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*Research article*

## **Psychosocial problems among mothers of children with cerebral palsy attending physiotherapy outpatient department of two selected tertiary health centres in Ogun state: A pilot study**

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**Abstract:** Background: Caring for a child with cerebral palsy (CP) can be exhausting and stressful. There is paucity of information on the consequence of having a child with CP on mothers of these children. This study explored psychosocial problems encountered by mothers of children with CP receiving physiotherapy care in two selected tertiary health centres in Ogun State, Nigeria. Methods: A qualitative study was conducted through focus group discussion (FGD) utilizing 17 questions identified in the literature as a FGD guide. Participants were seven mothers of children with CP. The framework approach was used for thematic analysis of data. Results: The psychosocial challenges encountered by the mothers were associated with nine common sub-themes. These are: (i) stress of caring for over dependent child; (ii) mothers' restricted participation in the society; (iii) financial constraint experienced by the mothers of children with CP; (iv) health problems experienced by mothers of children with CP; (v) feelings of uncertainty about the child's future; (vi) society's negative perception of child's problems; (vii) support obtained by the caregivers from others; (viii) availability of support from healthcare facilities; and (ix) Personal belief about condition. Conclusion: Mothers of children with cerebral palsy experience substantial psychological and social problems that are often ignored by the general populace.

**Keywords:** psychosocial; cerebral palsy; children; physiotherapy

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**Abbreviations:** CP: Cerebral Palsy; FGD: Focus Group Discussion; CDC: Centre for Disease Control; QSR: Quality Service Regulation

## 1. Background

Cerebral Palsy (CP) is a chronic disabling condition resulting from permanent damage to the immature brain. CP contributes significantly to the poor health status of children in Nigeria. The incidence of CP varies significantly across different geographical zones, although the Centers for Disease Control and Prevention (CDC) study found that the average prevalence of CP in 2004 and 2008 was 3.3 per 1000 live births and 3.1 per 1000 8-year-old children respectively [1,2]. The prevalence was significantly higher in boys than girls (male/female ratio 1.4:1) [1].

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 [3]. They also have several limitations in self-care functions such as feeding, dressing, bathing, and mobility [4,5]. These limitations can result in requirement for long-term care that far exceed the usual needs of normal children [6]. The difficulties faced by children with CP result in their parents experiencing a higher level of stress [7] which has an adverse effect on their physical health and social well-being [8,9]. 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. The ideal management of CP is comprehensive and effective physical rehabilitation [10] which is unfortunately expensive for the average Nigerian family.

The term psychosocial refers to the interaction between a person, the social environment, and the influence on their behaviour. The social environment includes family members, friends, co-workers, employers, compensation system and health professionals. Hence psychosocial problems are challenges that affect a person and his social environment. 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. Parents of children with Cerebral Palsy have severally been reported to present with varying psychosocial problems as reported in studies from western cultures [8,11].

Local studies [12–14] have evaluated socio-cultural, socio-clinical, and other risk factors associated with patient living with cerebral palsy using quantitative design. This study seeks to explore the psychosocial problems experienced by the parents of children with CP using a qualitative design. This approach may precipitate new domains which hitherto had not been explored for developing interventions that may encourage improvement of the psychosocial wellbeing of parents of children with cerebral palsy.

## 2. Methods

A qualitative study using focus group discussions (FGDs) was conducted among mothers of children with CP. Two FGDs (involving 3 to 4 parents) were conducted at the physiotherapy department of the Federal Medical Centre Abeokuta and Olabisi Onabanjo University Teaching Hospital. Ethical approval was obtained from the Federal Medical Centre Abeokuta Human Research Ethics Committee. The head of physiotherapy department in the two hospitals were informed of the entire study plan. The physiotherapists (DAO, OOO) contacted the parents of the children with cerebral palsy coming for treatment and enlightened them about the study. The diagnosis of cerebral

palsy was based on the information contained in the medical records of the patients. All those who agreed to participate, and who met the inclusion criterion of basic English and or Yoruba language proficiency, were included in the study. A round table sitting arrangement was followed during the FGDs, each of which was conducted in rooms devoid of any disturbance. The rooms were well ventilated and with adequate space, enough to accommodate all participants and researchers. Health assistants working in the physiotherapy department were assigned the responsibility of taking care of the study participants' children for the duration of each FGD.

Socio-demographic characteristics of the parent and child with Cerebral Palsy were obtained through a self administered questionnaire that contain questions on the age, gender, educational status, occupation, type of family and family size of participants. The age, gender and duration of illness of the children with cerebral palsy were obtained from this questionnaire. Audio recordings were done for both FGDs, and the consents were obtained before beginning the FGD. The FGDs were facilitated by a team, comprising one moderator (OOM, OOO), one recorder (FLJ), one observer (DAO), and two persons (AMO, LAI) taking; written notes. Each FGD began with an introduction by the moderator of the entire team of researchers, followed by introduction from all the participants. The moderator used an FGD guide during the focus group discussions comprising 17 questions for conducting the FGD as follows:

- 1) How has your life changed after having a child with disability as compared to before?
- 2) What problems are you faced with day by day in the upbringing of your child?
- 3) What kind of feelings do you experience for yourself or for your child? For example, anger, embarrassment, shame, depression and anxiety.
- 4) How is your sleep?
- 5) What are the health problems you suffer at present that you think is as a result of caring for your child?
- 6) What are the kinds of worries you have for the future of your child and for yourself?
- 7) Who do you blame for your child's disability?
- 8) Can you describe moments during which you have felt happiness or satisfaction related to your child?
- 9) How do (i) Relatives (ii) Neighbors perceive the problems encountered by your child?
- 10) What is the effect of the current status of your child on your day to day work/occupation?
- 11) What is the effect of the current status of your child on your social relationship?
- 12) What is the effect of the current status of your child on your marital relationship?
- 13) Can you mention experiences you have had as a result of your child's health challenge?
- 14) What kind of support have you obtained from your family and others?
- 15) What are financial the problems you have experienced as a result of caring for your child?
- 16) What help do you expect and from whom in the upbringing of your child?
- 17) What is your personal belief/understanding of the condition of your child?

### 3. Data analysis

The framework approach [15] was used for thematic analysis of data. The FGDs were transcribed verbatim in the language they were conducted (English and Yoruba). The Yoruba transcript was then translated to English. All transcripts and reflective notes were entered into Nvivo version 11, QSR international, Melbourne, Australia. Transcripts were coded inductively to develop

descriptive codes that were grounded in the data. The descriptive codes were used to organize the data which increased familiarization and immersion in the data. Higher order analytical categories were generated from the codes. The categories were used to develop initial thematic framework which was used to index the entire data. The final themes and narrative were emerged from the abstraction and interpretation of the thematic framework. All analytical steps were validated by the research team to ensure that the emerging codes, categories, themes and narrative reflected the original data.

#### 4. Results and discussion

All participants in the FGDs were mothers of children with CP who brought their children for treatment at the respective hospitals. There were a total of seven participants in both FGDs. The socio-demographic profile of the participants is presented in Table 1. Most of the mothers are petty trader prior to the ailment of their children. This may implied that they are of low socioeconomic strata. The children with CP were either diagnosed from birth or not later than the first six months of life.

**Table 1.** Socio-demographic characteristics of the study participants and the affected ones.

Items	Federal Hospital	State Hospital
Number of Participants	4	3
Mean age in years	35	33
Level of Education		
No formal Education	1	0
Primary	0	0
Secondary	1	2
Tertiary	2	1
Occupations		
Housewives	1	0
Working	3	3
Type of Marriage		
Monogamous	4	2
Polygamous	0	1
Religion		
Christianity	2	0
Islam	2	3
Children of the participants		
Mean age of the children in years	2.5years	1.5years
Age Range	0.5–4 years	0.75–2 years
Sex		
Male	4	2
Female	0	1

On analysis of the transcript of the FGDs the following categories, themes and sub-themes emerged (Table 2).

**Table 2.** Emerged theme and sub-theme.

Category	Theme	Sub-theme
Social/emotional barriers	• Isolation from community	• Problems experienced in caring for the child
	• Perception of spiritual or other failure as cause of disability	• Social problems experienced by the parents
	• poor sleep	• Child's future
Pragmatic barriers	• Access to care	• Societal perception of child's health status
	• Loss of wages	• Personal belief about condition
	• Physical discomfort	• Health problems experienced by the parents
Benefits of parenting a child with CP	• Sparing financial support	• Support from health services
	• Moral support	• Financial problems experienced by the mothers
		• Support obtained by the caregivers from others

#### 4.1. Problems experienced in caring for the child

Certain problems were experienced by the parents while caring for the child. One of the problems experienced is the over dependence of the children on the mothers due to the inability of the children to attain successive developmental milestones which if attained would have reduced the extent of dependence of the children. The comments made by the discussants were “I know that at a particular age, a child should be sitting but my child can't sit until I support him on a chair, even to bath him, I have to hold him with my left hand to do that. I have to carry him on my back whenever I want to go out because he cannot sit or stand”, “I have to be with him every time even when he is sleeping”, and “I am the only one that carries him and this hinders me from going out”. The overdependence of the child also restricts the movement of the mothers hence they cannot maintain a regular job nor manage their businesses. Inability to work reduces their capacity to earn a living leading to reduced financial resources. Comments like; “I have not been able to go to work” “taking her to crèche is very expensive and I cannot afford it” “I am not free”. The other problem reported is the frequent sleep disturbance experienced by the parents. This sleep disturbance was said to be directly and indirectly associated with the children health status. The comments made by the discussants were “I don't sleep well, when I hear him cry, I wake up and check, he can't turn over by himself, I have to stand up and turn him over”, “sometimes when I think of the problem, I don't sleep well especially when I can't work and it's only the father bringing money to feed the family”, “my sleep is not smooth”.

The overdependence of a child with CP induces a lot of stress on the caregivers as suggested by previous studies [5,9,16–18]. These are in the form of insufficient time for other chores, responsibilities and isolation from community activities because of time spent attending to the child at home [18]. This stress may lead to poor quality of sleep with attendant result of day time dysfunctioning [19]. Invariably, resulted in reduced quality of life of the parents [4,20]. This raises concern in regard of providing support for the parents of children with CP to alleviate the overdependence and stress. Many caregivers of children with CP have expressed a need for someone to stand in for them to have a chance to do other duties [17]. It is pivotal therefore, to provide these caregivers with continual support through interventions, which may help to improve quality of life and assist caregivers to deal with the different stressors attendant on caring for a child with CP [21]. In the absence of social support by the government in Nigeria, employing sufficient community

health workers in the community health centres will go a long way in reducing the stress parents undergo in bringing their children to the hospital. These community health workers can conduct treatment sessions in their homes or nearby community which the parents will appreciate [17].

#### *4.2. Social problems experienced by the parents*

One common problem reported by all the participants was that they lacked freedom to interact with their social environment. Comments made by the discussants were “I cannot go out like before and I am not free to move around”, “I am the only one that carries him, this hinders me from going out”. Some of the mothers revealed that having a child with CP has adversely affected their marital relationships with comments like “there is problem because my husband believes that I am the cause of our child’s problem” while some other respondents said they do not experience any marital problems associated with their child’s problems with comments like: “my husband said it’s nobody’s fault, there is no friction in our relationship”, “my husband loves me the more”. Many families suffered from lack of understanding from families and friends thereby resulting in adverse social relationships. One of the participants reported that she does not have friends, as all of them ran away and another commented that she does not have time to go out with friends. Some friends and relatives were said to have described the child’s condition as a spiritual problem and that the mothers should dispose of the child so that the government may take over the child’s care if found. Some relatives perceive the child’s condition as something to keep away from.

Less interaction with social environment by mothers of children with CP has been previously observed [22,23]. They have low participation in social gatherings such as marriages and other ceremonies [23]. This poses some problems from families and friends due to lack of understanding and marital problems [5]. This may call for education of the public and the family members about CP so as to preserve the family joy.

#### *4.3. Child’s future*

All the parents were worried that the child may not be able to perform the normal functions of apparently healthy children. They fear the child may be dependent all through life and may not be able to acquire education like any regular child. Even when one of the mothers is convinced of gain in developmental milestone of the child, she submits that these milestones may come late. What the future holds for the children with CP has always been with mix feeling among their parents [23,24]. Providing parents with relevant information such as special schools may relieve their anxiety.

#### *4.4. Societal perception of child’s health status*

Parents reported that most people perceive the child as having a spiritual problem and some family members perceive the child as a burden that needs to be disposed of (murdered) and that when the government sees the child alive, it will be their responsibility. Some parents reported that their relatives see the child’s condition as communicable hence they avoid contact with the child and even rain insults on the parents directly or indirectly sometimes describing the child as lazy for not attaining developmental milestones at the set time. Other parents reported that the neighbors sympathize with the child’s condition and pray for the family.

This is worrisome, as the society that is supposed to provide support is often negative towards the children with CP. In an African setting like Nigeria, attributing the fault to the mother or being spiritual problems are common [5]. Again, this may necessitate public enlightenment to address this negative attitude.

#### *4.5. Personal belief about condition*

Some of the mothers felt responsible for the condition of their child, like one of the mothers said, “I feel the herbal concoction I collected affected the health of my child”. Another mother responded, “I don’t really understand why my child did not cry immediately, the only thing I can say is my child did not come out on time, and that prevented him from crying early”. This statement is an indication that some of the mothers might have been well educated about the possible causes of the condition, as one of the mothers reported, “I was told he had jaundice and he did not cry on time which is what affected him”. However, most of the mothers were optimistic in their beliefs about the improvement in attainment of developmental milestone by the child. Generally, the mothers of children with CP are often unaware of the cause of their children’s ailments until they come in contact with health providers [5]. Adequate education provided to the caregivers may produce positive belief among the caregivers.

#### *4.6. Financial problems experienced by the mothers*

It was agreed by most mothers that inadequate financial resources affect the upbringing of the child. Mothers revealed that they have to keep borrowing money to be able to buy drugs and pay for the treatment of the child. Fund that would have been useful for feeding the family is used in buying drugs. The financial problem was said to be associated with the fact that only the children’s fathers earn money to take care of the family. Some discussants commented that they had to resign from their regular job to be able to take care of the child. Since they cannot work their financial resources are limited. Mothers reported that the financial requirement for taking care of the child has affected the fund available for their personal family upkeep. Some of them commented that “we would rather buy his drugs than buy food for the family”, “we are into debt and the money we spend on him is too much”.

Finance plays a vital role in taking care of children with CP. Financial constraints imposed by having a child with CP may lead to handicap in providing optimal care to the children. As all the external resources available to facilitate good caring practices are reduced by poverty [18]. Health insurance policies in Nigeria can be strengthened to accommodate free care for children with CP. This may facilitate an optimal health care provision for the children with CP and relieve parents financially.

#### *4.7. Health problems experienced by the parents*

All participants reported physical problems like excessive fatigue, back and bodily pains because of carrying their child. They also reported negative emotions like sadness, anger and feelings of embarrassment for the child. One of the parents said “I pity him because as of 2 years, he is behaving like 6 months and I am not angry at him”.

Previous studies have shown that the health of parents taking care of children with CP was substantially impacted [4,23,25]. A family-centered approach to the care of children with cerebral palsy and their families is essential to ensure both receive adequate care and support [7,26]. They should focus on how the caregiver can be supported and rendered less exhausted in addition to treatment of children with CP. Counseling and relaxation techniques made available to the caregivers may result in adoption of healthy lifestyle for themselves and their disabled child [4].

#### *4.8. Support obtained by the caregivers from others*

Majority of the parents reported that they had moral support in the form of advice on the use of drugs and prayers. However, this seemed to be considered insufficient by the mothers as one of the mothers commented “There is no support, except advice that we should take care of him”. While some mothers said they received no support at all, some mothers said they received financial and moral support. The inadequate support from others strengthens the call for organized social support by the government in Nigeria for children with disability in general. Social support has been shown to have negative correlation with mothers’ burden and stress experienced for caring of children with CP [27]. In other word, social support reduces the burden and stress of parenting experienced by mothers. Social support is a significant coping resource, reducing stress and improving personal adaptation levels by reducing pessimistic emotions while promoting optimistic emotions [27]. Therefore, provision of social support including formal and informal social support will go a long way in ameliorate the adversity, physiological and psychological afflictions experienced through parenting of children with CP.

#### *4.9. Support from health services*

Most of the mothers reported that they would want the government to provide more equipment to the hospital, provide more awareness on the condition and employ competent doctors. Other mothers reported that they want the hospitals to give them drugs that would help the child; some reported that they wanted help from everyone who could help and one of the mothers reported “The help I want is from the doctors, if they should diagnose well, they will be able to discover the drugs that will work well and help heal my child quickly”. Effective communication between the health care professionals and caregivers may lead to well-informed families who are better able to care for, and less likely to neglect or abuse their child [24]. More so, early presentation/access to care by children with CP should serve as advantage in reassuring the mothers of positive outcome if adhere to clinic and treatments. It should be noted that both facilities are tertiary health provider and this informed early diagnosis of the children conditions and hence the age range of the children with CP. It is not unlikely that the young age of the children may inform expectation of the mothers.

#### *4.10. Mini case study*

A succinct look at the experience of the mothers can be categorized into three: pragmatic barriers (access to care, loss of wages, physical discomfort), social/emotional barriers (isolation from community, perception of spiritual or other failure as cause of disability, poor sleep), and benefits of



parenting a child with CP (financial support, moral support). A vignette about experience of a mother of CP is herewith present.

#### 4.10.1. Pragmatic barriers

Taking care of a child with CP impact negatively on the finance, health and comfort of the mother. Probing the mother what changes has occurred in her life since having a child with disability or the effect on her day to day work and finance. Here is the response of a mother (MM). Before I gave birth to this child, I do go to market to buy and sell goods; I do go out to do things myself. Now that I have given birth to this child, I can't go out like before especially to market to buy and sell because I can't leave the baby alone and there is no one to take care of the baby except me. During pregnancy, I had setback in my business, I lost my business to thieves, so since then there is no job to do because of my child, then the body pain too. I can't work. This imposed financial burden on the family. I can't even work because there is no one I can drop the baby with. Taking her to creche is very expensive and I can't afford it. There are financial problems oh, because we have to keep borrowing money and we have ran into debt. The mother also reported physical discomfort which impacted her health. We know that at a particular age, a child should be sitting but my child can't sit until I support him on chair. Even to bath him, I have to hold him with my left hand to do that. I have to carry him on my back whenever I want to go out because he can't sit nor stand. I am always having body pain. I should have gotten pregnant now but the stress of taking care of him won't allow it. These problems are compounded because access to care is not free. Mothers have to pay out of pocket for the health care of their wards or themselves. Thus, mothers are looking for help from government and even spiritual. I am expecting help from God, the government and individuals that are capable.

#### 4.10.2. Social/emotional barriers

Taking care of a child with CP portend a social or emotional problem. The mother reported experience of social isolation as a result of having a child with disability. Now that I have given birth to this child, I can't go out like before. I don't even have time to go out with friends. The emotional barriers were strong as a result of wrong perception by the mother and the society at large concerning a child with disability. The mother reported: I feel the doctors are not competent. When I was pregnant, a doctor gave me a drug in which a nurse told me is dangerous for pregnant women. So I blame those two hospitals that I went initially because they don't know their job. Most people that see him keep saying that his problem is spiritual but I keep telling them that he is fine. Then from my husband family, they told me I should go and drop him somewhere else, that when the government sees him, they will carry him. Also the mother reported poor sleep which may compound her emotional barriers. I don't sleep well at all. During the day, I can't rest, and even at night, he will just start crying and so I can't sleep well.

#### 4.10.3. Benefits of parenting a child with CP

The mother reported financial and moral supports from family and other people in taking care of her child with disability. There is help; sometimes they give us money, prayers and advice.

## 5. Limitation

The results of this study should be considered with caution. Small convenient sample of mothers of CP involved in the study may limit generalizability of the results to entire population. Our results cannot affirm that the experiences are peculiar to mothers of CP only as we did not include other mothers of children with different disability or mothers of normal children as a control. However, this pilot study provides preliminary information which may help policy makers and health care providers in providing family-centered care. There is a plan follow-up study to recruit more samples including mothers of children with different disability and mothers of normal children as a control.

## 6. Conclusion

This study highlighted substantial psychosocial problems encountered by parents of children with cerebral palsy. For adequate care and support of both children with cerebral palsy and their families, a family-centered approach is crucial to ensure their welfare. This also calls for provision of social support on the part of government to alleviate these psychosocial problems.

## Declarations and acknowledgment

Ethics approval and consent to participate: Ethical approval was sought and obtained from the Federal Medical Centre Abeokuta Health Research Ethics Committee with protocol number FMCA/470/HREC/07/2017/13. Informed consent of the parents of children with cerebral palsy was obtained before participating in this research.

Consent for publication: Alongside the informed consent form, consent for publication was obtained from the participants with assurance that no identifying information will be published.

Availability of data and material: The datasets generated during and/or analysed during the current study are not publicly available because they contain individual person's information but are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: DAO and OOO were involved in recruiting participants for the study. The FGDs were facilitated by a team, comprising one moderator (OOM, OOO), one recorder (FLJ), one observer (DAO), and two persons (AMO, LAI) taking; written notes. OOM, OOO and FLJ analysed the data and composed the manuscript. All authors critically review the manuscript.

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## Conflict of interest

The author declares no conflicts of interest in this paper.

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