Factors Influencing Adherence to Physiotherapy Appointments for Children with Cerebral Palsy

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Abstract
Adherence to treatment appointments by mothers of children with Cerebral Palsy is one of the factors affected in rehabilitation of a child with Cerebral Palsy, and this is cardinal to ensure effective rehabilitation outcomes for the child. Hence this study aimed to explore the factors influencing poor adherence to physiotherapy appointments by mothers of children with Cerebral Palsy at Chilenje Hospital, in Lusaka. A qualitative case study design utilising a phenomenological approach was conducted with a sample of 12 mothers of children with Cerebral Palsy from Chilenje Hospital, Lusaka. Convenient sampling was utilized where mothers who were non-adhering were also purposefully selected into the study to better understand the factors affecting adherence to physiotherapy. The factors that contributed to caregivers defaulting scheduled therapy included economic constraints like unemployment and low education level, caregiver related factors such as marital challenges, and service centered factors such as challenges with the diagnosis of Cerebral Palsy and negative clinician attitudes. Majority of the caregivers admitted that they were motivated to attend therapy by observable improvements in their children. A combination of psychosocial, economic, child centered and service centered factors contributed to caregivers defaulting scheduled therapy. Interventions that may potentially improve caregiver attendance to scheduled therapy include community outreach services, efficient rehabilitation service provision at the hospitals, and facilitation of income generating programs for mothers and caregivers.

Keywords: Cerebral Palsy, Perspectives, Physiotherapy

1. Research Background
Cerebral Palsy (CP) is defined as a group of permanent or non-progressive disorders of movement and posture. It is the most common motor disability in childhood (Andrew et al., 2010). It causes activity limitation and may be accompanied by disturbances of sensation, perception, cognition, communication, behavior, by epilepsy and by secondary musculoskeletal problems (Arneson et al., 2009; Bailey, 1991, Bax, 2005).
The population-based studies from around the world report prevalence estimates of CP, which range from 1 to 4 per 1,000 live births (Borst, 2005). However, the prevalence of CP in Zambia is unknown due to limited research and documentation. This seems to be one of the main contributors to childhood disability in many Zambian communities (Chiluba & Phiri, 2019).

Caring for a child with a developmental disorder such as CP can prove to be daunting for mothers and caregivers, posing a significant risk to parents’ physical and emotional well-being (Charcot, 1989). One of the main challenges for parents on one hand is to manage their child’s chronic health problems effectively while on the other maintaining the requirements of everyday living. Other studies observed that in some cases, the provision of such care could prove detrimental to both the physical health and the psychological wellbeing of parents of such children (Chiluba, 2017). The impact could be felt in the family income, family functioning, and sibling adjustment.

Involvement of mothers and caregivers in the rehabilitation of the child with CP is very important. The interaction of the physiotherapist and the parents of a child with CP is a necessity because their joint work makes it possible to strengthen the father-mother-child bond and is a key for successful therapy interventions (Creswel, 2013; Degenais, 2006; Deon, 2001) also added that the active participation of parents during these activities has demonstrated positive effects on the children’s outcomes, such as gains in motor skill attainment.

Rehabilitation is defined as a process used to restore lost function to individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environments (Deon, 2001; DiMatteo, 2004; Donovan, 2008). Other authors alluded that rehabilitation requires a developmentally oriented approach that is not limited to the care of the motor disorder (Failla, 1991). Thus, it is important physiotherapy practice to direct more and more attention to parental participation.

One of the most significant barriers to effective medical treatment is the patient’s failure to follow the recommendations of his/her physician (Gona, 2010). Poor adherence to treatment has been identified across many healthcare disciplines including physiotherapy and can have can have negative effects on outcomes and healthcare costs (Greenberg, 1997; King, 1999). Further literature identified many forms of patient non-adherence (sometimes-called noncompliance) including misunderstood advice from healthcare professionals by patients to cure or control disease that may be carried out incorrectly, forgotten or even completely ignored (Gona, 2010). Other authors recorded an extent of non-adherence to treatment and exercise performance as high as 70% (Klok, 2011).
The World Health Organization defines adherence as, “the extent to which a person’s behavior corresponds with agreed recommendations from a healthcare provider” (Law, 1993). The concept of adherence is multi-dimensional in physiotherapy and this could relate to attendance at appointments, following advice, undertaking prescribed exercises, frequency of undertaking prescribed exercise, correct performance of exercises or doing more or less than advised [20]. However, other authors alluded that, it is unclear which factors act as barriers to adherence within physiotherapy (Mbungua, 2011; Melusa, 2013).

A study in Zimbabwe and identified factors contributing to defaulting scheduled therapy sessions by caregivers of children with disabilities (Miller, 1997). These included economic constraints (52%), child related factors (43%), caregiver related factors (42%), service centered factors (30%) and psycho-social factors (58%). The Majority of the caregivers (98%) were motivated to attend therapy by observable improvements in their children. Other motivators were incentives given in the rehabilitation department (45%), availability of rehabilitation personnel to provide the required services (48%) and psychosocial support from fellow caregivers, families and the rehabilitation staff (68%).

There seems to be a paucity of research on the factors relating to adherence to physiotherapy appointments in Zambia. Only two studies have been published to highlight some of the challenges and experiences mothers face in caring for a CP child (Morris, 2007; Mpofu, 2012). Hence, the motivation for this re-search was to find out the factors affecting adherence to physiotherapy appointments by mothers of children with CP.

2. Research Methodology

2.1 Design and setting
This study utilized a qualitative phenomenological design. This was to emphasize on describing the meaning of several caregiver’s perceptions, feelings and lived experiences in order to have a deep understanding of the phenomena. The research was carried out in Lusaka, at Chilenje Level One Hospital.

2.2 Selection of participants and data collection
The working sample size was 5 mothers with a CP child; this was considered an initial sample size for phenomenological studies (Nota, 2015). This method is based on theoretical saturation technique, meaning if the theory were not reached at sample size 5, the number where the theory was reached was to be considered the actual sample size. Theoretical saturation was reached at sample size 8. A combined focus group discussion of 4 mothers with a CP child was done. Two (2) physiotherapists were also conveniently chosen with regards to number of years served in therapy of children with CP. Therefore, 14 participants were the sample size for the study.
In total, interviews and focus groups with 8 mothers and 4 mothers of children with CP, respectively led to richness, saturation, and repetition of data. Through data analysis, 150 codes were extracted that were classified in 14 subcategories and 6 main categories and included Perceived psychological challenges, Physical health challenges, Socio-economic challenges, Environmental challenges, Marital challenges and challenges with diagnosis of the condition of CP, of which some themes came as emerging themes. Data collection was done with the assistance of an interview guide and an audio recorder and the data later transcribed.

A systematic Interpretative Phenomenological analysis approach was used as a method of data analysis. Coding was also used for data analysis. Data were transcribed into English whilst at the same time ensuring that there is no loss of meaning during translation for parts where different languages was expressed. Themes were identified, coded and categorized. Once all interviews were completed, each interview was transcribed on to the paper from the tape recorder which was used and each interview was coded on a line-by-line basis in terms of classifying themes and events. Content was analysed to explore in detail common themes which brought meaning to the data. Field notes and information documented were also regularly reviewed.

The transcripts were analyzed thematically in order to identify commonalities and variances among the participants' responses. The Nvivo software program was used to aid the analysis. Organizing qualitative data involves being initially faced with completely uncategorized data (Gona, 2010). The primary task is to look for patterns in the data. The researcher therefore engaged in careful observations which led to the uncovering of connections and patterns in the data.

3. Results

The socio-demographic factors of the participants captured are illustrated in Table 1 below.
Table 1. Demographic profile of mothers and their CP children at Chilenje hospital

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Marital status</th>
<th>Education level</th>
<th>Employment status</th>
<th>Sex of child</th>
<th>Age of child (years)</th>
<th>Type of CP</th>
<th>Other siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>W1</td>
<td>33</td>
<td>Divorced</td>
<td>Secondary</td>
<td>Employed</td>
<td>Male</td>
<td>4</td>
<td>Athetoid</td>
<td>None</td>
</tr>
<tr>
<td>W2</td>
<td>37</td>
<td>Married</td>
<td>Tertiary</td>
<td>Unemployed</td>
<td>Male</td>
<td>5</td>
<td>Spastic Quadriplegia</td>
<td>4</td>
</tr>
<tr>
<td>W3</td>
<td>27</td>
<td>Single</td>
<td>Secondary</td>
<td>Self-Employed</td>
<td>Female</td>
<td>4</td>
<td>Spastic Diplegia</td>
<td>1</td>
</tr>
<tr>
<td>W4</td>
<td>38</td>
<td>Widow</td>
<td>Primary</td>
<td>Self-Employed</td>
<td>Male</td>
<td>8</td>
<td>Hemiplegia</td>
<td>None</td>
</tr>
<tr>
<td>W5</td>
<td>24</td>
<td>Single</td>
<td>Secondary</td>
<td>Unemployed</td>
<td>Female</td>
<td>2</td>
<td>Athetoid</td>
<td>None</td>
</tr>
<tr>
<td>W6</td>
<td>28</td>
<td>Married</td>
<td>Tertiary</td>
<td>Unemployed</td>
<td>Female</td>
<td>3</td>
<td>Ataxia</td>
<td>1</td>
</tr>
<tr>
<td>W7</td>
<td>35</td>
<td>Divorced</td>
<td>Secondary</td>
<td>Self-employed</td>
<td>Male</td>
<td>5</td>
<td>Diplegia</td>
<td>1</td>
</tr>
<tr>
<td>W8</td>
<td>21</td>
<td>Single</td>
<td>Secondary</td>
<td>Unemployed</td>
<td>Female</td>
<td>1</td>
<td>Athetoid</td>
<td>None</td>
</tr>
<tr>
<td>W9</td>
<td>42</td>
<td>Married</td>
<td>Primary</td>
<td>Unemployed</td>
<td>Male</td>
<td>7</td>
<td>Hemiplegia</td>
<td>3</td>
</tr>
</tbody>
</table>

Six main themes were identified and the subthemes that arose are shown in Table 2 below:

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional challenges</td>
<td>Perceived depression</td>
</tr>
<tr>
<td></td>
<td>Perceived stress</td>
</tr>
<tr>
<td>Physical health challenges</td>
<td>Musculoskeletal challenges</td>
</tr>
<tr>
<td>Socio-economic challenges</td>
<td>Low levels of education</td>
</tr>
<tr>
<td></td>
<td>Unemployment</td>
</tr>
<tr>
<td>Environmental challenges</td>
<td>Social environmental challenges</td>
</tr>
<tr>
<td></td>
<td>Clinician’s attitudinal challenges</td>
</tr>
<tr>
<td>Marital challenges</td>
<td>Misunderstandings</td>
</tr>
<tr>
<td></td>
<td>Divorce</td>
</tr>
<tr>
<td></td>
<td>Conflicts</td>
</tr>
<tr>
<td>Challenges with diagnosis of the condition of CP</td>
<td>Delayed diagnosis</td>
</tr>
<tr>
<td></td>
<td>Misdiagnosis</td>
</tr>
</tbody>
</table>

3.1 Emotional challenges

Over 50% of all the mothers in this study had experienced some emotional challenges, owing to having children with CP. These challenges included depression (22.2%) and stress (66.7%). This was due to many factors as described under the subthemes.
Perceived depression

The 22.2% of the mothers in this study admitted that they have been experiencing some depression symptoms such as feeling of loneliness, guilt, self-isolation, sorrow, self-pity, insomnia and loss of appetite. One of the mother’s perceived depression was due to regret, self-pity, living an isolated life and her husband leaving her after giving birth to a child with CP as shown in the quote below.

“…It is my entire fault that my child turned out to be like this. Some people always told me that nothing good will come out of my marriage to the married man I married… he left me the moment I gave birth to my son with CP and left to live with his first wife… I have no one to help me with my son and it gets difficult for me to even leave the house to go anywhere with him. It is stressful and embarrassing”. W7

Another mother’s source of perceived depressive symptoms included feelings of hopelessness, suicidal thoughts and thoughts of neglecting the child. This is illustrated in the quote below.

“I feel like a disappointment to my family, and I sometimes feel useless… I feel like ending my life every day, or maybe just running away with no trace and leave my child with my sister whom I stay with, to do whatever it is she pleases with her…I am usually sad”. W8

The researcher found that one of the participating mothers had a permanent and reoccurring experience of pervasive sadness and loss which may have led her to suffer from depression.

“…I can’t shake this sorrow off. I cry a lot especially when I pass through hard times. My sister’s in-law really laugh at me, they say ‘even if I take this child for physiotherapy, the child will not get better’. It hurts so I cry”. “…Another thing that bothers me is that I am educated. I have finished my grade 12. I really want to do something about my life, find a job or go to college. I would like my child to walk fast as I need to do something about my life”. W2

Perceived stress

More than half of the participating mothers (66.7%) had perceived stress symptoms. The symptoms described included, constant headaches, persistent worry, perceiving their situation to be extremely difficult and having a burdensome feeling.

One of the mothers’ perceived stress was the unemployment situation of her and her spouse, failure to afford basic needs of life, assistive devices and transportation for the child to and from rehabilitation centers. This is shown demonstrated below.

“I get worried mostly, because my husband and I are unemployed and can hardly manage to provide the basic needs such as proper food and shelter to our two children and dependents… sometimes I get sick just thinking about it, especially
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after crying for a long time. We are suffering and it is harder with a child like this. I can’t go anywhere else without him, if I am not with him I can’t think well”. W6

For one of the other mothers, her perceived stress was due to her frequently asking for time off work to go home when her child with CP felt unwell. She feared that her boss would fire her because she was unusually absent from duty when the child was unwell or did not have anyone to look after her. Her worry was how she was going to provide for her child if she lost her job, especially that she had no tertiary training.

“He is always getting sick and I worry the nanny is not capable of managing him well enough, especially when she forgets to give him his baclofen. I am usually leaving work early or not going all together because of my child…if my boss fires me, we are going to suffer… where will I find another job I don’t even have any qualifications”. W1

3.2 Physical Health Challenges

Musculoskeletal and physiological problems are common in mothers with the task of taking care of the children with functional limitations who need assistance with ADLs. The mothers complained of symptoms such as chest pains, neck pain, back pain, headaches and hypertensive symptoms. Approximately 67% of the mothers were suffering from musculoskeletal problems, 22% had physiological problems and only one mother reported not to suffer from either physiological or musculoskeletal disorders.

Musculoskeletal Disorders

Among the mothers who were experiencing musculoskeletal disorders, activities such as lifting, carrying, transferring and pushing of their children with CP which are repeated several times a day subject the musculoskeletal structures of the mothers into stress causing injury. A 37 years old mother was suffering from shoulder chest, neck and lower back pain as she does everything for her 5 years old child with spastic quadriplegia including carrying him on her back and walking long distances, especially when she cannot afford a bus fare. This is shown in the statement below.

“At his age, he still soils his nappies, requires feeding and I have to do everything for him…bathing and feeding him are the most difficult, especially with the regular pain I feel in the neck, back and shoulders… Sometimes I carry him on my back just to come to the hospital for physiotherapy when I cannot afford to get on a bus. When I get to the department, I am in so much pain that sometimes I even fail to sit in a chair… I can’t bother my husband because he is the one that works so that we can even have a plate of food everyday”. W2

A single 27 year old mother reported having back pains and feeling restless after constantly lifting her 4 year old child with spastic diplegia who is only beginning to shuffle, but cannot sit or communicate.

“…She does not talk, she cannot even sit, her leg muscles are very stiff, she is starting to shuffle herself around but I still have to do everything for her. I lift her a lot. It gives me a lot of back pains. My body is so tired, it needs to rest”. W3
**Physiological Disorders**

About 45% of the mothers were suffering from physiological disorders that resulted from elevated stress hormones stimulating further physiological activities that might have led to negative health outcomes. A 38-year-old widowed mother was very affected by the condition of her 5 year old child such that she struggles to make decisions as she does not think straight and frequently suffers from amnesia that she even forgets appointment dates for physiotherapy. At least she does not perceive the condition of her child to be severe as the child can communicate and even feed himself though he has weakness on the right upper and lower limbs, can walk on his own and does not depend on his mother entirely for ADLs. The mother expects the child to be fully independent given the age.

“…Even though he can walk, his legs are weak. I have to guide him for bathing and going to the toilet. At least he talks and feeds himself. It affects me in my mind, I can’t think straight and I suffer from memory losses… He is 8 years old, he should be doing things for himself, but I have to do it for him…” W4

One 37 years old mother suffers from constant headaches as she struggles to divide attention between her 5-year-old child who is incontinent with quadriplegia and her other younger children. Her roles as a mother and caregiver for her disabled child, which includes cleaning after him when he soils his napkins, were overwhelming and tiring causing the condition that she suffers. The statement below illustrates this.

“…The child has stiff muscles all over the body he cannot move. He does not sit or move. Everything is done for him. You have to feed him, wash him, lift him a lot and clean him after he soils his nappies. That is too much for me to handle considering I have other small kids now. I am constantly tired and have these headaches that don’t go away… It gets hard for me to even bring him for physiotherapy if my husband is busy with work and can’t help me bring him”. W2

3.3 Socio-economic challenges

Nearly all the participating mothers were experiencing socio-economic challenges, owing to their poor educational backgrounds, lack of employment opportunities for others, and high poverty levels for some.

**Education**

The level of education of the mothers as indicated in the demographic data was categorized as primary, secondary, primary or none. It was found that all mothers who participated in the study had obtained some level of education. Only two (22.2%) of the mothers had a tertiary education, five (55.6%) had a secondary education and two (22.2%) had only attained their primary education. A 38-year-old mother with only primary education blamed her lack of tertiary education to be the cause of her inability to get a good paying job and opted to stay at home to look after her child as jobs for people without education are generally low paying. This was making her struggle to raise her child with CP.
“The upbringing of my child has not been an easy one because I am not employed. Even if I found work, what sort of job would it be and how much could I get considering that I am not educated? I would rather stay at home and look after my child…But I know I have to look for something to do especially that I lost my husband and have no one to support my child and I”. W4

Another 42-year-old married mother blamed her parents for her low level of education which she believed was hindering her from looking for a job. She also felt like if she had a job, she would have bought the much-needed assistive devices for her child with CP.

“…If it were not for my poor education status, I would not be struggling to raise my child like this. I would have looked for a job and my child would be much better now… She is not okay as she does not have any of the assistive devices, which I could have bought if I had a job… I blame my parents for not educating me. They told me marriage was more important than education”. W2

Another divorced mother blamed her low level of education to be attracting minimal income which was not sustaining her and her child. She could not even afford to pay for her child’s CT scan when it was recommended some years back at a specially hospital. Four years down the line, she has not managed to have the scan done but has continued with physiotherapy. This is shown in the quote below.

“Sustainability is not there. I earn so little working as a self-employed marketer and part time genitor… I could be earning much better if I had a trade…. I even explained to the health personnel 4 years ago who said the child needed to have a CT scan that I could not afford it. It almost costs K4500... Where can I get such money from? We will just continue with physiotherapy, that’s why I try not to miss many sessions”. W7

**Employment**

The demographic data shows that only one mother ((11.1%) was employed, three (33.3%) were Self-employed and the rest of the mothers (55.6%) were unemployed. The mother that was employed reported that her salaries was not enough to sustain her and her child with CP and those who were self-employed reported that from time to time they ran out of business or were forced to not work on some days because of their child with CP’s illness. The unemployed mothers reported to be suffering from financial hardships. One of the unemployed mothers was eager to look for a job as a general worker, but the condition of her child could not allow. She was hoping that the child could start walking so that she would be able to look for a job and be able to buy the recommended assistive devices which she has not been able to afford as her husband was also unemployed.

“At the moment I do not work, it is difficult as my husband is only a piece worker. We could not even afford the chair that the physiotherapist suggested that we buy for the child… I was earnestly hoping that the child walks fast so I can go and look
for a job as a maid or general worker. I am eager to look for employment; someone needs to help my husband”. W2

Another unemployed mother stays at home to look after her child with CP reported not coping financially as the money the she gets from her elder sister who keeps her and the child is not sufficient. This she said was even worse in the rain season when her sister and husband were having financial problems, then she would struggle to transport her child to and from the rehabilitation centre. This is demonstrated below.

“I do not work; I stay at home to look after my child and those of my elder sister. My sister’s husband is a local bus driver. We do not manage financially with the money he gets from the trips. We struggle especially when my sister’s fish selling job is not doing fine… Transportation to and from rehabilitation is a huge burden as I cannot afford. W8

3.4 Environmental challenges

Nearly all the mothers were experiencing some form of the social, attitudinal and physical environmental challenges due to having a child with CP.

4. Social environmental challenges

The social environmental challenges experienced by the mothers were due to living in social isolation, lack of support from family and friends and lack of support from the community. 55.6% of the mothers were living in social isolation, 33.3% of the mothers were lacking support from their families and friends and 11.1% of the mothers lacked community support.

A 35-year-old divorced mother admitted that she was living in isolation for fear of people not accepting the condition of her child. She was equally afraid that people will blame her for the condition of her child and her divorce as stated below.

“…I have not had so much contact with my friends and neighbors as I stay indoors with my child most of the time. I am afraid of being laughed at or other people not accepting my child the way he is, it would hurt. I also don’t want anyone to blame me for the condition, especially that my husband left me for this same reason”. W7

Another 24-year-old single mother was living in isolation after losing her friends whom she believes have been bad mouthing her. Due to the child’s behavior in public places, the mother has also decided not to have any social interaction except when her mother helps her to look after her child. This is shown in the quote below.

“…My friends laugh at me, in fact they are not even my friends anymore because they were telling everyone in the community that the baby is sick because of my promiscuous ways ‘She sobs’… He is a very difficult child, if I go with him to church, we spend the whole time outside so I have stopped going to church, not even town. Unless I’m in dire need then I ask my mother to help look after him…” W5
One of the married mothers was experiencing negative attitudes from her husband and his family who do not like her and blamed her for the condition of her child. They go to an extent of forcing her husband to leave her and marry someone else. As if that is not enough, her friends laugh at her and refer to her child as mentally challenged. This is shown in the quote below.

“...My husband's family does not like me and the fact that I have a child with CP. They have been trying to force my husband to leave me and marry someone else...I struggle and the fact that my husband and his family accused me of being the cause of the condition it is difficult... My friends say all sorts of things and refer to my child as a mentally ill child and that my husband wants to leave me because of that, they are all hypocrites”. W6

5. Clinician attitudinal challenges

This study found that 33.3% of the mothers were experiencing challenges not only with their family, friends and community but also with the clinicians at Chilenje Hospital towards the care of their child with CP.

One of the mothers who is employed but divorced experienced negative attitudes from healthcare professionals. This was after a misunderstanding with one of the nurses who urged her to report her (nurse) if she was not happy with the services. The nurse was nearly fired after she was reported, this made the other nurses to give her negative attitudes whenever she needed help.

“...the nurse I found on duty gave me a very bad attitude and said the only way she would help me was if my child had TB. I tried to reason with her, but she would not listen and told me to report her to the district health board if she wasn’t happy with the services. Desperate for help, I reported her to the district board which did not turn out well as she was nearly fired. Equally this did not work well for me as now all the nurses started giving me negative attitudes”. W1

Another 21-year-old single mother also experienced negative attitude from the nurses who said she too young to have a child and related the child’s disability to her young age. The nurses were ignorant of her pleas and she was constantly scolded when her child cried so much and she could not calm her down. This is shown in the quote below.

“It is as though I don’t exist when I come to the hospital for my child. They ignore me until all the other mothers with normal children have been attended to...I feel embarrassed and have regrets. Sometimes when my child is sick, I do not even want to take him to the hospital because of such attitude. I don’t want to report them because I am afraid...I am even afraid of coming for physiotherapy sometimes because I afraid they will also treat me the same”. W8
5.1 Marital Problems

The study shows that some of the mothers were having conflicts with their spouses because of having a child with CP. Some of them were divorced as a result. This was mainly due to lack of acceptance of the child with CP especially by the male spouses, influence from relatives, poor spousal support and poor coping mechanisms. Of the 9 mothers, 3 were single, 2 were married, 2 were divorced and 2 were divorced due to conflicts with their spouses about their child with CP. A 33-year-old married mother reported to having conflicts with her husband as she could not agree with him when he wanted to move out of town so they can keep the child’s condition a secret and no one will be able to visit them. This is what she said:

“… He was too embarrassed about the condition of the child and did not want others to know about it and sympathize with us. He wanted us to keep the child’s condition secret. I could not. This put a strain on our relationship as we were always fighting and sometimes, he would not even talk to me… I sometimes suspect he is seeing another woman”. W1

Another 42-year-old married mother reported that her husband thought the child’s condition was as a result of a curse and sought assistance from a traditional healer without consulting her. This is illustrated in the quote below.

“… I felt betrayed when he took my child to a traditional healer even when he knows it goes against our faith. He made me feel like the child was from the devil, like he was nothing… my relationship with my husband is not the same after my son was born. It’s like we are just housemates with children… it is difficult to share duties over our son with CP like this, so if I don’t take care of my son, I now he won’t help me”. W9

A 35-year-old divorced mother related the break of her marriage to the guilt her husband felt because of being promiscuous, which she said was the cause of her giving birth to a child with CP. This is shown in the quote below.

“Everyone knows that when a husband is cheating on his pregnant wife, something goes wrong with the child she is carrying, it is a curse… when my son was born like this, I blamed it all on my husband for sleeping with other women. I could not stand him, so I filled for a divorce. I don’t regret it, even when taking care of my son gets hard for me alone”. W7

5.2 Challenges with the diagnosis of CP

Only one mother (11.1%) reported that she initially had a challenge with the diagnosis of her child with CP while the remaining 88.9% of the majority of the mothers had no challenges with CP diagnosis of their child. One 42-year-old mother despite noticing that there was something wrong with her child, the medical professional kept assuring that her child was okay. This was despite the fact that the child was being able
to perform activities that children his age could perform. This is illustrated in the quote below.

“I was told the child was okay. However, I knew there was something wrong because that is not how my other 3 children were… ‘You are just anxious to see change fast’, as the baby was looking healthy and was very fat. I was assured that it was because of his weight. I should expect some differences from my three girls… months down the line there was no improvement I thought of going back”. “He was 8 months old when I went back after seeing no change… He couldn’t even move the leg and arm on the right side, I noticed all that but they still said I should give him time…after pushing for two more months when he was a year old, an Indian doctor referred me to- a physiotherapist who diagnosed him with CP and explained everything to me”. W9

To the contrary, another 38-year-old widowed mother with a spastic hemiplegic child reported that it was hard for the medical professionals to figure out what was wrong with her child even when it was that noticed an abnormality. A CT scan taken later reviewed the brain abnormality and referral was made for physiotherapy.

“In the beginning, I thought my child was fine. However, there was one young doctor who stated that she noticed an abnormality with my child and did not discharge us until we did a CT scan. She explained to me that my child had CP and I needed to start physiotherapy immediately…I was not told what the disease was and if my child could be cured of it, so I just came to physiotherapy and then I was told what it meant. I have been coming since he was born.” W4

5.3 Physiotherapist’s perceptions

Therapists were asked about challenges that mothers experienced with the health care system that included a lack of identification of personal problems, inability to relate the personal problems to relevant factors of the environment, and lack of assessment/treatment tools. The service providers of children with cerebral palsy confirmed this. This is shown in the quote below:

“... In my own opinion, our approach is centered so much on the child and very little/non is actually designed for the mothers/caregivers. We have no incentives at the department to help most struggling mothers. There are some mothers who are passionate about physiotherapy for their children but are struggling even to come to the department”. PT2

“....most of us actually fail to relate and integrate the personal problems such as the space of the house the child is coming from due to inability to physically examine the residence...the department is also too small and we have few staff specialized in handling of these children. Mothers wait for hours to get their turn because they can’t all fit in the treatment room and have a physiotherapist promptly attend to their child....we don’t even have toys and other equipment for treatment such as standing frames, special chairs and walkers. It’s hard to guide mothers when we can’t even demonstrate with our own equipment.” PT1.
5.4 Root cause analysis of mothers of CP children defaulting physiotherapy for their children

The factors associated with defaulting physiotherapy for children with CP by their mothers in this study was shown to be influenced by social, environmental, physiological and individual level characteristics that are proximal to that behavior, including perceived depression and stress, negative clinician attitudes, low levels of education and unemployment, marital challenges and physiologic challenges. Most defaulting mothers were found to have been affected greatly by their low socio-economic statuses and educational backgrounds that influenced their understanding for the child’s condition and the benefits of physiotherapy, hence the defaulting.

![Figure 1. Root cause analysis of mothers of CP children.](image)

6. Discussion

Although this phenomenological qualitative study confined to one of the five first level hospitals offering rehabilitation services in Lusaka, the results obtained demonstrate the profound importance attached to rehabilitation of children with CP. Despite all the caregivers having missed at least one scheduled therapy session, the majority concurred to the importance of rehabilitation for their children. This study discovered various factors which included economic, psychosocial, environmental, caregiver-centered, service provider centered and child centered factors as contributing to caregivers defaulting scheduled therapy sessions.

This current study found that there was interplay of socio-economic difficulties, inadequate resources, dissatisfied services providers and social stigma towards physical
disabilities and socio-political and cultural histories, all of which make it arduous for caregivers to adhere to scheduled therapy sessions. This is similar to the findings of a study in Zimbabwe on resource-constrained settings, without excluding Zambia (O’Neil, 2009). In this study, the median age of the mothers of children with CP was 33 with a mean age of 31.7 years, similar to other studies (Mpofu, 2012; Ong et al., 2005; Patel, 2005) which captured a wide age group. This is because challenges experienced by younger mothers may not necessarily be the same as those experienced by older mothers. Literature also reported that mothers of varying age groups view disability differently (Paul, 2008). Younger mothers worry not only about the condition of their children, but also about their future in terms of marriage, education and employment, whereas older mothers worry about financial and mostly physical health challenges (Press et al., 2001).

The current study showed that mothers with older children experienced more challenges than those of younger children. The majority of the mothers recruited in this study, were those with children below 5 years old and the remainder were those with children between 5 years and above, but not more than 8 years old. Other studies have shown that challenges faced by parents raising children at different ages can be very different and unique and it is thus arguably very difficult and unreliable to compare challenges amongst parents of children whose ages are vastly varied (Resch et al., 2010). This is why the variety in ages of the children with CP in this study was not greater than 12 years of age, but it was still noticed that those with children over 5 years old faced even more challenges with defaulting rehabilitation due to physical/musculoskeletal challenges associated with transportation of the child to the hospital.

Mothers whose children with CP had other siblings faced more challenges with care giving than mothers who had a CP child with no siblings. These results are in contrast to the findings of another study which found that in the absence of major feeding difficulties, the burden of caring for a baby or toddler with cerebral palsy is in fact very similar to caring for a child of a similar age with no disability (Rofail et al., 2013). Since both are completely dependent on the parent for all needs and as such, there is less of a discrepancy between normative expectations and actual events.

The participants of this study showed that those with low levels of education and were not in employment had financial hardships and failed to afford transportation for the rehabilitation of their children with CP. This was especially evident with others who had only attained up to primary school level of education. The progress in the rehabilitation of their children was slow and physical limitations were eminent. However, there were no differences in financial challenges between mothers with low levels of education and those with tertiary education and were in employment. The level of education among most mothers of children with CP has been found to be very low and tending towards low income (Rosenbaum et al., 2007). Another study on challenges
experienced by mothers of children with CP showed that among 40 participants, the majority had a secondary education, with a minority comprising only 1 mother who had tertiary education, similar to the findings in this study (Sen & Yurtsever, 2008).

The majority of the mothers were unemployed and this was linked to a number of factors including low level of education and marital challenges. On defaulting therapy sessions, the mothers reported that they encounter economic and service centered factors, which resulted in them defaulting therapy. Caregivers of children with special needs experience financial difficulties in caring for their children and this in turn adversely impacts their attendance to scheduled therapy sessions (Shreiber, et al., 2004). Other authors posited that family financial difficulties were related to an increased time to provide healthcare for children with special needs further reiterated this (Singogo et al., 2015).

Nearly all the mothers in this study had experienced some emotional challenges, owing to having children with CP. A significant depressive symptom noticed in this study, which had a major effect on attendance of therapy sessions, by mothers of CP children was amnesia, which manifested through forgetting of appointment dates, as admitted by some of the mothers. One study that looked into challenges experienced by mothers of children with CP correlated the high depression levels of mothers to the level of disability of their children (Skinner & Weisner, 20017). However, some researchers argue that the depressive symptoms observed in mothers of children with CP are not meaningfully related to a child’s developmental status or parent child interaction behaviors (Sluijs et al., 1993; Stanley & Alberman, 1984). This resonates with findings in the current study that the depressive symptoms experienced by the mothers may not be directly related to the level of disability of their children, but other reasons for their perceived depression were cited, such as marital and social interaction challenges.

Most of the mothers suffered social stigma from their family and community, which led to social isolation, as they were afraid that others in their family and community might not accept their children contributing to defaulting scheduled therapy sessions for their children with CP. In most cases their friends and family members failed to accept the condition of the children with CP and due to traditional beliefs, many choose not to associate themselves with a child with disabilities for fear of having a disabled child themselves. A study revealed that mothers of children with CP lack family time, they do not go on outings with their kids or spouses, they do not stay in touch with friends and extended family members and they rarely get together with friends (Taylor et al., 2004). Lack of social support increases the magnitude and reaction to stress which is considerably less for individuals with good social support from close friends and family members than for individuals with inadequate social support. However, social support has long been regarded to avert stress, and socializing has been seen as an important tool in mitigating psychological challenges experienced by mothers.
Some of the mothers in this study reported experiencing marital challenges due to misunderstandings and conflicts. Some of the mothers reported that their husbands left them as soon as they discovered their children had CP. Others reported they had constant fights with their husbands due to interference by relatives of their husbands. In many cases, they ended up being divorced. Cultural beliefs in Zambia just like in many African countries dictate those women cause physical disabilities on a child (WHO, 2003). A child’s disability attacks the fabric of marriage in different ways and excites powerful emotions in both parents, which create fertile ground for conflicts and divorce. This may interfere with the care of the child with a disability, as was evident with mothers who were victims of this and admitted where it affected their attendance for scheduled therapy sessions for their child with CP. A study in Canada that investigated marital relations among families of children with disabilities reported that relationships suffer unduly from the added stress of blame, guilt and anxiety (WHO, 2010,).

The current study revealed that the mothers/caregivers of children with cerebral palsy had many knowledge gaps regarding the condition of their children. This is expected given the high prevalence of low education levels among them, in addition to the low economic level. Similarly, low levels of knowledge and practice were reported in other studies among caregivers of patients with various chronic diseases (Taylor et al., 2004; WHO, 2010). Most of the mothers had no knowledge about CP prior the child’s diagnosis and some admitted that their child was initially misdiagnosed or diagnosed late. Due to inadequate knowledge prior to diagnosis the majority of mothers indicated they did not understand the condition fully followed by consequences of not following the treatment regimen. This indicated that these mothers/caregivers did not learn much about cerebral palsy and its treatment including the benefits of adhering to the prescribed treatment during the time they attended treatment of their children.

Currently the rehabilitation department at the hospital provides services to both adults and children. In other central hospitals in Zambia, the children’s rehabilitation units operate as an extension of the main rehabilitation department with services that are more child oriented. The services offered include physiotherapy, occupational therapy, workshops and group counseling, medical clinics and caregiver training. The therapists working in a solely solely child-oriented rehabilitation unit will have more time for individual sessions and for following up the children in their respective communities.

7. Conclusion

Despite the limitations to this study, its results lend weight to the notion that a variety of factors contribute to defaulting therapy among mothers of children with CP. This study paper has gone some way in exploring defaulting in for scheduled therapy and mother perceptions of rehabilitation services for children with CP in Zambia. It has highlighted service related as well as caregiver related challenges, which calls for greater
need to provide comprehensive and accessible rehabilitation services for this vulnerable group. Caregivers had physical, economic and psychosocial challenges that made it difficult to access rehabilitation services on scheduled therapy dates, which resulted in them defaulting therapy. Interventions that need strengthening include community outreach services, efficient rehabilitation service provision at the hospitals, and facilitation of income generating programs for mothers and other caregivers.

References


