

SCHOOL OF PUBLIC HEALTH
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA



ACCESS TO HEALTHCARE SERVICES AMONG CHILDREN WITH CEREBRAL
PALSY IN THE GREATER ACCRA REGION OF GHANA

BY

NATHANIEL LARBI ANDAH

(10883785)

THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON
IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF MSc
APPLIED HEALTH SCIENCE DEGREE

OCTOBER, 2020

DEDICATION

I dedicate this research work to my father Prof. Robert Kwei Anlah for the encouragement, love, and support he provided for me.

ACKNOWLEDGMENT

My first gratitude goes to the almighty God for granting me the grace and strength to finish up this study. I owe an appreciation to my supervisor Dr. Benedict Wabson who patiently guided me to the completion of this thesis. I appreciate all his genuine and constructive criticisms and recommendations based on his rich experience earned from many years of lecturing and research.

My special thanks go to my research assistants and any other person who contributed to the success of the thesis and the participants who facilitated their time to take part in this research.

My very special thanks go to my father Prof. Robert Kwei Andah for the encouragement and loving environment he provided for me to pursue this course.

| | |
|--|-----------|
| 2.2. Overview of Disability | 12 |
| 2.3 Access to Health Care | 15 |
| 2.4. Knowledge on National Health Policy in Ghana | 16 |
| 2.5. Perception of National Health Policy | 20 |
| 2.6. Parental factors that influence access to healthcare services | 22 |
| 2.7. Healthcare factors that influence access to healthcare services | 28 |
| 2.8 Interventions to enable access to healthcare services | 33 |
| 2.9. Summary of chapter | 34 |
| CHAPTER THREE | 36 |
| METHODS | 36 |
| 3.1. Introduction | 36 |
| 3.2. Study Design | 36 |
| 3.3. Study Area | 37 |
| 3.4. Study Population | 39 |
| 3.5. Selection of study participants | 39 |
| 3.6. Data Collection Technique | 40 |
| 3.7. Quality Control | 41 |
| 3.8 Data Collection Tools | 42 |
| 3.9 Pre-Testing of Tools | 42 |
| 3.10. Inclusion Criteria | 42 |

| | |
|---|----|
| 4.4 Perception on the implementation of the National Health Policy in Ghana | 52 |
| 4.4.1. Ineffectiveness of Persons with Disability Act | 52 |
| 4.4.2. Less health coverage by the National Health Insurance Scheme | 54 |
| 4.5. Parental Factors | 55 |
| 4.5.1. Knowledge of disability | 56 |
| 4.5.2. Perception of disability (CP) | 61 |
| 4.5.3. Financial burden on a child's health care | 63 |
| 4.5.4. Transportation | 65 |
| 4.5.5. Satisfaction | 69 |
| 4.6 Identification of health service needs (health care factors) | 72 |
| 4.6.1. Specialized services availability | 72 |
| 4.6.2. Proximity to an available health facility | 73 |
| 4.6.3. Availability of specialist healthcare providers | 74 |
| 4.6.4. Accessibility of building and equipment | 75 |
| 4.6.5. Healthcare providers attitude | 76 |
| CHAPTER FIVE | 78 |
| DISCUSSIONS | 78 |
| 5.1 Knowledge of National Health Policy | 78 |
| 5.2 Perception of implementation of National Health Policy | 79 |
| 5.3 Parental factors | 79 |

| | |
|--|-----|
| 5.4 Healthcare factors..... | 83 |
| CHAPTER SIX..... | 86 |
| CONCLUSION, RECOMMENDATIONS, AND LIMITATIONS..... | 86 |
| 6.1 Summary of Key Findings..... | 86 |
| 6.2 Conclusion..... | 87 |
| REFERENCES..... | 90 |
| APPENDIX I: PARTICIPANT INFORMATION SHEET..... | 103 |
| PARTICIPANTS INFORMATION SHEET..... | 103 |
| APPENDIX II: CONSENT FORM FOR RESPONDENT..... | 107 |
| APPENDIX III: INTERVIEW GUIDE FOR PARENTS /HEALTHCARE PROVIDERS..... | 109 |
| APPENDIX IV: ETHICAL CLEARANCE..... | 110 |

LIST OF FIGURES

| | |
|--|----|
| Figure 1. Conceptual framework- Factors influencing access to healthcare | 6 |
| Figure 2. Map showing health districts in Greater Accra | 38 |

LIST OF TABLE

| | |
|--|----|
| Table 1: Dimensions of access to health care services | 15 |
| Table 2: Reasonable accommodation and suggested approaches | 32 |
| Table 3: Socio-Demographic Characteristics of Participants | 48 |

LIST OF ABBREVIATIONS

| | | |
|----------|---|--|
| COVID-19 | - | Novel Coronavirus Disease 2019 |
| CP | - | Cerebral Palsy |
| CRPD | - | Convention on the Right of Persons with Disabilities |
| GAR | - | Greater Accra Region |
| ICF | - | International Classification of Functioning |
| IDs | - | Individual In-depth Interviews |
| KFI | - | Key Informant Interviews |
| MRI | - | Magnetic Resonance Imaging |
| NHIS | - | National Health Insurance Scheme |
| NHP | - | National Health Policy |
| OOP | - | Out of Pocket Payment |
| PWD | - | Persons with Disabilities |
| UHC | - | Universal Health Coverage |
| UNICEF | - | United Nations Children Fund |
| UNCRPD | - | United Nations Convention on the Rights of Persons with Disabilities |
| UNICEF | - | United Nations International Children's Emergency Fund |
| WHO | - | World Health Organization |

OPERATIONAL DEFINITIONS

- Access:** The ability of an individual to use his or her personal health services to achieve the best possible health outcome
- Healthcare:** Ability to take important medical procedures to improve well-being.
- Parental factor:** Individual factors that influence access to healthcare services for children with cerebral palsy
- Healthcare factors:** Factors from health facilities that influence access to healthcare services for children with cerebral

ABSTRACT

Background: Children with cerebral palsy (CP) have quite a lot of challenges (transportation, discrimination, financial constraints) in accessing health care than those without disabilities. Providing healthcare support services for persons with disabilities (Cerebral Palsy) has been captured in international instruments like the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) and the Persons with Disability Act (Act 715) of Ghana.

Methods: This study used a qualitative cross-sectional design employing phenomenology to identify factors that influence access to healthcare services for children with cerebral palsy in the Greater Accra Region (GAR) of Ghana. A total of fifteen (15) participants including parents of children with cerebral palsy and health care providers to children with cerebral palsy in the Greater Accra Region (GAR) were recruited in this study. Ten in-depth interviews (IDIs) were conducted among parents of children with cerebral palsy and 5 key informant interviews (KIIs) were conducted among healthcare providers during the study. The data collected were transcribed, coded, and thematically analyzed to generate themes with the aid of Nvivo version 12.0.

Results: The majority of the respondents have knowledge of the National Health Policy in Ghana, some of them believed the implementation of the National Health Policy is ineffective. The majority of the respondents were discriminated against and stigmatized both in public transport and hospitals. The study revealed that income, distance to a health facility, knowledge of disability, transportation cost, and satisfaction are some of the individual factors that influence access to healthcare services for children with cerebral palsy (CP). The study also showed that healthcare factors such as availability of specialized services, the attitude of health professionals,

the physical environment of hospitals, and the availability of rehabilitation specialists influence parent's access to healthcare services for their children with cerebral palsy.

Conclusion: Findings from the study revealed the challenges related to access to healthcare services for children with cerebral palsy. Improving access to healthcare services would involve a multi-sectoral approach and a cautious effort on the part of the government, private hospital owners, and all relevant stakeholders involved in the care of children with cerebral palsy.

CHAPTER ONE

INTRODUCTION

1.1. Background

Health is a state of being physically fit, mentally sound, and socially feeling well and not the absence of disease (WHO, 1948). Research has shown that good health is a requirement for active contribution to a wide variety of activities including education. According to Box, Sar, & Soyak, (2016) health care services can be categorized into four groups; curative care, preventive care, health promotion services, and rehabilitative care. Curative health care services include diagnosis-treatment processes after symptoms of disease or illness have occurred (Box et al., 2016). Preventive health care services include health education, food security that improve nutritional status and promote healthy eating habits, immunization, family planning, and environmental intervention that prevent health problems caused by the physical, biological, and social environment and protection through drugs and serum (Box et al., 2016). According to Juran and Ergin, (2018) health promotion services include promoting breastfeeding, child and family nutrition, physical activity (exercise), smoking cessation programs, stress management, and injury prevention. Rehabilitative healthcare services aimed at restoring an individual with disabilities in gaining back his or her optimum level of functionality to be useful to themselves and the society at large (WHO, 2015).

The World Disability report shows that approximately 15% of the global population are people with disabilities making them the largest minority group in the world (United Nations, 2006). WHO estimated that nearly 3% of the global population has cerebral palsy (WHO, 2015).

People who have experienced CP are disadvantaged in several settings than persons who experience physical or sensory impairments (Vickerman, 2012). Thirty percent of persons with cerebral palsy have some form of physical disabilities, twenty percent have mental health problems and hearing impairment whilst about ten percent have vision impairment than individuals in the general population (Dzuleto-kuntz et al., 2019; Bakr, 2016).

According to Janak-hawlat, (2015) persons with CP experience discrimination in healthcare than the general population. The Convention on the Right of Persons with Disabilities (CRPD) affirms that persons with disabilities have the right to achieve their highest standard of health care, without any discrimination or whatsoever (UN General Assembly, 2007). Access to healthcare is a development issue, as well as a question of the realization of rights. A significant focus of Sustainable Development Goal 3 "Good Health and Well-being" is to advance access to healthcare services for All through the behavior accomplishment of Universal Health Coverage (UHC) (Smile & Azets, 2010). UHC means that all individuals and communities can use the promotive, preventive, curative, rehabilitative, and palliative health services they need while also meaning that the use of these services does not expose the user to monetary problems (WHO, 2011). Despite this, children with cerebral palsy experience financial, structural, and social problems in accessing healthcare services (Cristina & Candidate, 2013). According to WHO (2015) children with CP usually don't benefit from health promotion and prevention programs because they are scarcely targeted. Children with CP continually face challenges as they often lack health insurance coverage for specialized rehabilitation services and assistive devices.

1.1. Problem Statement

Persons who live with some form of disability are estimated to be 15% of the world population and those, between 110 and 190 million have difficulties in functioning (WHO, 2011). Out of the estimated 15% prevalence, 150 million are particularly children with cerebral palsy. The prevalence of CP in Western developed countries has been estimated to be approximately 2 -2.5 per 1,000 children (Oukosa, Joseph, Dagnais, & Shovel, 2013). Despite concerns of underreporting, this prevalence has been suggested to be even higher in developing countries throughout Africa (Donald, Sarnia, Kakoozi- Mweziye, & Bearden, 2014). Ghana records 1.1% of children with cerebral palsy among which Volta Region has the highest prevalence of 0.7%, indicating that children with cerebral palsy are among the largest considered minority group in the country (United Nations, 2006). Ideally, children with disabilities should have full access to essential and appropriate healthcare services without experiencing any difficulties. Also, children with disabilities are supposed to have free access to general and specialized medical care, rehabilitative operation treatment, and periodic screening to detect, prevent, and manage their disability.

However, the health care needs of children with cerebral palsy are poor, particularly in low- and middle-income countries. In Africa, parents of children with CP experience social isolation from only, friends, and community members, discrimination from peers, transportation problem, a social challenge because of unemployment (Singogo et al., 2015). Aside from these challenges, parents of children with CP also experience challenges with the health care system including lack of provision of assistive devices, attitudes of health care professionals, and high cost of healthcare services (Singogo et al., 2015). In Ghana, parents of children with CP also face the challenges in accessing health facilities, these are due to inaccessible environment,

distance to a health facility, transportation, discriminatory attitudes of health workers, neglect, stigmatization, and inadequate healthcare services (WHO, 2011; Tait, Bagri, Dams, 2017; Ojoku, Akpo, Gyani, & Mprah, 2018). Anby et al., (2013) also confirmed that attitudes, physical environment, transportation, policies, lack of support are barriers to healthcare services for children with CP. There is, therefore the need to assess the knowledge of parents on National Health Policy in Ghana, the perception of parents on the implementation of National Health Policy in Ghana, identify parental factors and healthcare factors that influence access to healthcare services for children with CP.

This study is therefore designed to employ qualitative design using phenomenology to identify the factors that influence access to healthcare services for children with cerebral palsy and to contribute new and important information to the body of knowledge.

1.3. Justification

The purpose of the study is to identify factors that influence access to healthcare services for children with CP. Children with CP have quite a lot of challenges in accessing health care than one without disabilities. In most cases, the problem related to access to healthcare services is one rampant among people with the poorest health and severe disabilities (Drainon et al., 2006). Primary health care services like prevention, health screening, early intervention, curative, and management are provided in most health facilities. However, children with cerebral palsy receive fewer primary healthcare services and experience health inequalities than children without disabilities. Research indicates that children with cerebral palsy also exhibit several secondary disorders such as gastrointestinal dysmotility, resulting in dysphagia, oesophageal reflux, gastric emptying disorders.

In Ghana, several kinds of research have been carried out on disabilities that have a revealing fact. For instance, the National Population and Housing Census 2010 report, shows that children with CP encounter barriers and challenges throughout their lives than those without disabilities.

There is, therefore, the need to assess the knowledge of parents on national health policy in Ghana, the perception of parents on the implementation of national health policy in Ghana, identify parental factors and healthcare factors that influence access to healthcare services for children with cerebral palsy. Findings from this study will inform stakeholders (policymakers and the Ministry of Health) on the need to develop strategic plans and programs that will foster and enhance access to healthcare services that meet the overall health care needs of children with cerebral palsy.

1.4. Conceptual Framework

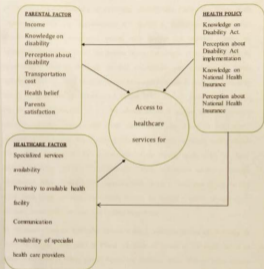


Figure 1. Conceptual framework- Factors influencing access to healthcare

Adapted from the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2011).

The conceptual framework as shown in figure 1 of this study is analyzed based on an adaptation of the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2011). The multidimensional ICF framework conceptualizes functioning and disability across four interconnected domains: body functions and structures, activities and participation, environmental factors, and personal factors. The domains of the ICF emphasize the biopsychosocial nature of functioning, providing an alternative way of viewing and treating disability (WHO, 2011) and forming a valuable framework for access to health care services for children and youth with CP (Rosenbaum & Stewart, 2004). The ICF framework was adapted from the biopsychosocial point of view. The adapted framework suggests factors that influence access to healthcare services among children with cerebral palsy. Access to health care is influenced by the personal factors including knowledge of parents on national health policy in Ghana, their perception of the implementation of the national health policy in Ghana. Environmental factors such as attitudes of health workers, stigmatization, physical environment, transportation, policies, among others influences parents' access to health care services for their wards. These factors may directly or indirectly influence the decision of parents to either access healthcare service of their children with Cerebral Palsy or not.

The framework shows the relationship between access to healthcare services and knowledge of parents on national health policy in Ghana, perception of parents on the implementation of national health policy in Ghana, parental factors, and healthcare factors. Parental factors such as faith beliefs, educational level, income, age, and occupation have been noted to influence access to healthcare services in both developed and developing countries. The influence of education on access to healthcare services can be argued in two ways. On one hand, parents with education may not know the existing national health policy in Ghana hence is less likely to

access free healthcare services for their wards with disabilities. However, parents with higher education may be aware of the national health policy hence are more likely to access free healthcare services for their wards as compared to parents with no education.

Age can be seen as an accumulation of experience with healthcare providers. Older parents may show weakness in physical strength and may not be able to travel long distances to access healthcare service for their wards with disabilities hence may be less likely to access healthcare services for their children with cerebral palsy. However, younger parents can be seen to be more energetic and may have the physical strength to travel long distances to access healthcare services hence younger parents may be more likely to access healthcare services for their wards with disabilities than older parents.

Income can have a direct influence on access to healthcare services. Parents with higher incomes are more likely to access specialized healthcare services as compared to parents with lower incomes. The occupation of parents can also have a direct influence on access to healthcare services as parents with a tight schedule of work are less likely to frequently access healthcare services for their children with cerebral palsy even though they may earn a higher income as compared to parents with no tight schedule of work who are more likely to frequently access healthcare services for their children with CP.

Parents who are satisfied with the cost of medical service, waiting time for treatment, and quality of services of a health facility are more likely to frequently access healthcare services for their children with intellectual disabilities than parents who are not satisfied with a health service of a health facility.

Other factors such as specialist care availability, proximity to an available health facility, communication, accessibility of healthcare services covered by the national health insurance

scheme, availability of specialist health care providers, accessibility of physical building and equipment, the attitude of healthcare providers, and cost of service may have a direct influence on access to healthcare service. Parents are more likely to access healthcare facilities that are closer and provide specialized care services than far ones. Also, communication is key in healthcare service delivery. However, parents who may experience communication barriers in a health center are less likely to access healthcare services for their children with cerebral palsy in that health facility. Parents are more likely to access health facility that accepts national health insurance than health facilities that do not. The availability of specialists in a healthcare facility may also encourage parents to access healthcare services for their children with cerebral palsy. Attitudes of health providers and inaccessible health facilities may also influence the health-seeking behavior of parents for their wards.

Health Policy may also directly influence parental factors. Parents who have knowledge of the Persons with Disability Act and the National Health Policy of Ghana are more likely to frequently access healthcare services for their wards with CP than parents who are not informed on the Persons with Disability Act and the National Health Policy of Ghana. Also, Health care factors such as specialized services availability, communication, rehabilitation specialist availability, accessibility of building and equipment, and attitudes of healthcare providers may be influenced directly by health policy. Healthcare providers who have knowledge of the Persons with Disabilities Act are more likely to have a positive attitude and good communication skills with children with CP. Moreover, health facilities are more likely to ensure a friendly environment of accessible equipment for children with CP than healthcare facilities that do not know the persons with Disabilities Act.

1.5. Research Questions

Informed by the conceptual framework of the study, the following research questions and objectives were pursued.

1. What knowledge do parents of children with cerebral palsy have about the National Health Policy in Ghana?
2. What is the perception of parents of children with cerebral palsy on the implementation of the National Health Policy in Ghana?
3. How do parental factors influence access to healthcare services for children with cerebral palsy?
4. How do healthcare factors influence access to healthcare services for children with cerebral palsy?

1.6. General Objectives

The study aimed to find out the factors that influence access to healthcare services for children with cerebral palsy in the Greater Accra Region of Ghana.

1.7. Specific Objectives

The specific objectives were to:

1. Assess the knowledge of parents of children with cerebral palsy on the National Health Policy in Ghana.
2. Assess the perceptions of parents of children with cerebral palsy on the implementation of the National Health Policy in Ghana.
3. Identify parental factors that influence access to healthcare services for children with cerebral palsy.

4. Identify healthcare factors that influence access to health care services for children with cerebral palsy.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

There is scant data on the prevalence of children with cerebral palsy. In this chapter, data will be accessed on the population other than children with cerebral palsy. This chapter is separated into six sections: an overview of disability in children, access to health care, health policy in Ghana, demand factors that influence access to healthcare services, supply factors that influence access to healthcare services, patient satisfaction factors that influence access to healthcare.

2.2. Overview of Disability

Disability is a permanent or temporal condition that every human being is exposed to at any point in life (WHO & World Bank, 2011). Disability is not a fixed social nor a biological construct; rather, it is based on the interactions that go on among health, environmental, and personal factors (WHO & World Bank, 2011). This means that disability is the consequence of an impairment that interacts with negative environmental factors including attitudinal, unfavorable policies, physical barriers among others. Disability can occur at three levels; these are activity limitations such as inability to move around; impairment in the body such as cardiovascular disease; a restriction in participation such as exclusion from work as a result of discrimination (Palmer & Hasky, 2012).

People with disabilities include those who are sensory impaired (affecting sight and hearing), neurologically impaired (affecting a person's ability to control movement), physically impaired (affecting mobility and a person's ability to use their upper or lower body. These generally relate

to the musculoskeletal, circulatory, respiratory and nervous systems) and intellectually impaired (these include intellectual and developmental disabilities which can relate to difficulties with thought processes, learning, communicating, remembering information and using it appropriately, making judgements and problem solving), cognitive impaired (affecting a person's thought processes, personality, and memory resulting, for example from an injury to the brain) and psychiatric (affecting a person's emotions, thought processes and behaviour) and those who experience a wide range of health conditions like multiple sclerosis, chronic diseases, mental disorder, old age, hypertension, and HIV/AIDS (UNICEF, 2013). The proportion of physical disabilities globally is 73%, followed by intellectual and psychiatric 17 % and sensory 10% (WHO, 2019).

The 2017 Global Burden of Disease report revealed that worldwide, the overall burden of disability including cerebral palsy has risen by 52% between 1990 and 2017. Most disabling conditions are driven mainly by non-communicable diseases including low back pain, headache disorder, and depressive disorder, which are considered to be the three top causes of disability globally in 2017. According to the 2017 Global Burden of Disease report, disability was found to be higher among females than in males globally. The distribution of disability among regions revealed that the African region reported slightly the highest proportion of people with severe disability at 3.1% while Americans reported 2.6% as the least.

According to the World Health Organization, over 700 million persons are living with disabilities in the world. Ghana as a middle-income country has a population of about thirty-one (31) million, 717,740 are persons with some form of disability (World Population Review, 2021). However, the Ministry of Health estimates that persons with disabilities in Ghana are around 7 to10 %.

In Ghana, persons with disabilities form the greater part of the marginalized group, as a majority lack access to public health, education, and other social services. Persons with disabilities in Ghana are classified among the poorest of the poor and are seen as unproductive and a burden to society as they are considered incapable of contributing positively to national development (Tadzi, Bagri, and Danso, 2017). Also, persons with disabilities are severely stigmatized, discriminated against, and excluded from all forms of development processes which results in limiting their opportunities to be engaged in public discourse and decision-making (Oyokun, Alapo, Gyareff, and Mprah, 2018). Among the various types of disabilities include cerebral palsy (CP). CP results from brain damage that affects one's ability to control his or her muscles. This can occur before birth, during birth, and after birth within a month. According to the Centers for Disease Control and Prevention, 85% to 90% of CP cases are congenital. Risk factors for congenital CP include infections during pregnancy, jaundice, and kernicterus, premature birth among others (Centers for Diseases Control and Prevention, 2019). According to the Cerebral Palsy Alliance (2018) children with cerebral palsy (CP) shows signs and symptoms like swallowing difficulties, poor muscle spasm, low muscle tone, poor muscle control, reflexes, and posture, drooling, developmental delay, gastrointestinal problems, and not walking by 12-18 months. According to McIntyre et al., (2011) cerebral palsy can be diagnosed through scans such as magnetic resonance imaging (MRI) or computed tomography scan (CT scan) and Hamman-Rich infant neurological assessment. However, treatment is not aimed at curing cerebral palsy (CP) but to manage it. Children with cerebral palsy (CP) can improve their motor skills with alternative therapy, medication, and surgery through a multidisciplinary team such as a neurologist, orthopedic surgeon, developmental pediatricians, physiotherapist, occupational

therapist, nutritionist, respiratory therapists, psychologists to assess ability and behavior and speech and language therapist (Cerebral Palsy Guide, 2020).

1.3 Access to Health Care

Access to health care refers to one's ability to use his or her personal health services to achieve the best possible health outcome (Institute of Medicine, 1993). According to the Agency for Healthcare Research and Quality (2010) access comes with gaining entry into a health care system and finding a health practitioner who can meet the health needs of the patient. Access to health is a term that is normally used to describe factors that influences one's early contact with or use of services. Levesque, Harris, and Russell (2013) presented five dimensions of access to health care which is similar to Penchansky and Thomas's (1981)'s dimensions of access.

The five dimensions are approachability, acceptability, availability, affordability, and appropriateness. Access can be said to be in a continuum. For instance, despite the availability of health care services, there may be other factors that can affect access to it.

Table 1: Dimensions of access to health care services

| Concepts | Operational definitions |
|--------------------------------------|---|
| 1. Approachability/ Accommodation | The extent to which health care services are provided in different ways to meet the health needs of clients irrespective of barriers. |
| 2. Acceptability | The level of conflict existing between client and provider with fixed characteristics including sex, age, race, ethnicity among others. |
| 3. Affordability | The relationship between providers charges and the client's ability to pay for services. Cost of service covered by health insurance and client's ability to pay the amount left. |
| 4. Appropriateness | The ability of health providers to properly use health services, products, and resources for the benefit of |

clients.

3. Availability

Provider's ability to have all the required resources needed to meet the client's health needs.

Source: (Levenson, Harris, & Russell, 2013)

According to WHO (2017) persons with disabilities have the same general healthcare needs as persons without disabilities and therefore need access to health care services.

2.4. Knowledge on National Health Policy in Ghana

According to the World Health Organization, 15% of the world's population lives with some form of disability. The majority of persons with disabilities in every society seem to have lower incomes, complex health conditions, and limited access to healthcare services. It has been estimated worldwide that about 52% of persons with disabilities lack access to healthcare services based on the fact that they are not able to afford it (World Health Organization, 2011).

Providing financial support on healthcare services for persons with disabilities (cerebral palsy) has been captured in international instruments like the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006).

In 2006 Ghana passed the Persons with Disability Act (Act 715) which serves as a legal framework and protection for all persons with disabilities. The Act has the objective of ensuring a constitutional obligation of enacting laws to protect, promote, and defend the rights of the person with disabilities and fulfil an international obligation of Ghana. The Act has about 61 clauses which are clustered into the following sections:

1. Rights of persons with a disability,
2. Employment of persons with a disability,
3. Education of persons with a disability,

4. Transportations,
5. Health-care facilities,
6. Miscellaneous provisions,
7. Establishment and functions of the National Council on Persons with Disability,
8. Administrative and Financial provisions.

Act 715 in Article 4 subsection (1) affirms that no one should discriminate, exploit, or subject a person with disabilities to abusive or degrading treatment. Article 6 also states that owners of public places should make available suitable facilities that are more friendly to and available for use by a person with disabilities. Article (31) in Act 715 emphasized medical treatment for a person with disabilities. It stated that "The Ministry of Health has the constitutional obligation in fulfilling its formulation of health policies to provide general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for a person with a disability". This means that persons with cerebral palsy have the right to free general healthcare services from public health facilities in Ghana. Article (32) also spoke about the need for training health professionals in training institutions. It revealed that "The study of disability and disability-related issues should be included in the curricula by the Ministry of Health in training institutions for health professionals to develop appropriate human resources to provide general and specialized rehabilitation services". This affirms the need to have more trained health professionals that will provide general and therapeutic healthcare services for persons with disabilities in both government and private health facilities.

Also, the Ministry of Health has the mandate in articles (33) & (34) to include education on disability and disability issues in health care programs and to provide periodic screening to detect, prevent and manage disability among children with disabilities.

Persons with Disability Act (2006) Article 3 mandates the State to provide good living conditions in specialised establishments and reduction in discrimination and exploitation against all persons with disabilities. The Persons with Disability Act is consistent with the 1992 Constitution of Ghana, (Articles 29 and 37 (2) (b)) that also serves as a legal framework to equip PWDs to exercise their cultural, economic, civil, social, and political rights on an equal basis with their non-disabled counterparts.

In 2007, Ghana signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) a year after Act 715.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was approved by the UN General Assembly on the 13th December 2006 due to consideration of a worldwide convention that promotes and increases respect for the rights of persons with disabilities (PWDs) by an Ad Hoc Committee (Gyameri, 2015).

The Convention on the Right of Persons with Disabilities (CRPD) is made up of 50 Articles that speak on the civil, political, economic, social, and cultural rights of persons with disabilities (PWDs). The UNCRPD (2006) also shows how countries must realize their responsibilities towards persons with disabilities (PWDs) by improving their lives, reducing discrimination against them, and providing equal opportunities that include financial access to healthcare. Persons with disabilities (PWDs) face a lot of financial constraints that make them unable to access healthcare services.

The World Report on Disability recognizes the need for States (Ghana) to ensure that persons with disabilities (PWDs) receive the same quality and standard of free and affordable healthcare as their non-disabled counterparts (WHO, 2011).

In 2003 the government of Ghana implemented the National Health Insurance Scheme (NHIS) as a social protection policy that improves financial access to quality health services. This policy was established in Ghana by the National Health Insurance Act (Act 652) and the National Health Insurance Regulation, 2004 (L.I. 1809). The NHIS policy was introduced to replace the "cash and carry" system of service delivery which demands the patient to make cash payments before gaining access to health services (Dixon et al., 2013). The health policy is not discriminatory as it covers both poor and vulnerable groups in society including children with CP.

The main aim of the health policy is to reduce health inequalities and make all persons living in Ghana have access to quality health services at an affordable cost that improves health and well-being. According to the National health policy in Ghana, NHIS covers the following:

In-Patient Services: malaria, acute respiratory tract infection, diarrhea disease, skin disease, typhoid fever, dental caries, diabetes mellitus, x-rays, out-patient physiotherapy, medication among others.

Out-Patient Service: general and specialist in-patient care, investigations including laboratory investigations, ultrasound scans, cervical and breast cancer treatment, diagnosis, and complications from other cancers, e.g. anemia or obstruction among others.

Oral Health: pain relief (incision), tooth extraction, dental restoration including simple amalgams, filling, and temporary dressing.

Eye Care Services: refraction, visual fields, scans, cataract removal.

Maternity Care: antenatal care, deliveries, cesarean section, post-natal care.

Emergencies) medical emergencies and surgical emergencies including brain surgery, pediatric emergencies, road traffic accidents, industrial and workplace accidents.

Also, in July 2008 Ghana implemented a free maternal health policy under the National Health Insurance Scheme. The policy gives room for all pregnant women to have free antenatal health checkups throughout pregnancy and at childbirth. However, according to Laura (2019), women with disabilities including cerebral palsy are 30% less likely to receive health-promoting services like breast cancer screening, eye exams, and dental checkups. Laura also asserted in her study that the mortality from breast cancer is highly statistically significant compared to women without disabilities. A past study conducted in California on health care equity revealed that people with disabilities avoid or delay relevant care due to memories of discriminatory attitudes and behaviors from healthcare providers. According to Yaw (2017) persons with cerebral palsy are mostly deprived of access to "freedom" or are compulsorily asked to pay the entire row of a seat for their wheelchair. According to the Americans with Disabilities Act (1990) section 504 of the Rehabilitation Act forbids discrimination based on disability.

1.5. Perception of National Health Policy

Financing healthcare which is one major channel to access healthcare in developing countries has gone through many reforms in Ghana. In healthcare, past reform resulted in the introduction of the national health insurance scheme in 2003. The aim of this is to reduce financial barriers in accessing healthcare by reducing direct payment for services at health facilities. There is a need to assess the perception of people on the National health policy in Ghana. A client and provider perception study conducted by Dedejong and Laar (2012) under the NHIS in two districts in the Northern parts of Ghana showed that there were major complaints by the insured patients relating longer waiting time, verbal abuse, not being physically examined and discriminations

they faced while receiving treatments and drugs. According to Bruce et al., (2008) findings in her study on "The national health insurance scheme: perceptions and experiences of health care providers and clients in two districts in Ghana" showed that insured respondents are not satisfied with the healthcare they received and perceived that they were given poorer quality services and had to wait longer as compared to those making Out of Pocket Payment (OOP). Another study by Kofi, Akande, and Akande (2003) on "The Awareness and Attitude of Practitioners on NHIS in Ikorin" showed that all respondents were aware of the scheme but only a few did not know. Similarly, Okigbenga-Bello (2010) in their assessment of knowledge and perception reported that television and billboard were the main sources of awareness on National Health Insurance (NHIS). However, better-educated individuals can access a diverse source of information, correctly process, and take advantage of benefits than those who are less educated and those without formal education. Those who could not afford to spend more on the healthcare needs of children with cerebral palsy may adopt other coping mechanisms such as alternative care, presenting late at the health facilities, or not receiving care at all (Gopalan & Darsing, 2012).

According to Dabjeog and Laar (2012), NHIS is working, promoting access for the insured, and mobilizing revenue for providers. Their study findings revealed that both insured and uninsured respondents had positive perceptions and were satisfied with the care provided.

Chu-Appiah et al., (2011) also conducted research and found out that Price (including premium and registration fees) convenience and benefits of NHIS are all factors that are significantly associated with enrollment and retention of clients. This finding is in line with other studies (Basam et al., 2007; Chinkanda et al., 2008). Also, it appears that there are delays associated with NHIS cards and distributions. The attitude of healthcare providers was perceived negatively

hence merit attention to improve overall satisfaction with being enrolled. Negative provider's attitudes and interpersonal relationships have been documented in other countries (Kyorougata et al., 2009; Dong et al., 2009). However, providers' attitudes, technical quality of care, and service delivery were perceived positively (Jaha-Appiah et al., 2011). Their findings show that both insured and uninsured households had a positive perception of the technical quality of care. Also, Patients perceive a constant supply of essential drugs as a requirement for the credibility of the scheme and the quality of health care provided (Marudani and Banger 2004).

1.6. Parental factors that influence access to healthcare services

Demand is an economic term that refers to giving up any asset in exchange for desired goods and services (Boo et al., 2016). Parents make a lot of choices that determine whether or not to seek medical care for their children with cerebral palsy. Demand for health care is generally determined by the level of consumption made by an individual who is sick or injured. The consumption level of health care services may be different among individuals as demand factors such as cost of care, income, health belief, education, social norms, quality of services, and insurance coverage can influence health-seeking behavior.

Also, intermediary determinants such as distance to health facilities, care-seeking practices, social supports, age, and access to quality services are likely to shape the health choices of parents (Khairi & Karkoe, 2018). There are two reasons why parents demand healthcare; consumption goods (which allow the consumer to feel better) and investment goods (good health status increases the consumer's quality of life and productivity).

Parent's demand in healthcare is affected by factors such as preference, financing method, physical facilities, health attitudes, and behaviors of healthcare personnel (Boo et al., 2016).

individual preference for preventive health care, dental services, aesthetic services, hair, and skin services also influence the demand for health care.

A study in the Philippines found that income level, insurance coverage, education, belief of mothers, age, and physiological characteristics of households have a significant impact on demand for some type of health services.

income level

The income level of parents does influence their ability to access consistent health care for children with CP. Children with CP from low-income families tend to experience more gaps in health care than children with CP from high-income families (DeVos, Tilston, & Wallace, 2011). There is a higher demand for healthcare services among families with higher income than families with lower income because families with higher income can afford medical bills and the cost of specialized services than families with lower income.

Parents with lower-income status tend to demand fewer healthcare services for their children with cerebral palsy especially with a higher cost of medical drugs and other services like specialized rehabilitation services which are not covered by health insurance. However, demand for healthcare services is much higher among parents with lower income especially when the cost for medical treatment is reduced.

Research has shown that parents of children with CP tend to sell their land and other valuable resources to pay for medical bills. This is in line with preceding studies that revealed that the out-of-pocket expenditure of families with a person with a disability is higher than a family with no disability (WHO, 2011). Physiopla (2020) also asserted that families with a child with a

ability are more prone to depression, suicide, financial problem, relationship challenges, divorce, and bankruptcy.

According to Akira, Gulkley, and Popkin, perceived seriousness of the illness, distance to a health facility, parent's education, and time costs played stronger roles in determining the use of health facilities. The pattern of healthcare utilization is not consistent among individuals as studies have shown that healthcare service utilization patterns are influenced by the direct costs of healthcare services, travel time, and patient's income (Review & Adkaine, 2017).

Health insurance coverage

Health insurance coverage plays a significant role as a demand factor in influencing access to health care services for children with CP. Studies have shown that the greatest recorded barrier to accessing healthcare services for children with cerebral palsy is insurance coverage (Pickard & Agnew, 2015; Volna, Madhavan, Saribanoothi & Peter, 2014).

Financial barriers to health care, among low-income families in the United States, have been reported to be higher than in families with higher income (Davis and Baltesch, 2014; Squires and Anderson, 2015).

Parents who have health insurance coverage for their children with CP tend to have a greater demand for health care services than parents who do not. Despite the lack of health service providers for children with cerebral palsy, parents tend to report a higher level of satisfaction with their child's health insurance coverage (Thomas, Williams & Morrissey, 2016).

Health insurance aids from reducing the net price of health care also increases the family's ability to secure health services, thereby increasing demand in the utilization of healthcare services. Ghana in 2003 introduced the National Health Insurance Scheme (NHIS) that aims at

improving financial access to quality health services. NHIS has covered 40% of the Ghanaian population making up 10.5 million registered people (Wang et al., 2017).

Education

According to Matt (2014) parents with higher education have a better understanding of their children's disability which influences access to health care services. Mothers usually supervise the household as their level of education can influence their health-seeking behavior for any member of the family. A higher level of education may enable a person to recognize the early signs and symptoms of illness, resulting in an increased willingness of the patient to seek early treatment. Parents with higher education tend to spend more on preventive services and less on curative services. However, a study in the Philippines indicated that a mother's education was significant in determining whether or not a sick child was taken to the hospital for treatment. According to Khan and Karkov (2013), illiterate mothers who belong to the lowest wealth quintile have low access and use of health care.

Health belief of parents

The health knowledge and belief of parents influence their efficiency in maintaining personal health for their children with CP through the practice of regular health checkups, personal hygiene, and immunization. The health belief of parents of children with CP is mostly based on superstition which significantly influences their choice of health facilities and access to health care services. Traditionally CP is generally associated with the socio-cultural belief of a curse, misfortune, and punishment from gods (Seale & Aarts, 2010).

Distance to a health facility

Parents of children with CP experience challenges in accessing health facilities due to distance and transportation. Parents with short distances to a health facility are more likely to access healthcare services frequently than parents with long distances to a health facility (Dassah et al., 2018). The indication from the Articles reveals that health care facilities are mostly located in urban centers than in rural areas due to resource constraints. From this, parents of children with cerebral palsy had to travel long distances to access a health facility. Poor road networks in rural areas also amount to the challenges parents of children with cerebral palsy face in accessing health care services. (Dassah et al., 2018). A study conducted by Balkema Healthcare (2019) in Uganda on "The state of healthcare in Uganda" found that patients spoke bitterly about poor sanitation, lack of drugs and equipment, long waiting times, rude behavior of health workers, and poor referrals. This irregular service discourages patients from seeking out professional care, especially in rural areas with longer travel times. Findings from the study indicated that over 1,000 rural Ugandans travel as far as 50 miles to attend a Balkema weeklong medical camp for healthcare.

Perception of disability

The perception of parents about cerebral palsy is another contributing factor that influences the demand for health care. Society perceives that cerebral palsy is a curse and a punishment from ancestors (Batsheer, 2020). According to Duran and Ergin (2018) majority of people often have negative perceptions and stigmatizing attitudes towards children with disabilities and their families. Parents of children with CP have no choice but to cope with insults and rude behaviors from community members while struggling with the challenges of their children with CP. A study conducted in Balkema has shown that parents of children with disabilities do not receive

efficient support from their social relations including families and friends. Stigmatisation and discrimination against parents make them experience emotional distress that influences their demand for healthcare services (Duran and Ergin, 2018). A parent in an interview during qualitative research in the United Kingdom revealed that living and caring for a child with cerebral palsy can harm one's health through an increase in stress and anxiety. It can also affect all aspects of family life, including the decision about work, education, family finances, and social relations. A study on people with epilepsy in the rural part of Ghana revealed that spiritual beliefs surrounding epilepsy influenced health and seeking medical treatment.

satisfaction

Consumer satisfaction plays a significant role in the quality of care reforms and health care delivery. One of the key factors underpinning government health policy is customer satisfaction which is maintained through exclusive health care services resulting in improved satisfaction.

Even though customer satisfaction is important, there is no universally accepted definition for satisfaction because of how it must be measured. Some researchers focus on the quality and the scope of health care services received by patients while others also focus on satisfaction with the health system (Manzoor et al., 2019).

Opinions of patients in recent times have become a gateway for the improvement of the health care delivery system. Patients satisfaction refers to the intrinsic feeling of happiness that a patient experiences while using a health service. This implies that every health provider has the responsibility of taking care of patients. This serves as one of the standards to measure the efficiency and effectiveness of a health facility. The efficiency of a health facility refers to the provision of service delivery and quality care whereas the effectiveness of a health facility refers to the patient's satisfaction. Patient satisfaction is an important measuring stick by which the

Quality of health care service is the measure. However, patients who show dissatisfaction tend to seek health care services from another health facility. Quality of health care service accounts for patient satisfaction especially in terms of waiting time, cost of service, coordination, information, and physician's behavior (Khatib & Karkov, 2018).

Some physicians or doctors in the public health facilities can be very rude, due to the amount of pressure and heavy workload mounted on them by the many patients seeking health care services (Anok-hawlat, 2015). For instance, patients repeated silly questions tend to provoke some physicians to act rudely. A physician's behavior towards patients also amounts to the patient's satisfaction. Many studies showed that patients always expect to have a comfortable and warm interaction with a physician who appears to be technically competent and gives adequate information about the patient's illness (Smide & Aarts, 2016).

7. Healthcare factors that influence access to healthcare services

Key factors such as specialist services, health insurance, available healthcare providers, the physical environment of health facilities, attitudes of healthcare providers, cost of health care services, and communication can influence parents' decisions in accessing healthcare services for their children with cerebral palsy.

Children with CP mostly need lifelong specialized services such as physiotherapy, speech, and cognitive therapy, occupational therapy among others other to be healthy. Physicians play a significant role in the functional attainments and quality of life of persons with cerebral palsy. among the specialist team include doctors, nurses, nutritionists, audiologists, dentists, rehabilitation specialists, ophthalmologists among others. According to Baki (2016) children do not receive muscle strengthening training, manual stretching, massage, neurodevelopmental treatment, conductive education, speech, and language therapy, occupational therapy, and dining

no good body posture, balancing, neck coordination, strong muscle control and can walk unaided. Health facilities with such available specialised services are more likely to positively influence parents' decisions in accessing health care for their children with cerebral palsy. Also, WHO (2017) reported that the minimum number of rehabilitation specialists per 1 million population should be 750. However, research findings from 71 countries around the world revealed that the registered number of rehabilitation specialists is far below the required minimum even in developed countries. Also, the lack of appropriate services for people with cerebral palsy is a significant barrier to health care. For instance, qualitative research in Uttar Pradesh and Tamil Nadu states of India revealed that after the cost, the lack of services in the area was the second most significant barrier to using health facilities (WHO, 2011). According to Awesemi et al., (2011) distance and total cost of healthcare influence the utilisation of both public and private hospitals and not just the availability of specialised services. Another study by Ibrahim et al., (2016) also found that distance from a health service provider, travel time, and waiting time to see a health professional have a strong influence on access to health care.

Health facilities that accept and provides services covered by health insurance are more likely to positively influence parents' decision in accessing health care (Awesemi et al., 2011). Health insurance aside from reducing the net price of health care also increases the family's ability to secure health services, thereby increasing demand for healthcare services for their children with cerebral palsy (Darin and Ergin, 2018). The availability of healthcare providers in a health facility also has a significant influence on people's decisions to access health care. Health care providers such as nurses, doctors, nutritionists, radiologists, dentists, ophthalmologists among others play a significant role in meeting the health needs of PwDs (Darin and Ergin, 2018).

A health facility with an accessible physical environment has a greater demand for health care services for children with disabilities than a health facility with physical barriers. Qualitative research conducted by Turk revealed that women with cerebral palsy have reported difficulties obtaining dental and gynecologic care due to accessibility problems. Health care facilities must be accessible for persons with cerebral palsy who may have physical and sensory impairments. Inadequate access to hospital buildings, consultation rooms, narrow doorways, insufficient restrooms, and inaccessible medical equipment all create barriers to healthcare facilities. For instance, women with mobility difficulties are often unable to access breast and cervical cancer screening because the examination table is not height-adjustable and mammography equipment only accommodates women who can stand. It is therefore important for hospitals to provide reasonable accommodation to facilitate access to health care services (Khatiri and Karkoo, 2018). According to Jarnehali et al., (2020) medical equipment adaptability, unit layout, ramps, elevators, and room features affect patients' access to healthcare. Also, a patient's need for personal space, a hospely welcoming atmosphere, a supportive environment, ramps, and elevators influences access to their healthcare (Douglas & Douglas, 2004). According to Cristina and Candace (2013) out of 256 respondents, 9 (4%) were unable to access the hospital building and 47 (18%) were unable to be transferred from their wheelchair to the examination table.

Attitudes of healthcare providers pose a lot of challenges to PWDs and their families. Parents, as well as their children with CP, experience stigmatization and discrimination in most health facilities thereby making them have difficulty in cooperating with examinations and health procedures (WHO, 2011). Healthcare providers need to be educated concerning the confusion, fear, and frustration that parents of children with cerebral palsy face when they access health care

services. A majority of studies revealed both positive and negative attitudes of health care providers that influence access to health care.

Positive attitudes such as showing kindness, being helpful, and willing to treat and encourage clients was a result of rigorous campaigns that strengthen providers' attentiveness in addressing the health needs of people with disabilities. Some health care providers build a strong rapport with their clients that supported quality health care delivery. Also, a negative attitude such as discrimination and stigmatization from providers posed a major barrier in health care access. For example, some health care providers do not provide that same level of care to clients with disabilities as they would do to clients without disabilities (Smole & Aarts, 2010). Roges et al. (2015) in their study on "Discrimination in healthcare settings is associated with disability in older Adults: Health and Retirement Study, 2008-2012" revealed that 12.6% experienced discrimination infrequently whilst 5.9% experienced discrimination frequently.

The willingness of people to access health care services is influenced by the cost of the services they need. The inability of PWDs to afford the high cost of medical services serves as a challenge to access health care. Despite health insurance coverage, PWDs still find it difficult to access specialized services such as speech and language services, occupational therapy which are very expensive and not covered by health insurance. The cost of transportation in accessing health care is also another big challenge for persons with disabilities (PWDs) as they travel a long distance to access health care (Wang et al., 2017).

The National Center for Health Statistics (2017b) NHIS reported that 10 percent of people between the age of 18 to 64 years in 2015 experienced difficulty in accessing needed medical care as a result of cost. Deucht, K.N, Dwoiatoky, and Biewas (2015) in their research asserted that parents in the rural areas of the United States are reluctant in seeking health care due to

ultural and financial constraints. Communication plays a very important role in addressing the health care needs of children with cerebral palsy. The majority of children with cerebral palsy face a communication problem which serves as a barrier to accurate medical evaluation. Studies have shown that the medical history of children with cerebral palsy is mostly gotten from parents and caregivers. Health care providers are dependent on the verbal or written report of parents or caregivers of children with cerebral palsy.

Table 2 below shows examples of reasonable accommodation and suggested approaches.

Table 2: Reasonable accommodation and suggested approaches

| Accommodations | Suggested approaches |
|---|---|
| Using features of universal design equipment | Height-adjustable examination tables, seated scales, accessible wheelchair diagnostic equipment including mammography equipment |
| Structural modification of facilities | Configuring the layout of clinical examination rooms, installing ramps and grab rails, ensuring barrier-free path from transit to the clinic, widening doorways, installing lifts, modifying washrooms (toilet and urinal), providing adaptable seats for those who cannot stand. |
| Communicating health information in appropriate formats | A health care provider can provide health information in large prints, braille, picture format, audio, or even in the video; speaking clearly and slowly to clients to ensure understanding, providing sign language interpreting services. |
| Using alternative models to deliver health service | Using mobile clinic services, telemedicine, assistance with transportation to a health facility. |

Source (WHO 2011)

3.8 Interventions to enable access to healthcare services

According to Peters et al. (2011), access to healthcare services is the timely use of services according to need. WHO endorsed primary health care in 1978 as a paradigm to reduce inequalities in health thereby enabling universal access to health services (Rasanathan et al. 2010). Interventions aimed at facilitating access to healthcare need to be implemented at the district level, as this is known to constitute the most appropriate geographical situation for primary health care (Ekman et al., 2014; Lawn et al., 2010; Rohde et al., 2010). Among the interventions to enable access to healthcare services to include the following:

- Counseling and provision of consumer information on health services, including their availability and associated costs (Ahmed et al. 2010).
- A range of preventive and curative interventions can be implemented by non-professional health workers through community-based interventions (Haines et al. 2007), which tackle issues related to services location, transport-associated costs and means (geographical accessibility), costs of services (affordability), and treatment availability. As these non-professional health workers are recruited from within the community.
- The National Health Insurance Scheme should be made to cover all specialized rehabilitation services needs by children with cerebral palsy. According to Hardeman et al. (2012), most parents of children with disabilities are poor. The benefits provided by the NHIS give parents of children with disabilities financial access to health services (affordability).
- Provision of essential health service packages for children with disabilities. This should consist mostly of cost-effective services delivered at the lowest echelon of the health system (Khan & Manderson, 2011).

- Provision of integrated outreach services for parents of children with disabilities in the community. This tackles the issue of the location of the health care provider and transport costs on the side of the service receiver. Bringing health care services to the doorstep of parents of children with disabilities saves them travel time and transportation cost Krishna (2012).
- Develop an anti-stigmatization policy to help mitigate the level of stigmatization against persons with disabilities by health workers and community members.

3. Summary of chapter

actors associated with access to healthcare services among children with cerebral palsy were viewed under four headings: knowledge of National Health Policy, Perception on the implementation of the National Health Policy, parental factors, and healthcare factors. The National Health Policy states that there should be free general and specialist medical care, rehabilitative operation treatment, and appropriate assistive devices for a person with a disability, however, it seems children with CP do not get some of these services for free. Also, parents' perception of the National Health Policy influences access to healthcare especially when the NHP is perceived to be ineffective. Moreover, demand for healthcare services is influenced by parental factors such as income, perception about disability, transportation, and health belief. Most parents complain of not having money to pay for medical bills for instance. Furthermore, healthcare factors such as available specialized services, attitudes of healthcare providers, communication, accessible building, and equipment also influence access to healthcare services. For instance, the unfavorable building of some health facilities discourages parents from consulting healthcare services for their wards with special needs. Parent's satisfaction in terms of

convenience, costs, and quality of services also influence their access to healthcare services for
our children with cerebral palsy.

CHAPTER THREE

METHODS

1. Introduction

This chapter shows the information on the research procedure and the methods used in the collection of data and data analysis. Topics covered embodies study design, study area, study population, sampling techniques, data collection technique, quality control, ethical consideration, data collection tools, pre-testing of data collection tools, training of research assistants, duration of the interview, inclusion criteria, exclusion criteria and data analysis.

2. Study Design

The study used a qualitative cross-sectional design using phenomenology to assess the knowledge of parents of children CP on National Health Policy, explore the perceptions of parents of children with cerebral palsy on the implementation of the National Health Policy in Tema, identify parental factors and healthcare factors that influence access to healthcare services for children with cerebral palsy. A qualitative method involving the use of in-depth interviews was used to collect data from parents or caregivers of children with cerebral palsy in two (2) Special Education Schools in the Greater Accra Region and a key informant interview (KI) was used to collect data from healthcare providers in both private and public health facilities who provide services to children with cerebral palsy in the Greater Accra Region of Tema during data collection. The duration for data collection for this study was two weeks.

1.3. Study Area

The study was conducted in the Greater Accra Region (GAR) of Ghana because there are quite a lot of parents of children with CP and an existing self-help group. There are over five hundred parents of children with CP and about twenty existing self-help groups in GAR. The study considered the Special Mothers Project self-help group in Okonglo in the Greater Accra Region. The Special Mothers Project has been existing for the past seven years and is open to every parent of children with disabilities especially those with children with cerebral palsy. GAR is the capital town of Ghana and has the smallest area of Ghana's sixteen (16) administrative regions. GAR can be found in the South-East part of the country and it is surrounded on the north by the Eastern Region, on the east by the Volta Region, on the south by the Gulf of Guinea, and the west by the Central Region. GAR is divided into sixteen districts and its political administration is through the local government. Each district is administered by a Chief Executive who represents the central government.



Figure 2. Map showing health districts in Greater Accra

Source: Google Maps (2019)

Demography

The second most populated region in Ghana is the capital (GAR) with an urban population of 2.27 million out of an estimated population of 30.42 million (World Population Review, 2019). Accra has ten (10) administrative health districts including Ledokuku-Krowor, Aduani Municipality, Accra Metro, Tema Municipality, Ga West District, Adenta Municipality, Dangme East District, Ga East District, Dangme West District, and Ga South District.

This study was conducted in two (2) special schools in GAR these include Woodfield Manor Special School and Dzorwala Special School. Woodfield Manor Special School has about one-hundred students and provides special education and other related support services like applied behavior analysis for the students. The student-teacher ratio is five to one teacher (5:1). Dzorwala Special School has over five hundred students. The school provides vocational

training and educational support for the students. The student-teacher ratio is ten to 1 teacher (10:1).

Health Facilities

There are over fifteen (15) public health facilities and more than seven hundred (700) private health facilities in the Greater Accra Region of Ghana, public health facilities include La General Hospital, Achimota Hospital, Ridge Hospital, Korle-Bu Teaching Hospital, and other polyclinics. Private health facilities include Airport Clinic, Alpha Medical Center, Cocoa Clinic, Accused Diagnostic Center among others as well as Community-based Health Planning and Services (CHPS) Compounds.

3.4. Study Population

The study population was parents of children with CP between the ages of 3 to 17 years who attend a special school in the Greater Accra Region, this is because 17% of children are diagnosed with cerebral palsy within the age range. Healthcare providers who provide services to children with CP within the study period will be part of the study.

3.5. Selection of study participants

The respondents for this study were recruited using a purposive sampling technique. This sampling technique is a non-probability sampling used to select participants based on the experiences and characteristics they possess that best fit for the study. The inclusion and exclusion criteria were considered in selecting the participants for the study. Parents of children with CP who met the inclusion criteria were purposively sampled at home for an interview in the study. Three (3) participants were selected each day for the in-depth interview (IDI's) while the key informant interview was also used for healthcare workers who met the inclusion criteria until

a point of saturation was reached. Saturation was determined when no new information was emerging up from the study participants. A total of fifteen (15) participants reached saturation, including 10 parents of children with CP and 5 health care providers. The study purposefully identified and selected ten (10) children with CP who are eligible for the study at the school level based on age, sex, and disability and proceeding to their homes to consent their parents or caregivers for recruitment for an in-depth interview.

Also, five (5) health facilities both private and public in the Greater Accra Region were selected for key informant interviews based on specialized and generalized healthcare services provided. Five (5) eligible healthcare providers within the selected health facilities who directly offer healthcare services to children with cerebral palsy were purposefully selected for the study based on a particular set of characteristics such as experience, skills, knowledge, and highest educational level for a key informant interview (KII). This is to get an adequate number of participants for the study.

1.6. Data Collection Technique

A permission letter was obtained from the head of the department of social and behavioral sciences (SOBS) under the School of Public Health, and an approved letter from the Ghana Health Service Ethics Review Committee as well as a permission letter from the Ghana Education Services was presented to the heads of the various Special Education Schools. Permission was first obtained from the special schools before starting data collection. A consent form with duplicated signature pages was given to all study participants. Study participants (parents and healthcare providers) were purposefully sampled at their homes through snowballing and were asked to show interest by signing or thumb printing the consent form and returning the duplicated copy of the signature or thumbprint page with their bio-data information such as

participant's name, relationship with the child, child's name, and child's age. Parents and healthcare providers who show interest and have signed or thumbprint the consent form were recruited for the study. For a face-to-face interview, time and venue were scheduled. The study used both in-depth interviews (IDI) and key informant interviews to collect primary data from study participants.

In-depth interviews were steered within the homes of identified parents of children with CP upon their convenience. Also, all key informant interviews were steered within the work premises of an identified healthcare provider upon appointment. Both key informant interviews and in-depth interviews were steered in English, and all face-to-face interviews. The in-depth interview and key informant interviews were directed by an interview guide containing questions and probes that directed the interviewer. All in-depth interviews and key informant interviews were tape-recorded for transcription.

Each in-depth interview and key informant interview lasted at least 50 minutes. The discussion was centered on the knowledge of parents on national health policy in Ghana, perception of parents on the implementation of the national health policy in Ghana, parental and healthcare factors that influence access to health care for children with CP.

3.7. Quality Control

A dependable and skilled research assistant who is conversant with the local dialects including Twi and Ga went through an intensive day of training for this research. The training involved explaining the objectives of the study, obtaining consent, maintaining neutrality, and confidentiality. Data collection tools were pre-tested by the researcher among a representative sample of the target population. Pretesting was carried out among a representative sample of the target population. Interview guide and tools were pretest at the homes of parents of children

is in the offices of healthcare workers who provides direct services to children with CP. Data collected in local dialect was translated back to English by someone who is conversant with the local dialect. This improved the reliability of the data.

Data Tools

A field notebook, a voice recorder, and a field diary were used to collect data. The interview guide for both in-depth interview and key informant interview included probes on; knowledge of parents on Persons with Disability Act of Ghana, Health Insurance Scheme, perceptions of parents about the implementation of the Policy in Ghana, parental factors in accessing health care, healthcare factors, specialized services available for children with CP. Both in-depth interviews and key informant interviews were recorded using a voice recorder and field diary to take key notes.

Validation

The interview guide was pre-tested among parents of children with CP and healthcare providers to identify challenges and have them adopted as possible. The Voice recorder was tested to ensure it recorded all sound.

Inclusion Criteria

Children with CP within the ages of 3 to 17 years whose child attends a school in Greater Accra Region for more than one year were included in the study. Healthcare providers with at least one year of experience who provide direct healthcare services to children with CP were included in the study.

11. Exclusion Criteria

Parents of children with CP who did not show consent were excluded from the study. Healthcare providers who offer services to children with CP and who have less than one year of experience were excluded from the study.

12. Data Processing and Analysis

Both in-depth interviews and key informant interviews were recorded with participants' permission. Interviews conducted in the local dialect were transcribed literally into English by the research assistant who was conversant with the language. All transcriptions were confirmed and transported into Nvivo version 12. The coding of themes was developed thematically in line with the objectives of the study and emerging themes in the field. The inductive and deductive approaches were used in the coding process. Themes were summarized into appropriate sub-categories using queries. A codebook was developed for themes that will emerge during interviews on the field and appropriate excerpts were used to support the theme.

13. Ethical Consideration

13.1 Ghana Health Service Ethical approval

Ethical approval was obtained from the Ghana Health Service Ethical Review Committee before starting the research.

13.2. Approval from the study area

Permission and approval were obtained from two heads of Special Education Schools in the Greater Accra Region.

Consent

When the study was conducted, an informed consent form was given to qualified participants of children with CP and healthcare providers for children with CP. Also, only participants who had shown consent were interviewed. Study participants were given their right to voluntarily participate and withdraw from the study at any time if they wish.

Confidentiality

The study was carried out in an enclosed space to ensure privacy. Study participants were given anonymity. Transcriptions were coded with Pseudonyms and records that can easily identify participants were kept confidential.

Risks and benefits

The risks to this study were psychological distress and discomfort in answering certain questions that felt uncomfortable in answering certain questions, were advised to stop if they wish. Participants that experience psychological distress were referred to a counsellor. The study did not directly benefit participants. However, findings from the study helped inform the Ministry of Health as policymakers and the Ministry of Health in developing strategic plans and policies to create and enhance access to healthcare services that meet the overall health care needs of children with CP.

13.6. Cost and compensation

In this study, participants did not incur any cost, as the principal investigator was the one to meet participants. However, children with cerebral palsy were given a small token like a pencil, book, and a toy.

13.7. Voluntary participation/withdrawal

Participants had the right to voluntarily participate and withdraw from the study at any time without any penalty or reason.

13.8. Data storage and usage

Data files on electronic devices were fingerprint and password protected that is only known to the principal investigator. Data was backed up on a CD-ROM and external hard drive. Hard copy data were kept in a safe and the key was only kept by the principal investigator. Both soft and hard copy data will be kept by the principal investigator for 5 years to allow for publication of the research, after which it will be destroyed permanently by formatting electronic devices completely and burning hard copy data.

13.9 Conflict of interest

The principal investigator ensured that there is no conflict of interest as far as the study is concerned.

13.10 Funding information

The principal investigator used his funds to sponsor the study.

13.11 Measures to reduce the spread of COVID-19 infection

The principal investigator provided and ensured that study participants did handwashing with soap under running water and used alcohol-based hand sanitizer at the study site. Participants were provided with a face mask at no cost while observing physical distancing before and during the interview. The principal investigator also adhered to these preventive measures outlined.

CHAPTER FOUR

RESULTS

In this study, the data were described, and the analysis of the data is presented in this chapter. The data were typed and transcribed verbatim following the objectives of the study and analysed using thematic analysis. Both deductive and inductive approaches were used in analysing the transcripts (Crabtree, 2009). The codebook was developed in line with the objectives of the study and the subject areas explored during the interviews. In establishing the codebook, it was given to statements that are of importance in most of the relevant data. In order to verify the reliability of the findings three different individual coders were employed to verify the codebook for acceptance. Excerpts from the transcripts were used to support the emerging patterns of themes identified from the data.

The data from the interviews are presented under the subsequent headings in line with the objectives of the study: Socio-demographic characteristics of participants, knowledge of parents on National Health Policy in Ghana, perception of parents on the implementation of National Health Policy in Ghana, parental factors, and healthcare factors.

Socio-demographic Characteristics of Participants

The participants were sampled from Woodfield Manor Special School, Dzorwulu Special School, Aklavie Special Clinic, La General Hospital, Achimota Hospital, Kaseshi Polyclinic, and Alpha Special School who were involved in this study shown in Table 4.1. The same number of participants were selected from each special school as well as an equal number of participants

were selected from each of the health facilities. The participants involved in the study included 10 parents of children with CP and 5 health workers. Out of the total participant, 4 were males and 11 were females. The age range of the parents of children with CP was between 20 and 45 years, whereas the healthcare providers were between the ages of 35 to 55 years. All the participants have some form of formal education and the majority of them were Christian except 1 who was a Muslim. Most of the study participants were employed in different jobs, however, only two (2) were unemployed. The majority (10) of the respondents were single while 4 were married.

Table 3. Socio-Demographic Characteristics of Participants

| Characteristics of Participants | | | Number of Participants | |
|---------------------------------|-------|---------|------------------------|-------------------------------|
| | | | Parents for IDAs | Healthcare providers for KIDs |
| Special schools | | | | |
| Woodfield | Manor | Special | 5 | - |
| School | | | | |
| Dzerwala Special School | | | 5 | - |
| Health Facility | | | | |
| Cocoa Clinic (Private) | | | - | 1 |
| Alpha Medical Center (Private) | | | - | 1 |
| La General Hospital (Public) | | | - | 1 |
| Achimota Hospital (Public) | | | - | 1 |
| Kantehia (Public) | | | - | 1 |
| Sex | | | | |
| Male | | | 1 | 3 |
| Female | | | 9 | 2 |

| | Children with CP | |
|-----------------------------|------------------|---|
| | 10 | 5 |
| Age Level | 1 | |
| Education | 7 | 4 |
| | 2 | 1 |
| | - | - |
| | 1 | |
| | 6 | |
| | 3 | 5 |
| Occupation | 9 | 5 |
| | 1 | |
| Profession | 5 | |
| | 3 | |
| Employment Status | 2 | |
| Specialist Therapist | | 2 |
| Therapist | | 2 |
| General Health Practitioner | | 1 |
| Other Health Status | | |
| | 6 | 4 |
| Gender | 4 | 1 |

Knowledge of National Health Policy in Ghana

The study revealed that the majority of the participants had a fair knowledge of the National Health Policy in Ghana, and explained it as a policy that aims to promote health for everyone in the country. Some participants also explained the National Health Policy according to their

understanding of health in the Persons with Disability Act (Act 715) and on the National Health Insurance Scheme in Ghana. The participants were therefore asked about their knowledge of health in the Persons with Disability Act. The participants described health in the Persons with Disability Act as a means of getting access to healthcare services without any barriers and discrimination. Participants believed that the health in Persons with Disability Act means having access to healthcare services without any discrimination, physical and attitudinal barriers as well as accessing free specialized services in the public health facilities. The belief of having access to healthcare services without any barrier was universal among the participants. Those who hold these beliefs also indicated that the persons with disability act mandates the State to provide financial support to persons with disabilities. The excerpts by study participants are shown below:

"I know that one of the articles even state that persons with disability should have access to health care services both primary, secondary and tertiary so that at least barriers that are not helping persons with disabilities to get the services will be removed such as organizational and building barriers" (ID1, 28yrs, Parent, Male)

"Health in the disability act is the provision made for people with disability to have access to a health facility without any discrimination" (ID1, 34yrs, Parent, Female)

"About health in the disability Act, what I know is that whether the child has a disability or not, the child should have access to healthcare facilities and services right from the CHPS compound to the big hospital." (ID1, 32yrs, Parent, Female)

"Assuming I am disabled, and I've been sacked from work, and now I have to get the financial means to go to the hospital, maybe to access primary health care and I don't

have the means, one of the clauses within the disability Act I mentioned says that the district assembly should give people with disabilities financial aid, so with this, I can easily access these funds and then go to whichever hospital I want" (KH, 38yrs, Healthcare provider-Private Hospital, Male)

"I think the act specifies that every public building has to be disability friendly and then there is a percentage of funds that should be given to persons with disabilities for them to access healthcare." (KH, 38yrs, Healthcare Provider-Private Hospital, Male)

4.3.1. Knowledge of National Health Insurance Scheme (NHIS)

The study showed that the participants were knowledgeable about the National Health Insurance Scheme. The respondents emphasised how the National Health Insurance Scheme serves as a safety net and has replaced the cash-and-carry system of service delivery. Some of the respondents also attributed the National Health Insurance Scheme to the means of ensuring sustainable financing for health. Below are some of the quotes from some participants:

"NHIS as a health policy came to reduce the financial burden for us, we the parents that have no money to access healthcare for our children with CP." (DM, 28yrs, Parent, Male)

"I know it is for all Ghanaians, everybody is entitled to it and I know you pay a little token. It helps when you have it, you go for a consultation you don't pay and some of the lab, health insurance takes part of it and some of the medications too, so for me it came to replace cash and carry" (DM, 38yrs, Parent, Female)

"With the NHIS I know it's really supporting parents with low-income status and also parents of children with disabilities since their ward's disability (CP) is developmental

and not acute which needs constant visiting the healthcare facility” (KH, 40y/o,

Healthcare provider-private, Male)

“In my facility the number of times you come for specialized services in a week, NHIS will take care of it, so you don't need to carry money on you when coming for therapy.”

(KH, 33y/o, Healthcare Provider-Private, Female)

4.4 Perception on the implementation of the National Health Policy in Ghana

The study findings showed that participants agreed on the implementation of the National Health Policy of Ghana. Participants were asked questions on their perception of health in the implementation of the Persons with Disability Act and on the National Health Insurance Scheme (NHIS). Some of the perceptions revealed in the study were the ineffectiveness of the Persons with Disability Act, poor quality health service, and less health service coverage by the National Health Insurance Scheme.

4.4.1. Ineffectiveness of Persons with Disability Act

From the results of the study, when participants were asked about the implementation of health in the persons with disability act the following were mentioned: little awareness of the persons with disability act, poor implementation strategy, and no reinforcement. Below show the quotes from some of the participants:

“The implementation of health in the disability act is falling apart and is not effective at all because there is no understanding of the Act and not many people are even aware that something like that exist, so how can they fight for their right to access health care.”

(ADI, 29y/o, Parent, Male)

"Mostly I see disability and I see the Act and I see that it is only on paper because seriously on grounds it is people who have a good heart that does something about it but it is not working as a law that should be enforced because people are there and they don't even know that they have a common fund at the assemblies that they are entitled to which could enable them access healthcare for their wards" (ID1, 38yrs, Parent, Female)

"Even some of the policymakers don't know about it (disability Act), like accessibility, how many organizations have their buildings accessible to people with disabilities, how many hospitals are accessible for someone in a wheelchair, how many hospitals are accessible for all these things, so we haven't implemented it the way we needed to do. The disability act is there but we see nothing." (ID1, 32yrs, Parent, Female)

"The Act has been drawn but its implementation is not effective, for me it not well implemented because it is said we are to access free rehabilitation services at the public health facilities but in most cases, we pay, no money no physio..." (ID1, 34yrs, Parent, Female)

"I think that we have people in authority who are a bit knowledgeable with some of these things (Disability), but we are not seeing anything, honestly it is not effective." (ID1, 40yrs, Healthcare Provider-Public, Male)

"It's there (disability Act) but implementing it is difficult because there is nothing like enforcing it. Everybody does what he or she thinks should be done and if a person with a disability is being neglected or not having access to healthcare, you could see that nobody cares because there is nothing like reinforcement or punishment on those who go

against the act, so it all depends on reinforcing the act if somebody does something against it, the person should be sanctioned according to what is written in it but nobody cares, we just talk about it but the truth is that it is not working.” (ID1, 33yrs, Healthcare Provider-Private, Female)

4.3.3. Less health coverage by the National Health Insurance Scheme

The study findings showed that participants were unanimous on the health service coverage by the national health insurance scheme. All participants acknowledged that the National Health Insurance Scheme does cover some aspect of healthcare services like consultation fee, patient card, half of the hip fees, part of medication, and one-month cost of physiotherapy but does not cover tertiary services like surgery and some specialized services like speech and language therapy, occupational therapy among others. Participants revealed in the study that these tertiary and specialized services are constantly needed by children with CP. Some of the excerpts from participants are shown below:

“For NHIS they need to expand the coverage. More attention needs to be put to it, in fact, I think they need to do monitoring and evaluation at the hospitals so that they will know how to make the coverage more attractive. NHIS is not like before, now only small things it takes care of like consultation fees and small small medicines.” (ID1, 38yrs, Parent, Female)

“The national health insurance policy in Ghana here is not working and even we going to the hospital with our children, some of the health providers don’t see them (our children) as part of human beings, they sometimes don’t want to even provide healthcare services to them, if they do then we have to pay huge.” (ID1, 40yrs, Parent, Female)

"I think they are doing a good job; they are doing very well. And if they can make other health issues also come on board on the health insurance package, I think it will also help" (ID1, 33yrs, Parent, Female)

"For the national health insurance scheme, it is good, though what I have realized is, it doesn't cater for specialized services like speech therapy for children with disabilities" (ID1, 33yrs, Parent, Female)

"Generally, NHIS is ok. For mothers with such kids, obviously, you don't need anybody to tell you that you must register for National Health Insurance, NHIS helps though it doesn't take care of some of the services needed by children with CP" (KI1, 34yrs, Healthcare Provider-Public, Male)

"So far the national health insurance policy is good but does not cater for all specialized services for children with disabilities, the coverage is very limited to higher healthcare needs" (KI1, 34yrs, Healthcare Provider-Private, Female)

4.5. Parental Factors

This section presents an analysis of the findings concerning parental factors that influence access to healthcare services for children with CP. The choices made by parents as to whether to seek healthcare for their children with CP is dependent on other factors. According to Khatri and Karkee (2018), parental factors are more likely to shape the health-seeking behavior of individuals. Study participants were therefore asked questions on parental factors that can influence access to healthcare services for children with CP. From the study findings, participants mentioned knowledge on disability, perception about disability (CP), income spent

on child's health care, transportation cost, and satisfaction as factors that influence access to healthcare services for children with CP.

4.5.1. Knowledge of disability

Findings from the study demonstrated that participants have a diverse knowledge of disability including causes of disability, signs, and symptoms of CP treatment which influences their access to healthcare for their wards with CP.

Causes of disability

Concerning the causes of disability, some participants attributed it to spirituality, brain damage (medical condition), and diseases. Some participants believe that hater from families can make a child have a disability through witchcraft and voodoo especially when the child has a bright future. The study revealed that parents with such beliefs do not seek medical care for their children but rather seek spiritual healing for their children with CP. Below are some quotes from participants:

"Disability can be given through juju (voodoo), my child wasn't born like this and when I trace back in my family's line there's nothing like that. No condition like this is in the family line and my husband too there's no such condition too. If there were to be one, we would have said perhaps it has happened before and has popped up again but there is nothing like this condition so you see it is juju that someone did to my son because he has a bright future. So, for me I go to see pastors for direction for my child to be healed"
(DD, 39y/o, Parent, Female)

"I also believe that disability can be given or brought to someone through witchcraft. Anything that comes from the spirit is dealt with in the spirit, some I have gone to so many places for healing for my child and not the hospital" (ID1, 32y/o, Parent, Female)

Also, some participants believe that disability has a medical root cause and not spirituality. Some participants attributed CP to neurological problems leading to brain damage. Those with such beliefs seek medical care for their wards with CP. Below show the excerpts from participants:

"For me, I don't know, people have been saying that disability is spiritual but me I don't believe it is spiritual. I believe that it is a medical condition and is from the brain. So, I seek medical care for my child". (ID1, 38y/o, Parent, Female)

"My son was diagnosed with cerebral palsy, meaning part of the brain that controls the nerves is not functioning, so his disability is a medical condition, that is what I believe... I do take him to the hospital for treatment and not the church like others do". (ID1, 32y/o, Parent, Female)

"when it comes to demons or evil spirits being the cause of my child's disability then I will say that these kinds of spirituality are not connected to my child's disability rather it brain damage and is purely medical... I do take my child to the hospital." (ID1, 28y/o, Parent-CP, Male)

Moreover, other participants believe that disability can be caused by diseases like jaundice and stroke. The study revealed that participants with such beliefs do access healthcare for their children with CP. Below show quotes from participants:

"Jaundice can cause a child to have a disability, you see my first child developed neonatal jaundice, so we sent him to the hospital that's the first hospital I delivered. We

were admitted for two days and that was when we were diagnosed with CP." (IDI, 32y/o,

Parent, Female)

"Immediately the child is born sometimes he will not cry, sometimes the child comes with this change of color on the skin that most parents are not aware of. Some children also become whitish, some become yellowish all this gives a sign of suspected disability... I visit the hospital with my child when he is sick." (IDI, 29y/o, Parent, Male)

"...even some people get disability through stroke... my child, for instance, I take him to the hospital most of the time". (IDI, 38y/o, Parent, Female)

Signs and symptoms of CP

From the results, when participants were asked about the signs and symptoms of CP the following were mentioned; poor eye contact, poor posture, and balance, communication, as well as impaired fine and gross motor function. The study revealed that participants have knowledge of symptoms and are influenced to seek prompt health care for their wards with CP. Below are some of the excerpts from participants on poor eye contact:

"... a child with CP doesn't look into people's eyes, for example with my child I noticed something was wrong because at least when you talk to him, he should watch you, but he will rather watch somewhere else, because of the I took him to the hospital." (IDI, 38y/o, Parent, Female)

"Most children with CP do not look into their mothers' eyes, so when you see this, it should tell you that something is wrong, it could be CP... I took my child to the hospital as soon as I noticed that". (IDI, 38y/o, Parent, Female)

Besides, poor posture and balance were also considered to be a sign of CP by some participants.

Below show the quotes:

"... around six months I expected her to be sitting down as I tried putting her down and I could see that she is very soft if you put her down then she is going down, she can't control her neck and as at that time she doesn't even cry, you can even pinch her and she will not do anything or cry." (ID1, 40yrs, Parent, Female)

"... for children with CP they have seating and neck control problems, for example for my child when he was sitting you could see that he's unable to control his neck, so we sent him to children's hospital. There, he was diagnosed with cerebral palsy" (ID1, 32yrs, Parent, Female)

Also, some participants demonstrated that children with CP have communication problems in terms of speech. Below are the extracts of participants:

"You know children with CP, for example, are not able to communicate or talk properly especially those in the severe category, it is difficult for them to talk with us" (ID1, 29yrs, Parent, Male)

"Children with CP have something in common which is impaired communication, so when you see this then it should ring the bell for you to go for a checkup because it can be a suspected case of CP" (ID1, 39yrs, Parent, Female)

Moreover, some participants considered impaired fine and gross motor function as a symptom of CP. Below shows the extract of a participant:

"For my child, I didn't give birth to him with this condition he was a normal child, on the seventh month he couldn't sit without being supported, we have to tie a cloth around him to a chair and you know normally with kids the moment you give them something the first place they send it is to their mouth but when you give him something he can't grab it when you give it to him after few seconds he just drops it." (ID1, 19yrs, Parent, Female)

Treatment for CP

The study findings revealed that the majority of the respondents believed that CP cannot be treated (cured) but can be managed through the following means: Specialized healthcare services including physiotherapy, occupational therapy, speech and language therapy, and generalised healthcare services including primary health care like screening and health checkups. Respondents with this knowledge seek healthcare for their children with CP as revealed in this study. The following excerpts below illustrate these points:

"well for me I know that children CP cannot be cured completely but can be managed through physiotherapy, speech therapy, and occupational therapy because of that I do go for these services for my child" (ID1, 19yrs, Parent, Female)

"People think this condition can be cured, but it cannot be cured rather stopped from worsening by going for physio and occupational therapy and even normal health care. This influences me to seek specialized services for my boy". (ID1, 19yrs, Parent, Male)

"It is not easy to treat CP for it to go, even spiritual healing cannot cure it, so what you need to do is to go to the hospital for normal health care and also going for physio and occupational therapy" (ID1, 19yrs, Parent, Female)

4.3.2. Perception of disability (CP)

The results of the study revealed that respondents share different perceptions of disability. Some of the respondents mentioned that disability can result in stigmatization, discrimination, disrespect, loneliness, depression, and even suicide. Respondents agreed that when someone has a disability stigmatization and discrimination are inevitable leading to depression, loneliness, and suicidal ideation. The study showed that respondents with such perceptions feel reluctant to seek healthcare for their wards with CP with the fear of being stigmatized and discriminated against. Some participants also mentioned that disability can be frustrating and lead to the loss of a job. The following excerpts illustrate these points:

"(sighed) you have no idea what disability can do err. Disability can make society hate you and you cannot even attend programs because people will look at you in a certain manner you won't be comfortable with." (ID1, 29yrs, Parent, Male)

"My brother, when someone gets a disability then that person will lose his or her job. Employers see people with disabilities as unproductive and cannot work efficiently and effectively. So, you see, for me, I think disability can make people lose their jobs" (ID1, 28yrs, Parent, Female)

"Disability can make people take their lives, because of how society treats them and even the frustration attached to this condition is also another thing on its own... I have thought of killing my child before, it is not easy my brother for me especially with how my own family and society treats me is unbearable as if I am not part of human beings. People say I am cursed that why I have a child with a disability" (ID1, 32yrs, Parent, Female)

"(bad face) here, this reminds me of how my family and friends used to keep me close but now they don't, why because I have a child with a disability. So, I think that disability can make you lose your family and friends' company, and that leads to loneliness. It is not easy for me on this matter" (IDI, 28y/o, Parent, Female)

Participants were asked about how their perception of disability influences their access to healthcare services for their wards with CP. Findings from the study show that participants believed that negative perception about disability may lead to less access to healthcare services for children with CP while the positive perception may lead to frequent access to healthcare services. Respondents with a negative perception of disability do not seek regular healthcare for their children with CP but rather go to seek spiritual healing for their wards with CP. Also, it was revealed that respondents with positive perceptions frequently seek healthcare for their children with CP. Below are the quotes from participants:

"you see when you have a bad idea about disability and considers what people will say or do, will rather make you not have the courage to go to the hospital with your child with CP but when you don't care about the attitudes of people and even the healthcare providers attitude then you are more likely to access healthcare services for your child with CP" (IDI, 28y/o, Parent, Male)

"...imagine you lose your job because of your child's disability; how will you be able to get money to access healthcare services for your child. So, the income also plays a role in influencing access to healthcare services but when you have the money you can access healthcare for your child with a disability." (IDI, 38y/o, Parent, Female)

"like I said earlier disability comes with frustration, when you are frustrated with this condition you won't even have the courage to even try to access healthcare services in the hospital because that place too there is another frustration, so you won't even go there but when you don't see disability as a frustrating condition then you are encouraged to visit the hospital even amidst the frustration over there" (ID1, 12y/o, Parent, Female)

4.5.3. Financial burden on a child's health care

The study showed that the majority of the respondents are not able to access healthcare for their wards with CP as they spend a greater part of their income on their child's health. Participants agreed that the healthcare needs of children with CP are a lot and most expensive. They stated that specialized services like physiotherapy, occupational therapy, speech and language therapy, and special nutrition help to manage children with CP but these services are expensive and sometimes they find it difficult to access. However, some participants also specified that because of the expensive nature of specialized services they tend to do basic physiotherapy for their wards in their homes since they cannot keep up with the services in the hospitals. Participants were unanimous on how they spend so much money on both primary and secondary healthcare services for their children with CP and this discourages them from accessing healthcare services for their children with CP. Below show quotes from respondents:

"The amount of money I have spent on my child's health is unimaginable, I spend a greater part of my salary on hospital bills, it is not easy" (ID1, 28y/o, Parent, Male)

"I spend about 80% of my money on my child's health, going for physio, speech therapy, buying medicines, CT (computerized tomography) scans, and others. It drains me out!" (ID1, 18y/o, Parent, Female)

"...even going for physiotherapy, OT (Occupational therapy), and health checkups is not a joke, the money that I pay is so crazy even with the national health insurance card. So, I spend a greater part of my money on my child's health... feeding too is another thing, children with CP don't just eat anything. Their food is specially made so you spend a lot of money on that too. I hardly go to the hospital with him I must say". (ID1, 32yrs,

Parent, Female)

"(Big right as for the money I spend on my child's healthcare I cannot mention because I don't keep records, but in percentage, I will say 70% of my salary goes to my child's health including going to physio, speech therapy, and a special diet. I must say that because of this I am broke (no money) all the time so I do basic physio at home for my child. So I don't go to the hospital frequently". (ID1, 34yrs, Parent, Female)

Also, study participants were asked about how income as a factor influences access to healthcare services for children with CP. Parents of children with CP all agreed that income level may influence access to healthcare services in either a positive or negative way depending on the kind of job a parent has. The study revealed that access to healthcare services for children with CP is higher among parents with a higher income than those with a lower income. Some participants also stated that the kind of job one does determines the level of income. Below are some excerpts:

"Some parents have good jobs and they are paid well, such a parent will be able to access healthcare for their child than someone who is not working or is paid little." (ID1,

30yrs, Parent, Female)

"... just imagine someone who works at the bank as a manager and gets a big salary compared to someone who is a mason. Clearly, you can see that the bank manager will have enough money to access healthcare services for his or her child but the mason will have little money and will not be able to access healthcare services for his or her child... I was teaching in a school and I was earning at least GHC1500 every month and I was able to access healthcare services for my child but after I gave birth to my child with a disability (CP), I wasn't getting time to go to work so I started my own small business which earns me little, I am not able to regularly visit the hospital when the need arises and it's because I don't have money. So, you see the difference now". (ID1, 39yo, Parent, Female)

"... money they say answers all things if I am having a good job and am well paid why can't I access healthcare for my child with a disability, but when I am not working or I earn a meager salary I won't be able to go the hospital. Rich people can access healthcare services frequently for their child with a disability than people who are poor and have no jobs". (ID1, 40yo, Parent, Female)

4.5.4. Transportation

The study revealed that parents of children with CP do experience transportation problems and that discourages them from accessing healthcare services for their children with CP. All participants agreed that transportation is another factor that influences access to healthcare services. The majority of the participants stated that their means of transportation to the hospital is public transport (metro, taxi, uber). All participants mentioned that transportation problems include access to public transport, transportation cost, and stigmatization in public transports.

Access to public transport

The study revealed that the majority of the respondents agreed that most public transport designs are not accessible and friendly to children with CP. This makes it difficult for them to access public transport to a health facility. It was also revealed in this study that all respondents agreed there is no designated space for persons with disabilities inside public transport. This makes them feel very uncomfortable when using public transport to a health facility. Findings from this study showed that respondents who use public transport do not frequently access healthcare services for their children with CP as they are discouraged from all the hassle and frustration, they face from accessing public transport.

Transportation cost

Some of the participants asserted that transportation cost to the closest health facility is expensive and, in most cases, uber or taxi drivers do not want to render services to them due to their children with disabilities. Participants also believed that commercial drivers (uber and taxi) charge them at a higher cost because of their children with disabilities. The study found that passengers, conductors (trotro), and commercial drivers (trotro) do stigmatize parents of children with CP when boarding a car to a health facility. Study participants specified that passengers do not want to sit by them with the belief that they will end up having a child with a disability and also bus conductors (trotro) and commercial drivers (trotro) also ask them to pay for the entire seat or else they won't pick them up. This discourages parents from accessing healthcare for their children with CP. Below are some quotes from participants:

"Most of us don't have cars we are not having means of transportation, so we have to rely on commercial buses and is the main problem for us... It is not easy; I had a taxi driver who was coming to pick my child and it got to a time he told me that his car owner

said he should not pick children like that in his car so he stopped picking us. Just as I was telling you that there are certain days you can't pick trotro, they will either tell you to get down or you will pay for the whole row". (IDI, 12y/o, Parent, Female)

"If the means are not there then you have to do the road transit before you get to the hospital, we have to pick "trotro" and most of the time when we pick "trotro" we have to buy an extra seat. My child is getting heavy so sometimes when you push him, he doesn't allow it, you see him crying. So, I have to buy an extra seat so that we feel a bit comfortable. And when it comes to loading taxis too, I have to buy an extra seat too so that we manage and go." (IDI, 14y/o, Parent, Female)

"So, I get so disturbed and stressed when I am going to take my daughter to the hospital. It is not easy for me because when you take trotro the way people will be peeping on you, you need to take dropping instead. Imagine where I stay at the hospital is far and it is not easy to take dropping all the time. So, when it comes to that I get stressed and frustrated." (IDI, 18y/o, Parent, Female)

"Well, because I have a car so I can put her in my car, but for another person who doesn't have a car, it's difficult because you either have to pick a taxi or endure a trotro with so much stigma." (IDI, 18y/o, Parent, Female)

Participants were asked questions on how transportation influences their access to healthcare services for their children with CP. Findings from the study showed that respondents have one way or the other refused to access healthcare for their wards due to transportation problems regarding cost and stigmatization. Respondents stated that transportation cost did influence their

decision not to access health care for their child with CP. Below extract are from some participants:

"... because of transportation cost, I did decide not to take my child to the hospital when she was sick. I rather went to the nearest pharmacy for drugs. If I cannot afford transportation how can I pay the hospital bill." (ID1, 32yrs, Parent, Female)

"You know if you have money this won't be a problem at all, but the issue is there is no money, I cannot afford transportation fees, so I decided to skip the hospital and do home remedies which worked anyway". (ID1, 34yrs, Parent, Female)

"At a point, I have to decide not to go to the hospital with my child though she needed it, I was not having money for transportation so I have to skip hospital though that is not what I wanted..." (ID1, 42yrs, Parent, Female)

"I remember I was having an appointment with a speech therapist and on that day, it was really hard for me to even feed, left alone to be able to afford transportation. Huh, I was so worried but I have to skip our appointment..." (ID1, 40yrs, Parent, Female)

Also, some respondents mentioned that stigmatisation from passengers, bus conductors, and drivers do put them off sometimes and not to access healthcare for their child with CP. Below are quotes from some respondents:

"The way passengers can look at you and be mummering will make you feel so bad and rejected. No one wants to seat by you, all because you have a child with a disability (CP). Sometimes passengers will say to your face that you are cursed and wouldn't want to seat by you. So, with this, I get hurt, so there was a time I decided not to go to the hospital using trotro". (ID1, 29yrs, Parent, Male)

"When, using trotros to the hospital is so easy. The way the mate and driver will talk to you seems as if you are not a human being, all because you have a child with a disability. You know I once used the trotro without my child and I was respected like anyone else in the car but the day I took my child with me, I regreted. So, I decided not to go to the hospital with my child if I have to use the commercial bus (trotros) other than that I have to use a taxi or uber". (IDI, 18yrs, Parent, Female)

4.5.5. Satisfaction

The results of the study showed that participants agreed that satisfaction with health care services does influence their access to healthcare. The participants attributed satisfaction to quality health care, waiting time for treatment, and cost-effectiveness of healthcare services. Respondents explained quality health care as the one that is considered to be safe, efficient, inclusive, patient-centered, timely, and that makes customers happy. Respondent also believed that when patients do not get quality healthcare, they may reduce the number of times they visit a particular health facility or they may stop accessing health care from those particular health facilities. Below are some extracts from respondents:

"... quality healthcare is the one that is inclusive enough for everyone to access and is more efficient and patient-focused that bring joy to the patient when leaving the hospital... when a hospital provides quality healthcare for their clients (patients), they tend to visit the hospital more but when patients are not happy with the services of the hospital they won't go to that place again. So, for me, I only go to hospitals that I am okay with their services". (IDI, 28yrs, Parent, Male)

"Quality healthcare is whereby a mother walks in with a special child with so much pain, tears and anxiety and walks out with a sense of hope, with a sense of belonging, with some kind of pride and laughter, that is quality healthcare to me. In this case, when I am happy about the services provided by a hospital that is where I will go all the time. I stopped going to certain hospitals because of their poor services". (ID1, 48yo, Parent, Female)

"Quality health care to me is enjoying my rights as a client to the health facility... I expect the doctor to be able to explain to me every step of the process, why they are doing what, why should I be given tablet A instead of B. This brings fulfillment to me and makes me happy... I remember when I went to a certain health facility, I wasn't so happy with their work at all, ever since that time I never went there again. Now I go to a different hospital in which their services meet my child's needs and make me happy". (ID1, 34yo, Parent, Female)

Also, findings from the study revealed that all participants' belief waiting time for treatment influences access to healthcare services. Some of the participants stated that they spend a lot of time at the hospital from morning till evening waiting to get treatment for their children with CP. This discourages them sometimes from accessing healthcare services for their children with CP in certain health facilities. Some participants also attributed stress and frustration to waiting time at the hospital. Below are quoted to buttress these points:

"Waiting time is a big deal, because even you are with the child who is already agitated about the environment and other things, and then you have to wait and wait to access healthcare, by the time it gets to your turn you're already frustrated and tired. Honestly

for this reason I have stopped going to the public hospitals...". (ID1, 19y/o, Parent, Female)

"It is tiring, it is mind-blowing especially when you have been at the hospital from morning to evening. This even led to stress and frustration, as for me I prefer going to the private hospital than the public one because the private hospital offers quick and quality service than the public one". (ID1, 49y/o, Parent, Female)

Moreover, the results of the study revealed that the cost-effectiveness of healthcare services influences parents' access to health care for their wards. Participants explained cost-effective healthcare as a good value for the amount of money paid. Participants believed that rehabilitation services for children with CP can be provided in two forms: home-based service and center-based service (hospital). Participants agreed on the cost-effectiveness of home-based service to center-based service. They believed that home-based services are more effective and better than center-based service that comes with a higher cost. Below are some excerpts from participants:

"I do go for physiotherapy at the hospital and in less than an hour we are done, I am asked to practice the training with my child at home. So, I realized paying that much at the hospital for physiotherapy and less is done, then I will rather do it at home to achieve a better result. (ID1, 42y/o, Parent, Female)

"When I go for occupational therapy in the hospital, I pay more but when I ask for home service from another professional OT I pay less. So, I prefer the home service to the hospital service since I will achieve better results at home with less payment". (ID1, 19y/o, Parent, Male)

4.6 Identification of health service needs (health care factors)

This section presents an analysis of the findings on healthcare factors that influence access to healthcare services for children with CP. Respondents were asked questions on healthcare factors that can influence access to healthcare services for children with CP. From the study findings, participants were generally able to identify healthcare factors that include specialized services availability, proximity to an available health facility, availability of specialist healthcare providers, accessibility of building and equipment, and healthcare provider's attitude do influence access to healthcare services for children with CP.

4.6.1. Specialized services availability

Respondents mentioned some specialized services that health facilities need to make available for children with CP, these include speech and language therapy, physiotherapy, occupational therapy, behavioral therapy, augmentative communication, and dietary approaches. Respondents believed that these specialized services help children with talking, walking, participating in the activities of daily life (such as brushing teeth and getting dressed), interacting with others, learning social skills, and managing their emotions. Study participants mentioned that they feel encouraged to access health care from health facilities that provide specialized services. Below are quotes from respondents:

"Hospitals that do not provide physiotherapy, occupational therapy, or speech therapy I don't access because my child needs it and I cannot be moving from one place to another searching for other specialized services... I am motivated to access health care for my child with CP when the hospital provides the needed specialized services I want. These services I mentioned can help my child to have good balance, strong muscles, and learn some activities of daily living skills". (DD4, Dhyia, Parent, Female)

"Specialized services are limited in Ghana and you cannot get all in one place. However, I prefer accessing health care for my child with CP in a hospital that provides specialized services like GP and behavior therapy than hospitals with no specialized services... the behavior therapy I know helps my child to socialize well". (IDI, 40yrs, Parent, Female)

4.4.2. Proximity to an available health facility

All study participants mentioned that distance from a patient's (clients) home to the nearest health facility can influence access to health care. Participants believed that clients are discouraged to access the closest health facility when they face a transportation problem and have to travel for distances. However, clients whose home is not too far from the nearest hospital is encouraged to access healthcare for his or her child with CP. Below are some extracts from participants:

"If the distance from my home to the nearest hospital is far, then I don't think I can access health care for my child, considering the stress and frustration attached to transportation. But for now, my house is not so far from the hospital so with that I can access healthcare for my child". (IDI, 29yrs, Parent, Male)

"My house is far from the nearest health facility, so you can imagine what I go through when I want to access health care for my child. Sometimes, I don't even go to the hospital at all with my child, we rather find alternative means to treatment. (IDI, 38yrs, Parent, Female)

"... it is true that distance to the hospital can make clients not even show up. I have a client (patient) who stays far away from the hospital she most of the time misses

appointments and other things. All she says is distance is the problem". (KH, 35yrs,

Healthcare Provider-Private Hospital, Male)

4.6.3. Availability of specialist healthcare providers

From the study findings, participants acknowledged and stated that the availability of rehabilitation specialists in health centers influences their access to healthcare for their children with CP. Respondents asserted that some hospitals have specialized services written on their signboards but do not provide such services because specialists are scarce. This influences their decision to access healthcare services from certain health facilities. Respondents believed that rehabilitation specialists like the physiotherapist, speech and language therapist, occupational therapist are very few and scarce in Ghana, especially in the rural areas. Respondents also asserted that they have to travel long distances to access these specialized services in the urban centers which sometimes transportation cost and rehabilitation cost becomes a challenge to them.

Below show some excerpts from respondents:

"Physiotherapy, OT, speech and language therapy, and others are good for children with CP, but the problem is that some hospital has these services written on their boards but when you go there they will tell you we are sorry we don't have a specialist yet... in fact sometimes I wonder why they write it in the first place, so as for me I will rather go to places with specialized services". (IDJ, 42yrs, Parent, Female)

"Well, I can say that these specialists are not plenty in Ghana when you need their services you have to ask people about it and sometimes it is difficult to get them, even when you get them in the hospitals there is a long queue. So, with all this frustration and waiting I sometimes won't go to the hospital". (IDI, 39yrs, Parent, Female)

"... for specialist availability in hospitals, I can say that they are there but just that they are not many. I am a physiotherapist in a private hospital in Accra here, sometimes the workload is so overwhelming as there are many clients you have to attend to. So, clients are scheduled for me to see them, besides we are not in every hospital". (R11, 34yrs, Healthcare Provider-Public, Male)

4.6.4. Accessibility of building and equipment

Study participants agreed that many health centers are not disability-friendly. They linked the accessibility of the building to the physical environment of the health facility including entrance to consulting rooms, OPD's and top floors. Some participants also stated that equipment like standing frame, power table, parallel bars and stand-assist devices in most hospitals are not friendly to children with CP. Participants believed that most rehabilitation equipment in certain hospitals is meant for stroke patients and not for children with CP. Below are quotes from respondents:

"Any time I have to go to the hospital I get so worried; this is because in the hospital I have to carry my child to the first floor. My child is heavy and I cannot be carrying her up and down at all times. At least if there was an elevator "kra no" it would have helped me a bit. So, honestly, I am thinking of going somewhere else". (R11, 38yrs, Parent, Female)

"I understand how some parents complain about the physical environment of hospitals, indeed it's a great challenge because some parents find it so difficult to even enter certain health facilities to access primary health care. I am a physiotherapist and I have witnessed how some parents of children with disabilities struggle in accessing healthcare

when they come to the hospital... you know these barriers can make parents not come to the hospital". (KH, 14yrs, Healthcare Provider-Public, Male)

"Most of them are not disability friendly especially when you are with a wheelchair. Most of them too their elevators are not working, those that are working, their plant is not too good so when it is light out you are locked in it. In certain situations, you need to move from one department to the other by carrying your child at your back... all these things I have mentioned make me not to go to the hospital". (IDM, 12yrs, Parent, Female)

4.6.5. Healthcare providers attitude

Attitudes of healthcare providers play a significant role in parents' decisions to access health care for their children with disabilities. Some participants acknowledged the fact that not all healthcare providers attitude is bad. However, the majority of the respondents stated that their experience with healthcare providers has been bad and that discourages them from accessing healthcare for their children with CP. It was strongly perceived that bad behavior like discrimination from healthcare providers toward parents of children with CP would rather discourage them from accessing health care. Below are some excerpts from respondents:

"I could see they were ignorant, most of them were ignorant about the condition. Proudness and unprofessionalism are also part because sometimes their domina tells it all, the look with which they will even talk to you will make you shut up and I think they lack that customer service relationship skills because there should be something about the client-doctor relationship but it is not there... Because of these things I decided not to go to the hospital with my child with CP". (IDM, 12yrs, Parent, Female)

"We mother's whose children are having cerebral palsy, immediately they even see the child, some of them panic, if they don't panic then their mood and attitude will change towards the children, so even if they had to take care of the child, they will delay you and this is not good. I experienced that some time and I didn't like it at all, I got frustrated and decided to do the basic therapy myself at home. So, some of them their attitude is sometimes not good at all". (ID1, 34y/o, Parent, Female)

"So, the attitude of health care providers also could be a factor, let me give you an example. I had this patient who had a child with a brain malformation. She told me that she went for weighing and some nurses passed comments on her child that are frustrating. She made mention that sometimes the comments make her lose hope, it looks like whatever she's doing "mpo", it wouldn't come to a better end. So, this puts her off from accessing healthcare for her child". (K11, 36y/o, Healthcare Provider-Private, Female)

CHAPTER FIVE

DISCUSSIONS

5.1 Knowledge of National Health Policy

The level of knowledge on the National Health Policy was well known among almost all the participants as it was considered as a policy that aims to promote health for everyone in Ghana.

This view is similar to Vietan and Montaschli's (2020)'s assertion that the national health policy has been developed to promote, restore, and maintain good health for all people living in Ghana.

Participants also explained their knowledge of the national health policy from the persons with disabilities Act perspective as a means of getting access to healthcare services without any barrier or discrimination. This finding in this study is consistent with the Americans with Disability Act (1990) section 504 of the Rehabilitation Act that forbid discrimination based on disability and also the Person with Disability Act (2005) of Ghana section 4 (1) and (5) that prohibit discriminate, exploit or to subject a person with disabilities to abusive or degrading treatment.

The present study findings indicate that the majority of the respondents had sufficient knowledge regarding the National Health Insurance Scheme (NHIS) describing it as a safety net that replaces the cash and system of service delivery in Ghana. This finding is in agreement with a study conducted by Akande and Akande (2003) on "The Awareness and Attitude of Practitioners on NHIS in Liberia showed that all respondents were aware of the scheme but only a few did not know. Another study conducted by Dooen et al., (2013) on "Ghana's National Health Insurance Scheme: a national level investigation of members' perceptions on service provision in Ghana" and found that the national health insurance scheme replaces cash-and-carry, which required

individuals to make a payment from their pockets at service usage. However, another study by Gopalani and Darsinj (2012) showed that better-educated individuals can access diverse sources of information, correctly process and take advantage of benefits than those who are less educated and those without formal education. Those who could not afford to spend more on the healthcare needs of children with CP may adopt other coping mechanisms such as alternative care, presenting late at the health facilities, or not receiving care at all.

5.2 Perception of implementation of National Health Policy

Findings from this current study revealed that respondents are influenced in accessing health care for their wards even when they are insured as they perceived the implementation of the National Health Policy to be ineffective concerning poor-quality health service for the insured. This finding is similar to Bruce et al., (2008) study results on "The national health insurance scheme: perceptions and experiences of health care providers and clients in two districts in Ghana" showed that insured clients are not satisfied with the healthcare they received and perceived that they were given poorer quality services and tend to wait longer as compared to those making Out of Pocket Payment (OOP). The present study also revealed that the implementation of the National Health Policy is ineffective as respondents perceived that the national health insurance scheme does not cover major specialized services and treatment for children with CP. This study finding is in contrast to Dalryjog and Larr's (2012) study on "The effectiveness of NHIS in Ghana" found that both insured and uninsured respondents had positive perceptions and were satisfied with the care provided.

5.3 Parental factors

The study discovered that participants were generally aware of some of the factors that influence access to healthcare services among children with CP. A study conducted by Khartei and Karkoe

(2018) showed that distance to health facilities, social supports, age, the behavior of health workers, and access to quality health services shapes how parents access healthcare for their children and themselves. This finding is in agreement with Ilor et al., (2016) study on "The affecting factors of healthcare services demand in terms of health services use: A field application in Ibadan city" found that personal income, gender, attitudes, and behavior of physicians affect access to health demand. In the same study, it was reported that family members, perception of economic level, attitudes, and behaviors of physicians were found to influence health demand. Findings from this current study revealed that participants know about disability regarding the causes, signs, and symptoms as well as treatment for children with CP. This positively influenced parents' access to healthcare for their children with CP. This finding is consistent with Matt (2014) study on "Perception of disability among caregivers of children with disabilities in Nicaragua" found that parents with higher education have a better understanding and knowledge of their children's disability and frequently access health care services for their wards than parents with lower or no education. The current study findings also agree with Khatri and Karkoo's (2018) assertion that illiterate parents who belong to the lowest wealth quintile have lower access and use of healthcare for their children with CP.

Also, considering the causes of disability, this current study revealed that respondents know the causes of disability. Findings from the study showed that disability can be caused by disease and neurological problems leading to brain damage. This finding is in agreement with the Center for Diseases Control and Prevention (2019) assertion that risk factors such as infections during pregnancy, premature birth, and diseases like jaundice can cause CP.

Respondents in this study linked signs and symptoms of CP to poor eye contact, poor posture and balance, communication difficulties, and impaired fine and gross motor function. This

finding agrees with the Cerebral Palsy Alliance (2018) assertion that children with CP show signs and symptoms like swallowing difficulties, poor muscle spasms, low muscle tone, poor muscle control, reflexes, and posture, drooling, developmental delay, gastrointestinal problems, and not walking by 12-18 months. It was found from this study that treatment for children with CP includes physiotherapy, occupational therapy, and speech and language therapy. This finding is consistent with the Cerebral Palsy Guide (2020) statement that children with CP can improve their motor skills with alternative therapy, medication, and surgery through multidisciplinary teams such as neurologist, orthopedic surgeon, developmental pediatricians, physiotherapist, occupational therapist, nutritionist, respiratory therapists, psychologists to assess ability and behavior and speech and language, therapist.

It was also found out in this study that perceptions of parents about their children's disability (CP) also influence their decision to access healthcare for their children with CP. It was also established that stigmatization, discrimination, disrespect, loneliness, depression, and suicidal ideation are linked to disability (CP). This is similar to Physioplas's (2020) assertion that families with a child with a disability are more prone to depression, suicide, financial problems, relationship challenges, divorce, and bankruptcy. This statement is also in line with another study by Bachner (2020) on "society attitude towards persons with disabilities" found that society perceives that disability is a curse and punishment from ancestors and gods. Also, Duran and Ergun (2018) in their study on "The stigma perceived by parents of children with disability: an interpretative phenomenological analysis study in Balkisir" found that majority of people often have negative perceptions and stigmatizing attitudes towards children with disabilities (CP) and their families. In the same study, it was found that parents of children with disabilities cope with insults and rude behaviors from community members while they struggle with the

challenges of their children with CP. This is similar to a previous study by Opoku, Akpo, Gyamfi, and Mprah (2018) who affirmed that persons with disabilities are severely stigmatized, discriminated against, and excluded from all forms of the development process that results in limiting their opportunities to be engaged in decision-making and accessing healthcare.

Income was found from this current study to influence parents' access to health care services for their children with CP. Respondents emphasized that the level of income of a parent is dependent on the kind of job the parent does. This present study revealed that parents of children with CP who have no jobs find it difficult to access healthcare services for their wards due to the cost of treatment. This finding is in line with DeVoe, Titelson, and Wallace's (2011) assertion that children with CP from lower-income families experience more gaps in healthcare than children with CP from higher-income families.

Moreover, this study discovered that transportation is another factor that influences access to health care. Findings from this study indicated that transportation cost, distance to the nearest health facility, and stigmatization from drivers, passengers, and bus conductors (male) influence respondent's ability to access healthcare services for their children with CP. A previous study showed that healthcare utilization is influenced by the direct costs of healthcare services, travel time, and patient income (Review & Africans, 2017). This is in line with another study conducted by Bukuru Healthcare (2019) in Uganda which specified that patients complain about poor sanitation, lack of drugs and equipment, long waiting times, rude behavior of health workers, and poor referrals. However, in that same study it was revealed that over 8,000 rural Ugandans travel as far as 50 miles to attend a Bukuru working medical camp for healthcare.

Also, findings from this present study showed that respondents are not satisfied with the waiting time and cost of health care services. Respondents from this present study linked healthcare

satisfaction to quality health care, waiting time for treatment, and cost-effectiveness of healthcare services. This assertion is consistent with Khatri and Karkar's (2018) statement that quality health care account for patient satisfaction especially in terms of waiting time, cost of service, coordination, information, and physician's behavior. This finding agrees with Janak-hovela's (2015) findings that some physicians in public health facilities can be very rude due to the workload mounted on them.

3.4 Healthcare factors

Considering specialized services available, the present study found that respondents were informed about the available specialized services for their children with CP. It was discovered that speech and language therapy, physiotherapy, occupational therapy, behavioral therapy, augmentative communication, and dietary were some of the specialized services available but scarce and that makes it difficult to access healthcare for their children due to waiting time for treatment. Respondents in this present study believed that children who can access these services will be able to walk, interact with others through play, learn social skills, seat properly, have good muscle and neck control as well as good balance and body posture. This finding agrees with Baki (2016) study on "Current Rehabilitation Methods for Cerebral Palsy" found that children with CP that undergo muscle strengthening training, manual stretching, massage, neurodevelopmental treatment, conductive education, speech and language therapy, occupational therapy, and dieting have good body posture, balancing, neck coordination, strong muscle control and can walk sometimes. However, the lack of appropriate services for individuals with CP is a significant barrier to health care. For instance, qualitative research in Uttar Pradesh and Tamil Nadu states of India revealed that after the cost, the lack of services in the area was the second most significant barrier to using health facilities (WHO, 2011).

Also, it was found from this current study that proximity to an available health facility is another factor that influences access to healthcare for children with CP. From the study, respondents were discouraged to access the nearest health facility when transportation and distance to the health facility are problems. This finding is similar to *Aweyemi et al., (2011)* study on "Effect of Distance on Utilization of Health Care Services in Rural Kogi State in Nigeria" which found that distance and total cost of healthcare affects the utilization of both public and private hospitals. This finding also agrees with *Nesbitt et al., (2016)* study on "Barriers and facilitating factors in access to health services in the Republic of Moldova" found that distance from a health service provider, travel time, and waiting time to see a health professional is are strong factors that influence access to health care.

Moreover, the availability of specialists in hospitals was found from this present study to be scarce in most hospitals, and because of that, only a few respondents travel a long distance to access these specialized services for their wards. This finding is consistent with WHO (2017) reported that the registered number of rehabilitation specialists is far below the required minimum of 750 per 1 million even in developed countries. In addition to this, the present study revealed that most public and private hospitals are not environmentally friendly for children with CP who use wheelchairs. Respondents asserted that most public hospitals do not have elevators and ramps making it difficult to access healthcare services for their wards. This finding is in line with *Jamshidi et al., (2020)* study on "The effects of environmental factors on the patients' outcomes in hospital environments: A review of the literature" found that medical equipment adaptability, unit layout, room features, ramps, and elevators affect patients' access to healthcare. Another study by *Douglas and Douglas, (2004)* revealed that patients' need for personal space, a homely welcoming atmosphere, a supportive environment, ramps, and elevators influence access

to their healthcare. Cristina and Candiate (2013) also found in their study that out of 256 respondents, 9 (4%) were not able to access the building and 47(18%) were not able to be transferred from their wheelchair to the examination table.

It was also found from this study that some healthcare providers discriminate against parents of children with CP when seeking primary healthcare services and physiotherapy. This finding agrees with the WHO (2011) report that parents of children with disabilities face stigmatization and discrimination in most health facilities. This finding is also in line with Rogers et al. (2015) study on "Discrimination in healthcare settings is associated with disability in Older Adults: Health and Retirement Study, 2008-2012" revealed that 12.6% experienced discrimination infrequently while 5.9% experienced discrimination frequently.

CHAPTER SIX

CONCLUSION, RECOMMENDATIONS, AND LIMITATIONS

6.1 Summary of Key Findings

Firstly, it was found that many respondents believed the National Health Policy was developed to promote good health among Ghanaians. They affirmed that the National Health Policy includes improving the physical environment in hospitals and ensuring sustainable financing for health through NHIS for patients as ideal because hospitals with ramps and elevators encourage them to access healthcare services for their children with CP. Regular use of NHIS reduces the cost of medical bills on respondents. This complies with WHO guidelines on health-related rehabilitation and the National Health Insurance Scheme (Act 852).

Secondly, many respondents perceived the implementation of the National Health Policy to be ineffective. They acknowledged that most hospitals are not environmentally friendly and also the NHIS does not cover most of the medical treatments. This creates concern because unemployed parents of insured children with CP may feel reluctant to access health care.

Also, most participants seemed to have some appreciable knowledge of the causes, signs, and symptoms, and treatment for CP. They were aware of the individual factors that may influence access to healthcare for children with CP. They affirmed that income, transportation cost, distance to a health facility, perception of disability (CP), and satisfaction (quality health care) influences their access to healthcare for their wards with CP. This creates concern because parents of children with CP who face these challenges may be unwilling to access healthcare for their wards with CP.

Moreover, the study also pointed out that several participants have been stigmatized and discriminated against in public transports and hospitals because of their children with CP. Such participants believed that stigmatization and discrimination are inevitable with disability leading to suicidal ideation, depression, and loneliness. Such believes may not be easily changed because they have lived and experienced them for long.

Furthermore, the study also revealed that respondents know healthcare factors that influence their access to healthcare for their children with CP. They affirmed that even though there may be specialized services like physiotherapy, occupational therapy, and speech therapy in certain hospitals they still are scarcely making them face challenges with waiting time for treatment and cost of services. Participants asserted that proximity to the nearest health facility is a problem as transportation costs may be high. Also, the study found that negative attitudes of healthcare providers influence respondents' access to healthcare services for their children with CP. This concern can be addressed through awareness-raising and educating physicians in hospitals.

4.2 Conclusion

The study established that many respondents believed that most healthcare facilities are not physically accessible due to the absence of ramps and elevators. Respondents are discriminated against and stigmatized both in hospitals and public transports. It was also found that many public means of transport are not accessible to children with CP. Respondents believed that the National Health Policy is ineffective and the NHIS does not cover a wide range of services for children with CP. Moreover, the study also pointed out that the majority of the respondents seek medical care for their children with CP however others also seek spiritual healing for their children with CP.

6.4 Areas for Further Research

Further research should investigate the barriers to health care and its impact on quality healthcare for children with other disabilities since it has not been established in this study.

6.5 Study Limitations

Due to the small study size and limited geographical setting, the results of the study cannot be generalised to other regions. Additionally, this study did not include teachers of children with CP and so their views are not represented. The study also focused on only cerebral palsy.

6.4 Areas for Further Research

Further research should investigate the barriers to health care and its impact on quality healthcare for children with other disabilities since it has not been established in this study.

6.5 Study Limitations

Due to the small study size and limited geographical setting, the results of the study cannot be generalised to other regions. Additionally, this study did not include teachers of children with CP and so their views are not represented. The study also focused on only cerebral palsy.

REFERENCES

- ACT, D. (2006). *Persons With Disability Act, 2006 Act 713* (Vol. ACT 713).
- Ahmed, S.M., Petzold, M., Kabir, Z.N., and Tomson, G. (2016). Targeted interventions for the ultra-poor in rural Bangladesh: does it make any difference in their health-seeking behavior? *Social Science & Medicine* 63: 2899–911.
- Analy, D., Hand, C., Bradley, L., DiRocco, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability and Rehabilitation*, 35(19), 1589–1598. <https://doi.org/10.3109/09638288.2012.748840>
- Americans With Disabilities Act (1990). Pub. L. No. 101-336, 104 Stat. 328 (1990).
- Agency for Healthcare Research and Quality (2010). *2009 National Healthcare Quality and Disparities Reports*. Rockville, MD: AHRQ.
- Awoyemi, T. T., Obayek, O. A., & Opalawa, H. I. (2011). Effect of Distance on Utilization of Health Care Services in Rural Kogi State, Nigeria. *Journal of Human Ecology*, 33(1), 1–9. <https://doi.org/10.1080/09709274.2011.11906385>
- Baka, N. C. (2016). *We are InTechOpen, the world's leading publisher of Open Access books Built by scientists, for scientists TOP 1 %*.
- Basza R, Criel B, van der Stuyf P. (2007). Low enrolment in Ugandan Community Health Insurance Schemes: underlying causes and policy implications. *BMC Health Services Research* 7: 103.

- Bauer, A., Taggart, L., Rasmussen, J., Hinton, C., Owen, L., & Knapp, M. (2019). *Access to health care for older people with intellectual disability: a modeling study to explore the cost-effectiveness of health checks*. 1–16.
- Bot, C., Sur, H., & Soysak, S. (2016). The Affecting Factors of Healthcare Services Demand in term of Health Services Use: A Field Application. *International Journal of Health and Life Sciences*, 1(2), 33–41.
- Bruce E, Nath-Bam S, Agepong I. (2008). *Community Satisfaction, Equity in Coverage, and Implications for Sustainability of the Dangme West Health Insurance Scheme*. Project No. 2001/GD/08. Technical Report Series No. 9. Accra: Ghanaian Dutch Collaboration for Health Research and Development
- Bularu Healthcare. (2019). *The State of Healthcare in Uganda*. Retrieved from <https://bularuhealthcare.org/healthcare-in-uganda/>
- Burner P. (2020). *Society's Attitude Towards Persons with Disabilities*. Retrieved from <https://paul-burner.dental.ufl.edu/oral-health-care-for-persons-with-disabilities/societysattitude-toward-people-with-disabilities/>
- Centers for Disease Control and Prevention. (2019). *Causes and Risk Factors of Cerebral Palsy*. Retrieved from <https://www.cdc.gov/ncbddd/cp/causes.html>
- Cerebral Palsy Alliance. (2018). *Signs and Symptoms of Cerebral Palsy*. Retrieved from <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebralpalsy/signs-and-symptoms-of-cp/>
- Cerebral Palsy Guide. (2020). *Treatment for Cerebral Palsy*. Retrieved from

<https://www.cerebralpalsyguide.com/cerebral-palsy/>

- Charlson S, Sabbach S, Day F. (2008). Impact of mental health organisations: evidence from West Africa. *Health Policy and Planning* 23: 264-7
- Ching, P. (1992). *Factors Affecting the Demand For Health Services in The Philippines Profile*
- Ching *WORKING PAPER SERIES NO. 92-06 June 1992 Philippine Institute for Development Studies*. 92.
- Cooper, A. S., Melville, C., & Morrison, J. (2019). *And Men Their health needs differ and need to be recognized and met*. *JGIM*(34(3)), 414-415.
- Crossell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods approach. *Research Design Qualitative Quantitative and Mixed Methods Approaches, 3rd*, 260.
- Cristea Atenfido, M. M., & Cardinale, L. (2013). *Discrimination in Health Care against Persons with Disabilities: The ADA on Health*. *JGIM*(7), 12182. http://www.ada.gov/medicare_mobility_to/medicare_to.htm.
- Dahjong, P. A., & Lant, A. S. (2012). The national health insurance scheme: perceptions and experiences of health care providers and clients in two districts of Ghana. *Health Economics Review*, 2, 13. <http://dx.doi.org/10.1186/2191-1991-2-13>
- Dassah, E., Aldersey, H., Mocol, M. A., & Davison, C. (2018). *Factors affecting access to primary health care services for persons with disabilities in rural areas: a "best-fit" framework synthesis*, 1-13. *Framework synthesis. Global Health Research and Policy*. BioMed Central Ltd. <https://doi.org/10.1186/s41256-018-0091-x>

<https://www.cerebra.org/uk/about-us/cerebra-policy/>

- Chankova S, Sulzbach S, Diep F. (2008). Impact of mental health organizations: evidence from West Africa. *Health Policy and Planning* 23: 264-7
- Ching, P. (1992). *Factors Affecting the Demand For Health Services in The Philippines Pamphlet*
- Ching WORKING PAPER SERIES NO. 92-06 June 1992 Philippine Institute for Development Studies. 92.
- Cooper, A. S., Melville, C., & Morrison, J. (2014). *And Met Their health needs differ and need to be recognized and met. J29(7463)*, 414-415.
- Creswell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods approach. *Research Design Qualitative Quantitative and Mixed Methods Approaches, 3rd*, 260.
- Cristina Atencido, M. M., & Candiate, L. (2013). *Discrimination in Health Care against Persons with Disabilities: The ADA on Health. J2181(7)*, 12182. http://www.ada.gov/medicare_mobility_fa/medicare_fa.htm.
- Dahijong, P. A., & Laar, A. S. (2012). The national health insurance scheme: perceptions and experiences of health care providers and clients in two districts of Ghana. *Health Economics Review*, 2, 13. <http://dx.doi.org/10.1186/2191-1991-2-13>
- Dassah, E., Aldersey, H., Mccoll, M. A., & Davison, C. (2018). *Factors affecting access to primary health care services for persons with disabilities in rural areas: a "best-fit" framework synthesis*. 1-13. Framework synthesis. *Global Health Research and Policy*. BioMed Central Ltd. <https://doi.org/10.1186/s41256-018-0091-x>

- Davis, K., and Halbroich, J. (2014). Equitable access to care-how the United States ranks internationally. *New England Journal of Medicine* 371(17):1567-1570.
- DeVos, J. E., Titmson, C. J., & Wallace, L. S. (2011b). Insurance coverage gaps among US children with insured parents: are middle-income children more likely to have longer gaps? *Maternal and Child Health Journal*, 15(3), 342-351.
- Dixon, J., Tenkorang, E. Y., & Lagnaah, I. (2013). Ghana's National Health Insurance Scheme: A national-level investigation of members' perceptions of service provision. *BMC International Health and Human Rights*, 13(1). <https://doi.org/10.1186/1472-688X-13-35>.
- Donald, K. A., Sarris, P., Kakooza-Mwesigi, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology*, 21(1), 30-35. <https://doi.org/10.1016/j.spn.2014.01.001>
- Dong H, De Allegri M, Gassoul D, Soares A, Sauerborn R. (2009). Drop-out analysis of community-based insurance membership at Nouna, Burkina Faso. *Health Policy* 92: 174-8.
- Douglas, C. H., & Douglas, M. R. (2004). Patient-friendly hospital environments: Exploring the patients' perspective. *Health Expectations*, 7(1), 61-73. <https://doi.org/10.1046/j.1369-6513.2003.00251.x>
- Douthé, N., Ko, S., Dworkin, T., and Bwasa, S. (2015). Exposing some important barriers to health care access in the rural USA. *Public Health* 129(8):611-620.
- Drumoni, M.-L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Matich, L. (2006). Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives.

Journal of Disability Policy Studies, 17(2), 101-115.

<http://doi.org/10.1177/10442073060170020101>

Duran, S., & Ergin, S. (2013). *The stigma perceived by parents of intellectual disability children: an interpretative phenomenological analysis study* *Taramlayası bir fenomenolojik analiz çalışması*. <https://doi.org/10.5455/apd.282536>

Gopalan SS, Durairaj V. (2012). Addressing women's non-maternal healthcare financing in developing countries: what can we learn from the experiences of rural Indian women? *PLoS One* 7: 8

Oyarefi, E.A. (2013) *Country Report on Ghana, African Disability Rights Yearbook*, Vol. 1, pp. 221-243.

Haines, A., Sanders, D., and Lehmann, U. (2007). Achieving child survival goals: potential contribution of community health workers. *The Lancet* 369: 2121-31.

Handeman, W., Van Durme, W., and van Pelt, M. (2012). Access to health care for all: User fees plus a health equity fund in Sotikara, Cambodia. *Health Policy and Planning* 19: 22-32.

Ekman, B., Pathmanathan, I., and Liljestrand, J. (2014). Integrating health interventions for women, newborn babies, and children: a framework for action. *The Lancet* 372: 990-1000.

Institute of Medicine. (1993). *Access to Health Care in America*. Washington, DC: National Academy Press.

- Jarrahli, S., Parker, J. S., & Hasbani, S. (2020). The effects of environmental factors on the patient outcomes in hospital environments: A review of the literature. *Frontiers of Architectural Research*, 9(2), 249-263. <https://doi.org/10.1016/j.foar.2019.10.001>
- Jarzech-Jawlas, S. (2015). *Impact of waiting times in health care*. *Ann*. <https://doi.org/10.13140/RG.2.1.4164.6240>
- Jehu-Appiah C, Aryeetey GC, Spann E (2011). Who is enrolling, who is not and why? An assessment of equity of the national health insurance in Ghana. *Social Science & Medicine* 72: 157-62
- Katbi, I. A. Akande, A. A. & Akande, T. M. (2003). Awareness and attitude of medical practitioners in Ibadan towards national health insurance scheme. *The Nigerian Medical Practitioner*, 43 (2)
- Khatri, R. B., & Karkas, R. (2018). Social determinants of health affecting utilization of routine maternity services in Nepal: a narrative review of the evidence. *Reproductive Health Matters*, 26(54), 33-46. <https://doi.org/10.1080/09688080.2018.1535686>
- Khan, S., and Manderson, L. (2011). Health seeking and access to care for children with suspected dengue in Cambodia: an ethnographic study. *BMC Public Health* 7: 262.
- Khan, S. and Manderson, L. (2007). Health seeking and access to care for children with suspected dengue in Cambodia: an ethnographic study. *BMC Public Health* 7: 262.
- Krishna, A. (2012). Pathways out of and into poverty in 26 villages in Andhra Pradesh, India. *World Development* 34: 271-88.

- Kyomugisha EL, Itanganya E, Ekimpa E, Mugisha JF, Bazzyo W. (2009). Strategies for sustainability and equity of prepayment health schemes in Uganda. *African Health Sciences* 9(S2): 559-65.
- Laura VanPeymbroock. (2019). *People With Disability Face Barriers to Basic Health Care*. Retrieved from <https://www.usnews.com/news/healthiest-communities/articles/2019-10-04/commentary-people-with-disability-face-barriers-to-basic-health-care>.
- Lawn, J.E., Robde, J., and Rafkin, S. (2010). Alma-Ata 50 years on: revolutionary, relevant, and time to re-evaluate. *The Lancet* 372:917-27.
- Levesque, J. F., Harris, M. F., and Russell, G. (2013). Patient-centered access to health care: Conceptualizing access at the interface of health systems and populations. *International Journal for Equity in Health* 12(1):18.
- Mansoor, F., Wei, L., Hussain, A., & Aali, M. (2019). *Patient Satisfaction with Health Care Services: An Application of Physician's Behavior as a Moderator*. 1-16.
- Muradani M, Bangser M. (2004). Poor people's experience of health services in Tanzania: a literature review. *Reproductive Health Matters* 12: 138-153. [http://dx.doi.org/10.1016/S0968-8090\(04\)24135-0](http://dx.doi.org/10.1016/S0968-8090(04)24135-0)
- Man, S. B. (2014). Perceptions of disability among caregivers of children with disabilities in Niue: Implications for future opportunities and health care access. *International Journal of Medical and Public Health*, 1-17.

- Mohile, C. A., Frisayon, J., Cooper, S., Allan, L., Robinson, N., Burns, E., Trust, N. H. S. (2005). Enhancing primary health care services for adults with intellectual disabilities. *Care J Public Health*, 190-198. <https://doi.org/10.1111/j.1365-2788.2005.00640.x>
- McIntyre, S., Morgan, C., Walker, K., & Novak, I. (2011). Cerebral palsy-Dan's delay. *Developmental Disabilities Research Reviews*, 17(2), 114-129. <https://doi.org/10.1002/ddr.1106>
- National Center for Health Statistics (2017b). Health, United States. In *Health, United States, 2016: With chartbook on long-term trends in health*. Hyattsville (MD): National Center for Health Statistics (US).
- Nesbit, R. C., Lohela, T. J., Sorensen, S., Vesel, L., Mars, A., Okyere, E., Grandy, C., Arangakulasinge, S., Ovwaa-Agyei, S., Kirkwood, B. R., & Gabrysch, S. (2016). The influence of distance and quality of care on a place of delivery in rural Ghana. *Scientific Reports*, 6(June), 1-8. <https://doi.org/10.1038/srep10291>
- Ogijeri, O.M. (2017). Awareness and Perception of National Health Insurance Scheme (NHIS) among Librarians in Nigeria. *International Journal of Perceptions in Public Health*, 2(1)36-43.
- Obhango-Beko, A.I. & Adesherpe, W.O. (2010). Knowledge and attitude of civil servants in Oyo State, Southwestern Nigeria towards the national health insurance. *Nigerian Journal of Clinical Practice*, 13 (4), 421-4.
- Oyeka, M. P., Akpo, B. A., Ojarefi, N., & Mprah, W. (2018). *The Family and Disability in*

Ghana. *Highlighting Gaps in Achieving Social Inclusion*. (March)

<https://doi.org/10.3463/ideid.v2i34.666>

Osková, M., Joseph, L., Dugrain, L., & Shevell, M. (2013). Prevalence of Cerebral Palsy in Quebec: Alternative Approaches. *Neuroepidemiology*, 40(264-268). doi:10.1159/000345120

Ouellette-kuntz, A. H., Garcin, N., Lewis, M. E. S., Mirmes, P., Martin, C., Holden, J. J. A., Ouellette-kuntz, H., Mirmes, M. P., Garcin, N., Martin, P. C., Lewis, M. E. S., & Holden, M. D. J. J. A. (2019). Addressing Health Disparities Through Promoting Equity for Individuals with Intellectual Disability. *Canadian Journal of Public Health*, 96(Suppl 2), S8-22.

Palmer, M. & Herby, D. (2012). Models and measurement in disability: an international review.

Health Policy and Planning, 27,357-364.

Peters, D. H., Garg, A., and Bloom, G. (2011). Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences* 1136: 161-71.

PhysioPha. (2020). *Parents of Children with Cerebral Palsy; Raising a Child with Cerebral Palsy*. Retrieved from https://www.physio-pha.com/Parents_of_Children_with_Cerebral_Palsy

Ramanathan, K., Montesinos, E.V., Matheson, D., Eterno, C., and Evans, T. (2010). Primary Health Care and the social determinants of health: essential and complementary

approaches for reducing inequities in health. *Journal of Epidemiology and Community Health*. [Epub ahead of print].

- Review, A. S., & Alkaine, B. (2017). *Employment status, medical support, and income as significant factors in Access to Essential Medicines*. *JG11*.
- Rogers, S. E., Trasher, A. D., Mao, Y., Boscardin, W. J., & Smith, A. K. (2015). Discrimination in Healthcare Settings is Associated with Disability in Older Adults: Health and Retirement Study, 2008–2012. *Journal of General Internal Medicine*, *30*(10), 1413–1420. <https://doi.org/10.1007/s11606-015-3233-6>
- Rohde, J., Coovadia, S., and Chopra, M. (2010). 30 years after Abu-Ata: has primary health care worked in countries? *The Lancet* 372: 950–61.
- Rosenbaum, P., & Stewart, D. (2004). The World Health Organization International Classification of Functioning, Disability, and Health: A model to guide clinical thinking, practice and research in the field of cerebral palsy. *Seminars in Pediatric Neurology*, *11*(1), 5–10. <https://doi.org/10.1016/j.apen.2004.01.002>
- Singayo, C., Mwash, M., & Rhoda, A. (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, *71*(1), 1–6. <https://doi.org/10.4102/sajp.v71n1.274>
- Srindo, B., & Aarts, C. (2010). *Family perceptions in caring for children and adolescents with mental disabilities: a qualitative study from Tanzania*. *JG12*.

- Squires, D., and C. Anderson. (2015). US health care from a global perspective: Spending, use of services, prices, and health in 13 countries. *Issue Brief (Commonwealth Fund)* 13:1-15.
- Thomas, K. C., Wilkins, C. S., & Merribooy, J. P. (2016). Examination of parent insurance ratings, child expenditures, and financial burden among children with Autism: A mismatch suggests new hypotheses to test. *Pediatrics*, 137 (Supplement 2), S186-S195.
- Tadzi, E. P., Bagri, J. T., & Danso, A. K. (2017). *Human Rights of Students with Disabilities in Ghana: Accessibility of the University Built Environment*. *Human Rights of Students with Disabilities in Ghana: Accessibility of the University Built Environment*. 8/11(September). <https://doi.org/10.1080/18918131.2017.1348678>
- UNICEF (2013). *The state of the world's children 2013: children with disabilities*. Geneva: UNICEF.
- UN General Assembly. *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106*, available at: <https://www.refworld.org/docid/45d79632.html> [accessed 13 June 2021]
- United Nations. (2006). United Nations Web Services Section, Department of Public Information. *Convention on the Rights for Persons with Disabilities: Some facts about persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/facts.shtml> on 9th October 2019.

- Vartan, C. K., & Montachi, E. (2020). National Health Policy. *British Medical Journal*, 343(12), 279. <https://doi.org/10.1136/bmj.2.4312.279>
- Volos, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 18(7), 815-826.
- Wang, H., Otso, N., & Dano-odby, L. (2017). *Ghana National Health Insurance Scheme*. Debra Naylor, Naylor Design, Inc. www.worldbank.org
- World Health Organization & World Bank (2011). *World report on disability*. Geneva: WHO.
- World Health Organization (2011). *World Report on disability: Main Report (Main ed., Vol. 1 of 2)*. World Health Organization and the World Bank.
- World Health Organization (2015). *World Report on disability: Main Report (Main ed., Vol. 1 of 2)*. World Health Organization and the World Bank.
- World Health Organization (2017). *Health impact assessment (HIA), determinants of health*. Geneva, Switzerland: WHO. <http://www.who.int/hia/evidence/doh/en> (accessed March 8, 2017).
- WHO. (2017). The need to scale up a rehabilitation. *Rehabilitation*, 1-9. <https://www.who.int/disabilities/care/NeedToScaleUpRehab.pdf?ua=1>
<http://www.who.int/disabilities/care/Need-to-scale-up-rehab-July2018.pdf?ua=1>

World Population Review. (2021). *World Population Review*. Retrieved from <https://worldpopulationreview.com/countries/ghana-population>

YAW, O.-D. (2017). *Persons with Disabilities displeased with disability act*. Retrieved from <https://newsofghana.com.gh/persons-with-disabilities-displeased-with-disability-act/>

APPENDIX I PARTICIPANT INFORMATION SHEET

PARTICIPANTS INFORMATION SHEET

The Information Sheet provides information about the research for participants to make an informed decision of whether to participate in the study or not. It outlines the nature of the research, what the research involves, risks, benefits, compensation (if there is none, this should be stated).

Title of Study

Access to healthcare services among children with cerebral palsy in the Greater Accra Region of Ghana.

Introduction

My name is Nathaniel Laifu Asidah, P. O. Box LG 1141, Legon., Graduate student, School of Public Health, University of Ghana, 0547654290, nasidah@st.ug.edu.gh

Background and Purpose of research

Children with cerebral palsy face a lot of challenges in accessing healthcare services which results in them having unmet healthcare needs. Parents/caregivers of children with cerebral palsy also do experience challenges in accessing mainstream and specialised healthcare services for their wards. The purpose of the study is to identify factors that influence access to healthcare services.

Nature of research

The study is about access to healthcare services for children with cerebral palsy. The researcher seeks to identify the factors that facilitate and hinder access to healthcare services for children with cerebral palsy. The number of participants for the study is fifteen (15) and will be interviewed at an enclosed space in their homes.

Participants involvement

If you agree to participate in this study, you will first of all be asked to sign a participant consent form after which you are required to share your experiences with accessing healthcare services for your child through an interview. The interview will last for at least 50 minutes.

Potential risks and benefits

The risks attached to this study are discomfort in answering questions and psychological distress. If you feel uncomfortable answering certain questions, you will be advised to withdraw from the study if you so wish. In situations where you experience psychological distress, you will be referred to a counsellor.

The study does not come with any direct benefit to participants. However, findings from the study will help inform stakeholders such as policymakers and the Ministry of Health on the need to developing strategic plans and programs that will foster and enhance access to healthcare services that meet the overall health care needs of children with cerebral palsy.

Cost and compensation

In this study, you will not incur any cost as the principal investigator will be making time to come to you. However, your child with cerebral palsy will be given a small gift like a pencil, book, and a toy.

Confidentiality

The interview will be carried out in an enclosed space to ensure privacy. Study participants will be guaranteed anonymity. Transcription will be coded using Pseudonyms and records that can easily be traced to participants will be kept confidential.

Voluntary participation/withdrawal

You have the right to voluntarily participate and withdraw from the study at any time if and when they so wish without any penalty and having to give reasons.

Provision of Information and Consent for participants

A copy of the information sheet and consent forms will be given to you after it has been signed or thumb printed.

Recording of interview

The interview will be recorded for direct transcription in order not to miss information. Data files on electronic devices will be fingerprint and password protected only known to the principal investigator. Data will be kept by the principal investigator for 5 years to allow for publication of the research, after which it will be destroyed permanently by formatting electronic devices completely.

Conflict of interest

The principal investigator would ensure that there is no conflict of interest as far as the study is concerned.

Funding information

The principal investigator will use his funds to sponsor the study.

Measure to reduce the spread of COVID-19 infection

The principal investigator would provide and ensure that study participants undergo handwashing with soap under running water and use alcohol-based hand sanitizer at the study site. Participants would also be provided with a face mask at no cost while observing physical distancing before and during the interview. The principal investigator would also adhere to these preventive measures outlined.

Who to Contact for Further Clarification/Questions

If you have any questions concerning the study, please do not hesitate to ask at any point in time. For more information about the study contact me on: Nathaniel Lartey Andah, 05476540290, nandah@ug.edu.gh OR Robert Andah, 0209515582.

You can contact the administrator of the GHS Ethics review committee, Nana Abena Agya on 0501539896 and also at ethics.review.hs@ghsnet.org for ethical issues and rights to participation.

APPENDIX II CONSENT FORM FOR RESPONDENT

PARTICIPANTS' STATEMENT

I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and satisfactorily explained to me in a language I understand (English, and Twi). I fully understand the contents and any potential implications as well as my right to change my mind (or withdraw from the research) even after I have signed this form.

I voluntarily agree to be part of this research.

Name or Initials of Participant..... ID Code

.....

Participants' Signature OR Thumb Print..... OR Mark (Please specify).....

Date:.....

INTERPRETERS' STATEMENT (where applicable)

I interpreted the purpose and contents of the Participants' Information Sheet to the aforementioned participant to the best of my ability in the (Twi) language to his proper understanding.

All questions, appropriate clarifications sought by the participant, and answers were also duly interpreted to his/her satisfaction.

Name of Interpreter.....

Signature of Interpreter.....

Date:.....

STATEMENT OF WITNESS (where applicable)

I was present when the purpose and contents of the Participant Information Sheet was read and explained satisfactorily to the participant in the language, he/she understood (Two)

I confirm that he/she was allowed to ask questions/seek clarifications and the same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research.

Name:.....

Signature:..... OR Thumb Print OR Mark (please specify).....

Date:.....

INVESTIGATOR STATEMENT AND SIGNATURE

Brief statement or declaration that the investigator has given enough information to participants to make informed decisions.

Example: I certify that the participant has been given ample time to read and learn about the study.

All questions and clarifications raised by the participant have been addressed.

Researcher's name Signature Date.....

APPENDIX III: INTERVIEW GUIDE FOR PARENTS /HEALTHCARE PROVIDERS

A) INTERVIEW GUIDE FOR PARENTS SECTION A: PARTICIPANTS SOCIAL DEMOGRAPHIC INFORMATION

1. Age:
2. Sex
3. Marital Status:
4. Level of Education:
5. Religion:
6. Working experience (years):
7. Occupation:

NATIONAL HEALTH POLICY IN GHANA

1. Please, do you know anything about Ghana Disability Act?

Probe 1: What do you know concerning health in the disability Act?

Probe 2: What kind of services do you think should be made available for children with intellectual disabilities?

2. What is your perception of the implementation of the Disability Act?
3. Please, do you know anything about health policy in Ghana?

Probe 1: Which services are you able to access for your ward?

Probe 2: Are these services from public or private health facilities.

4. Please what do you know about the National Health Insurance?

Probe 1: Do you have a health insurance card for your child. If YES, how long have you been using it, and if NO, what is your reason?

Probe 2: Are the health services you access covered by the insurance card?

Probe 3: Which among the health services is/are not covered by the insurance card.

5. Please how often do you use the health insurance card to access healthcare?

Probe 1: What is your perception of the National health insurance policy?

Probe 2: What areas do you think need to be improved on the health policy?

PARENTAL FACTORS

6. Please, what is the condition of your child?

Probe 1: How did you get to know about your child's condition?

Probe 2: How do you perceive your child's condition?

Probe 3: How are you perceived by others?

Probe 4: Do you think spirituality is connected to your child's condition?

7. Please tell me, on average what percentage of your income goes into your child's health?

Probe 1: Have you had to delay health care because of cost?

Probe 2: How are you able to cope with or without work and your child's condition?

Probe 3: Tell me, have you had to seek financial support from others due to the cost of health care?

8. Please how often do you access a health facility for your child?

Probe 1: Which type of health facility do you access (Private and/or Public)?

Probe 2: How far is the health facility from your home?

Probe 3: Tell me about the transportation system. Do you get it easy or not and why is that?

9. Tell me, what belief do you have about health care?

Probe 1: Explain to me how often do you visit the clinic with your child?

Probe 2: How do you go about accessing health care for your child?

Probe 3: What motivates you to seek health care services for your child?

HEALTHCARE FACTORS

10. Does the health facility you access provide specialized rehabilitation services for children with special needs?

Probe 1: Please can you mention some of these services you access for your ward?

Probe 2: Are these services you mentioned covered by health insurance? If YES, please tell me how much it covers, and if NO how do you go about with the bill.

Probe 3: Do you think the specialized services offered are expensive?

Probe 4: How often do you access these services for your ward within a week or month?

11. How close is the health facility you access away from your home?

Probe 1: What do you think about the transportation system?

Probe 2: What do you think about the cost of transportation to the health facility?

12. In terms of communication, how do the health providers communicate with your child?

Probe 1: What are some of the barriers encountered?

Probe 2: How do the health providers overcome these challenges you have mentioned?

Probe 3: In what ways do you think health providers can help improve communication between them and your ward?

13. Please, how do you access healthcare for your child using the National Health Insurance card?

14. Aside from the availability of specialized services, are there available specialists to render the services?

Probe 1: What specialized services are needed for your child.

Probe 2: What do you think about the cost of specialized services?

15. What are the challenges experienced in accessing healthcare services?

Probe 1: How do you understand what the doctor says about your child's condition?

Probe 2: What do you think about the environment of the health facility?

Probe 3: What do you think about the waiting time to get treatment for your child?

Probe 4: How are the healthcare provider's office and equipment accessible?

Probe 5: Does healthcare providers consider your perceptions about your child's health in decision making?

16. How do you perceive the attitudes of healthcare providers towards you and your child?

Probe 1: Describe the healthcare provider's attitude towards your child during treatment and appointments?

Probe 2: Please can you share with me your experience (if any) on discrimination at a health facility against your child?

Probe 3: In what ways do their attitudes affect your demand for health care?

SATISFACTION

17. In your perspective, how will you describe quality healthcare?

Probe 1: What makes up the quality of healthcare?

Probe 2: What do you think about the waiting time to get treatment?

Probe 3: What do you think about the cost of the service?

Probe 4: What do you think about how the health facility gives information

B) INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS

SECTION A: PARTICIPANTS SOCIAL DEMOGRAPHIC INFORMATION

1. Age:
2. Sex
3. Marital Status:
4. Level of Education:
5. Religion:
6. Working experience (years):
7. Occupation:

INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS

Q1. HEALTHCARE FACTORS

1. Please can you share with me your experience in working with children with cerebral palsy?

Probe 1: What are the major healthcare needs of children with cerebral palsy.

Probe 2: What barriers do parents of children with cerebral palsy face when accessing health care.

Probe 3: What services are available and currently provided for children with cerebral palsy.

2. What constitute the challenges (if any) in recruiting, training, and maintaining specialist in the health facility

Probe 1: In your perspective how can the challenges be resolved?

3. In your own opinion, do specialist healthcare providers have adequate knowledge of children with cerebral palsy.

Probe 1: what about general healthcare practitioners?

4. Please share with me your thought on discrimination and stigmatization against children with cerebral palsy.

5. How do healthcare providers communicate with children with cerebral palsy when they

Probe 1: how do healthcare providers overcome communication barriers when offering service to children with CP?

Q2. NATIONAL HEALTH POLICY IN GHANA

6. How do you perceive the implementation of Ghana's health policy?

Probe 1: Please describe to me how NHIS works for children with CP in accessing specialized services.

7. How best do you think access to healthcare can be facilitated?

8. Please, do you know anything about the Ghana Disability Act?

Probe 1: Could you share with me what you know concerning the Ghana Disability Act.

Probe 2: what is your perception of the implementation of the Ghana Disability Act.

9. In your own opinion do specialists for children with CP have knowledge of Ghana Disability Act?

Q4 PARENTAL FACTORS

10. In your perspective what could be the possible factors that can affect parents' access to healthcare services for their children with CP.

Probe 1: How do these factors affect parents' access to healthcare for their children with

CP negatively?

11. In your perspective how will you describe quality healthcare?

Probe 1: What do you think about the waiting time for parents to access treatment for their children with CP.

Probe 2: What do you think about how the health facility gives information to parents with children with CP.

Probe 3: What do you think about the cost of specialist services for children with CP.

Probe 4: Please what do you think about parents keep up with the specialized services for children with CP.

APPENDIX IV: ETHICAL CLEARANCE

GHANA HEALTH SERVICES ETHICS REVIEW COMMITTEE

Review of reports the
number and date of the
Letter should be quoted



Research & Development Division

Ghana Health Service

P. O. Box 958 Accra

Accra

GPO Address: GH-001 1300

Tel: +233-30-4831700

Fax: +233-30-4831620

Email: ethics.review@ghghs.gov.gh

Meeting Laboratory/Health Care G.C. 195
Four Afl. St.

17th March, 2021

Subsequent Letter Number
P. O. Box LG 1141
Legon - Accra

The Ghana Health Services Ethics Review Committee has reviewed and given approval for the implementation of your study proposal.

| GHS-ERC Number | GHS-ERC 021/01/20 |
|------------------|--|
| Project Title | Factors Associated with Access to Healthcare Services among Children with Intellectual Disabilities in the Greater Accra Region of Ghana |
| Approval Date | 17 th March, 2021 |
| Expiry Date | 17 th March, 2021 |
| GHS-ERC Decision | Approved |

This approval requires the following from the Principal Investigator:

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months.
- Reporting of all serious adverse events related to the study to the ERC within three days verbally and within days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings
- Please note that any modification of the study without ERC approval of the amendment is invalid

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approval process!

SIGNED: _____

Dr. Cynthia Nantambu
GHS-ERC, Chairperson

Dr. The Director, Research & Development Division, Ghana Health Service, Accra