

Perceptions of Primary Caregivers about Causes and Risk Factors of Cerebral Palsy in Ashanti Region, Ghana

Ernest Appiah Kyei^{1*}, Joslin Dogbe¹

1. Centre for Disability Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

ABSTRACT

Purpose: Cerebral palsy (CP) is the most common chronic childhood disability, but in most cases the primary causes are largely unknown. The study sought to determine the perceptions about the causes and risk factors of CP among primary caregivers of children with CP in the Ashanti region of Ghana.

Method: A descriptive study design with a quantitative approach was used. A simple random sampling technique was adopted to select 100 participants from among the primary caregivers whose children with CP were attending the physiotherapy unit of the Komfo Anokye Teaching Hospital in Ashanti region. A structured questionnaire was administered to the respondents and data were analysed using SPSS version 21.0.

Results: CP was perceived as a disease caused by witchcraft (40%), punishment from God or Gods (12%), or by being cursed (10%). More than half (54%) of the respondents did not know of any risk factor for CP.

Conclusion and Implications: The perceived negative causes, as well as ignorance about the risk factors for CP, could result in primary caregivers stopping their children with CP from availing of the physiotherapy services. Public education and campaigns should focus on the causes and risk factors for CP, in order to change negative perceptions and improve awareness among the general public.

Key words: Primary caregivers, children with cerebral palsy, causes and risk factors for cerebral palsy.

* **Corresponding Author:** Ernest Appiah Kyei, Centre for Disability Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana. Email: rastugajr@yahoo.com

INTRODUCTION

Cerebral palsy (CP) is a chronic condition, generally of the motor function, which happens in children as the result of a non-progressive insult to the immature brain (Alikor, 2007). It has been recognised as the most common chronic disability in infancy (Rosenbaum, 2003) by a great number of health and social services (Morris, 2007). Cerebral palsy can be described by spasticity, movement disorders, muscle weakness, ataxia, and inflexibility (Koman et al, 2004). Again, it is believed that children diagnosed with cerebral palsy are at risk of feeding difficulties as a result of clinically significant motor, in addition to associated sensory, difficulties (Wilson and Hustad, 2009). The prevalence of feeding difficulties among children with cerebral palsy is estimated to be 40% to 90% (Trier and Thomas, 1998). A successful diagnosis and intervention for cerebral palsy is dependent on continuous assessment of the clinical presentation, pattern of development of symptoms, family history, obstetric history and environmental factors (Kriger, 2006).

Cerebral palsy remains a condition that cannot be cured; however, it can be managed (Levitt and Pickering, 2010) by physiotherapy treatment methods like exercise therapy, massaging and manual stretching. Studies have shown that physiotherapy plays an important role in managing children with CP, as the concentration is on function, active movement, and optimal use of the child's potential (Caspersen et al, 1985). The key objectives of physiotherapy for children with CP are: to reduce the effect of physical impairments, to enable them to gain independence in the society, and to improve the quality of life of the affected children as well as their families (primary caregivers) (Cusick et al, 2006). Besides these, there are methods obtained from motor learning-based concepts like Neurodevelopmental Treatment, muscle education and braces, progressive pattern movements, and synergistic movement patterns (Levitt and Pickering, 2010).

Globally, it is estimated that the population of persons with cerebral palsy has surpassed 15 million (Winster et al, 2002). According to Centres for Disease Control and Prevention (CDC) the average prevalence of CP in 2004 was 3.3 per 1,000 live births (Arneson et al, 2008). In the developing world, the prevalence of cerebral palsy is not well proven but it is estimated to be 1.5 - 5.6 per 1000 live births (Donker et al, 2008). Even though there have been arguments concerning the variations in the prevalence rates over time, current investigations have reported a prevalence rate of 2 - 3 per 1,000 live births (Winster et al, 2002). The

prevalence is higher among boys as compared to girls, with male to female ratio being 1.4:1 (Arneson et al, 2008). It has also been revealed that the prevalence rate of cerebral palsy is higher in developing countries (Wu et al, 2011).

According to a non-governmental organisation, Cerebral Palsy Africa (2014), the prevalence of cerebral palsy in Ghana is estimated to be 1 per 300 births. Also, the prevalence of cerebral palsy among the rural communities in Ghana is estimated to be high as a result of the poor usage of health professionals for delivery, in spite of the accessibility of free obstetric care (Mills et al, 2008).

There are several factors that contribute to higher risks of CP. In countless cases, the primary causes of CP remain largely unidentified (Nelson, 2009). However, information available indicates that perinatal asphyxia accounts for between 6% and 8% of CP (Yudkin et al, 1995). Studies done in Africa revealed that birth asphyxia, kernicterus and neonatal infection which are all developed in the course of the perinatal period, are the most common causes of cerebral palsy (Donald et al, 2015). Again, it appears the most important factors associated with cerebral palsy in Nigeria are birth asphyxia, severe neonatal jaundice and prematurity. Other factors include chorioamnionitis, maternal infection, antepartum haemorrhage (vaginal bleeding), second stage labour lasting beyond four hours, untreated hyperbilirubinaemia, foetal anoxic events, and foetal infection, for example meningitis (Nelson and Grether, 1999).

The beliefs about sickness, health and disability vary in all societies. Different societies have diverse meanings on causes of disability, beliefs and attitudes, perceptions and behaviour towards disability (Munsaka, 2012). In Zimbabwe, the belief is that people's lives are controlled by ancestral spirits and that disability (including CP) is of spiritual cause (Marongwe and Mate, 2007). In Saudi Arabia, mothers' perceptions of their children's disability are attached to religious beliefs and cultural norms, as they believe that it is the role of the evil spirit (Jinn) that causes them to have a child with disability (Mohamed et al, 2019).

In Ghana, disability (including CP) is found to be a seriously stigmatising condition as a result of the cultural beliefs attached to it (Tinney et al, 2007). Disability at birth is usually understood to be a punishment from God or the Gods for one's wrongdoing, or by a family member or by the community (Avoke, 2002). It is sometimes perceived to be the result of witchcraft, sorcery, "juju" and magic, and also seen as being cursed or possessed, and this certainly affects access to education, treatments, and other basic needs (Agbenyaga, 2003). Children with

cerebral palsy are understood to be children given by the River God, and are therefore known as “Nsuoba” (meaning- water children) (Avoke, 1997). Another study done in Ghana by Zuurmond et al (2018) revealed that primary caregivers lacked knowledge about their children’s condition, and held strong traditional beliefs about it.

However, there is a perception that caring for a child with disability, including one with cerebral palsy, is by way of performing God’s work, for which there will be a blessing from God (Green, 2007).

Objective

This study sought to determine the perceived causes and risk factors of cerebral palsy among primary caregivers of children with CP who attend the physiotherapy unit in the Komfo Anokye Teaching Hospital (KATH) in the Ashanti region of Ghana.

METHOD

Study Design

A descriptive study design was used, with a quantitative approach.

Study Site

The study was carried out at the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana. It is the second largest hospital in Ghana and the only tertiary health institution in the Ashanti region. This is the main referral hospital for Ashanti and Brong Ahafo regions, and formerly used to handle referrals from the Northern, Upper East and Upper West regions until the Tamale Regional Hospital was upgraded to a Teaching Hospital.

The Komfo Anokye Teaching Hospital is governed by a Board made up of 4 Non-Executive members (government appointees), 6 Executive members, and the Dean of the School of Medical Sciences. It currently has about 1000 beds, and has child health, diagnostic, pharmacy, oncology, polyclinics and physiotherapy units.

Study Sample

A total of 128 primary caregivers had visited the physiotherapy unit of Komfo Anokye Teaching Hospital during the previous 9 months to seek rehabilitation services for their children with CP.

A simple random sampling technique, using Yamane (1967) simplified formula, was adopted to select 100 respondents.

$$n = \frac{N}{1 + N(e)^2}$$

Where n = sample size, N = population size, and e = level of precision.

The formula was applied to the aforementioned sample:

$$N = 128$$

$$1 + N(e)^2 = 1 + 128(.05)^2$$

$$n = \frac{128}{1 + 128(.05)^2}$$

$$n = 96$$

A 5% non-respondent rate was assumed; thus, to account for those who would opt out of participation at some point (despite initial acceptance), 4 was added to the 96 to give a sample size of 100 primary caregivers. The number 4 was obtained after calculating 5% of 96, which is 4.8.

Sets of even and odd numbers were written on pieces of paper. Primary caregivers, who visited the hospital's physiotherapy unit on a daily basis with their children with CP, were asked to pick one of the paper pieces, and those who picked even numbers were selected for the study.

Inclusion Criteria

Primary caregivers were selected on the basis of the following criteria:

- Those whose children were between 1 and 5 years of age,
- Those whose children had been officially diagnosed as having cerebral palsy, and
- Those who consented to be part of the study.

Data Collection

Data collection was done over a period of 3 months to allow time to reach all primary caregivers. Each caregiver spent about 30 minutes to answer all questions during the data collection.

The researchers developed an instrument (see Appendix) to determine primary caregivers' knowledge about the causes and risk factors of CP. Respondents were made to choose from each of 5 options about the perceived causes and risk factors of CP, the ones that best described the cause and risk factors of their child's condition. These options were based on people's perceptions of a child born with a disability that had been presented in earlier literature.

The purpose of the study was explained to the respondents before they signed a consent form. Verbal consent was taken from respondents who could not read or write.

Data Analysis

Data were entered and analysed with computer-based software Statistical Package for Social Sciences (SPSS) version 21.0 and the results were presented using simple descriptive statistics of percentages and frequencies in Tables and Graphs such as pie charts.

Ethics Approval

Before data collection, ethical approval was obtained from the Committee on Human Research, Publications and Ethics, Kwame Nkrumah University of Science and Technology, School of Medical Sciences and Komfo Anokye Teaching Hospital. Prospective study respondents were given the translation of a written informed consent. Explanations were given in a language they could understand,

before they were enrolled in the study. Anonymity and confidentiality were assured by assigning codes in place of their formal names in the data, and the information was not passed on to anyone. They were also free to decide whether to participate in the study or not.

RESULTS

Demographic Characteristics of Respondents

Table 1 shows that the mean age of the respondents was 33 years; half (50%) were between 30-35 years of age and the rest (26%) were between 36-41 years old. Most of them (90%) were females and only 10% were males. While 56% of them were married, 30% were single and 9% were divorced. More than half (53%) were Akan. Although 30% of the respondents had no formal education, 70% had at least completed primary education.

Table 1: Demographic Characteristics of Respondents

Variables	Frequency	Percentages (%)
Age (Years)		
18 – 23 years	7	7
24 – 29 years	12	12
30 – 35 years	50	50
36 – 41 years	26	26
42 – 47 years	5	5
Mean	33	
Gender		
Male	10	10
Female	90	90
Marital status		
Married	56	56
Single	30	30
Widowed	5	5
Divorced	9	9
Ethnicity		
Akan	53	53

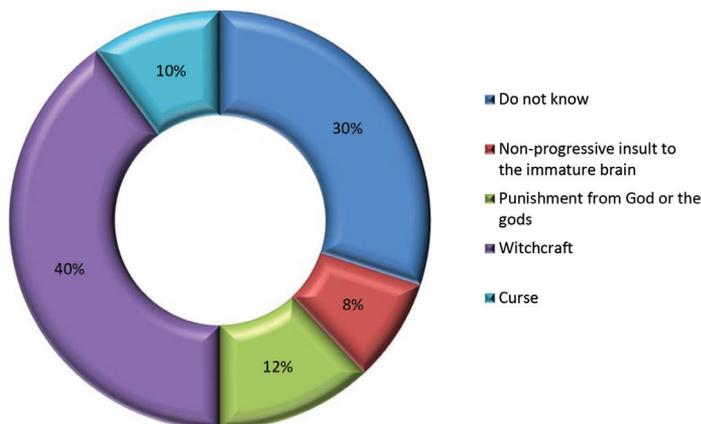
Dagomba	9	9
Ga/Adangme	13	13
Ewe	18	18
Gonja	5	5
Others	2	2
Education		
No formal education	30	30
Primary	15	15
Middle/JHS	29	29
SHS/A Level	17	17
Tertiary	9	9
Occupation		
Unemployed	30	30
Civil servant	15	15
Artisan	5	5
Trader	40	40
Apprentice	10	10

(Source: Field survey, 2016)

Perceived Causes of Cerebral Palsy

Figure 1 shows that 40% of the respondents felt that cerebral palsy was caused by witchcraft, 12% said it was punishment from God or Gods, 10% attributed it to a curse, 8% said it was non-progressive insult to the immature brain. However, 30% of the respondents did not know what the cause of cerebral palsy could be

Figure 1: Perceived Causes of Cerebral Palsy

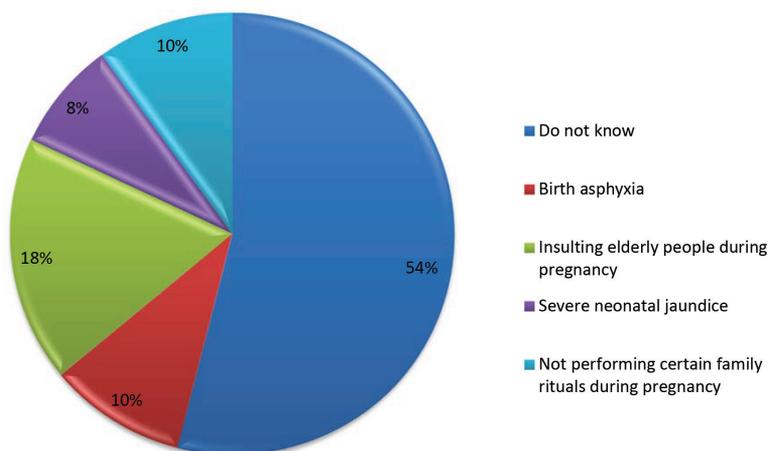


(Source: Field work, 2016)

Perceived Risk Factors of Cerebral Palsy

Figure 2 reveals that more than half (54%) of the respondents said that they did not know the risk factors of cerebral palsy, 18% mentioned insulting elderly people during pregnancy as a risk factor, 10% mentioned not performing certain family rituals during pregnancy, and another 10% mentioned birth asphyxia as risk factors. However, 8% of the respondents mentioned severe neonatal jaundice as a risk factor of cerebral palsy.

Figure 2: Perceived Risk Factors of Cerebral Palsy



(Source: Field work, 2016)

DISCUSSION

The study revealed that cultural beliefs attached to the causes of disability, including cerebral palsy, played a significant role. Most of the respondents believed that cerebral palsy could be caused by witchcraft, punishment from God or the Gods, and by being cursed.

The belief that a child born with disability (CP) is a punishment from God or the Gods is similar to the findings of Avoke (2002). Again, these findings are consistent with a study by Agbenyaga (2003) which showed that respondents felt children were born with a disability (CP) as a result of witchcraft, and were also regarded as cursed or possessed. The findings of Avoke and Agbenyaga are not surprising, as both studies were also done in Ghana where tradition, superstition and culture pervade all aspect of the people's lives. Studies done in other countries like Zimbabwe (Marongwe & Mate, 2007) and Saudi Arabia (Mohamed et al, 2019) also support the findings that disability is attached to religious beliefs and cultural norms, and is of spiritual cause or the role of the evil spirit.

It can therefore be deduced from the findings that the majority of the respondents viewed cerebral palsy from a cultural perspective in terms of the causes, and were ignorant of the reality. The implication is that some of the primary caregivers may withdraw their children from the physiotherapy services due to their cultural beliefs. Many of them may not see their children's condition as medical, or may not perceive biomedical interventions as effective or even necessary (Diken, 2006), as they hold strong traditional beliefs, leading them to discontinue outpatient physiotherapy (Zuurmond et al, 2018). These attributions also affect the access of children with disabilities (CP) to treatments and other basic needs (Agbenyega, 2003).

Consequently the health conditions of these children, which could have been managed with physiotherapy services, could deteriorate. Again, the caregivers' burden could also worsen as the children may not be able to lead independent adult lives. This could affect the caregivers' economic activities if they have to abandon their work and take up care-giving on a full-time basis. Moreover, studies have proven that physiotherapy helps in reducing the effect of physical impairments, thereby enabling children with CP to gain independence in the society and to improve the quality of life of the affected children as well as their families (primary caregivers) (Cusick et al, 2006).

In terms of risk factors, the study revealed that the majority of the respondents did not know of any risk factor for cerebral palsy. Poor knowledge about the

risk factors implies that some of the primary caregivers may engage in certain behaviours that could put them at higher risk of giving birth to children with cerebral palsy once again.

CONCLUSION

Cerebral palsy was perceived as a disease caused by witchcraft, punishment from God or the Gods, as well as by being cursed. Also, the majority of the primary caregivers did not know the risk factors for cerebral palsy. The respondents' superstitious beliefs, as well as lack of knowledge about the risk factors, could result in deterioration in their children's condition if they chose to withdraw their children from the available physiotherapy services.

Recommendations

- The Ministry of Health, in collaboration with the National Commission for Civic Education (NCCE), should devote attention and effort to furthering public education and campaigns on the causes and risk factors of cerebral palsy, in order to change the negative perceptions as well as improve awareness among the general public.
- The media houses, both television and radio stations, in partnership with the Department of Public Health of the Ghana Health Service, must organise regular cerebral palsy sensitisation programmes, in order to improve the knowledge-level of the general public.
- The National Communications Authority must also collaborate with various telecommunication networks in the country to send regular messages on cerebral palsy to the general public.
- Non-governmental Organisations (NGOs) that work for children with CP, in collaboration with experts in managing CP, should organise community or home-based training programmes for caregivers, in order to improve their attitudes towards caring for children with CP.

Limitations

The study was limited to only one hospital. It was further limited to only primary caregivers who visited the physiotherapy unit of the Komfo Anokye Teaching Hospital, without factoring in those who did not visit the hospital. While these

limitations might affect the generalisation of the findings, the quality of the data collected was not affected.

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APPENDIX

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
SCHOOL OF MEDICAL SCIENCES
DEPARTMENT OF COMMUNITY HEALTH
CENTRE FOR DISABILITY AND REHABILITATION STUDIES

QUESTIONNAIRE:

This questionnaire is aimed at collecting data for study on: "PERCEIVED CAUSES AND RISK FACTORS OF CEREBRAL PALSY AMONG PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY ATTENDING KOMFO ANOKYE TEACHING HOSPITAL IN THE ASHANTI REGION OF GHANA". This data are purely for academic purpose and your responses will remain confidential and will not be shared with anyone. Thank you for participating.

Section A: Socio-Demographic Characteristics

1. Gender: Male Female
2. Age
 - a. 18 – 23
 - b. 24 - 29
 - c. 30 - 35
 - d. 36 - 41
 - e. 42 - 47
3. Marital Status:
 - a. Married
 - b. Single
 - c. Widowed
 - d. Divorced
5. Ethnicity:
 - a. Akan
 - b. Dagomba
 - c. Ga/Adangme

- d. Ewe
- e. Gonja
- f. Other, (Specify).....

6. Level of education:

- a. No Formal
- b. Primary
- c. JHS/Middle
- d. SHS/A Level
- e. Tertiary

7. Occupational Status:

- a. Unemployed
- b. Civil servant
- c. Artisan
- d. Trader

Section B: Perceived causes of Cerebral Palsy

This questionnaire is to assess your perceived cause associated with your child with cerebral palsy. Kindly tick the most appropriate option that best describes your perceived cause.

- a. Non-progressive insult to the immature brain
- b. Punishment from God or the Gods
- c. Witchcraft
- d. Curse
- e. Do not know

Section C: Perceived risk factors of Cerebral Palsy

This questionnaire is to assess your perceived risk factor associated with your child with cerebral palsy. Kindly tick the most appropriate option that best describes your perceived risk factor.

- a. Birth asphyxia
- b. Insulting elderly people during pregnancy
- c. Severe neonatal jaundice (NNJ)
- d. Not performing certain family rituals during pregnancy
- e. Do not know