Titles: Facilitators and Barriers of Active Participation of caregivers of Children with Cerebral Palsy in their Rehabilitation: An Exploratory Study

**CURRENT STATUS:** UNDER REVIEW

BMC Health Services Research  •  BMC Series

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**DOI:**  
10.21203/rs.2.11065/v2

**SUBJECT AREAS**  
Physical Medicine & Rehab

**KEYWORDS**  
Cerebral Palsy, Rehabilitation, Caregivers, Facilitators, Barriers
Abstract
Background: Cerebral Palsy (CP) is a group of permanent disorders of movement and posture, attributed to non-progressive disturbance that occurred in the developing fetal or infant brain. The condition results in long term disability in carrying out activities of daily living (ADL). Thus, it most times required active participation of the caregivers of the children affected in their rehabilitation.

Objective: The aim of the study was to explore the facilitators and barriers of active participation of caregivers in the rehabilitation of these children.

Materials and Methods: The study design used was qualitative indepth interview. The participants consisted of caregivers of children with CP attending Hasiya Bayero Paediatric Specialists Hospital, Kano. The caregivers were sampled and interviewed by one of the researchers until theoretical saturation was attained. A note taker wrote down and recorded responses of the participants using a tape recorder. The data generated from the interview was then transcribed, coded and analyzed using matrix analysis using constant comparative analysis.

Results: Forty caregivers with mean age, 27.17±4.46 years participated in the study. The results of the study showed that, the factors that facilitate active participation of caregivers of children with CP in the rehabilitation of their children are improvement in the child’s condition, family support, improvement in the conditions of other children with CP, encouragement from the therapist managing the child, empathy, and cooperation of the child during home programs. The barriers are number of children the caregiver has, caregiver’s occupation and financial resources.

Conclusion: Therapists need to help reinforce these facilitators, and devise strategies to help caregivers overcome barriers during rehabilitation of children with CP. For example, since lack of finance is one of the barriers to the caregivers’ active participation in the rehabilitation of their children, there should be a policy on CP rehabilitation that will make rehabilitation services accessible to all children with CP. Similarly, since family support is a facilitator, sharing caregiving rehabilitation tasks among member of the family could help facilitate caregiver activation participation in the rehabilitation of their children with CP.

Background
At particular stages in life, the child is supposed to have certain abilities such as keeping the head
and neck upright in sitting, crawling, rolling, standing and walking. This is known as milestone (1-3). Following Cerebral Palsy (CP), these abilities may be either absent or come much later in comparison with a child without CP (4). Rehabilitation, which is the process of helping people to restore lost function or improve functional independence can help children with CP. However, CP is a long term condition as it results in permanent disorders of movement and posture (5-6). Thus, its rehabilitation may require active participation of the therapists and the caregivers. In Nigeria, rehabilitation services by the therapists are often accessed only in secondary and tertiary facilities in the urban centers, with no or little community rehabilitation services (7). Recently, it has been suggested that, there are opportunities for rehabilitation therapists to play important roles at the primary healthcare level (8).

Caregiver participation in the rehabilitation of children with CP pertains to assisting the children with daily care activities such as bathing, mobility, feeding and dressing (9). When caregivers participate in the rehabilitation of their wards, their participation can provide a more natural environment for the healthy development in physical and psychosocial wellbeing of the wards (10). However, systems of caregiving may differ from one place to another. In Nigeria, caregiving is provided by the family members of the patients. This is in contrast to South Africa where there is an organized community caregiving system, in which care is provided by the community organized by civil societies (11). Similarly, in the western world, caregiving may be provided by the local health community services, families which is some cases encouraged by cash for care and religious bodies (12-13).

Although caregivers may participate in developing strategies to aid with development in children with CP, elsewhere, it was noted that several challenges such as environmental barriers may be encountered (14). Additionally, caregiving was previously reported to cause huge mental and emotional stress as it imposes physical and time demands (15). The aim of this study is to therefore explore the barriers and facilitators of active participation of caregivers of children with CP in the rehabilitation of their children in Kano, Nigeria. Understanding of these two processes may help with devising strategies to either reinforce or improve them during rehabilitation. This is especially because CP prevalence stands at 42% of all paediatric cases in Kano, Nigeria (16).
Methods

Design

The study design was qualitative using in-depth interviews to explore the barriers to and facilitators of active participation of caregivers in the rehabilitation of children with CP. In-depth interview was chosen because it provides rigorous and deep responses of participants. Rigour in qualitative research assures quality (17).

Participants

The population of this study was caregivers of children with CP attending Hasiya Bayero Specialists Paediatric Hospital in Kano. In this hospital, children with CP receive rehabilitation by the therapists only once in a week. Purposive sampling technique was used for the selection of the study participants. In this regard, only primary caregivers such as mothers, aunts, uncles, sisters, brothers, grandmothers who are directly involved in taking care of the children were recruited in the study. Participants were included if they served as caregivers to a child with CP for at least one year. For the sample size, there are no hard and fast rules for sample size estimation in qualitative research as this type of study approach maintains some degrees of openness (18). Consequently, the number of participants available was used until theoretical saturation was attained. Theoretical saturation is a situation in which new interviews no longer produce new information or insights (19-20). The data collection instruments used were the study demographic information data sheet, a qualitative interview guide, pen and a notebook/pad and a voice recorder. The qualitative interview guide was practiced first on seven caregivers before the commencement of the main study, and it consisted of the following questions (1) what are the things that hinder you from actively participating in the rehabilitation of your child? 2) What are the things that motivate you or make it easy for you to actively participate in the rehabilitation of your child? Additionally, in each of the above cases/questions, probing technique to elicit more responses or better understand the responses was used. Two independent colleagues who are familiar with qualitative research methodology reviewed the interview guide and offered suggestions before it was finally produced.

Ethical approval was sought from Research Ethics Committee of Kano State Ministry of Health.
Participants’ consent was obtained after detail explanation of the study to them (this was to seek for their consent and to familiarize ourselves with each other). The consent involved each of the participants signing a consent form. Participants were interviewed individually at different times to ensure that their responses were not influenced by the views other participants. In addition, participants were asked only relevant and same questions to ensure coherence in their responses. According to Tracy, the aforementioned procedures help to achieve quality assurance in qualitative research (17).

Data analysis

The study participants were interviewed face-to-face by the interviewer (AA) who has a Masters degree and a certificate in Qualitative Methods and is an academic in Physiotherapy, individually by using the interview guide. The responses of the study participants were recorded using tape recorder and noted by a note taker (AI), the second author who has a Bachelors degree. Both researchers are males. The demographic characteristic of the study participants was analyzed using descriptive statistics of frequency, percentage and mean. The responses of the study participants were analyzed using constant comparative analysis, a grounded theory approach (21-22). For the constant comparative analysis, the data was transcribed during the interview, reread, categorized, coded and then connected using matrix analysis. The process of coding for themes was shown in appendix I. All the processes of the analysis were carried out by both, the authors.

Results

The duration of the interview sessions was meant to last for between 30 to 45 minutes. There were 40 caregivers of children with CP who participated in the study with mean age, 27.17±4.46 years. The details of the demographic characteristics of the study participants including mean age of the children, occupation of their caregivers, level education of the caregivers and the children and sex are presented in table 1.

Following the transcription and coding of the data obtained from the qualitative interview, several themes were generated for both the facilitators and the barriers. For the facilitators, there are improvements in the child’s condition, family support, improvements in the condition of other children
with CP, empathy, encouragement by the therapist managing the child and cooperation of the child
during home program. For the barriers, there are number of children the caregiver has, caregiver’s
occupation and inadequate financial resources. Figure 1 summarizes the barriers and the facilitators.

**The Barriers**

**Theme 1: Number of children**

The number of children a caregiver has, may impact on the kind of attention she may give to the child
with CP. In this society, women usually give birth to many children. In this study, the range of number
of children is 6.

“I have other children in addition to this one and they are all young. Thus, they always need my
attention, and this makes me some times to delay his home programs”………….Participant number 6.

“As I have told you earlier her mother has died since when she was 3 month; and as you can
see me too I have my own baby who is her age mate. But, I have no alternative other than to take her
as there is no one to take good care of her other than me as her aunt”……………Participant number 15.

“As now she have a younger sister so sometimes I have no choice other than to concentrate on
her younger sister especially when she is crying and that makes me to skip some of the activities
prescribed for her by the therapist”………………Participant number 38.

**Theme 2: Caregiver’s Occupation**

Caregiver’s occupation can take some parts of their time, and thus can interfere with the amount of
attention they give to the children. Most women in this society are full time housewives with no
occupation.

“I used to sell groundnut and palm oil in my house. So, sometimes customers used to distract my
attention from her, but I have no option as the business too is important to our
life”………………Participant number 5.

“I am a class room teacher in a primary school. Whenever I am having a class, I used to leave
her with a girl that is assisting me in our staff room and sometimes she used to cry before I finish
teaching my student”..................Participant number 34.

“I am working in secretariat and whenever I left for work, there is a girl that is taking care of her. But I know she cannot do it as appropriately as I am doing”..................Participant number 31.

**Theme 3: Lack of Financial Resources**

Financial resources are adequately required during rehabilitation especially where payments are made out pocket. However, in this community, most people live on under a dollar per day.

“Three months ago, the Physiotherapist asked us to buy some equipment that we will be using for him at home (for home program). But up to now, we did not buy some of them because of financial issues; but as soon as we get money we will buy the rest of the equipment”..................Participant number 19.

**The Facilitators**

**Theme 1: Improvement in the Child’s Condition**

What makes the caregivers to bring their children for rehabilitation is hope for help. Therefore, when they observe that their children are getting proper help and may be improving, they will be motivated to put more efforts.

“The time we started attending physiotherapy, my child cannot even sit but now he can stand and even walk a few steps. So this motivates me to carry out the activities that the Physiotherapists asked us to do for him at home”..................Participant number 4.

“It is really encouraging as within the few weeks that my child started receiving Physiotherapy treatment, he can sit for like 3-5 minutes unsupported. He could not sit at the time we first came.”...........Participant number 13.

“It is really impressive that within 5 months of treatment my son can now sit and I am confident that by God grace, one day he will walk and even run like his age mates. That is why I never play with the activities that the therapist asked me to do for him at home”...........Participant number 17.

**Theme 2: Family Support**

Help from family members can help reduce stress for the caregivers; and make them recharge and prepare to look after their children.
“Whenever we are asked to use some equipments that will help in the improvement for my child condition, my husband is trying his best to provide such equipments, and whenever he is at home like weekend he used to help me with some home activities like washing clothes. So this is giving me enough time to take care of my child”..................Participant number 3.

“My first daughter is now 18 years old and the second one is 15 years old. Whenever they are at home, they are the ones doing most of the home activities like cooking, and sweeping. So what remains for me is just to take care of my child”..................Participant number 17.

“Since the time the Doctor told us that our child is having this condition, my husband employed a girl who is helping me with some work at home. So, this motivates me to utilize my time for taking care of my child”..................Participant number 39.

Theme 3: Improvement in the Condition of other Children with CP

Seeing other children with CP who may even have more number deficits than one’s child, may help caregivers to tighten their belts as per as the care for their children is concerned.

“I have been seeing so many children that their condition is worse than that of my child, but as they are attending clinic, their condition is improving. Thus, I am confident that my child will get better. That is why I am taking my time to do the activities that the therapist asked me to do for him.”...............Participant number 33.

“My neighbor has a son that has experienced the same condition with my daughter. But now, he is even attending school. So, that is why I have courage that, with time my daughter too will get to that stage. So that is why I don’t joke with anything the therapist says I should do for her”...............Participant number 13.

Theme 4: Encouragement from the Therapist Managing the Child

Encouragements from the therapists are needed in order to boost the morale of the caregivers.

“Before, my perception was my son will never walk like the other children. But the therapist managing him keep encouraging me that one day my child will even run, and he kept citing many examples to me. So those words of his motivate me to concentrate on my child more than anything”...............Participant number 35.
Theme 5: Empathy

“The rest of my children can perform some of their activities of daily living by themselves, but this child cannot do anything by himself. So this makes me to pity him and pay more attention in taking care of him”.............Participant number 30.

Theme 6: Co-operation of the Child during the Home Program

The way the child cooperates during the time of rehabilitation by the caregiver at home, can make an opportune time for the caregiver to devote their effort in the rehabilitation.

“When I am doing the exercises for her at home, she will not be crying as some of the children are doing. So this is encouraging me to do the exercises for her comfortably without difficulties”.............Participant number 31.

“My child found most of the exercises enjoyable especially the rollator. So, whenever I am doing the exercise for him he doesn’t even want me to stop. So this is motivating me to do it well for him as he is enjoying it”.............Participant number 36.

“As my child is co-operating during the exercises- nothing like crying, I find it encouraging; and enjoyable to do the exercises for her”.............Participant number 7.

Discussion

The aim of the study was to explore and identify the barriers and facilitators of caregivers of children with Cerebral Palsy in the rehabilitation of their children. The results showed that the barriers are number of children the caregiver has, caregiver’s occupation, and lack of financial resources. The facilitators are improvement in the child condition, family support, empathy, improvement in the condition of other children with cerebral palsy, encouragement from the therapist managing the child and co-operation of the child during the home program. Therefore, it is important for the therapists to recognize these barriers and facilitators in order to help caregivers to participate actively in the rehabilitation of their children. This is especially that CP is a long term condition which requires care 24/7. Consequently, the caregivers are considered as those who can help extend the care for their children by actively participating in their rehabilitation (23). Fortunately, caregivers of children with
CP recognize how important physiotherapy is at improving motor and psychosocial functions of their children, and as such they are always willing to carry out the tasks the therapists recommended for their children at home (24). In addition, when caregivers participated in the rehabilitation of their children, motor function improved better compared to institution based rehabilitation (25). However, barriers such as number of children the caregiver has, financial constraint and caregiver’s occupation may affect their zeal or willingness to actively participate in the rehabilitation of their children. Although from the results of this study, the number of children a caregiver has can serve as a barrier to their participation in the rehabilitation of their children, a previous quantitative survey had a contrary result. According to Olagunju and colleagues, there was no significant association between number of siblings and compliance with home programs provided by a caregiver to a child with CP (26). One of the probable reasons for the difference in the findings of the two studies could be because of the different methodologies used in the studies. A qualitative approach which was used in the present study has the advantage of getting subtle and nuance insights on a particular phenomenon which cannot be detected by a quantitative study, a methodology used by the latter study (27). Secondly, the validity of the questionnaire used in the latter study is sketchy as only poorly explained content and face validation were mentioned. Therefore, it is possible that the questionnaire did not measure what it was purported to measure. This is more so that other studies reported that number of children a caregiver of a child with CP has can cause so much burden on the caregiver and result in family adjustment (24, 28).

Since number of children can add more strain and stress to a caregiver, it is therefore important to counsel caregivers to do adequate child spacing in order to give adequate attention to the child with CP. This is more so as the caregivers in the present study are still young, and may have potentials to give birth for many years. However, if the children are older and they can help in the caregiving, this may be a blessing. In the present study, help or support from the family is a facilitator, and it was previously reported to be a primary source of support for caregivers and that it helps reduce caregiver stress (29, 30). Therefore, therapists should devise strategies to reinforce it. This can come in form of division of labour whereby one member of the family can do one thing for the child during a
particular time, and another some other time. According to Chiluba and Moyo, caregivers of children with CP expressed the need for someone to stand in for them sometimes (28).

For lack of financial resources, it was reported previously that, low income is associated with increased caregiver burden (31-32). Additionally, caregivers of children with CP have reported that one of the barriers to accessing care for their children is lack of financial resources (28). However, CP is a long term condition, and it requires care in the long term that may cost huge financial resources. Consequently, cost of care can add more strain to the caregivers and constrain their ability to afford services for their children (33-34). This is more difficult in places like Nigeria where people make out of pocket payments for health services. Similarly, in other low resource settings such as in Zambia, families pay healthcare services bills for their children which are most times difficult to afford (28, 33). Therefore, governments need to make health services very accessible or subsidize the cost of rehabilitation through enrolling children with CP in National Health Insurance Scheme (NHIS). For now, for instance in Nigeria, the enrollment seems to be restricted to only Government employees and to some extent, students in tertiary institutions who comprise just a small percentage of the population. In contrast, in developed countries such as the United Kingdom, health care services are largely free (35); and in 2005, out of pocket payment accounted for only 11.9% of total expenditure (36). Thus, it is pertinent for low resource settings such as Nigeria to critically analyze their healthcare delivery and come up with a system that will be accessible to all and sundry irrespective of their socioeconomic status.

Another barrier is caregiver’s occupation which can limit the time the caregivers can devote in rehabilitation of their children. Although, there is assistive technology such as Switching that can help decrease caregivers’ effort, energy expenditure and burden (24, 37); the technology is relatively costly and needs time and skills to operate. Consequently, it is important for therapists to devise other simple and affordable means such as reinforcing family support. Family support or social support can help reduce caregiver stress (32). This family support can come in form of sharing responsibilities among spouses and members of the household or engaging a paid caregiver if it is possible. Similarly, improvement in the child’s condition during the rehabilitation program is one of
the most important facilitators that motivate the caregivers to put more effort in the rehabilitation of their children with CP. The reasons for this could be because mothers or caregivers of children with CP value and recognize the benefits of Physiotherapy, and they believe that, it is important that the therapy continues (24, 28). This appreciation is especially as regards to improvement in functional status. Secondly, the family or the caregivers are empowered following CP rehabilitation (38). However, at the same time the caregivers feel that the care is sometimes not well coordinated and they do not receive the kind of encouragement they feel they need from the therapists (28).

Therefore, therapists need to do more to invest in research and professional skills in order to improve the conditions of children with CP. In addition, there is a need for the therapists to incorporate techniques such as motivational interviewing to encourage caregivers to participate actively in the rehabilitation of their children. Motivational interviewing improves self-efficacy (39).

Similarly, even improvement in the conditions of other children with CP other than their own that may even have more number of deficits than their children, may motivate them to put more efforts in the process of rehabilitation of their children. Number of deficits a child with CP has is associated with increased caregiver burden (29). Consequently, group therapy, whereby a number of children can have their rehabilitation sessions at the same time may help foster confidence in the caregivers of children with CP. Other facilitators that need to be reinforced by the therapists during rehabilitation include empathy and caregiver encouragement by the therapists. According to Cerebral Palsy Guide, empathy is greatly required in the process of care for a child with CP (40). In addition, encouragement from the therapist is also greatly required; but it may be lacking (28). Therefore, therapists need to find means of training the caregivers adequately on the care of their children and use of motivational interviewing to encourage them actively participate in the rehabilitation of their children. However, one of the limitations of this study is that, only participants who were attending Specialists Paediatrics Hospital were included in the study. As such, their views may differ from those attending Primary Healthcare Centers where the system is less advanced than the one in the former.

Conclusion
Caregiver participation in the rehabilitation of their children with CP is greatly required. However,
there are barriers or facilitators that can hinder or encourage their participation. Therefore, therapists need to recognize these barriers and facilitators to help discourage or reinforce them. In addition, government needs to make healthcare services for children with CP accessible irrespective of the family’s socioeconomic status.

**Implication for Policy, Research and Practice**

Since lack of finance is one of the barriers to the caregivers’ active participation in the rehabilitation of their children, there should be a policy on CP rehabilitation that will make rehabilitation services accessible to all children with CP. In addition, since CP is a long term condition and the caregivers are required to actively take part in the rehabilitation of their children, there should be tasks shifting training whereby the caregivers are taught how they can adequately carry out rehabilitation techniques for their children. Similarly, techniques such as motivational interviewing should be used to help therapist encourage caregivers to actively participate in the rehabilitation of their children. Furthermore, mixed methods studies should be employed in order to adequately understand the barriers and facilitators of active participation of caregivers of children with CP in their rehabilitation. Lastly, this type of study should also be carried at different levels of the healthcare delivery (Primary, secondary and tertiary).

**Declarations**

Ethics approval and consent to participate
The study was approved by Research Ethics Committee of Kano State Ministry of Health. Participants’ consent was obtained after detail explanation of the study to them (this was to seek for their consent and to familiarize ourselves with each other). The consent involved each of the participants signing a consent form.

Consent for publication
Study participants provided consent to publish the study

Availability of data and materials
The data and all materials for this study are available on written request to the corresponding author.

Competing interests
The authors declare no competing interest

Funding
The authors did not receive any funding for the study

Authors' contributions

Both authors equally contributed in the study design, data collection and writing up of the manuscript; however, the data was analyzed by AA.

Acknowledgements

The authors would like to thank our study participants for their invaluable time.

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Table

Table 1: Demographics and Characteristics of the Study Participants (N=40)

| Variable                                      | %               |
|-----------------------------------------------|-----------------|
| Mean age of the caregivers                    | 27.17±4.46 (21-40) years |
| Gender (female/male)                          | 40/0            |
| Relationship with the child (mother/others)   | 38/2            |
| Mean time since caregiving started            | 2.90±1.55 (1-8) years |
| Mean age of the children                     | 3.00±1.68 (1-8) years |
| Range of number of children                  | (2-8)           |
| Range of number of dependents                | (2-9)           |
| Level of education (primary/ secondary / higher institution/ none) | 3/ 31/ 6/ 0 | 7.5%/ 77.5%/ 15%/ 0% |
| Religion (Islam/ Christianity/ Others)        | 40/ 0/ 0       |
| Occupation (housewife/ business/ civil servant/ others) | 23/ 14/ 3/ 0 | 57.5%/ 35%/ 7.5%/ 0% |
| Marital status (married/ single)              | 40/ 0          |

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## Appendix

### APPENDIX I (DATA ANALYSIS MATRIX)

| Participant | Responses | Coding for |
|-------------|-----------|------------|
| 1           |           |            |
| 2           |           |            |
| 3           |           |            |
| And so on   |           |            |

Figures
Figure 1

Schematic Representation of the Barriers and Facilitators of Active Participation of Caregivers of Children with Cerebral Palsy in the Rehabilitation of their Children

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

Implication for Rehabilitation.docx