

# Psychosocial Problems and Well-Being of Children with Cerebral Palsy in Idoma Cosmology

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## Abstract

The birth of a baby with congenital malformations, such as cerebral palsy, is probably one of the events in life which results in some of the strongest human emotions. Feelings of compassion, disgust, fear, guilt and curiosity are often expressed when this happens. Care of a child with cerebral palsy is a source of tension and struggle for parents and causes many problems in meeting the child's needs. This study explored the psychosocial problems faced by children with cerebral palsy (CP) and their parents among the Idoma people. *Design.* Qualitative research design using interviews and focus group discussions (FGDs) was used for the study. *Setting.* Two FGDs comprising traditional birth attendants and others at an urban and rural area were conducted. *Participants.* A total of thirty individuals participated in the two FGDs. The data were gathered by an in-depth semi-structured interview and focused group discussion. *Main Outcome Measured.* Psychosocial problems experienced by the children suffering from CP and their parents were measured. *Results.* The interviews were transcribed and analysed inductively. The identified problems were associated with common themes. The content analysis revealed three themes namely, a) social relationships and challenges, with four subcategories ("social seclusion of the child and parent", "limitation of parents' social relations", "unsupportive interactions"), b), psychoemotional challenges, with three subcategories ("intrapersonal conflicts," "worries, especially about future of the child," and "sense of loneliness,"), and c) health economic problems ("financial needs", "burden of care and daily needs", "employment and income"). *Conclusions.* Caring for a child with cerebral palsy exposes the children with cerebral palsy and their parents to a wide range of psychosocial problems and challenges among the Idoma people, some of which are related to the nature of the child's disease, and some are due to a shortage of facilities and lack of attention to the parents' needs. Therefore, to promote the parents' health and provide better care services to the afflicted child, it is important to recognise the parents' problems and remove such obstacles. Studies like this can provide valuable information for designing a family centered care programme for children with cerebral palsy.

**Keywords:** Psychosocial Problems, Well-Being, Children, Cerebral Palsy, Idoma Cosmology

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## 1. Introduction

Cerebral palsy, the most common cause of motor disability in children, is a chronic condition and developmental disorder with some degree of movement and posture dysfunction (Richards and Malouin 188; Yeargin-Allsopp et al. 550). With an estimated prevalence of 2.11 - 2.83 per 1000 live births (Oskoui et al. 515), Cerebral palsy (CP) is one of the most common causes of disability in children aged 0 to 19 years.

A child with CP suffers from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual impairment, and gastrointestinal and feeding problems (Odding et al 187). They also have several limitations in self-care functions such as feeding, dressing, bathing, and mobility. These limitations can result in requirements for long-term care that far exceed the usual needs of normal children (Breslau et al 684). The difficulties faced by children with CP result in their parents experiencing a higher level of stress (Parkes et al 2316) which has an adverse effect on their physical health and social well-being (Davis et al 66, Parkes et al 218). Many children with cerebral palsy experience sensory, communicative, and intellectual impairments; have limitations with self-care; and require specialized care (Raina et al. 630). Long-term dependence on the parent and the child's need for special care services throughout development imposes different roles for the parents.

This also provides the parents with challenging responsibilities and care management experiences, especially for mothers who must provide constant and exclusive care, as a result of which, they fail to take care of themselves, their children, and other family members (Mendenhall and Mount 187; Tsai and Wang 545).

Changes in healthcare systems and societal attitudes have resulted in most children staying at home in the care of family rather than in an institution. Moreover, in western countries, a greater emphasis is laid on family-centered care, wherein the focus of attention is the entire family, rather than just the child, and this has been found to be highly effective (Kazak 23, Friesen and Koroloff 19, Viscardi 46, Rosenbaum et al 16, King et al 82). The family, together with service providers, is able to make informed decisions about the services and supports the child and family shall receive. In order to develop a family-centered care practice, it is imperative to understand and address the psychosocial problems experienced by the caregivers of the affected children. Several studies of this kind have been undertaken in western countries (Davis et al 66, Raina et al 630, Ketelaar et al 827), however, Knox (58) argued that the realities of cerebral palsy, as well as the worries and expectations of parents of children with cerebral palsy, were understudied. Although the voice and interpretations of those that are the focus of study can help us to understand the phenomenon of interest (Polit and Beck 156), there are few studies that have explored the problems of parents of children with cerebral palsy based on their thoughts, perceptions, and experiences. Previous studies have assessed the parents' mental health and quality of life using a quantitative approach, but largely omitted exploring the psychosocial impacts of cerebral palsy on the index sufferers. Furthermore, the researcher is not aware of any similar study in this country, let alone among the Idoma people of Benue State. Hence, this qualitative study sought to explore the psychosocial problems experienced by children with cerebral palsy and their the parents who care for them.

## **2. Methods**

Qualitative research design using interviews of key informants and focus group discussions (FGDs) was used for the study. Using purposive sampling, the researcher interviewed 42 participants.

### *2.1 Participants*

The participants were drawn from two out of the nine local areas in Benue South (Zone C) senatorial district of Benue State, which is the homeland of the Idoma people of Benue State. The participants consisted of key-informant group (KIG) comprised 12 participants (6 chiefs – all males, and 6 elders: 3 each male and female), and focused group discussion (FGD) groups of 30 participants (12 traditional birth attendants, TBAs, and 18 others) distributed equally into two separate discussion groups.

### *2.2 Procedure*

Participants were given an explanation regarding the study purpose and methods, and participated only after giving their informed consent, and they were informed of their right to anonymity and could withdraw from the study at any time. The data were collected with in-depth interview and focused group discussion, guided by semi-structured questionnaire conducted by the researcher. The interviews were recorded, and short notes were completed immediately after the interview. The interviewees and researcher confirmed the correctness of the interviewer's notes. The interview durations varied from 30 to 60 min. Similar exercise held for the focused group discussions.

### *2.3 Data Analysis*

The study was carried out with a qualitative approach by content analysis. This is an appropriate method for obtaining condensed and broad descriptions of a phenomenon (Elo and Kyngas 112; Hsieh and Shannon 1284). The method of Graneheim and Lundman (109) was used in the present study. This method has four stages: choosing a unit of analysis (whole interviews); detecting the meaning units and referring to a keyword or phrase (a code in relation to context); condensation, or the process of shortening with preserving the core; and abstraction, or descriptions and interpretations on a higher logical level and creation of categories. The audio files were transcribed verbatim for the data analysis. The transcripts were then read several times and their meaning units were specified and condensed with a description close to the text. After that, a list of codes was provided and reviewed semantically. Then, by determining the similarities and differences in the meanings, similar codes were assigned at a more abstract level using a reduction and induction method. Thereafter, the researcher defined some acceptable subcategories and categories.

## **3. Results**

Based on the responses, three main categories identified: social challenges, psychoemotional challenges, and economic/ health challenges, with their subcategories.

### 3.1 Social Challenges

This category relates to the various problems that parents may experience in regards to the social environment, and others' behaviour and actions towards the parents while coping with their children with cerebral palsy. The subcategories included inadequate facilities and services, unsupportive interactions, limitation of parents' social relations, and social seclusion and denial, as well as stigmatisation of the Child and Parent.

#### 3.1.1 Inadequate Facilities and Services

Respondents believe there was a shortage of social welfare and therapeutic services for cerebral palsy children. The social welfare shortage included a lack of daycare centres for the child, lack of respite care services for their parents, wheelchair unavailability in some public and private places (stairs, entrances without ramps, no elevator, uneven surfaces), problems with civil transportation, and a lack of appropriate toilets for children with cerebral palsy and other disabilities in medical and recreational centres or other public places. Regarding the need for a daycare centre so that the mother can pay more attention to her other children, one respondent stated:

"I wish there were a special place in the society in which we could leave these children during the day; I may ignore my other children for taking care of this child..." FGD

With respect to the shortage of therapeutic services, it was the popular view that there existed limited access to some medical facilities, rehabilitation centers, a shortages of skilled therapists, and a lack of financial support in the area. These factors forced some parents, even those with financial problems, to rely on traditional therapies from herblists, or to scarcely use private orthodox facilities with more expensive services that this adversely affected the child's health since "insurance often does not cover all rehabilitation services". Participants observed that affected families depended on out-of-pocket expenses since they hardly get any financial support from any supporting organizations or government agencies. It was generally believed that financial support was the most important factor for the promotion and maintenance of the health of the child with cerebral palsy. Regarding the lack of financial and service supports, one respondent stated:

"Insurance doesn't accept these children at all. It doesn't accept some of their medications at all. These expenses are really difficult and burdensome." FGD

A chief also disclosed that:

"Because of the expenses, parents take the child for treatment once a week, while the child's need is more than that". KIG

#### 3.1.2 Unsupportive Interactions

Observations under this subcategory included a lack of understanding for the parents' troubles, sympathy, questioning and curiosity, regret, and isolation by relatives and other community members. Some participants believed that the sympathies curiosity resulted from a lack of awareness of the child's disease and improper interactions. A birth attendant mentioned:

"People could ask index mothers irrelevant questions: 'Why do you carry the child by yourself all the time, you get tired'. They may say this due to sympathy and because of their unawareness. These words could force a mother to say that her child is tired". FGD

#### 3.1.3 Limitation of the Parents' Social Relations

Some participants posited,

"providing constant care for the afflicted child, the child's movement impairments, his or her care dependency, the parents' time spent engaging in the care and treatment of the afflicted child, and a lack of trained individuals that can provide temporary care for the child restricts the parents' social interactions and relationships (especially for the mothers who have the primary responsibility of taking care of the child)". FGD

Another observed,

"sometimes, because of others' awareness of the child's movement impairments and care problems, the parents are not invited to or informed of family events and ceremonies. As a result, they spend less time with their relatives and others in the community, which cause a separation from others. When it is necessary for the parents to attend a ceremony or event (family or recreational), one of the parents will not attend the event to care for the child". FGD

About the constant care for the child, a woman declared:

“The child would always be with the mother. What can she do; her biggest problem would be that there is nobody to keep the child for her to have a time for herself. She will really feel as if there is a chain on her hands and feet, because with the child with her, she cannot do anything”. KIG

#### *3.1.4 Social Seclusion, stigmatisation and denials of the Child and Parent*

Another experience the parents may face was stigma that appeared in the form of unusual looks or gazing and speculations, judging the parents by blaming, and castigating them. Regarding stigma, one of the participants stated (with sorrow):

“The people will look at the mothers with suspicion in a way as if the parents have the misfortune of the whole world that is difficult to bear. Unfortunately, this is the mother who is always considered guilty.”. FGD

It was the observation of many of the participants that because of physical limitations, that many of these children would be deprived of outdoor activities. A lack of acceptance for the child’s condition, for communicating with other children, the presence of environmental obstacles, and a lack of necessary structures for his or her presence in different sporting and recreational spaces, a lack of well-trained teachers for training the child in public sporting settings may add to the child’s limitations and separation from his or her peers, and force the parents to stay home more often to take care of the child. According to some respondents, sometimes, to hide the child’s physical and mental problems in public, and to avoid undesirable interactions with people, the parents reduce their contact and communication with others by avoiding public places and staying home more frequently. A female respondent opined:

“They always put the child at home; his father is at home while the mother go shopping. They don’t take the child to places with stairs or they themselves don’t go there.” KIG

Another woman mentioned the affected nuclear family would always feel isolated, rejected, unwelcomed and unappreciated, “preferring to always sit somewhere far from the view of others since they would not be wanted in their company because of their child who is not normal”. FGD

#### *3.2 Psychoemotional Challenges*

Participants were concerned about the parents’ feelings and emotions of having a child with cerebral palsy, taking care of him or her in the present and future, and about their own condition as a caregiver. Three subcategories in this category include Intrapersonal Conflicts, Being Worried, and a Sense of Loneliness.

##### *Intrapersonal Conflicts and Worries*

This was defined as tension and negative feelings, such as feeling sinful, throbbing conscience, a lack of self-esteem, feeling culpable, feeling jealousy or shame, regret for losing time and life experiences, preferring death, aversion towards the child and the wish of his or her non-existence, feeling sorrowful watching other children, and wishing healthy children with the afflicted child. It was observed that these feelings arose due to parents’ feeling that they have no control over their child’s health problems and have a disabled and depended child. A participant observed in this respect:

“The mother may feel, ‘Maybe I have done something wrong sometime; perhaps I have committed sins and God is at vengeance. I have a troubling conscience’. In some cases, the parents may also consider themselves as culpable and may attempt suicide”. FGD

Participants strongly believed that encountering the cerebral palsy disease and treatment, the distress and manipulation to the child during the treatment (especially in the early years after the disease diagnosis) and a lack of child’s cooperation and improvement with treatment, could produce tension in the parents that would manifest as nervous pressure.

Participants posited that parents’ constant worries may include the child’s health and education, how to maintain and provide care for the child in the future, because they would not expect their healthy children or relatives to care for their afflicted child in future. Additionally, the dependency level of an afflicted child is associated with the intensity of the parents’ concerns.

### *Feeling of Loneliness*

The most popular opinion was that others' avoidance and ignorance of the parents' needs for communication, the absence of a guide for child care in critical situations, the feeling of being deprived of support in caring for and keeping the child all contribute to a "sense of loneliness," especially for parents of children with severe cerebral palsy. In some cases, the parents may experience a sense of helplessness with a feeling of burdens on their shoulders, and nobody to help. It was agreed that others' providing caring attention to the child and having a sense of the importance for the child's existence can decrease the parents' sense of loneliness.

### **3.3 Economic Challenges**

It was agreed that to be a cause of sorrow, depression, stress, confusion, desperation, apprehension, and hopelessness, putting the parents in horrible and challenging conditions causing grief, shame, with a feeling of being cursed and apathetic, cerebral palsy could be a reason for the family's economic crises and hardship arising from the huge financial expenses required for the management of the condition, and due to the restrictions imposed on the caring parents who have to spend most of their valuable times caring for afflicted child rather than getting involved in gainful economic activities.

## **4. Discussion**

The findings of this study showed that the parents of children with cerebral palsy experienced unique psychosocial challenges related to the child's care and health problems. A lack of financial support, limited access to medical services, limited welfare facilities for their social presence and their child were among the problems that most participants observed in the present study. A lack of financial support from insurance organisations for the afflicted child's treatment further would increase the parents' out-of-pocket medical expenses. Sen and Yurtsever (244) observed that the economic load of the treatment, care, and training for the afflicted child were mostly experienced by families who also lacked financial support. Several studies indicated the feeling of a lack of support in most parents was due to limited access to services, long waiting lists, increasing treatment expenses that exceed the family income, a lack of appropriate sanitary facilities (such as toilets), and a disparity between the parents' needs and social resources (Ambikile and Outwater 8; Davis et al. 68; Lutenbacher et al. 167; Raman et al. 56; Resch et al. 139). In this study, Palisano et al. (88) reported that the parents of children with movement disorders had needs for relief, temporary rest, recreation, and a temporary place for keeping the child. The study by Yantzi et al. (52) also indicated that mothers faced social problems such as limited access to an alternative and trained caregiver; therefore, they sought help from their friends or family members when leaving the house.

In this study, participants described unsupportive interactions and stigma as reproach and being judged or considered culpable by relatives. Other researchers, especially those in the Asian countries, reported similar findings that support the present findings: mothers reproached by family members, scrutinizing and sorrowful looks, a lack of social understanding for individuals with disabilities, in the form of regret and sympathy as undesirable experiences, whereas understanding attitude towards a child with cerebral palsy could help generate a sense of equality with other healthy children (Huang et al. 194; Raman et al. 57; Whittingham et al. 1564). Park et al. (355) discovered that Korean families of children with a chronic disease faced more negative social responses as compared to their counterparts in Western countries. These researchers suggested that supportive programs should be designed to help improve understanding of afflicted children and their families.

A lack of acceptance for the afflicted child in the community by healthy peers, a shortage of environmental facilities, inadequate public facilities for people with disabilities, coercion of the parents for staying at home, and caring for the afflicted child were some of the social problems highlighted in this study. According to the International Classification of Function, Health and Disability (ICFHD), environmental factors (physical, social, and cultural) play important roles in the social modeling of disabled individuals in the form of their involvement at home, school, broader environments, and different life situations (Lawlor et al. 225; Rosenbaum and Stewart 7). In addition, Lawlor et al. (227) argued that the obstacles for the social presence of a child with cerebral palsy in England were implied in the themes of activity and movement (uneveled surfaces in the physical environment, the dependence of the afflicted child on the adults, difficulty in access to public transportation, a lack of parking facilities, a lack of an elevator, and improper paths for wheelchairs), individual attitudes (in the form of still and sympathetic looks) and socially institutionalised attitudes. Generally, the deficiencies in facilities that impede the child's social presence and his or her greater dependence on adults increase the parents' supportive and caring engagements for their child. Dixon found a lack of support from public services and stigma as the main reasons for the isolation of families with children who have disabilities.



Acts 5 and 23 of the Convention on the Rights of the Child, which was approved by the general assembly of the United Nations, and Part II of the 2003 Nigeria's Child Rights Act, placed an emphasis on the rights of children with disabilities, attention to these rights, the parents' responsibilities, and provisions for appropriate facilities for children with disabilities and their parents. However, ignoring these issues and concerns can create problems for the parents of children with disabilities. Parents of children with chronic disorders experience social problems, such as a lack of or poor access to health care services, school services, or family support, in addition to experiencing a continual struggle to include their children in the school and community, financial strain, a lack of public awareness about the child's illness, and stigma (Ambikile and Outwater 8; Klassen et al. 560; Resch et al. 139).

In this study, the parents' social seclusion were attributable to unpleasant social interactions (inappropriate relationship with parents and low acceptance of children in the community). These results are compatible with those of Nelson (526), who declared that a mothers' social separation (physical and psychological) was due to therapeutic diets, a high sense of responsibility for the child's well-being, and a lack of understanding for the child's acceptance by others. The parents' separation from others, the way others think about the ability of managing the child, and being ashamed of his or her own performance could contribute to the parents experiencing a social stigma (Pullmann et al. 227). The above findings, along with the results of the present study, represent social ignorance towards children with disabilities and their parents.

The results of this study indicated the existence of intrapersonal conflicts for parents in different stages of childcare. Having a disabled child results in emotional downturn, a low level of tolerance, a willingness to escape, and wide changes in all aspects of the family's life (Shakoor et al. 54). Huang et al. (196) posited that feelings of guilt, helpless, hopelessness, sorrow, anger, and self-blame were experienced by the mothers who were exposed to their child's disability. Of course, when the parents receive more support, the negative effect of a child's disability on the parents' mental health decreases (Ha et al. 408).

In this study, it was opined that the parents may express considerable worries about their child, especially in the face of lack of improvement in the child's ability and independence. The child's level of disability is said to influence the extent of the parents' concerns (Knox 58). Ambikile and Outwater (8) reported that the parents of children with disability experienced inner pain and worries about the present, in addition to the child's future. Huang et al. (196) argued that Taiwanese mothers experienced modes of being concerned when faced with challenges and obstacles in caring for their child. One of the concerns was the marginalisation of disabled children due to a lack of attention to the child's rights and physical security in society and schools. The results of the present study showed that parents may not expect their healthy children or relatives to care for their afflicted child in future. Meanwhile, Coffey (57) argued that the parents' worries were due to their doubts about the ability of brothers and sisters to care for the child in the future. Sometimes, a parent's worry about a child's health in the future causes the parent to make more of an effort in promoting the child's health. Of course, resources such as emotional support, financial ability, physical help, access to services and social supports, attention from policy makers in the health field to the improvement of environment and appropriate transportation structures, and greater consideration for psychological and social work services in the rehabilitation centers, can decrease parents' worries, and improve their quality of life, family well-being, and the quality of parenting (Armstrong et al. 274; Davis et al. 68; Khayatzaheh 8; McCubin and Hung 441).

The sense of loneliness in this study, especially in the mothers, showed the lack of a social support network in addressing the parents' needs. Barbosa et al. (48) found that the mothers of children with disabilities experienced a sense of helplessness when they were unable to change their situation. Therefore, based on the results of the present study and previous studies, a lack of provision for the parents' emotional and practical needs when caring for the child creates a sense of loneliness. Emotional loneliness (an emotional state of feeling isolated) has negative consequences on an individual's physical health (Bogaerts 810).

Social resources and emotional security could help to decrease the parents' stress and worries and improve their quality of life. However, the findings of the present study showed that parents would endure many social and emotional problems in living with their children because of the lack of social facilities and social support networks.

In conclusion, this study finds that many Idomas believe in supernatural causes of cerebral palsy, such as witchcraft, and/or in the role of improper relationships of family members as causes of cerebral palsy; and that community responses to Idomas with cerebral palsy are often negative. However, many people, particularly

parents with cerebral palsy, often have strong positive views of cerebral palsy as well, reflecting the complex and changing nature of cultural beliefs. This study suggests that the implementation of disability inclusion policies is more likely to be successful if it builds upon positive aspects of cultural beliefs about disability.

### **5. Limitations of the Study**

Given the nature of qualitative studies and the small number of participants, the findings cannot be generalised to a larger population; however, all concepts in this research reached saturation and nearly provided a comprehensive perception of socio-emotional problems among Idoma people towards a child with cerebral palsy. Therefore, it is recommended that further studies be conducted to explore parent strategies for confronting the social and emotional challenges.

### **6. Recommendation**

Based on the findings in this study, when taking care of their children, the parents need more societal conveniences, comprehensive health care facilities, and critically rehabilitation-medical services. However, organising a facilitating system and providing integrated support to parents would play a critical role in promoting both the child's and the parents' health. Furthermore, it is necessary that decision makers provide more supportive resources for these parents to be able to effectively manage themselves and the afflicted child's situations.

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