2016).

**Children:** is used to describe any human being between the ages of 0 to 17 years generally anyone between birth and puberty (UNICEF, 2017).

**Disability:** is the term that is used to explain impairments, activity limitations and participation restrictions (WHO, 2012).

**Children with disabilities:** any human being between the ages of 0 to 17 years who has impairment, activity limitations and participation restrictions.

# CHAPTER TWO

# LITERATURE REVIEW

## 2.0 Introduction

This chapter presents the literature review for the study. The literature review covered the following sub themes raised from the research questions:

- Conceptual framework
- Healthcare seeking behaviours of parents who have children with disabilities.
- Factors that influence the behaviours of parents in seeking healthcare for their children with disabilities.
- Strategies that can be adopted to support parents to improve on their healthcare seeking behaviours.

## 2.1 Conceptual Framework

In a study, Blaxter, Hughes and Tight (1996) explained that the components of conceptual framework define the key concepts and contexts of a research project and assist the researcher in focusing on the research. Conceptual framework defines the territory for the research, indicate the literature that the researcher needs to consult and suggest the methods and theories he or she might apply. Conceptual framework is a visual display of the current working theory being used by the researcher, a picture of what he or she thinks is going on with the phenomenon under study.

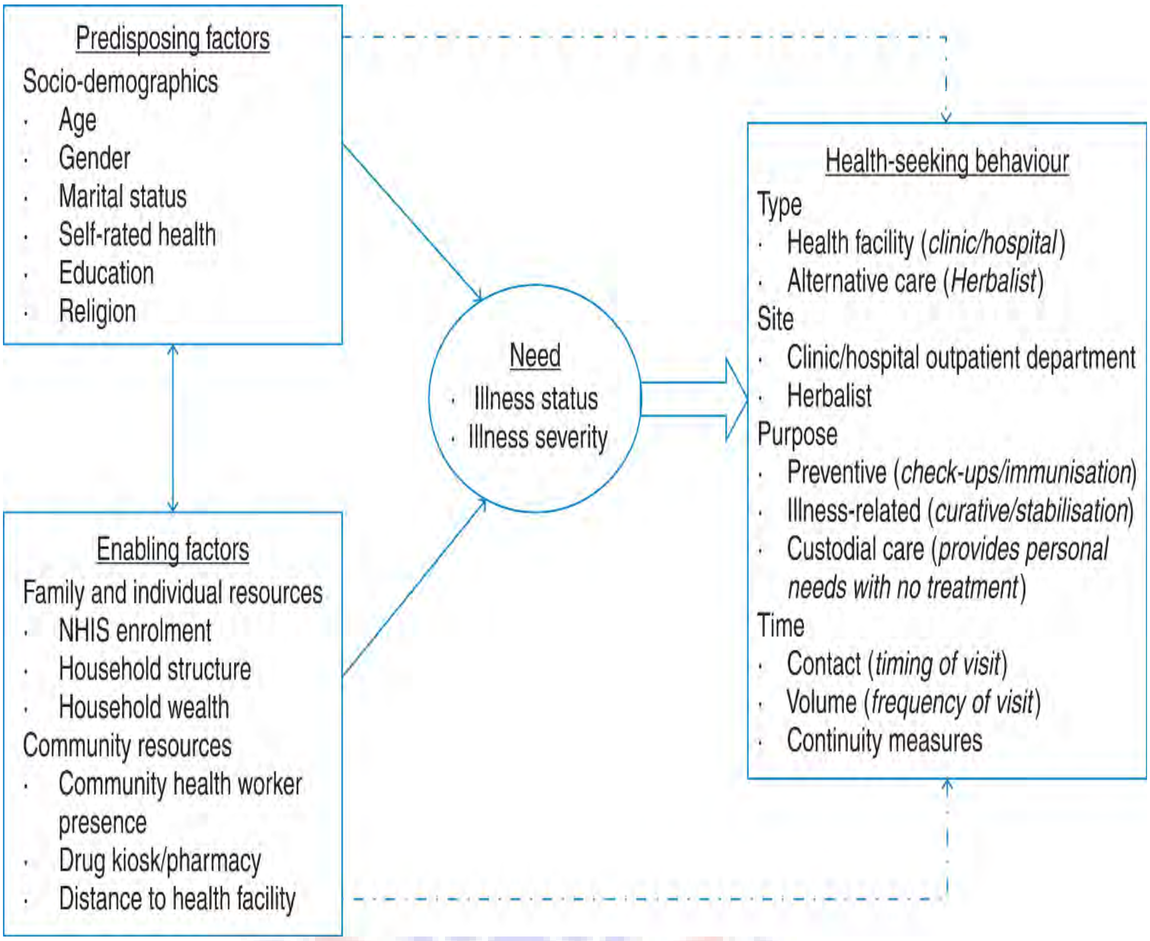

**Figure 2.1: Conceptual framework based on Andersen's theory of health-care services utilization**

**Source:** Kuuire, Bisung, Rishworth, Dixon & Luginaah (2015)

There are multiple theories and models that explain individuals‟ healthcare seeking behaviour, of which Andersen‟s model of health care utilization is one. Andersen‟s (1986) model suggests that healthcare seeking behaviour of individuals is a function of three groups of factors (determinants): predisposing, enabling, and need (Kuuire et al., 2015).

Predisposing factors describe the individual‟s tendency to utilize health care services. An individual is more or less likely to use health services based on demographics, position within the social structure, and beliefs of health services benefits. Andersen (1968) indicated that although predisposing and enabling factors are necessary for health service utilization, they are not sufficient for actual use. Actual use is initiated by need, which might arise as a result of illness level (Mosiur, Haque, & Sarwar, 2011). The enabling factors also describe the means available to use health services, including personal and family resources (e.g., wealth status and social support) and community resources (e.g., residence, access to health resources, and availability of persons for assistance). Also, need-based characteristics include the perception of the need for health services, whether they are individual, social, or clinically evaluated perceptions of need. This model, according to Anderson, shows that a complex interaction of individual, household and community factors exists during healthcare seeking and such complex dealings are likely to result in delayed care for young children.

Early identification of severe illness at the household level and timely access to evidence-based interventions are important for achieving further improvements to child mortality, particularly in vulnerable and underserved communities. Therefore, it is important to understand the ways in which communities seek healthcare for sick children and the factors that influence health care seeking behaviour by caregivers of young children, especially children with disabilities, in order to design appropriate interventions to improve healthcare seeking (Ellis, 2013).

## 2.2 Healthcare seeking behaviours of parents who have children with disabilities

Healthcare seeking behaviour can be described with data collected from information such as the time difference between the onset of an illness and getting in contact with a healthcare professional, type of healthcare provider patients sought help from, how compliant patient is with the recommended treatment, reasons for choice of healthcare professional and reasons for not seeking help from healthcare professionals (Hunte& Sultana, 1992).

According to (Bhuiya, 2009) healthcare seeking behaviour can be defined as a sequence of remedial actions that individuals undertake to rectify perceived ill health. In other words, it is the time spanfrom the onset of symptoms to contacting a healthcare provider, the type of healthcare providerchosen by the patient or the patient"s relative, and how compliant the patient is with treatment (Bhuiya, 2009).

UNICEF (2009) estimated that approximately 6.6 million children including those with disabilities under the age of five died worldwide. Diseases such as pneumonia, diarrhoea and malaria accounted for 33% of these deaths. These diseases take a huge toll on the children"s physical and cognitive abilities. Deaths from these diseases can be prevented if timely treatment is initiated. Thus, utmost care should be taken to prevent diseases, recognize the danger signals and treat them urgently. Healthcare seeking behaviour is of prime importance and is pivotal to the well-being of the individual child as well as the community.

According to Sreeramareddy, Shankar, Sreekumaran, Subba, Joshi and Ramachandran, (2006), the process of responding to perceived „illness" or seeking healthcare involves multiple steps. Therefore, it is important for parents or caregivers to be able to identify various signs and symptoms of diseases and seek timely treatment for them, which can help to reduce the mortality rate of children in developing countries. A holistic framework has been developed that encompasses the major dimensions of healthcare seeking behaviour, and the framework is useful for assessing healthcare seeking behaviour in developing countries (Sreeramareddy, et al., 2006).

In a research, Croot, Grant, Copper and Mathers (2008) looked at the disability perceptions of Pakistani parents of children with disabilities living in the United Kingdom. The study involved interviewing some fifteen (15) parents and one (1) grandparent of children with disabilities. The researchers found out that all interviewees described traditional beliefs around the cause of the disability, including that „"the child with the disability was a gift from God; the child was a test from God of their ability to parent the child; the parents were chosen by God for a purpose unknown; and the child was a punishment from God for something done in the parent's life"". Although, all of the informants cited traditional beliefs, they also gave biomedical explanations for the disability as well as other explanations, including that the disability was a result of the mothers" behaviour during pregnancy and the belief that the disability could have been caught from other children.

In another study conducted by Maloni, Despres, Habbous, Slatten, Gibson and Landry (2010), eleven (11) mothers who have children with disabilities in Bangladesh were interviewed to explore their perceptions of disability and look at how their perceptions impacted on the healthcare they sought for their children. The authors found out that disability was perceived by these parents as limitations in activities, particularly walking and activities of daily living and the cause was thought to be both traditional and biomedical in nature. Traditional causes included „„possession by ghosts or evil spirits"", while biomedical causes included those related to labour and delivery problems or maternal behaviour during pregnancy (that is, a fall or an accident). It was concluded in the research that parents" perceptions of disability influenced their healthcare seeking behaviours; however, it appeared that they were most influenced by the attitudes and perceptions of their family members. The study included an exploration of the parents' expectations for the future of their children. The most commonly cited goals for their children were independence in activities of daily living and participation in formal education (Maloni, et al. 2010).

In a research conducted by Morgan and Tan (2011) on parental beliefs regarding disability causation in their children with cerebral palsy in Cambodia, twenty-four (24) parents and primary careers were interviewed. Of these twenty-four (24) care givers, fifteen (15) were mothers, four (4) were fathers, two (2) were grandmothers, one (1) was an aunt and two (2) were non-relative carers of children with disabilities. The researchers found out that 10 participants had "no idea as to why their child had a disability". Eight (8) of the respondents believed the cause of disability to be at least partially biomedical (that is, vaccinations, the mother's health and nutrition during pregnancy or trauma) and eight (8) believed it to be at least partially related to traditional factors (that is, spiritual forces).

### 2.2.1 Healthcare seeking behaviours: The two main approaches

Researchers have long been interested in what make individuals access healthcare services, and what influences people to behave differently in relation to their health. There has been a plethora of studies addressing particular aspects of this debate, carried out in many different countries. According to MacKian (2003), they can basically be divided into two types, which roughly correspond with a division identified by Tipping and Segall (1995). Firstly, there are studies that emphasize the „end point‟ (utilization of the formal system); and secondly, those that emphasize the „process‟ (process of illness response).

#### 2.2.1.1 Health care seeking behaviours: utilization of the formal system

There is often a tendency for studies to focus specifically on the act of seeking healthcare as defined officially in a particular context. Although data are also gathered on self-care, visits to more traditional healers and unofficial medical channels, these are often seen largely as something which should be prevented, with the emphasis on encouraging people to opt first for the official channels (Ahmed, Adams, Chowdhury, & Bhuiya, 2001). These studies demonstrate that the decision to engage with a particular medical channel is influenced by a variety of socio-economic variables, sex, age, the social status of the family or parent, the type of illness, access to services and perceived quality of the service (Tipping & Segall, 1995).

In mapping out the factors behind such patterns, there are two broad trends. Firstly there are studies which categorize the types of barriers or determinants which lie between patients and services. In this approach, there are as many categorizations and variations in terminology as there are studies, but they tend to fall under the divisions of geographical, social, economic, cultural and organizational factors. Secondly, there are studies that attempt to categorize the type of processes or pathways at work.

Bedri (2001) developed a pathway to care model by exploring abnormal vaginal discharge in Sudan. She identified five stages where decisions are made and delay may be introduced towards adoption of modern care. There are four sub pathways that women may follow; namely, from seeking modern medical care immediately to complete denial and ignoring of symptoms. This approach offers an opportunity to identify key junctions where there may be a delay in seeking competent care, and is therefore of potential practical relevance for policy development. For example, in order to optimize the pathways taken by women, Bedri suggests husbands should be involved in health education programmes about vaginal discharge and women should be enabled to conduct home vaginal swabs.

Bedri"s study is particularly interesting as it compares health are seeking behaviour around vaginal discharge and malaria revealing; perhaps not surprisingly, that women follow quite different pathways for different conditions, relating predominantly to the role of the husband, social networks and cultural customs. This clearly has implications for health systems development.

Often, the view is that the desired health seeking behaviour is for an individual to respond to an illness episode by seeking, first and foremost, help from a trained allopathic doctor in a formally recognized healthcare setting. Yet a consistent finding in many studies is that, for some illnesses, people will chose traditional healers, village homeopaths or untrained allopathic doctors above formally trained practitioners or government health facilities (Ahmed et al. 2001).

There are variations in health care seeking approaches, and apart from differences according to type of illness, gender is a recurring theme. For example, Yamasaki-Nakagawa, Ozara, Yamada, and Mori (2001) found women in Nepal were more likely than men to first seek help from traditional healers. his may be reflected in findings from a recent study by Rahman (2000) in rural Bangladesh, where 86% of women received healthcare from non-qualified health care providers. This has implications for diagnosis and women have been found to have significantly longer delays to diagnosis than men [Needham, Foster, Tomlinson, & Godfrey-Faussett, (2001); Yamasaki-Nakagawa, Ozasa, Yamada & Mori, (2001)].

Despite the ongoing evidence that people do choose traditional and folk medicine or providers in a variety of contexts which have potentially profound impacts on health, few studies recommend ways to build bridges to enable individual preferences to be incorporated into a more responsive health care system. For example, Ahmed et al.

(2001) conclude: “efforts should be made to raise community awareness regarding the importance of seeking care from trained personnel and the availability of services”. Nonetheless, there is now a growing recognition of the need to be more sensitive to the realities of healthcare seeking behaviour. For example, in Bangladesh, there is a large and growing sector of non-qualified allopathic providers engaged in the traffic of modern pharmaceuticals. They provide an accessible means of reaching Western medicines to a wider range of the population, yet lack formal medical training. There is therefore the accompanying problem of bad, unregulated prescriptive practices. Incorporating these unqualified providers into more formal training may therefore be beneficial (Ahmed et al., 2000).

Uzma, Underwood, Atkinson, and Thackrah (1999) also suggested incorporating unqualified traditional birth attendants (TBAs) into training programmes for maternal health in order to improve the health status of women and children. Thus, increasingly, healthcare seeking behaviour studies are coming to the conclusion that traditional and unqualified practitioners need to be recognized as „the main providers of care‟ in relation to some health problems in developing countries (Rahman, 2000). In acknowledgement of the fact that untrained non-Western practitioners remain a strong favourite, Outwater, Nkya, Lyamuya, and Dellabeta (2001) interviewed traditional healers about their knowledge and relationship with „modern‟ medicine and explored in far more depth the preferences of women who attended traditional healers and unofficial sources of health care. Through this, they recognized that some groups appeared to wonder between practitioners rather than seek care through other avenues (Moses, Ngugi, Bradley, & Plummer, 1994). Similarly, Rahman (2000) found that different facilities will be frequented for different needs, according to a complex interplay of factors, sometimes regardless of the intended purpose of those facilities. Thus, there is growing acknowledgement that healthcare seeking behaviours and local knowledge need to be taken seriously in programmes and interventions to promote health in a variety of contexts (Price, 2001; Runganga, Sundby, & Aggleton, 2001).

With this broader appreciation of behaviour, some authors have suggested the need to improve integration of private sector providers with public care (Needham et al, 2001). Measures are being put in place for explicit recognition of the potential to combine the two worlds by involving unofficial providers in official training and service provision.(Green, 1994; Outwater et al, 2001). However, Ahmed et al. (2000) conceded that while extending training to such providers may enhance their services, training in itself will not change practice. For this, managerial and regulatory intervention is needed. Thus, the provision of medical services alone in efforts to reduce health inequalities is inadequate. Clearly, any research interest in healthcare seeking behaviour, focusing on end- point utilization needs to address the complex nature of the process involved, cognisant of the fact that the particular „end point" uncovered may be multi-faceted and not correspond to the preferred end points of service providers.

### 2.2.1.2 Health seeking behaviours: the process of illness response

The second body of work, rooted especially in psychology, looks at healthcare seeking behaviours more generally; drawing out the factors which enable or prevent people from making healthy choices in either their lifestyle behaviours or their use of medical care and treatment. Thus, in the literature, healthcare seeking behaviour is conceptualized as a sequence of remedial actions taken to rectify perceived ill-health (Ahmed et al, 2000).

In the second approach, the latter part of the definition, responding specifically to perceived ill-health, may be dropped as a wider perspective on affirmative health promoting behaviours is adopted. These are based on a mixture of demographic, social, emotional and cognitive factors, perceived symptoms, access to care and personality. The underlying assumption is that behaviour is best understood in terms of an individual‟s perception of their social environment. A number of genres of model exist and variations have been developed around them.

One of the most widely applied is the health belief model. Sheeran and Abraham (1996) categorized the range of behaviours that have been examined using health belief models into three broad areas: preventive health behaviours, sick role behaviours and clinic use. In this type of model, individual beliefs offer the link between socialization and behaviour. One of the earliest examples was Ahmed, Tomson, Petzold, and Kabir‟s (2005) study of the uptake of screening for tuberculosis (TB), where the authors discovered that a belief that sufferers could be asymptomatic was linked to screening uptake. Sheehan and Abraham concluded that health belief models focus on two elements; (1) threat perception, and (2) behavioural evaluation (. Threat perception depends upon perceived susceptibility to illness and anticipated severity; behavioural evaluation consists of beliefs concerning the benefits of a particular behaviour and the barriers to it. „Cues to action‟ and general „health motivation‟ have also been included (Becker, Haefner, & Maiman, 1977) . The health belief model has been criticized for portraying individuals as a social economic decision makers and its application to major contemporary health issues, such as sexual behaviour, have failed to offer any insights.

Another genre of model is linked to the general assumption that those who believe they have control over their health are more likely to engage in health promoting behaviours (Normand & Bennett, 1996). The health locus of control construct is therefore utilized to assess the relationship between an individual‟s actions and experience from previous outcomes. The most popular of these is the multidimensional health locus of control measure (Wallston, 1992). However, this approach to social cognition models has been criticized for taking too narrow an approach to health and, because, the amount of variance explained is low (. Other approaches, including protection motivation theory, and theory of planned behaviour, have equally met with mixed reception (Boer & Seydel, 1996; Conner & Sparks, 1996).

Healthcare seeking behaviour has emerged as a tool to tackle perceived ill health by taking remedial actions and currently, a lot of efforts are being directed toward encouraging people to learn and use health-promoting behaviours. Parental attitudes toward their children with disabilities, the resources they are willing to invest in treatment, training and education of these children, and parental expectations for the future of their children with disabilities are strongly influenced by a variety of factors, including the culture in which they live (Danseco, 1997).

## 2.3 Factors influencing the healthcare seeking behaviours of parents who have children with disabilities

Healthcare seeking is recognized to be a result of a complex behavioural process that is influenced by several factors, including socioeconomic and demographic characteristics, perceived need, accessibility and service availability (Ahmed et al., 2000). The patterns of healthcare seeking behaviour also depend on the quality of health care providers, effectiveness, convenience, opportunity costs and quality of service.

In addition, symptoms of illness, duration and an episode of illness as well as age of the sick person can be important predictors of whether and where people seek care during illness. In view of these factors, it could be concluded that a number of factors influence the behaviour of parents of children with disabilities in seeking healthcare for their children. Amongst these are:

### 2.3.1 Causes of disability

Several researchers have found out that many parents of children with disabilities in developing countries believe that their child‟s disabilities are the result of traditional or spiritual causes, rather than biomedical or they cite a combination of biomedical and traditional causes (Croot et al., 2008; Daudji, et al., 2011; Morgan & Tan, 2011).

In a study of disability culture in Ghana, Reynolds (2010) interviewed five community leaders to examine current views of people with disabilities in the country. The researcher found out that, although the informants expressed awareness that there were biomedical and environmental explanations for disabilities, traditional spiritual explanations were also offered, including cause by an ancestor who did something wrong and caused a curse on the family, witchcraft and fear that touching someone with a disability might cause the birth of a child with a similar problem. The study focused on community leaders‟ perceptions rather than parents of children with disabilities.

According to Danesco (1997), parental beliefs and perceptions related to disability may influence their decisions regarding seeking healthcare for their children with disabilities. In a study conducted by Danesco (1997), her findings were that parents who adhere to the biomedical cause of their child‟s disability are more likely to seek the services of medical practitioners whereas those who believe that the cause of disability is related to traditional or spiritual phenomena are more likely to seek the services of traditional healers or spiritual practitioners.

This confirms why some parents of children with disabilities do not sought to health facilities for help when their child is sick but rather prefer to go to prayer camps or see herbalists when the need arises. Oti-Boadi (2017) explains that, parents‟ interpretation of their disabled children‟s condition in Ghanaian context is influenced by their spiritual interpretation of disability. From her study, although some parents reported on the medical basis for their children‟s condition, majority of them knew of the spiritual interpretations of having children with disability. According to Oti-Boadi (2017), parents did not debunk the possibilities of these spiritual connotations even though they created the impression that they did not believe in evil interpretations society associated with their children‟s condition.

Research has shown that in Africa, health beliefs have been described as holistic, where many families and communities hold multiple beliefs, consisting of medical and African traditional and supernatural belief system explanations and treatment of diseases (Andin, 2008; White, 2015). However, Mashego (2005) asserts that Black parents of children with behavioural problems could not tell the cause of their children‟s condition due to their external locus of control of attributing their children‟s situation to supernatural causes.

### 2.3.2 Implications for the healthcare system

According to Aiken, Sochalski, and Lake (1997), it is important for healthcare professionals to understand that different factors affect parents of children with disabilities when it comes to making decisions to seek healthcare treatment for their children. This is to ensure that better professional services are provided to such parents who are already stressed because of their child‟s disability to promote their healthcare seeking behaviours instead of providing options that might drive these parents away. Having some knowledge of the challenges these parents go through can help healthcare providers improve their professional-patient relationships and develop strategies to encourage people to seek appropriate treatments as soon as possible.

### 2.3.3 Stigmatization

Goffman (1963) describes stigma or social devaluation as a mark of social disgrace often leading others to see us as untrustworthy, incompetent, or tainted. Stigma spoils identities, disqualifying individuals from full social acceptance and reducing them from a whole and usual person to a tainted, discounted one (Goffman, 1963). Bodily stigmas such as physical disabilities cause affected individuals to be considered incompetent, out of control and/or incapable of functioning in normal and socially desirable ways (Keusch, Wilentz, & Klienman, 2006). Stigmatization associated with disabilities and other negatively marked attributes are linked to a number of negative consequences for the individuals involved.

Gender, race, social status, and mental and physical health are topics vulnerable to stigma. It is important to note that some cultures or individuals feel that having a child with disability is shameful and because of that parents with such children tend to have negative behaviours in seeking healthcare when it comes to their children. It is common for society to discriminate against parents of children with disabilities and even the children themselves, for families to be ashamed of them and hide them from the public, and for these individuals to lack access to healthcare (Maloni et al., 2010). In a study by Baffoe, (2013), he contended that stigma is a devastating experience for persons living with disabilities especially those with mental health challenges.

A study conducted by Gona, Mung‟ala-Odera, Newton, and Hartley (2010) revealed that families of children with disabilities felt excluded from the society due to a shortage of services and negative attitudes. Community members of where these parents and their children live tend to ridicule, point fingers at them, gossip about them, shun them and even tell them there is a curse upon their family that is why they have such a child. Due to the attitude of community members, these parents feel ashamed and uneasy to send their children with disabilities out, especially to public places and health facilities. According to Shabalala (2000), in the past, Swazi people, like many others of different cultures all over the world looked at disability as a curse from the gods as a sign of bad omen. There is enough evidence of culture disrespect for those labelled disabled. Thwala (2004) states that culturally disabled is seen as different from the normal being as a result disabled people are treated as a weaker social beings. They are discriminated, ridiculed and even not considered in the community, when then choose people to represent the community somewhere they are not considered. Education is therefore needed to break this negative stigma in order to increase healthcare seeking behaviours of parents of children with disabilities.

### 2.3.4 Severity of disability

Although there are standard operationalized definitions for mild, moderate, severe, and profound disability, no standard measure exists for determining the severity of a disability (MacKian, n.d.). According to Oltmanns & Emery (2001), there has been a current shift in terminology which focused on level of disability to intensities of needed supports (that is, intermittent, limited, extensive and pervasive needed supports replace mild, moderate severe and profound levels of disability). However, Jackson (2004) argues that these terms have specifically been instituted for use among people with mental retardation. Most available measures for assessing level of developmental disability focus on levels of functioning in various key areas (for example, personal hygiene, language skills, learning capacity, mobility, capability for self-sufficiency and self-direction).

Levels of developmental disability have been globally defined as mild, moderate, severe and profound but a limited number of study results suggest otherwise (Bromley & Blacher, 1989; Hodapp & Zigler, 1985). Several studies, for instance (Blacher & Baker, 1994; Martin & Colbert, 1997; Westling, 1997) have found that the severity of a child"s developmental disabilities is positively correlated with time demands, pessimistic parental attitudes, negative parental perceptions of the child, family deterioration and out-of-home placement (Jackson, 2004). People with severe or profound disabilities frequently have multiple disabilities. It is not unreasonable to posit that with each additional disability a child"s special needs tend to increase accordingly; thus, children with severe and profound disabilities are the most likely to need special care and services due to the significant impairments to their growth and development.

Consequently, children with multiple disabilities are necessarily considered to have more special needs. In fact, the vast majority of children with developmental disabilities in out-of-home care are those who have been diagnosed as having severe or profound developmental disabilities (Blacher, 1994). In view of this, the extent to which parents of children with disabilities experience challenges depends significantly on the level of the children"s disabilities. For instance, consider raising a child whose legs are different lengths (mild); a child who has blindness (moderate); a child with extreme mental retardation (severe); and a child living with autism, cerebral palsy, epilepsy and diabetes (profound). Accordingly, the more serious the impairment, the more intensely stresses are experienced by parents (Palfrey, Walker, Butler & Singer, 1989).

Depending on the severity of the illness and the clinical manifestations they present, people might select different forms of treatments and medications to curb the situation. Parents of children with disabilities in their quest to seek healthcare for their children turn to use their discretion as to whether the child"s illness is severe or not and whether to go to the health facility for help or buy over the counter drugs. In a study by Ember and Ember (2004), the researchers found that individuals perceived their illness to be either mild or not for medical treatment, which prevented them from seeking healthcare treatment. In addition, poverty emerged as a major determinant of healthcare seeking behaviour as treatments were often perceived as either a waste of money, lack of money or poor attitude of health worker.

### 2.3.5 Availability and accessibility to healthcare facilities

Securing appropriate services can prove to be a stressful responsibility for parents. According to Jackson (2004), to acquire the necessary services as a parent for your disabled child is a very confusing and frustrating process. Some of the common services needed by parents include respite care, occupational therapy, physical therapy, speech and language therapy, educational and recreational services (Martin & Colbert, 1997).

Depending on the area a person lives, some treatment might be available but other forms of treatments may also not be available. Therefore, a patient is limited to what is accessible and available to them when seeking treatment for a disease. Traveling quite a distance to access healthcare will have a negative impact on the behaviours of parents of children with disabilities due to the stress involved. Due to the proximity of a health facility, parents of children with disability tend to manage their child healthcare needs at home when the need arises.

### 2.3.6 Socio-economic status (SES)

Socio-economic status (SES) is a social and economic total measure of a person‟s work experience and an individual or family‟s economic and social position in relation to others, based on income, education and occupation (Marmot, 2004). SES is one of the predictors for healthcare seeking behaviour of parents who have children with disabilities. People from higher SES levels (for example higher incomes and/or education) are less likely to request placement than are people from lower SES levels (Emerson & Hatton, 2010; Jackson, 2004), presumably because the latter cannot afford the supplemental services necessary to adequately care for their child. The financial strains on parents are further magnified by the frequent finding that in two-parent households, only one parent is able to work so that the other parent can remain at home to provide the necessary care, substantially reducing household income (Martin & Colbert, 1997). This scenario plays out even more harshly for single parents.

The American Psychological Association (2012) opines that low socio-economic status and its correlates, such as lower education, poverty and poor health, ultimately affect our society as a whole. Low income has been shown to be strong predictor of a range of physical and mental health problems. A study by O‟Neil (1989), stressed the importance of the social relationship between a doctor and patient. O‟Neil explained that, an unequal distribution of power and knowledge of health leads to patients being unsatisfied with their healthcare provider, which in turn leads to patients stopping to seek treatment or healthcare.

However, social determinants of health are argued to have influence on gender, race, and education are factors of healthcare seeking behaviour (WHO, 2011). The WHO defined the social determinants of health as the conditions in which people are born, grow, live, work and age. The WHO argued that the distribution of money, power and resources at global, national and local levels, creates these conditions.

### 2.3.7 Cultural factors

Sandstrom, Lively, Martin, and Gary (2014) opine that factors such as cultural values and gender roles are significant in influencing the decision-making process associated with healthcare seeking behaviour. Asian-American cultures for example, are strongly influenced by Confucian doctrines (a way of life), which emphasized the importance of interdependence, collectivism (giving a group priority over each individual), and familism (family‟s value is held in higher esteem than the values of individual members of the family). These values reinforce the expectation of individuals to place the needs of the family before their own, which may discourage them to pro-actively seek healthcare in a timely manner.

Furthermore, these values of Asian-American cultures suggest that physical and mental distress are family problems rather than an individual one meaning that they should not be revealed to people outside their family. Seeking help from healthcare professionals for treatment would be exposing the problem beyond their family network, which is considered shameful and could pose a threat to the status or reputation of the family (Sandstrom, Lively, Martin & Gary 2014).

Consequently, Asian-American people tend to turn to family members before pursuing external help, thereby delaying the act of seeking professional healthcare. Thus, this behaviour greatly affects parents of children with disabilities in seeking healthcare as well. Green (2003) found that parents of children with disabilities experience high levels of stigma from society. These negative attitudes are possibly due to the cultural and spiritual beliefs associated with disability in Ghana (Avoke, 2002). Avoke further argues that, parents raised their children under the influence of powerful traditional beliefs that devalue people with disabilities.

### 2.3.8 Gender

According to Lazarus (1994) in most African countries including Ghana, men are considered to be of greater value as compared to women. This belief starts right from the birth of a child up to old age. Therefore, when a child is born with a disability, society is quick to say that the child can grow to fit into society when it is a male, but they have little hope when that child is a female. They would more likely tell the parents of that child to send her to the sea shore or a thick forest to perform rituals to send her away. When such a child is sick, sending her for medical attention is often delayed. Also, Lazarus stated that, the difference between gender roles is significant in the patterns of healthcare seeking behaviour between men and women.

Currie and Wiesenberg (2003) contended that, women tend to engage in less healthcare seeking behaviour compared to their male counterparts. In their article, Currie and Wiesenberg highlighted three components regarding women‟s decision-making process for seeking healthcare. Firstly, women generally are less likely to identify disease symptoms. Women might shrug off symptoms as normal everyday muscle aches or normal regular occurrence. To be able to recognize and identify a health problem, one needs to have some form of knowledge and awareness of symptoms and illnesses. Secondly, the study revealed that women tend to believe that they are more restricted compared to their male counterparts in terms of healthcare accessibility. This is due largely to cultural ideas about the social value of women, which is lower compared to men.

Thirdly, it is revealed that women do not engage in healthcare treatments even if they recognized that they have a health problem. This behaviour may influence mothers in seeking healthcare for their children. In Ghana, women are mostly associated with housekeeping; therefore, even when their child is sick, they still have the responsibility of keeping the home and managing it before seeking for healthcare for their child. Often, mothers detect the ill health of their child quickly more than fathers because they are mostly found home with them whilst the fathers go out to work all day. This means that the father only has to provide financially sometimes when his child is sick but it is up to the mother to send the sick child for medical help (Currie & Wiesenberg, 2003).

## 2.4 Strategies to support parents to improve on their healthcare seeking behaviours

Parents and their children with disabilities experience challenges that differ from those experienced by parents of typically developing children (Woodman, 2014). When a child with one or more disabilities is born into a family or when parents receive the diagnosis of their child"s disability, they often experience a range of emotions, for example, shock, grief or anger, that are somewhat similar to those experienced upon learning about the death of a loved one (Kandel & Merrick, 2003). Parents experiencing such emotional reactions require a period of time to adjust, and during that time, parenting and care giving may be affected. Some children with disabilities pose particular challenges because of developmental needs and behaviours that require specific parenting skills.

Moreover, parents of children with disabilities tend to experience challenges at certain points of transition during the early childhood years (Malone & Gallagher, 2009).For example, moving children from home to hospital, one school to another and so on. It is argued that, children with disabilities affect families in different ways, but a common finding in the literature is that parents of children with disabilities experience more stress than parents of typically developing children (Woodman, 2014).

Several studies for example, Corden et al. (200 and Sloper (2001 have noted the financial struggles that families especially parents go through during illness trajectory of their children. Having a disabled child often leads to extra expenditure (for example in areas such as travel, telephone calls, catering for a special diet, fuel) at a time when family incomes are changing. During the illness trajectory many parents, especially mothers, readjust their paid working hours or give up work in order to accommodate caring for their sick child.

According to Corden, Sloper and Sainsbury, (2002) financial changes can impact upon families in many ways; from the immediacy of a reduced income, the stress of negotiating state benefits, to career implications for women wishing to return to work at a later date. In light of these many changes and uncertainties, it is unsurprising that parents have been found to want well-timed information or advice about the benefits available to them and the financial implications of potential actions, such as giving up work. Here, parents not only wanted information delivered in a sensitive manner by well trained staff but also recognition of the importance of bridging support, that is, not losing one‟s benefits immediately after the death of a child.

Dobson, Middleton, and Beardworth (2001) opined that parents having a child with disability can dig deeper into the pocket of the parent. This is because, the nature of the daily care giving activities, employment and financial challenges which they are often not prepared for, overwhelmed the parents of children with disability (Pisula, 2007). Also, for parents of children with severe disability, the concern for their child‟s welfare and the challenges related to health care provision and coverage may affect their ability to provide positive parenting. One of the most promising approaches for supporting these parents is parent management training (Patterson et al., 1982). According to Sahota (2011), parent management training (PMT) is one of the earliest training programs for parents, involving parents of children with externalizing behaviour, originated with Gerald Patterson and colleagues. Parents participate in therapy sessions to learn behaviour management techniques they would use with their children. From Patterson, Chamberlain and Reid, (1982) experimental study, they observed a significant reduction in children"s externalizing behaviour relative to the control group. Similarly, Sahota (2011) followed the PMT model to teach parents of children with conduct disorders and also found significant changes in child behaviour and parent attitudes for the intervention relative to the control group.

Appropriate healthcare seeking behaviour could prevent a significant number of child deaths and complications due to ill health. Improving mothers" healthcare seeking behaviour could contribute in reducing a large number of child morbidity and mortality in developing countries (Chopra, Sharkey, Dalmiya, Anthony, & Binkin, 2012). Proper record of every child in the Effutu Municipality should be kept by community health nurses who live in the community where these parents and their children with and without disabilities live as well. One of the responsibilities of community health nurses is home visiting where children are checked in their homes and necessary health advice is given and referrals made. If this is properly done, parents who feel embarrassed to send their children with disabilities to health facilities when they are sick will feel more comfortable in dealing with the community health nurse.

Also, there should be periodic sensitization within the various communities by the Ministry of Health using video vans to show the strengths of persons with disabilities and their contributions to the development of their communities and the country as a whole. The services of specially trained nurses in the area of disabilities should be employed in the various health facilities. This will help reduce the long queues parents have to be in when they send their children with disabilities for treatment. Furthermore, healthcare facilities should be user friendly for persons with disabilities to make accessibility easier for them because the nature of some facilities deters clients from going to such places for medical assistance.

### 2.5 Summary of literature

The study highlighted several literatures that relate to healthcare seeking behaviours of parents who have children with disabilities. The chapter also presented the conceptual framework, healthcare seeking behaviours of parents who have children with disabilities, factors that influence the behaviours of parents in seeking healthcare for their children with disabilities and strategies that can be adopted to support parents to improve on their healthcare seeking behaviours.

# CHAPTER THREE

# METHODOLOGY

## 3.0 Introduction

This chapter presents the methodology of the study. The following areas were covered: research design, population, sample size, sampling techniques, instrumentation, trustworthiness, procedure for data collection and data analysis.

## 3.1 Research design

According to Creswell (2009), research design is described as the plans and the procedures for research that span the decisions from broad assumptions to detailed methods of data collection and analysis. This study sought to explore the healthcare seeking behaviours of parents who have children with disabilities. In order to achieve the purpose of this study, the study used a case study research design. Case study is one of several forms of social science research. According to Yin (2014), a case study investigates a case in its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident. The case study design was adopted for a number of reasons.

According to Cohen, Manion, & Marrison (2007), case study design enables the researcher to gather data at a particular point in time with the intention of describing the nature of the existing conditions. The choice of the case study design enabled the researcher to make in-depth study of the phenomena through interactions in the form of an interview. The researcher therefore had a personal interaction with the participants in order to be sure that the data provided came from the right participants. This was done to avoid any doubt as to whether it was really those who matter who answered the questions. As a result, the researcher collected data directly from participants through one-on-one interviews

In respect of the methodology, the study employed the qualitative approach. Qualitative method was deemed appropriate because the researcher aimed at exploring healthcare seeking behaviours of parents of children with disabilities. Qualitative research shares its philosophical under pinning with the naturalistic or interpretive paradigm which describe and explain a person‟s experiences, behaviours, interactions and social contexts without the use of statistical procedures or quantification (Strauss & Corbin, 1990). Again, the qualitative approach was selected due to the nature of the study which seeks in-depth information concerning the issue under study. A qualitative approach therefore enabled the researcher to interact with participants to get first-hand knowledge and an in-depth study of the topic. This helped to analyze the healthcare seeking behaviours of parents of children with disabilities.

## 3.2 Study setting

The study was conducted in Winneba in the Effutu Municipality. The Effutu Municipality is one of the 20 administrative districts in the Central region of Ghana. It is situated between latitudes 5°16‟ and 20.18"N and longitudes 0°32‟ and 48.32‟‟W of the eastern part of Central region. The administrative capital is Winneba, a town renowned for its specialised major institutions of higher learning. The name Winneba originated from European sailors who were often aided by favourable wind to sail along the bay. From the use of the words „windy bay‟; the name Winneba was coined. At the time this study was done, the population of the Effutu Municipality was 68,592 (49 percent males and 51 percent females). The population of the Municipality constituted 3.1 percent of the total population of the Central region and the second lowest in terms of population in the region. Out of a total current enrolment of 29,862 in the municipality, 33.8 percent are at primary level, 13.3 percent at the Junior High School (JHS) level and 6.9 percent are at the senior high school (SHS) level with almost three-tenth (27.8%) at tertiary level. Apart from the tertiary level where the proportion of males is higher than that of females, at each of the subsequent levels, the proportion of females is higher than that of males. A higher proportion of females (36.3%) than males (31.6%) were enrolled at the primary level. Similar patterns were observed for females who constituted 13 percent and males 12.9 percent at the JHS and SHS levels (Ghana Statistical Service, 2014).

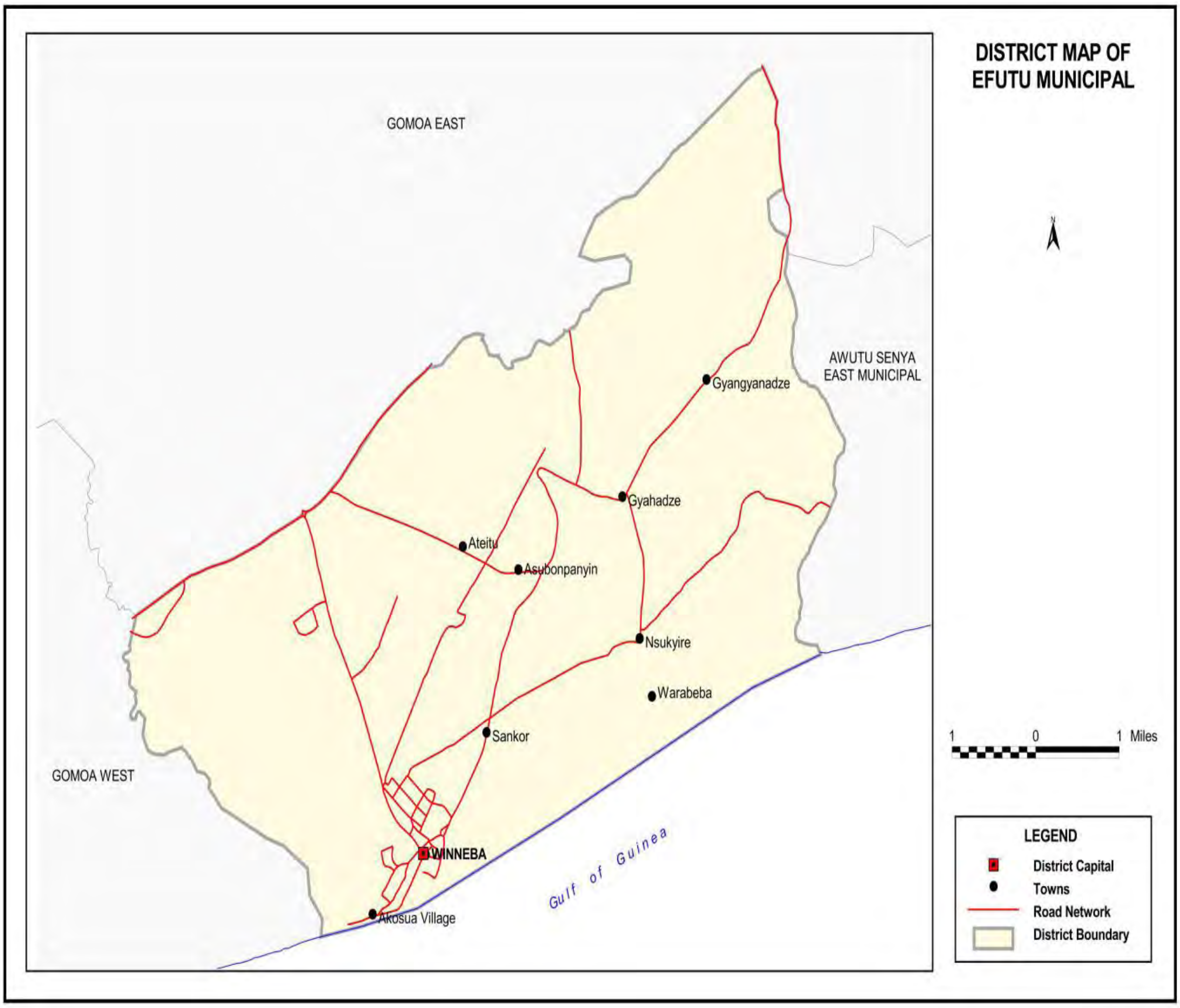

**Figure 3.1: District Map of Effutu Municipality**

**Source:** Ghana Statistical Service, GSS (2014)

### 3.3 Population

A population is an entire group of people or objects or events which all have at least one common characteristic and must be defined specifically and unambiguously (Dampson & Danso-Mensah, 2012). The target population for this study was all parents of pupils with disabilities at the University Practice Inclusive Basic School, South Campus in Winneba and Rev. Fr. John Memorial School., also in Winneba.

The accessible population for the study was 33 parents who have children with disabilities at the University Practice Inclusive Basic Schools and 56 parents who have children with disabilities at Rev. Fr. John Memorial School, summing up to 89 parents.

### 3.4 Sample size

A sample is a small portion of a target population. Sampling means selecting a given number of subjects from a defined population as a representative of that population (Kothari, 2004). Kothari, adds that the size of the sample should neither be excessively too large nor too small and generally it must be optimum. He further argues that the sample size depends on size of population, kind of study as well as the nature of the population. A total number of 10 parents (4 from University Practice Inclusive Basic School and 6 from Rev. Fr. John Memorial School) were used for the study. Yin (2014) however recommends at least six sources of evidence in case study. In order words, six or more interviewees are recommended per case study.

**Table 3.1: Sample size**

| Sample School | Number of Parents |
|---|---|
| University Practice Inclusive Basic School | 4 |
| Reverend Father John Memorial School | 6 |
| **Total** | **10** |

### 3.5 Sampling technique

Sampling technique is a process of selecting just a small group of people as representatives from a large group called the population (Walliman, 2006). In the study, non-probability sampling technique was employed in selecting the sample size. According to Kothari (2004), the non-probability sampling technique also known by different name such as deliberate sampling, purposive sampling and judgement sampling. In this type of sampling, items for the sample are selected deliberately by researcher; this choice concerning the items remains supreme. In other words, under non-probability sampling the organizers of the enquiry purposively choose the particular units of the universe for constituting a sample on the basis that the small mass that they so select out of huge one will be typical or representative of the whole. Therefore for this study the non-probability techniques including convenience sampling and purposive sampling were used. The researcher, after introducing herself to the two schools understudy made arrangements with the headteachers in the schools to invite parents who have children with disabilities to meet her on a proposed date. These parents were parents whose children have disabilities and fell sick often.

## 3.6 Research instrument

### 3.6.1 Semi-structured interview guide

In research, interviews enable the interviewer to get the experiences and views of the person being interviewed through a dialogue (Matthews & Ross, 2010). Semi-structured interview was conducted for the various parents (participants). Interviews allow for reframing and rephrasing of ideas to arrive at a desirable level required by the study. Robson (2003) states that interviews typically involve the researcher, asking questions and hoping to receive responses from people he or she is interviewing. Bryman (2008) asserts that, using semi-structured interview when interviewing informants ensures flexibility of follow-up questions that may arise in the course of interviewing and create room for easy responses to these questions. The use of semi-structured interviews helped the researcher to explore the views, feelings and perspectives of the research participants on the research topic. For the purpose of this study, the interview guide specified themes in accordance with the objectives and research questions. The interviews aided by an interview guide lasted for 20 to 25 minutes with each participant. Fante and English languages were used for the interviews, because the participants were able to speak at least one of the two languages. The interviews were recorded by the researcher herself with Samsung Galaxy S4 with the permission of the participants.

### 3.7 Procedure for data collection

The following procedures were followed in the collection of the data. First of all, a clear written brief (Appendix A & B) from UEW which explains the intended research and its purpose was used to seek permission from the two selected schools. The researcher went to the designated areas such as homes and shops chosen by parents who have children with disabilities where she interacted with them in their natural settings.

Three visits were made in all; the first visit was to circulate the introductory letter to the selected schools. This was done for the purposes of seeking permission to conduct the study from the authorities. The second visit was made during the Parent Teacher Association (PTA) meetings of the various schools upon the agreed schedule. At the PTA meeting, the researcher was introduced by the head teacher after the meeting to parents who have frequently sick children with disabilities. At that point, the researcher explained to parents the purpose and the objectives of the study. She then sought their consent so that those who were willing to participate were included in the study. She then made arrangements with each of the parents to meet them at convenient locations for the interview. Convenient date for participants (parents) to be interviewed was decided on that day. The third visit was to the various agreed locations of the parents to carry out the interview. Individual face-to-face semi-structured interviews were conducted during these visits. All the interviews were conducted at different times at various locations chosen by respondents. The interview for the study was recorded with a Samsung Galaxy S4 phone and lasted from twenty to twenty-five minutes.

### 3.8 Data trustworthiness

Trustworthiness in qualitative research refers to the extent to which the researcher is able to justify that the study"s findings and interpretations truly reflect participants experience and are reliable. Cohen et al. (2011) proposed the concepts of trustworthiness to comprise of credibility, transferability, dependability and confirmability and suggested strategies that researchers could use to enhance the worth of their study.

### Dependability

According to Bitsch (2005), dependability refers to "the stability of findings over time" (p. 86). In other words, dependability concerns the degree to which the results of the study are consistent or replicable with the same subjects or in similar context. To ensure that the findings and conclusions are dependable, the researcher closely worked with her supervisor throughout the study and also kept audit trail of all the events and procedures followed in the study.

The researcher used the code and recode procedure in analyzing the data. This procedure requires that, after coding a segment of data, the researcher should wait at least 2 weeks and then return and recode the same data and compare the results. The researcher has also provided detailed description of the research design, procedures used in collecting and analyzing the data and background information on respondents.

### Confirmability

Confirmability concerns with establishing the fact that data and interpretations of the findings are not figments of the inquirer‟s imagination, but are clearly derived from the data (Tobin & Begley, 2004). Studies suggest that confirmability of qualitative inquiry is achieved through an audit trial, reflexive journal and triangulation (Bowen, 2009). In order to establish confirmability the researcher has kept an audit trail of audiotapes, field notes, transcriptions, interview questions, consent forms and all other relevant information and documents regarding the study. These will be made available for any future auditing of the study for confirmatory purposes. The researcher also worked closely with her supervisor who has provided concurrent audit throughout the entire research process.

### 3.9 Method of data analysis

In qualitative studies, data analysis begins even before data collection and is a continuous process. Merriam (2009) recommended on-going analysis of data collected. According to Merriam, researcher runs the risk of ending up with data that are confused, repetitious, and overwhelming in the sheer volume of material that needs to be processed when the analysis is delayed. With this in mind, data was analysed concurrently with data collection. The researcher carried out the analysis of all the daily interviews to identify major ideas and kept record of them. The volumes of data that were generated from the study were manually coded and analysed by the researcher. Prior to this activity, the researcher transcribed the interviews before beginning analysis. This enabled the researcher to determine areas which needed to be probed in subsequent interviews. This was, to a large extent to reduce, simplify, consolidate and organize the ideas into more easily manageable concepts and categories (Merriam, 2009).

In transcribing the interview data, the researcher employed thematic analysis as a methodological tool to analyse the data. Thematic analysis is a descriptive presentation of qualitative data (Anderson, 2007). This method involves looking across all the data to identify the main themes that summarize all the views you have collected. In applying this process, the researcher first read and re-read the transcripts in order to familiarize with the data. The researcher then identified and grouped the data units or statements under the predetermined themes which are based on the constructs of the model guiding the study. This was done for all interview transcripts. All other data which could not be categorized under any of the themes was content analysed into new themes or categories

### 3.10 Ethical consideration

In conducting research, it is important that ethical considerations be given due attention. The researcher took a due cognizance of ethical responsibility in the collection and analysis of data, and the reporting of the information. Permission to conduct the study was obtained from the head teachers in the selected schools. Informed verbal consents were obtained from all parents that participated in the study and, their participation was voluntary.

The purpose of the study was explained and the participants were assured of the confidentiality and anonymity of the responses. In reporting the findings, the researcher used pseudonyms in place of the actual names of research participants. Participants were also assured that the information obtained from the study was solely for academic purposes and would be held confidentially. All the participants were assured of their rights to participate; to decline or to withdraw from the study at any time if they felt uncomfortable. This means that participants were well-informed about what the participation entailed, and were reassured that declining would not affect any services they received. The researcher held interviews at participants" homes where the participants deemed it comfortable. However, all the participants were acknowledged and given a summary of the report so that goodwill could be maintained in future research.

### 3.11 Limitations of the study

Among the limitations in the study, care should be taken in generalizing the finding to the general population would not be possible as the sample size is too small in this study. Again, the study was limited by the level of detail provided by the participants in their responses to the questions posed by the researcher in the interview. Some parents may have been hesitant to articulate the real case on the ground as far as their healthcare seeking behaviour regarding their children with disability is concerned. This to some extent could threaten the internal validity of the study instrument.

# CHAPTER FOUR

# RESULTS AND FINDINGS

## 4.0 Introduction

This chapter presents the report and findings of the study. The purpose of the study was to explore healthcare seeking behaviours of parents who have children with disabilities in University Practice Basic Inclusive School at the South Campus and Rev. Fr. John Memorial School both in Winneba. Data were gathered for the purpose of answering three research questions: (1) How do parents behave in seeking healthcare services for their children with disabilities? (2) What are the factors that influence the behaviours of parents who have children with disabilities? (3) What strategies can be put in place to improve on healthcare seeking behaviours for parents who have children with disabilities? In answering these research questions, ten (10) major themes emerged based on the contextual analysis of the data. These themes include: awareness of the kind and cause of disability, parents response to children"s health needs, choice of healthcare services, availability and accessibility of health service, socio-cultural factors, acceptance, parental support system, training of professionals, and expansion of resources. These themes are described with supporting quotes from the interviews. The demographic characteristics of participants are presented first, followed by the themes.

## 4.1 Demographic characteristics of participants

In all, ten (10) parents were involved in the study comprising eight (9) biological mothers and one (1) biological father. All the parents who participated in the study had among their children one child who had a disability. The ages of the parents ranged from 23 to 55 years with nine (9) being below 50, and only one (1) being above 50 years. The parents had different educational backgrounds. Majority, six (6) of the parents had tertiary education with one (1) SHS leaver, one (1) Vocational/Technical leaver and the rest (2) with JSS leaver. Also, three (3) of the parents interviewed were teachers, one (1) being a quantity surveyor, one (1) being a secretary with another one (1) being sanitary worker. Apart from these, some of the parents (4) also engaged in private businesses and trading to support their main work. Most (7) of the mothers were married and living with their husbands, a few (2) being single and one (1) divorced. The children were aged between 11months and 14years with majority (8) between 2 and 14 and only one (1) below 1year.

### 4.3 Research question 1: How do parents behave in seeking healthcare services for their children with disabilities?

To answer this research question, the interview data collected from parents and analyzed were used:

- shopping remedies;
- utilization of healthcare services (buying over the counter drugs/drugstore);
- the hospital/clinic as a last resort.

#### 4.3.1 Shopping for remedies

One of the questions on the interview guide was, “Where do you seek healthcare for your child when he/she is sick?” This statement was meant to find out where parents who have children with disabilities seek healthcare for their children when they are sick. From the participants‟ responses in the interview, it was revealed that most of the parents resorted to drugstores, herbalists and spiritualists for healthcare for their children with disabilities. Some of the respondents expressed their experiences in the following way:

> I go to the drugstore to buy her medicine. It is easier and faster there and no one would see my daughter either. (*A verbatim expression of a parent* ).

Another respondent said this:

> I go to the drugstore. Sometimes, my mother"s herbalist or my pastor.
>
> *(A verbatim expression of a parent* )

The researcher through the interview further explored on how participants respond to their child"s healthcare needs. For some of the parents, the severity of their child"s sickness determined their healthcare responses. Below are some of their narrations:

> When the sickness is not serious, I sometimes give her para or tricilicate depending on what is wrong with her. I always have some first aid at home because of my daughter. (*A verbatim expression of a parent* )

Another parent said that:

> For me, I have some herbal medicine that I give to my son thrice a week. It prevents malaria and fever so he is often strong but when he falls sick, I have a nurse friend that I call for direction. She always tells me the type of medicine to buy for my son. I don"t remember the last time I took my son to the hospital. *(A verbatim expression of a parent* ).

When parents were asked what home remedies they give to their child first before send him or her for further management, the following were the views expressed:

A parent said that:

> My mother will make me give him enema for two or three days. If we don"t see any result, then she"ll make us take my son to her prophet. *(A verbatim expression of a parent* ).

Another parent said that:

> Hmmm…madam, depending on the type of sickness, I either give him herbal medicine or I go to the drugstore to tell the attendant what is wrong with my son so that I can be given some medicine to buy for him. *(A verbatim expression of parent ).*

### 4.3.3 Utilization of healthcare services (over the counter/drugstore)

Undoubtedly, parents respond differently to various signs and symptoms that are manifested when their children who have disabilities are sick. Consequently, they may vary in utilization of healthcare services for their children with disabilities. In view of this, the researcher asked parents of where they seek their child"s healthcare when he/she is sick. Some of the parents disclosed that they rely most often on drug store medication for the treatment of their children"s sicknesses. Some of the views expressed were:

> Oh, I just go to the drug store whenever she is sick and tell them what is wrong with her and I buy medicine for her. I don"t want to go the hospital to waste my time and everybody will be watching us. *(A verbatim expression of a parent).*

One parent also commented that:

> Depending on the sickness, I sometime take her to the drug store, sometimes to the herbalist or the spiritualist. But last month I took her to the hospital when she was very sick and was told that she had an infection. *(A verbatim expression of a parent).*

Some of the parents were found to have strong belief in herbalists and spiritualists. Participants who gave their comments with regards to their choice of healthcare services for their children with disability.

Another respondent narrated that:

> To be frank with you Madam, I normally don"t take my child to hospital/clinic. I take her to the herbalist for treatment because all this while, he has been taking care for her. *(A verbatim expression of a parent).*

A parent commented that:

> I send her to one of my prophets or pastors to be prayed for. Though she hasn"t been healed yet of her disability, they pray for her to be healed whenever she is not well. I can"t remember the last time I took her to the hospital; people stir at her too much and that makes me uncomfortable. *(A verbatim expression of a parent).*

### 4.3.4 The hospital/clinic as a last resort

As children are difficult to assess and may be more unwell than they appear, a face-to-face assessment which includes an examination is advised. Managing a child with disability therefore can be a frightening experience for everyone involved especially parents. The study explored how parents respond to the health needs of their children with disability. Through the interview, parents narrated the steps they took in responding to the heath needs of those children. It was revealed that, some of the parents after the first diagnosis consulted spiritualist and herbalist but had to later return with their child to the hospital for medical treatment when they are sick. The following were views expressed:

> Madam, I always try my best to cater for my child at home when she is sick but if her sickness becomes worse, I take her to a small clinic close my house. Sometimes, I am referred to send my child to the main hospital which I don"t feel comfortable going there but I try my best to go. *(A verbatim expression of a parent )*

One of the parents also said that:

> My mother took me to a certain herbalist in a village near Winneba for herbal treatment. At the age of one when my child had severe jaundice, the herbalist was the one who treated my child so I‟ve been sending my child to him whenever he is not well. But recently my child was seriously sick and the herbalist couldn‟t cure him so I sent him to the hospital. *(A verbatim expression of a parent).*

However, one parent reported that she sought for healthcare from health professionals after the first diagnosis and haS since been sending him to the hospital whenever he is sick. She explains that:

> My mum came to live with us to help care for my boy when I delivered so it was my mum who noticed that something was wrong with him when he was around six months. When we reported at the Trauma Hospital, the Paediatrician referred us to a specialist in Accra to examine him for proper management. We were scheduled for monthly check ups which we still attend up till now but I am yet to see any major improvement. He will be seven years this November. I send him to the hospital whenever he‟s not well. *(A verbatim expression of a parent )*

Similarly, another also reported that she first healthcare for her child from health professionals but later on went to see a spiritualist. She commented in the following way:

> I was told that there is no cure for her condition but she can be managed small, small. We were referred to the National Assessment Resource Centre for assessment and management. I sent her there a couple of times but I stopped going because they lack equipment and the centre is in a poor state and I was not seeing any results. But I can‟t accept that my child is like this so for the past two years, even though I take her to the hospital, whenever she‟s sick, anytime I hear that there

> is a prophet or a pastor who works miracles, I just send my daughter there in case she will be healed for me. She"s all that I have. *(A verbatim expression of a parent ).*

After examining parents" behaviour in seeking healthcare for their children with disabilities, a question about how parents respond to these children when they are unwell was asked. Some parents stated that their response to children"s healthcare depended on the severity of the sickness.

A parent narrated:

> As for me, the severity of the sickness will determine whether I should act quickly or delay to see if the child will calm down. If he has a cold, it"s not an emergency or Madam? *(A verbatim expression of a parent ).*

One respondent also revealed that she feel always relaxed in responding to her child"s health needs because, the child can be prayed for to regain her health. Below is her statement:

> Okay, for my child her sicknesses are often not too serious so I don"t normally rush in attending to her health needs; moreover, I know she can be prayed for to receive her healing so I am relaxed. *(A verbatim expression of a parent ).*

Another parent said:

> Madam, when I realise that my child is not feeling well I first call the herbalist. I then ask him what I need to do. If he says I should bring her, then I send her. (*(A verbatim expression of a parent).*

While many participants reported that the rate of their response to children‟s health needs is determine by severity of the sickness, one of the participants disclosed that:

> As I have said to you already, he is my only child and therefore dear to my heart. As soon as I see that he‟s not well, I get him ready for the hospital. This is because, I personally don‟t believe in self-medication at all. *(A verbatim expression of a parent).*

## 4.4 Research question 2: What factors influence how parents who have children with disabilities behave in seeking healthcare for their children with disabilities?

To answer this research question, the interview data collected were used. Themes that emerged from the data collected reflected on these: *availability and accessibility to healthcare services; socio-cultural factors and stigmatization.*

### 4.4.1 Availability and accessibility to healthcare services

Availability and accessibility of health services is one of the major factors that influenced parents‟ behaviour in seeking healthcare for their children. In quest to answer the question "Why do you choose such intervention for your children?" parents shared their reasons for choosing such intervention.

One parent stated that:

> At the drug store, I will be attended to quickly and I don‟t need to go with my son so no one will know that I have such a child. As for the hospital, I have to take him with me for all to get to know that my child is suffering from such disability. (A *verbatim expression of a parent* )

A parent commented that:

> Most people who are health professionals talk too much. And I don‟t want these people to see her disability that is why I don‟t go to the

> hospital but rather go to the pastors. *(A verbatim expression of a parent).*

While many participants commented that they are apprehensive about stigmatisation or being teased by the public. However, one participant disclosed that she chose a particular service due to the delay factor.

This is depicted in the following excerpt:

> Madam, as for me I am used to the herbalist and also when we go there, we are attended to very quickly. Unlike the hospital, where I will join long queue from morning to the evening. The people who come to see too are not many so we feel comfortable when we go there. *(A verbatim expression of a parent).* )

### 4.4.2 Socio-cultural factors

A clear link exists between social and cultural inequality and disability. The wrongful perception of society with regards to disability, and bad cultural practice are linked to worsening condition of people who are suffering from one disability or the other. Participants were asked to share their experience in relation to the ways by which family members help in caring for their children with disabilities when they are sick. Most of the parents stated that they have been neglected by even their own family due to the fact that they have given birth to disabled children. Their views were expressed this way:

> Hmmm…Madam (Sobbing), our family members don"t want to come anywhere near us. They don"t help us in any way. They say we are cursed because there is no such child in the family. They don"t want to have anything to do with us. *(A verbatim expression of a arent ).*

One parent also said that:

> Eii! Madam, you have really asked a question! Hmm!! All of my family members have deserted me and my child. I have never received any form of social support from any of them. It is only my bosom friend who helps me out once a while. *(A verbatim expression of a parent ).*

However, a parent said that though she has been deserted by the husband‟s family, she receives encouragement and support from her own family. She said taht:

> Madam I must say that in the case of my family, they have supported and encouraged me that it shall be well. But for my husband‟s family hmm! They don‟t want to have anything to do with me and my son. They say we don‟t deserve to be a part of their prestigious family. They even advised my husband to divorce me. *(A verbatim expression of a parent).*

Again, on the part of the community, parents were asked on how the members of the community behave towards them due to their child‟s disability. Some of the parents commented that:

> Eiiii…they say if they even pass in front of our house, they can also have a child like my son. They call me names like "aboa no ne maame (the animal‟s mum)". Stop Madam, I can‟t say *all. (A verbatim expression of a parent ).*

Another parent commented:

> Madam, could you believe that they say I am a ritualist, meaning I have used my only son for money rituals (juju). That is how come I have no other child but have a lot of money and businesses. Hmmm!! It is serious. *(A verbatim expression of a parent).*

Some of the parents also revealed that they have been slandered and ridiculed to the point that they had to move from the place where they were living to another place.

A parent also commented that:

> Madam, people in my community don"t even want to pass by our house as if having a disability is contagious.*(A verbatim expression of a parent).*

### 4.4.3 Stigmatization

Stigmatization associated with disabilities and other negatively marked attributes are linked to a number of negative consequences for the individuals involved. When parents were asked how their children with disabilities are treated in their various communities, some of the views they expressed were:

The following views were expressed by some parents:

> Our community I will say has added to my pain and my child"s difficulty. They have ridiculed me a lot. I must testify that I nearly committed suicide last year had it not been the timely intervention of my friend. I regret for try that but I was frustrated and I had no one to talk to at that time. *(A verbatim expression of a parent).*
>
> Eiiii as for them, hmmmm! We even had to relocate because they were not talking to us and they refused to even sell to us. They point fingers at us and also say that they don"t want to attract a curse. *(A verbatim expression of a parent).*

A parent also commented that:

> People point hands at my son and I whenever we pass by certain places. We are ridiculed in our community every now and then. *(A verbatim expression of a parent).*

### 4.5 Research question 3: What strategies can be adopted to improve on their healthcare seeking behaviours?

To answer this research question, the interview data collected from parents were used. The themes found within the data regarding this research question were: *Acceptance by community members; expansion of resources; training of professionals and support for parents.*

#### 4.5.1 Acceptance by community members

Acceptance here involves the activity of people to welcome the family who have children with disabilities and the children with disabilities themselves. Families and their children with disabilities should be embraced in love and made to feel that they are also as human as they are. Some parents recounted how the community members can help to improve on seeking healthcare for children with disability among parents. They were of the view that, the community can support this worthy cause by first accepting and welcoming them into the community.

These were evident in the following statements:

> Members of the community should be welcoming so that we the parents who have children with disabilities would not feel embarrassed to take our children to public places especially the hospital. This will go a long way to improve our healthcare seeking behaviours. *(A verbatim expression of a parent ).*

A parent also stated that:

> In my view, they should accept children with disabilities into the community just as they are because the children are innocent. They didn"t choose to become who they are. It could have been them or even their children. *(A verbatim expression of a parent).*

Another parent whose child was suffering from cerebral palsy shared her view that the community should keep stop to mockery.

She said that:

> I would say that community members are the main cause of the negative healthcare behaviours parents who have children with disabilities exhibit. We as parents feel uncomfortable to send our children to public places for healthcare including the hospital. We always try to hide these children from the public view because of mockery. I think if it were to be you, Madam you would have the same. *(A verbatim expression of a parent ).*

### 4.5.2 Expansion of resources

This burden of parents who have children with disabilities can be lessening through the support systems put in place. Some of the parents commented that they should be given some financial assistance and other facilities to help manage their children‟s conditions.

Some parents shared their opinions in the following ways:

> I have heard that in some countries, children with disabilities are given monthly stipends to help with their up keep. The Government of Ghana can adapt this so that we can have some support to care for our children‟s needs including their healthcare. In fact, I am suffering in taking care of my child‟s health needs. *(A verbatim expression of a parent ).*

One parent also commented this way:

The Effutu Municipal Directorate should set up an office which will tackle issues of children with disabilities. At the office, free counselling services should be given to parents on the challenges they go through in caring for their children. *(A verbatim expression of a parent).*

Similarly, another parent said the following:

> The Effutu Municipal Directorate should build smaller clinics in every community so that when we send our sick children with disabilities there, we won‟t join any long queue. In this case too, there would not be too many people around to watch us. *(A verbatim expression of a parent ).*

### 4.5.3 Training of professionals

In-service training and workshops also have major impact in the attempt to support parents to cope with their children situation. Some of the parents believed that health professionals‟ conduct can be improved in order to support parents in providing health needs for their children with disability especially when they are sick.

One commented this way:

> A special workshop or in-service training on how to counsel parents who have children with disabilities should be organized for health professionals to enhance the services they provide. Madam, I saying this because most of them even don‟t how to talk to patients left alone to attend to their health needs. (*A verbatim expression of a parent).*

However, one of the parents acknowledged the good work health professionals do in support of quality healthcare delivery. She suggested that there should recruit more of the specialists to cater for these disabilities.

One parent had this to say:

> They should continue the good works but more specialist healthcare professionals should come on board to reduce the amount of time a patient spends at the hospital. I remember one day I went to hospital with child, came back home at 6:00pm meanwhile we went there in the morning. *(A verbatim expression of a parent).*

Some of the participants also believed that, for this battle to find a better end the training for parents should not be discarded.

Some parents had this to say:

> Parents should be provided with a special workshop or in-service training on how to give holistic care. I am saying this because, we parents spend much time on our children in the house. *(A verbatim expression of a parent)*.
>
> There should be counselling services specially made available for parents who have children with disabilities. *(A verbatim expression of a parent).*
>
> Some health professionals should be selected to visit homes where children with disabilities live and offer free counselling services to us the parents. *(A verbatim expression of a parent).*

### 4.5.4 Support for parents

Child upbringing, from my experience, is not an easy task. Both husband and wife have important role to play in the home front so as to raise good children that will be useful to the family and society at large. The researcher therefore asked the parents of what they think can be done to help them in carrying out this herculean task.

Some parents in their suggestions expressed the following:

> It is very difficult to raise children with disabilities. Financially, it"s not easy so I suggest that if it"s possible some funds should be given to parents in my situation help us with the upkeep of our children. (*Parent 2*) I am pleading that there should be some funds allocated to support parents who have children with disabilities because we spend a lot. My son cannot do anything by himself. He still wears diapers. *(A verbatim expression of a parent*).

One of the participants also noted that:

> I think sensitisation could do. Every individual member of the municipality should be sensitised about disability and the need to accept every person the way he or she is. Because, it could happen to everyone. *(A verbatim expression of a parent).*

In summary, the interview data analyzed revealed that all parents who participated in the study had among their children one child who was having a particular type of disability. The demographic characteristics revealed that all the parents who were participants have had at least one form of formal education starting JHS to tertiary. Also, most of the parents were found to be married with only few being single or divorced. Narrations of the parents of children with disability revealed varied kinds of disability and their challenges, parents‟ behaviours in seeking healthcare for their children, the factors that predisposed them to such kind of behaviour and strategies that can be adopted to improve healthcare seeking behaviours.

From the results, it was revealed that parents gave varied descriptions of their experiences in relation to what has informed their health-seeking behaviour. These experiences included the delay factor, stigmatization, neglect, and other social challenges. It was revealed that most parents resort to drugstore medication and herbalists in receiving treatment for their children with disability. In view of parents‟ suggestions, the community members should exhibit positive attitude that will embrace parents and their disabled children, and not to stigmatise them. It was also suggested that some financial assistance and other facilities to help manage their children‟s conditions can be provided by the Government of Ghana. Others suggested that the municipal directorate should provide them with counselling sessions and training for health professionals.

# CHAPTER FIVE

# DISCUSSION OF FINDINGS

## 5.0 Introduction

This chapter presents the discussions of findings on healthcare seeking behaviours of parents who have children with disabilities in the University Practice Basic Inclusive School, South Campus and Rev. Fr. John Memorial School both in Winneba. The discussions highlight the major findings based on the research questions raised.

1. What healthcare seeking behaviours do parents who have children with disabilities exhibit?
2. What factors influence how parents who have children with disabilities behave in seeking healthcare services for their children with disabilities?
3. What strategies can be adopted to parents to improve on their healthcare seeking behaviours?

## 5.1 How parents behave in seeking healthcare for their children with disabilities

Understanding human behaviour is prerequisite to behaviour and change behaviour and improved health practices. In view of this, one of the study objectives set out to explore how parents behave in seeking healthcare for their children with disability. Health seeking behaviour could be defined as the behaviour of people towards seeking their own health through provided health services.

### 5.1.1 Shopping for remedies

The findings revealed that most parents tend to look for help from all angles whenever their children with disabilities fell sick. They sought for help from herbalists and spiritualists.

A parent said that:

> I think it"s spiritual because ever since I got pregnant with this child, I had sleepless nights full of bad dreams until I delivered three years ago. My Pastor even told me that a curse is following the pregnancy so when the pregnancy was even five months old, I wanted to abort it but I didn"t have the courage. *(A verbatim expression of a parent).*

This however agrees with Oti-Boadi"s (2017) assertion that, parents" interpretation of the condition of their children with disabilities in the Ghanaian context is influenced by their spiritual interpretation of disability. From her study, although some parents reported on the medical basis for their children"s" condition, majority of them knew of the spiritual interpretations of having children with disability.

Also, findings of the study suggested that some of the parents practiced certain home remedies such as enema and herbal concoctions. They usually gave home remedies to their children with disabilities in order to cure their diseases.

A parent expressed her view that:

> I have some herbs that I use to give him enema. I don"t stress myself going to the hospital at all because the enema works perfectly well. *(A verbatim expression of a parent).*

Inconsistent to these findings, Mashego, (2005) asserted that parents of children with behavioural problems could not tell the cause of their children"s condition due to their external locus of control of attributing their children"s situation to supernatural causes.

### 5.1.2 The hospital/clinic as the last resort

It was revealed from the findings that, some of the parents after the first diagnosis by health professionals consulted spiritualist or herbalist and this has become their practice whenever their children with this disabilities fall sick.

One parent said that:

> I was told that there is no cure for her condition but she can be managed small, small. We were referred to the National Assessment Resource Centre for assessment and management. I sent him there a couple of times but I stopped going because they lacked equipment besides the centre is in a poor state and I was not seeing any results. But I can"t accept that my child is like this so for the past two years, whenever I hear that there is a prophet or a pastor who works miracles, I just send my daughter there in case she will be healed for me. She"s all that I have. *(A verbatim expression of a parent).*

Another parent said that:

> Madam, I treat my child at home o. my mother is a retired midwife so she helps me to manage my daughter when she is sick. We only go to the hospital when the sickness becomes worse. *(A verbatim expression of a parent).*

This finding is consistent with what researchers have found out, that many parents of children with disabilities in developing countries believe that their child"s disabilities are the result of traditional or spiritual causes, rather than biomedical or a combination of biomedical and traditional causes (Croot et al., 2008; Daudji et al., 2011; Morgan & Tan, 2011). In a study conducted by Danesco (1997), the findings were that parents who adhere to the biomedical cause of their child"s disability are more likely to seek the services of medical practitioners whereas, those who believe that the cause of disability is related to traditional or spiritual phenomena are more likely to seek the services of traditional healers or spiritual practitioners. Some parents stated that their response to their children‟s healthcare depends on the severity of the sickness.

A parent expressed her view that:

> As for me, the severity of the sickness will determine whether I should act quickly or delay to see if the child will calm down. If he has a cold, it‟s not an emergency or Madam? *(A verbatim expression of a parent).*

In the Ember & Ember (2004) study, it was found that individuals perceived their illness to be either mild or not for medical treatment, which prevented them from seeking healthcare treatment. This implies that, people might select different forms of treatments and medications to curb the situation depending on the severity of the illness and the clinical manifestations they present.

### 5.1.3 Utilization of healthcare services

From the data analysis, it was found that some parents rely most often on drug store medication for the treatment of their children‟s sicknesses. However, some of the parents were found to have a strong belief in herbalists and spiritualists. An expression of a parent was that:

> To be frank with you Madam, I normally don‟t take my child to hospital/clinic. I take her to the herbalist for treatment because all this while, he has been taking care for her. *(A verbatim expression of a parent).*

Andin (2008) and White (2015) have asserted that, health beliefs have been described as holistic in Africa, where many families and communities hold multiple beliefs, consisting of medical and traditional and supernatural belief system explanations and treatment of diseases.

## 5.2 Factors that influence the behaviours of parents who have children with disabilities

Health care seeking behaviours can be influenced by the socio-cultural factors, and the availability and accessibility of health services. Based on the interplay of these determinants, healthcare seeking behaviour is a complex outcome of many factors operating at individual, family and community level.

### 5.2.1 Availability and accessibility to healthcare services

Availability and accessibility to healthcare services was one of the themes deduced from participants‟ responses on factors that influence the behaviour of parents with disability. As part of the study findings, some parents disclosed that they choose a particular service due to the delay factor, and also in order not to draw attention to themselves.

From the results, one parent said that:

> At the drug store, I will be attended to quickly and I don‟t need to go with my son so no one will know that I have such a child. As for the hospital, I have to take him with me for all to get to know that my child is suffering from such disability. *(A verbatim expression from a parent).*

This may be due to the fact that, securing appropriate services can prove to be a stressful responsibility for parents. This finding agrees to the assertion made by Jackson (2004) that, to acquire the necessary services as a parent for one‟s disabled child is a very confusing and frustrating process.

### 5.2.2 Socio-cultural factors

In addressing the question about the factors that influence parents‟ behaviour in seeking healthcare for their children with disability, socio-cultural factors were identified. Research emphasizes the significant role of family, friends and entire community in supporting parents of children with disability in order to alleviate stress and difficulty they experience (Aldersey, 2012; Gyekye, 2003). However, it was evident from the findings that, some parents have been neglected by their own families due to the fact that they have given birth to disabled children.

As it was disclosed by one of the respondents:

> Hmmm…Madam (Sobbing), our family members don‟t want to come anywhere near us. They don‟t help us in any way. They say we are cursed because there is no such child in the family. They don‟t want to have anything to do with us. *(A verbatim expression of a parent).*

This is consistent to the research reports that, parents of children with disability experience enormous burden as a result of the limited support they receive from their family and the community (Aldersey, 2012; Boyd-Franklin, 2003; Gyekye, 2003). They argue that the communal nature of the African family which provides support for individual members within the families in times of stress seems to be eroding as many community and extended family members no longer share in the problems of other members.

### 5.2.3 Stigmatization

The findings of the study revealed that most parents are apprehensive about stigmatization or being ridiculed by the public as a result of their children‟s disabilities. These negative attitudes of society constitute culture disrespect for persons with disabilities.

As some parents shared their ordeal that:

> Our community I will say has added to my pain and my child‟s difficulty. They have ridiculed me a lot. I must testify that I nearly committed suicide last year had it not been for the timely intervention of my friend. I regret for trying that but I was frustrated and I had no one to talk to at that time.*(A verbatim expression of a parent).*

Thwala (2004) states that being culturally disabled is seen as different from the normal being as a result disabled people are treated as a weaker social beings. They are discriminated, ridiculed and even not considered in the community, why then choose people to represent the community somewhere they are not considered. This however supports the study findings gathered from the interview that parents are stigmatized and ridiculed to the point that some had to move from the place where they were living to another place.

Contrary to this finding, it was revealed that few parents receive some form of encouragement and support from their own family though the partner‟s family have deserted them. A study conducted by Gona, Mung‟ala-Odera, Newton, and Hartley (2010) revealed that, families of children with disabilities felt excluded from the society due to a shortage of services and negative attitudes.

## 5.3 Strategies that can be adopted to improve on the healthcare seeking behaviours of parents who have children with disabilities

Parents and their children with disabilities experience challenges that differ from those experienced by parents of typically developing children (Woodman, 2014). Therefore, parents with these children who are suffering from disabilities need to be supported in order to carry out this tedious task of caring for the child. These supports are referred to as the strategies that are employed to improve healthcare seeking behaviours of parents of children with disabilities.

### 5.3.1 Acceptance by society

From the study results, some parents noted that the community can help complement their effort in seeking healthcare for their children by first accepting and welcoming them into the community. They entreat the community to desist from the negative attitude of ridiculing and stigmatization and welcome them in that larger family.

One parent stated that:

> Members of the community should be welcoming so that we the parents who have children with disabilities would not feel embarrassed to take our children to public places especially the hospital. This will go a long way to improve healthcare seeking behaviours. *(A verbatim expression of a parent).*

Similarly, Green (2003) found that parents of children with disabilities suffer high levels of stigma from society. Avoke (2002) attributes these negative attitudes to the cultural and spiritual beliefs associated with disability in Ghana. Therefore, parents together with their children feel isolated from society because of negative comments and stares from people that characterize such attitude.

### 5.3.2 Expansion of resources

The significance of parents‟ finances to the care of their children and the need for financial support was evident in their response. The interview results revealed that parents of children with disability have financial problems. Some of the parents commented that they should be given some financial assistance and other facilities to help manage their children‟s conditions.

One parent had this to say:

> I have heard that in some countries, children with disabilities are given monthly stipends to help with their upkeep. The Government of Ghana can adapt this policy so that we can have some support to care for our children‟s needs including their healthcare. In fact, I am suffering in taking care of my child‟s health needs. *(A verbatim expression of a parent).*

These responses were in agreement with Dobson et al. (2001) findings where parents accounted that, having a child with disability can dig deeper into the pocket of the parent. Pisula (2007) also in his assertion said that, the nature of the daily care giving activities, employment, and financial challenges, which they are often not prepared for, overwhelmed the parents of children with disability. Undoubtedly, raising a child with disability can be more expensive than raising a typical child. This is because parents may have to spend on the child‟s medication, care giving services, and supplies such as diapers, wheelchair, and so on. Most parents complained that they do not have enough money to provide the child with these necessities.

### 5.3.3 Training of health professionals

On the theme „training of health professionals", some of the parents emphasized that the training for parents of children with disability and health professionals should be introduced and/or intensified in order to improve coping strategies especially as parents. A parent said that:

> Parents should be provided with a special workshops or in-service training sessions on how to give holistic care. I am saying this because we parents spend much time on our children in the house. *(A verbatim expression of a parent).*

This is supported by the assertion that, one of the most promising approaches for supporting these parents is Parent Management Training (Patterson et al., 1982).

### 5.3.4 Support for parents

The last theme identified during the data analysis regarding strategies that help improve the healthcare seeking behaviour of parents of children with disability is that of parental support system. From the study findings, some parents suggested some funds could be allocated to them in support of these children. This is evident in one of the parental expressions:

> I am pleading that there should be some funds allocated to support parents who have children with disabilities because we spend a lot. My son cannot do anything by himself. He still wears diapers. *(A verbatim expression of a parent).*

Parents of children with disabilities in their response described a life of hard work and exhaustion in caring for their children which demands serious attention and support. This is confirmed by several studies by Corden et al., (2002) & Sloper, (2001) which noted that, families especially parents go through financial struggles during illness trajectory of their children. Having a disabled child often leads to extra expenditure (for example in areas such as travel, provision of special aids such as hearing aid, wheel chair and so on and catering for a special diets where necessary) at a time when family incomes are depreciating.

# CHAPTER SIX

# SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

## 6.0 Introduction

This chapter presents the summary of findings, conclusions, and recommendations.

## 6.1 Summary of findings

This study focused on finding out healthcare seeking behaviours of parents who have children with disabilities in the University Practice Basic Inclusive School, South Campus and Rev. Fr. John Memorial School, both in the Effutu Municipality of the Central Region of Ghana. A qualitative approach was adopted for the study. A sample size of 10 parents was involved in the study through the use of purposive sampling. The researcher used an interview guide as the primary tool for collecting data. The interview guide was employed to collect qualitative data, and the data were thematically analysed.

### 6.1.1 Main findings of the study

The results of the study revealed the following:

- For research question one that focused on healthcare seeking behaviours of parents who have children with disabilities, the results were that: most parents tend to shop for remedies such as going to herbalists or spiritualists to receive cure for their children with disabilities whenever they fall sick. The results again revealed that parents preferred buying medications from drug stores to cure their children and the hospital or clinic was the last resort of most of the parents especially when the child‟s ailment worsens.

- For research question two that focused on factors that influence the behaviours of parents who have children with disabilities, the results were that: some parents have been ridiculed by their own families due to the fact that they have given birth to a child with disability. Again, the results of the study revealed that most parents are apprehensive about stigmatization or being ridiculed by members of their communities as a result of their children"s disabilities. It was revealed that some parents choose a particular service due to how quick they could have solutions from those services. As a result, parents were found to rely most often on over the counter medications for the treatment of their children"s sicknesses. Most of the parents stated that availability and accessibly to healthcare services contributed to their healthcare seeking behaviours as they sometimes had to be referred to health facilities outside Winneba for services that are not available in the Effutu Municipality.
- Finally, for research question three that focused on strategies can be adapted to improve on the healthcare seeking behaviours of parents who have children with disabilities, the results were that: some parents required community members to welcome and accept their children with disabilities as they are and not to be treated differently. The results further revealed that parents of children with disabilities have financial problems and requested that government should allocate some funds to them to support them to cater for their children with disabilities. Again, some parents proposed that healthcare professionals should be given special training on disability care in order to handle persons with disabilities, especially children when they fall sick. Finally the results also revealed that there should be an expansion in resources

such as disability assessment units where persons with disabilities to visit for all their healthcare needs and would be attended to.

## 6.2 Conclusions

This study concluded that parents who have children with disabilities had certain healthcare seeking behaviours such as shopping for remedies through herbalists and spiritualists, buying over the counter drugs and seeing the hospital as their last resort. Also, the study concluded that factors such as availability and accessibility to healthcare services, socio-cultural factors such as religious beliefs and cultural practices as well as stigmatization affect parents who have children with disabilities in seeking healthcare for their children with disabilities. Finally, the study concluded that strategies to support parents who have children with disabilities included acceptance by society, support for parents, expansion of resources and training of healthcare professionals.

## 6.3 Recommendations

Based on the findings of the study, it is recommended that:

1. Government of Ghana through the appropriate agencies such as the Social Welfare Department and the Ministry of Gender, Children and Social Protection should sensitize parents who have children with disabilities on the need to make the clinic/hospital their first point of call whenever their children with disabilities are sick to prevent further complications.
2. Advocacy and support groups should be involved in embarking on anti-stigma programs to educate the public on the causes of disability, experiences of family members and the need to show love and concern for families of children with disabilities. This will help to eradicate stigma and

discrimination often levied against parents and their children who have disabilities. Also, there should be adequate healthcare facilities in the municipality to serve the healthcare needs of children with disabilities.

3. The Ministry of Health (MoH) should ensure that all health professional have adequate knowledge about disability, and also train specialists in disability care. The study again recommends that, health professionals at the various health facilities give priority to children with disabilities at all Out Patient Departments (OPDs) whenever they visit the facility for treatment or management.

### 6.4 Implications for further research

This study explored healthcare seeking behaviours of parents who have children with disabilities in the Effutu Municipality. It is suggested that a further study be conducted on the coping strategies normally employed by parents who have children disabilities.

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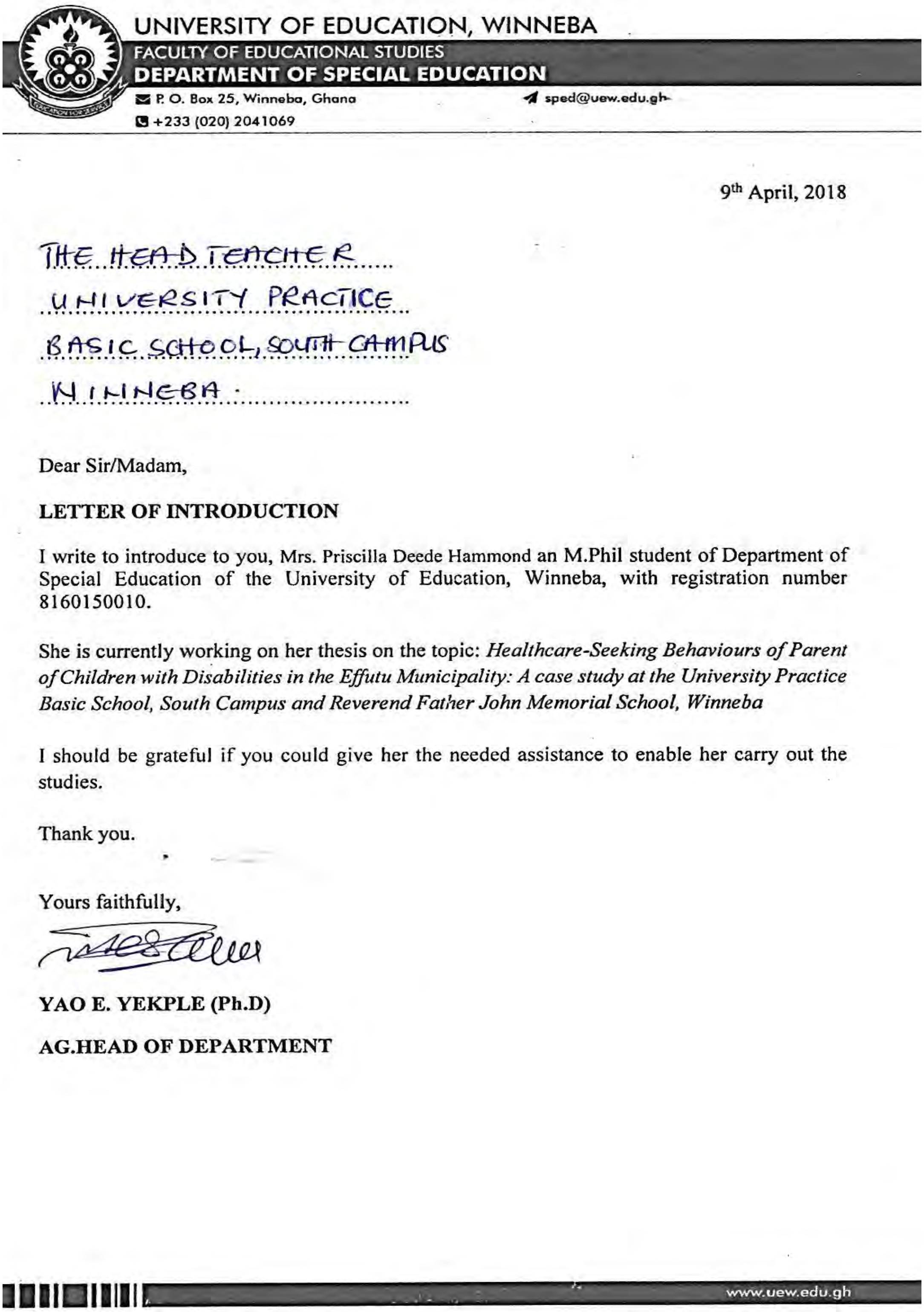
# APPENDICES

## APPENDIX A

## LETTER OF INTRODUCTION 1



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9th April, 2018

THE HEAD TEACHER
UNIVERSITY PRACTICE
BASIC SCHOOL, SOUTH CAMPUS
WINNEBA.

Dear Sir/Madam,

**LETTER OF INTRODUCTION**

I write to introduce to you, Mrs. Priscilla Deede Hammond an M.Phil student of Department of Special Education of the University of Education, Winneba, with registration number 8160150010.

She is currently working on her thesis on the topic: *Healthcare-Seeking Behaviours of Parent of Children with Disabilities in the Effutu Municipality: A case study at the University Practice Basic School, South Campus and Reverend Father John Memorial School, Winneba*

I should be grateful if you could give her the needed assistance to enable her carry out the studies.

Thank you.

Yours faithfully,

**YAO E. YEKPLE (Ph.D)**

**AG.HEAD OF DEPARTMENT**

# APPENDIX B

## LETTER OF INTRODUCTION 2

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9th April, 2018

THE HEADTEACHER
REVEREND FATHER JOHN
MEMORIAL SCHOOL,
WINNEBA

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Thank you.

Yours faithfully,

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**AG.HEAD OF DEPARTMENT**

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# APPENDIX C

# INTERVIEW GUIDE FOR PARENTS

This interview is designed to solicit the behaviours of parents in seeking healthcare for their children with disabilities in the Effutu Municipality. The following research questions have been chosen to assist the researcher to delve into the healthcare seeking behaviours of parents who have children with disabilities. You are kindly requested to provide answers to enable the researcher contribute to the knowledge in the field of study. Please be assured that your responses would be treated with utmost confidentiality.

**Demographic information of respondents**

1. How old are you? Range 21-30years, 31-40years, 41-50years, 51-60years, Above 60years
2. What is your level of education?
3. What is your occupation?
4. What is your marital status?
5. How many children do you have?

**Research question 1:**

How do parents behave in seeking healthcare for their children with disabilities?

1. Which of your children is suffering from disability?
2. What kind of disability does he/she have?
3. At what age was he/she first diagnosed?
4. What do you think might have caused his/her disability?
5. How often does your child fall sick?
6. Where do you do seek your child‟s healthcare when he/she is sick?

7. How do you respond to your child"s health needs especially when they are sick?
8. Which home remedies do you give him/her before sending him/her for further treatment?

**Research question 2:**

Which factors influence how parents of children with disabilities behave in seeking healthcare for their children?

1. Where do you access healthcare services for your child when he/she is sick?
2. Why do you choose such intervention for him/her?
3. How far is your house to the nearest health facility?
4. How does your spouse support you in seeking healthcare for your child?
5. In what ways do your family members help in caring for your sick child?
6. How do members of your community behave towards you due to your child"s disability?
7. How do you feel for having a child with disabilities?
8. How are you treated by health professionals when you send him/her to the hospital?

**Research question 3:**

What strategies can be used to improve healthcare seeking behaviours of parents who have children with disabilities?

1. What can you as a parent do to improve on your healthcare behaviour towards your child?
2. What should your family members do to improve your healthcare seeking behaviours?
3. What role can community members play to help you improve on your healthcare seeking behaviour?
4. What should health professionals in the Effutu Municipality do to improve your healthcare seeking behaviour?
5. What measures should the Effutu Municipal Directorate put in place to help parents who have children with disabilities to improve their healthcare seeking behaviours?
6. What do you think can be done to help you in carrying out this herculean task?