

PSYCHOSOCIAL EXPERIENCES AND COPING STRATEGIES OF PARENTS OF CHILDREN WITH CEREBRAL PALSY IN ZAMBIA

Madalitso K. Banja & Kenneth Kapalu Muzata

Department of Educational Psychology, Sociology and Special Education, School of Education, University of Zambia

Corresponding author: rmluschichibanja@gmail.com

Abstract

The general purpose of this study was to inquire into the psychosocial experiences of parents of children with cerebral palsy (CP) in Lusaka, Zambia. The study investigated the psychological and social experiences of parents of children with CP, how parents cope with their children's condition of CP, and parents' perceptions of the life prospects of their children living with CP using the phenomenological design. The study conveniently selected eight parents of children with Cerebral Palsy at two Special Needs Education schools who met the inclusion criteria. The study used in-depth interview guide to collect data. Data were analysed through the inductive thematic analysis to answer the research questions. Major findings of the study showed that parents were emotionally and financially affected by the gravity of the disability of their children; they faced stigmatization from society; parents largely depended on spiritual reserves for support in coping with the calamity of having a child with CP. In addition, parents showed unwavering belief in the ability of their children to overcome adversity and achieve some level of success. The paper recommends that psychosocial counselling and financial support be provided to parents of children with CP.

Keywords: Caregivers, cerebral palsy, coping mechanisms, disability, psychosocial experiences

Introduction

This article builds on the rich, diverse literature on CP, which is a condition of severe motor dysfunction resulting from lesion to the brain. The condition is non-progressive, usually present at birth or infancy (Freeborn & Knafl, 2013). The developmental behaviour and experiences of children with CP show that it is a neurological disability resulting from damage to the neuro system. In response to the negative global picture on the plight of persons with disabilities, (Banja & Mandyata, 2018), reported that disability has increasingly become a major source of concern for both the government and communities in Zambia. In Zambia, the Persons with Disability Act of 2012 states that a person with a disability is a person with a permanent physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may hinder that person to fully and

effectively participate in society on an equal basis with others,' (Ministry of Justice, 2012: 72). CP falls within this category of disability. Specific causes of CP vary from accidents during delivery, lack of oxygen, and pre-maturity. (Olawale et al, 2013) report that as a result of this condition, the daily lives of children with CP are fraught with challenges that range from impaired motor function, sensory, communicative, and intellectual impairments, as well as challenges of behavior, nutrition, feeding, medications, and therapies.

In addition to the challenges that children with CP face, studies report several consequences that come with the birth of a child with a disability in a family. The parent goes through a series of adaptation stages from shock, denial, guilt, anger, chronic sorrow and symbolic death reminiscent of a stillbirth, sadness, and adaptation, which are usually the first reactions parents exhibit upon the birth of a child with a disability (Kirk et al., 2009).

Without a doubt, families find it difficult to adapt to having a child with CP. A study of family adaptation to CP by (Guyard et al., 2017) found that out of the 286 families of teenagers [13–17 years] in their study, 31.8% of parents living with an adolescent with CP showed clinically significant high stress requiring professional assistance. Similarly, (Kumari & Singh, 2013) report that 80% of mothers of children with CP suffered a moderate level of stress. This affected their self-image, health status, family & social environment, occupational and psychological status. Additionally, the stress mothers go through caring for the child with CP may also have repercussions on other family functions.

As expected, the condition can be debilitating to parents as care for a child with CP brings tension and struggle for parents and causes many problems. Literature shows that parents become stressed emotionally, physically, and financially as a result of the demands that come with this type of disability. Research by several scholars (Kirk et al., 2009; Pinilla-Roncancio, 2017; Chirwa, 2017), shows that parents are affected emotionally when a child is born with a disability. Similarly, in a study on mothers of children with CP in Zambia, (Singogo et al., 2015) reported that mothers experienced physical and emotional challenges, marital problems, lack of social support, and emotional breakdowns which were experienced more at diagnosis. Parents of children with CP also experienced job losses, lack of concentration at work, strained family relationships, and derangement of financial affairs (Olawale et al., 2013). In Zambia, challenges included marital conflicts such as strained sexual relations, divorce, and limited access to assessment services as these services were centralized in Lusaka, making it expensive and difficult for mothers from outside Lusaka to access them (Chirwa, 2017). Furthermore, parents experience a loss with regard to dreams they may have harboured for their child, and social isolation due to the child's limited mobility or behavior problems Ketelaar et al., (2008 as cited in Chirwa, 2017).

It is therefore clear that the gravity of disability can affect the normal functioning of the family because of the demands it brings. However, while studies in disability, including CP, have focused more on the child with a disability, the parents of the children with disability, who are the caregivers, and how they cope, appear to have been accorded a peripheral status. And yet, parents of children with CP face double challenges; that of

managing the child's chronic health problems effectively and that of coping with the requirements of daily living (Olawale et al., 2013). These concurrent demands place daunting challenges on parents and may affect the physical health and the psychological well-being of parents of children with CP. According to Chawla (2007), parents with children with special needs often exhibit psychosocial problems ranging from depression, anxiety, and angry behavior.

Coping with raising a child with CP is dependent on the severity of the disability (Kumari et al., 2013; Singh, 2013), and the level of stress. It does not seem farfetched therefore to conclude that, a negative image of oneself as a result of having a child with a disability may affect the pace and quality of coping. However, whatever the nature of the challenges, coping strategies should be directed at easing the burden of daily care and offering appropriate psychosocial support to help mould parental perception and expectations (Olawale et al., 2013). This is important because the health of children with disabilities, and their future all depend on how their parents/guardians cope with those problems.

Literature shows that the provision of support helps parents of children with CP to cope with stress. Several strategies for coping when raising a child with CP are suggested in the literature. Despite all the challenges, parents have to find a lasting solution to support their children with CP in the same manner they support their non-disabled children. Coping is a process, but must be accompanied by support in order for the parents to withstand the negative circumstances caused by CP. For instance, (Wanamaker & Gleniwick, 1998) found a link between social support satisfaction and low levels of depression and parenting stress and higher levels of parenting satisfaction. (Skok et al., 2006) also reported that perceived stress and social support significantly predicted family or parents' wellbeing. In this regard, (Krstić & Oros, 2012) found that parents tended to seek spiritual support to cope. Spirituality appears well documented as a means of social support that helps families to accept the condition of their children with CP (Dezoti et al., 2015).

The main aim of this article was to explore the psychosocial experiences of parents living with children with CP and how such experiences affect family functioning so that interventions to reduce the gravity of effect on the family are instituted through enhancing parents/guardians' competence and resources to help children with CP not only survive but succeed in life. In this regard, the study aimed at answering three main questions:

- i. What are the psychosocial experiences of parents of children with CP?
- ii. How do parents cope with their children's condition of CP?
- iv. What are parents' perceptions of the life prospects of their children living with CP?

In answering the above research questions, the current study was guided by the family systems approach by Murray Bowen, a psychiatrist. The Family systems theory attempts to understand human functioning by focusing on interactions between people within a family and between the family and the context(s) in which that family is situated. The family systems theory was an appropriate framework for this study as it

helps in understanding that when a family member is affected, all other members equally become affected. Thus, having a child with a disability in a family certainly affects the way the family functions. In the context of his study, this entails some family members having to alter their relationships and regulate their behavior in response to the misfortune that had befallen the family.

Methods

The study used a phenomenological research design within the qualitative paradigm. The goal of phenomenological studies is to describe the meaning that experiences hold for each subject (Donalek, 2004) such as the study by Daly (2005) who studied the lived experiences of mothers of suicidal adolescents. In line with this phenomenological understanding of research, participants were asked to narrate their experiences raising their children with CP.

In line with Mason (2002), since the purpose of the study was to learn from the parents' perspective, this qualitative study was conducted in 2019 by the participation of 8 parents/guardians aged between 29 and 59 years old of children with CP at 2 Special Needs Schools in the city of Lusaka. In order to gain rich insight into the experiences of parents of children with CP, unstructured interviews were conducted with 8 parents/guardians of children with CP. All of the interviews were transcribed and analyzed inductively.

The study settled for eight parents because, using unstructured interviews, the study reached a point of data saturation whereby themes and patterns that were being sought in the data from participants began to be similar to the previous one. At this stage, it was decided by the researchers not to interview any more parents. In line with the phenomenological design, the researchers tried to uncover the meaning of the lived experience for each subject. In this vein, participants were asked questions such as "Explain some of the difficulties you practically face handling and parenting a child with cerebral palsy", and proceeded to explain what the parent/guardian was saying about how he/she was living through this experience and how each participant has interpreted and assigned meaning to their experiences.

The study area was Lusaka. The two schools were government-run and grant-aided school respectively. The government-run school is located at the state-owned University Teaching Hospital (UTH) located in the heart of the capital city of Lusaka while the grant-aided Bauleni Special Needs School is run by the Catholic Church and is located in a poor neighborhood on the outskirts of Lusaka. The study population was based on caregivers of children with CP. In terms of the inclusion and exclusion criteria, the target population of the study had to be parents/guardians of all ages of a child that had CP at either of the 2 research sites, male or female gender, and had to be domiciled within the city of Lusaka.

The sampling technique used in this study was convenience sampling that targeted two schools that were closest to each other from a possible 6. Henning (2004) cited in Viviers (2019: p.68) argues that "when selecting research participants, the driving

considerations behind the selection, should be getting relevant people who can talk about their experiences, and in the process, provide rich data". This is particularly important when considered that working with qualitative data is anchored on interpreting it and making sense of it and not on measuring it (van Aardt, 2019). This was the case in this current study.

In this study, we listened to the stories of parents of children with CP regarding their psychosocial experiences. Primary data were collected from the participants through one-on-one in-depth interviews that relied solely on open-ended questions thereby creating an atmosphere where the parents/guardians felt comfortable and at ease to explore this rather emotive topic with us. This enabled us to obtain rich, reliable, relevant, descriptive first-hand information necessary to unlock the research questions through the eyes of and regarding the lived experiences of the 8 participants Maree (2007), cited in Viviers (2008).

Each participant was interviewed separately for periods between 30-40 minutes each and in secluded places but within the school premises where their child attended school to ensure confidentiality and encourage participation. All the interviews were audio-recorded with participants' consent and fully transcribed with initial analysis and data collection occurring concurrently. Only one interview was conducted with each parent. These were interviewed at the school when they went to pick up their children. A combination of English and Nyanja was used in the interviews. While the majority of the participants were conversant in English, a few were more comfortable in Nyanja which is the Lingua Franca most common in the cosmopolitan town of Lusaka where both research sites are located. The interview guide was designed by the researchers. Recruitment of participants was done through respective school authorities who spoke to the parents and made appointments on behalf of the researchers since the participants were parents/guardians of children attending school at the two schools. The school administration was asked to identify for inclusion in the sample any parent that would be available for the interviews. This was necessary because attendance at school by the children with CP was not constant due to the many challenges that parents faced. Among these is the fact that children had to be picked at mid-day. Most of the parents had challenges of who to pick the child as most mothers had no spouse to help. In most cases the child had to be carried on the back hence limiting the potential number of family members who could help take and get the child from school, but also affecting the number of days the child could attend school.

In addition to the data on the psychosocial experiences of parents/guardians of children with CP, information on the demographics of the participants was collected. The details of the contexts of the respondents and their children is provided in table 1.

Interviews were complemented with secondary data from various documents which included theses and dissertations, policy documents from the Ministry of General Education, and so on. These documents provided data on the different categorization of disability in Zambia, schools which offered education for children with CP, and UN statutes on disability.

In terms of data analysis, thematic and content analysis of the in-depth interviews were used as these were crucial in guiding us to identify key themes, subthemes and meanings that emerged through the data analysis process by focusing on keywords/phrases that emerged during the interviews (Cohen et al, 2011). After analyzing the data, it unfolded numerous themes that seemed to summarise the general thinking of the 8 participants. Extracts from the data analysis are presented via verbatim transcriptions.

Ethical clearance to conduct this study was granted by the University of Zambia Ethics Committee (*Appendix A*). The study objectives, aims and potential benefits were explained to participants. They were assured of privacy and were not asked any questions that could create personal discomfort. Participants were requested to sign consent forms to show their willingness to participate in the study and encouraged to state if they were uncomfortable with any aspect of the interview (Viviers & Lombard, 2013). Not only were participants' voices regarding their experiences respected, we, the researchers, have reported the participants' voices and contributions as authentically and truly as possible.

Results and discussion

This section of the paper combines a presentation and discussion of the results of the study on some psychosocial experiences of parents of children living with CP. While our focus is on the experiences of parents of children living with CP, in the process of data collection and analysis, which occurred simultaneously, four themes emerged: parental response to child's CP status, challenging experiences of parenting a child with CP; coping mechanisms of parents of children with CP; and parents' perceptions of the life prospects of their children living with CP.

Demographic profiles of the participants

In this study, eight parents/guardians participated by way of in-depth interviews. Table 1 illustrates the demographic characteristics of the participants who represented a rich milieu of backgrounds, namely, parents (06), grandparents (02) and guardians (02), the married (02) and the unmarried (06) with different education backgrounds and places of residence. Significantly, there was only one male parent in the sample. Most of the participants were single, either divorced or widowed. The participants provided independent real life experiences that were similar in many cases because of the common condition (cerebral palsy) that all were exposed to. If parenting children with CP were to be considered a burden, then this would suggest that it is burden mainly borne by females.

Table 1: Demographic profiles of the participants

PARTICIPANT ID NO	GENDER & Marital status	AGE & no of children	EDUCATION BACKGROUND	OCCUPATION	PLACE OF RESIDENCE	GENDER/AGE OF CEREBRAL PALSY CHILD	GRADE OF
1 Parent; TT; 11/09/2019)	Female& single	29; Mother of 2	Grade 8	Sells artefacts	Kabwata	Girl of 10 years	
2 Parent; AN 11/09/2019	Female & single	42 years mother of		Hair dresser	Mtendere	Girl of 15 years	7
3 Parent IM; 11/09/2019	Female& single			Stone crusher	New Kasama	Boy of 5 years	N/A
4 Parent PP; 16/09/2019	Female& single	Mother of 2	Grade 9		Bauleni	Girl of 6 years	N/A
5 Parent AC; 16/09/2019	Female& Married		Grade 11	Used to sell clothes	Bauleni	Girl 10 years	
6 Guardian JP; 16/09/2019	Female & single			Sells in school Canteen		Boy of 3 years	N/A
7 Parent VC; 17.09.2019	Male and married	Father of 3, Cerebral Palsy child is 1st born	Tertiary	Artist	withheld	Girl of 10 years	4
8 Guardian CC; 17/09/2019	Female			Works for private org	Matero	Boy of grade 3	gra

We can see from Table 1 that the demographic characteristics of participants shows that the majority of the respondents were female, with poor socio-economic backgrounds. Mothers and grandmothers were the main care-givers of the children. These demographics entailed that the care given to the children with CP was to a large extent interfered with by the caregivers' needy circumstances in life. This scenario is not peculiar to this study but confirms the findings of Eyong et al., (2017) who found that most parents with children with CP are from low income background.

The experiences of parents of children living with cerebral palsy

Parental response to Cerebral Palsy Status

The in-depth interviews identified a number of themes that were common among most participants. Data shows that parental response to CP was affected by their lack of knowledge of CP. Knowledge of CP and its effects on the child is one working strategy for coping. With appropriate knowledge, parents are likely to positively support the child and cope with demands of the disability (Olawale et al., 2013). In attempting to understand their knowledge of CP, parents were first asked to explain the background to their children's' CP conditions. What came out common from the findings is that most parents/guardians lacked knowledge of CP until diagnosis at the hospital was done on

their children. For instance, the first participant we interviewed expressed shock at the diagnosis that her child had CP;

Sincerely I cannot tell how it happened. We stayed in the University Teaching Hospital for about 3 months. My child was sick but the doctors didn't tell me the diagnosis of the problem. At about 9 months, I noticed that she had a challenge. She was not like any other normal child. She was not sitting straight and she was putting the legs behind and as if she has lost strength until I was advised by UTH to be taking her for physiotherapy (Parent TT; 11/09/2019; UTH).

Similarly, another parent narrated;

His condition came after birth. We only discovered that she had cerebral palsy after about five months old. Being a parent you would go and visit fellow parents and maybe you would be able to see a child born at the same time as yours and then you discover that your child is less active as that of your friend, and so that is when we thought of taking the child to the hospital and that's when we were told of the condition and we were told to immediately start taking her for physiotherapy and that's what we have been doing since then. (Parent VC; Male, 17.09.2019)

What is significant is that from the excerpts, it is clear that although parents were quite observant about the abnormal development of their children after birth, and generally understood the signs, they did not know what condition affected their child until after diagnosis at the hospital. From the findings of this study, and drawing upon the position of Olawale et al, (2013) that parental knowledge of CP condition helps them to cope with its demands, and considering the huge struggles they go through, we argue that parents need to be provided with not just correct diagnosis of CP but in good time from the time of diagnosis so that they begin to develop coping strategies from the outset. The lack of knowledge about what the child is suffering from creates anxiety and stress on the families. The diagnosis of children with CP was followed by disbelief and stress;

My first reaction was very bad. When I was first told that my child has a condition which will make her be slow in doing things and so on, I was depressed and thinking why my child should be like that while the children of my friends were just ok. I used to hide my child in the house because I used to feel shy because of the child. I only came to accept the condition of my child because of my husband who used to encourage and strengthen me saying everything will be fine and that God knows why our child is like his. That is when I became strong and accepted the condition of my child (Parent AC; Female; 16/09/2019)

Another guardian acknowledged the difficulties, pain and suffering experienced raising a child with CP;

Oh no! It's difficult, care for the children is difficult, very difficult and different from the children without these disabilities. Usually when I think too much I wonder and ask God why, so I just need to teach people to take care of such children because if I died, who would take care? (Guardian JP; Female; 16/09/2019)

Aside from this, as mentioned in the introduction, disability generally affects family functioning. The demands that come with a disability in a home create stress and strain on family resources. Sometimes family functioning structures have to change in response to the demands created by the birth of a child with a disability in the family. This point is emphasized by Olawale et al (2013) who suggest that the demands that come with a disability in a home create pressure on the family as expressed by one of the guardians:

I stopped work where I was doing a bit of work in order to take care of the child. I started taking the child to the hospital, UTH and we started going to Cheshire for exercises and because the child was always with me, people thought he was my child. (Guardian CC; Female; 17/09/2019)

It is for such reasons that parents need help emotionally, and financially to be able to adapt and nurse their children with CP. This is consistent with the writings of Kirk et al (2009), who state that, there are two types of crises parents go through when a child with a serious disability is born in a family namely symbolic death and the challenge of providing care. Under symbolic death, the parent in particular goes through a series of adaptation stages from shock, denial, guilt, anger, sadness and adaptation before accepting. Although the nature of work two of the parents reported was informal, it was a means of survival for them. Another parent reported stopping crashing stones, which was a means of livelihood.

Challenging Experiences of Parenting a child with Cerebral Palsy

Overly, challenges of parenting children with CP included difficulties in adaptation to the condition, financial demands of caring for a child with CP, and negative attitudes from the community leading to stigmatization of children with CP and the families in which these children were found as demonstrated in the following statements;

In the compound where I live, they started laughing at me and asking why I kept carrying the child on my back when he was grown up. But I explained to people that the child was God's gift and I needed to take care (Guardian CC; Female; 17/09/2019).

They are always laughing at her because of the way she walks. When I walk with her I usually see people laughing at her. When people laugh at her I just tell them that they should not laugh at her because even me I did not know that I will have a child like this and that such disabilities can even be in our family. (Parent AN; Female; 11/09/2019)

At the same time, parents of a child with CP experience the lack of financial support for the children's development and education. Since children with CP have little or no

control over their bowels, they most of the time defecate or urinate in their clothing. Taking this into consideration, parents explained that as a result, they needed to have washing and bathing soap all the time. Parents also reported the need to buy diapers for their child. In a bid to access financial help, two of the parents had applied for and accessed the social cash transfer, a government initiative to help empower vulnerable people while two other parents reported that they had applied several times for the same but to no avail. Worse still, parents that managed to access support for their child indicated that the support was inadequate and inconsistent;

No sponsors as at now that supports the child in terms of finances, food and others. We do not know of social cash transfer. The church once bought him a blanket. The church also helped buying books for his young sister who is in grade 11. When he close school and I come here for work, his young sister helps look after him by bathing and feeding him. We do not get any help from family members and do not know why they do not help us. We get help from his school that teaches him. (Parent IM; Female, 11/09/2019)

I don't have support. All the needs for the child, I don't manage. These children need good food and to stay very well, sitting with him but I go to sell at the market, but I have to carry her on my back every time. Where I sell it's not safe to stay there. The K300 I get from the father is not enough because I need 4 dippers per day, he needs groundnuts, sugar, so I fail to keep him well. I have to do some bit of works here and there (Guardian JP; Female; 16/09/2019)

However, one beneficiary of the Social Cash Transfer had this to say;
We also receive support from Ministry of Community where the child is on social cash transfer but we do not usually get it every month. I came to know of the social cash transfer as they were passing through in the community announcing that if you have a child with special educational needs you should bring them to the clinic to register them. (Parent AN; Female; 11/09/2019)

It should be noted that many parents did not know where to access financial support for their children while those who managed to access support from the social cash transfer and from family members said the support was inadequate and inconsistent to meet the transfer. As noted above, the findings show that, most parents were not aware about the fund and where they could register for it while the few that were registered under the fund did not receive the funding consistently. This finding is in tandem with the viewpoint taken by (Arruda & Dubois, 2018) who acknowledge that the initial rollout of the cash transfer in Kalomo in the Southern Province for example, faced logistical constraints leading to failure to distribute the cash transfer money on a daily basis as planned. One parent had school fees for the child paid for by the Zambia Association for Persons with Disabilities (ZAPD).

An important aspect to note is that financial challenges lead to other challenges such as challenges of mobility as illustrated in the case of a 5 year old boy who was a single orphan and was a severe case of CP. Without exception, when taking the child to

school or when moving around the community to look for things, the child needed to be lifted on the mother's back all the time. In this view, parents were very categorical about the difficulties they faced raising such a child;

When his father was alive we used to help each other looking after the child. He had accepted his condition. Sometimes I feel bad especially when he does not eat, as sometimes he just fists and not eat the whole day. I do everything for him. Washing for him, taking him to the toilet, feeding him and everything else. (Parent IM; Female, 11/09/2019)

I face many challenges because she can walk but she cannot stand because sometimes even going to the toilet is a challenge, you have to go with her. You have to be always with her because sometimes she messes herself up. So I need to be always with her or tell her to toilet in a chamber nearby instead of stretching to the toilet There are challenges even bringing her to school, she needs to be lifted. Sometimes when am at the gate of UTH and there is no car, I have to hold her hands to come here). (TT; 11/09/2019; UTH)

As the excerpts above show, we established a measure of commonality across the parents with regard to the numerous challenges they faced raising a child with CP. Implicitly, having a child with a disability was construed as a burden. We say implicitly because parents did not come out openly to express disappointment or displeasure for having a child with a disability but expressed the difficulties they faced raising such a child. We have already seen that caring for a child with CP exposes the parents to challenges, some of which are related to the nature of the child's disease, shortage of facilities and lack of solutions to the parents' needs. This agrees with the views of Raina et al. (2005) who state that children with disability need more attention and effort from parents than non-disabled children. Similarly, Singogo et al (2015), also found that mothers of children with CP in Zambia experienced isolation and lack of social support. Therefore, to promote the parents' health and provide better care services to the afflicted child, it is important to recognize the parents' problems and find appropriate solutions.

Coping mechanisms of Parents with Children living with Cerebral Palsy

We now turn to the issue of coping mechanisms or support systems reported by parents. The results of this study show that parents' sources of coping were somewhat similar, basically emanating from a strong belief in God and His power to heal the sick. Thus, even without financial and material assistance, parents still reported receiving encouragement from the church for their children with CP. This spurred them on to keep supporting their children. Spirituality has been documented to be one of the significant forms of social support that helps families to accept the condition of their children with CP (Dezoti et al., 2015). There appears to be so much hope in God that the child with CP will one day recover sufficiently to attain a level of independence. Microsoft word finds text query analysis revealed that the word 'God' was mentioned 16 times, which was twice the number of participants in the study to express how reliance on God has helped them cope with the difficult experiences of raising a child with CP.

The findings from the study extend the findings of (Krstić & Oros, 2012) that parents tended to seek spiritual support to cope. The implication is that with the belief in Godparents appear to have higher prospects for their children with CP. Other parents think accepting the child with a disability and working for him or her will earn a reward from God:

I have learnt a lot from working for children with disabilities and I believe God will bless me through this child (Guardian CC; Female; 17/09/2019).

Such hope based on spiritual conviction is further enhanced by the exposure, encouragement and strength parents got when they saw the improvements that other children with the same condition had recorded out of physiotherapy at UTH and Bauleni Special Needs Unit;

I get more help from Physiotherapy. I also attended Sheris Park, where I saw many people with different conditions, that's how I even became stronger and accepted the condition of the child. My husband does not accept any help from organizations; he says we are able to manage to take care of the child (Parent AC; Female; 16/09/2019).

There are good lessons from the above excerpt. There is no doubt that if social support provided to parents was maximized, it would help parents adapt. What appears eminent is that the few institutions providing social and other forms of professional support themselves need support to provide such services to parents. In this way, when parents see other children with disabilities succeeding in school and in life generally, they become motivated and encouraged to support their own children with disability. What this reveals therefore, is that other children with CP who had shown signs of improvement acted as beacons of hope and success for other parents of children with CP. When services that improve motor movements and manipulative skills are provided, parents become encouraged and regain hope in their children's success in life. These findings agree with the literature that shows that provision of support helps parents of children with CP to cope with stress. For instance, (Wanamaker & Gleniwick, 1998) found that social support satisfaction was related to low levels of depression and parenting stress and higher levels of parenting satisfaction. Skok et al (2006), also reported that perceived stress and social support significantly predicted family or parents wellbeing.

The results of this study demonstrate that a parent who has accepted the disability and is positive about it is devoted to meeting the child's needs like those of other children in the home. The only male parent reported that work was second to her child with CP and he made sure that the child was a priority to be taken to and from school before other activities. Improvement in the condition of their children with CP after accessing physiotherapy services at hospitals tended to give hope to the parents. This calls for increased specialized support services for children with CP so that the condition is not taken as an end in itself which could affect parents'/guardians' ability to cope with it.

We would like to emphasise here that parents even in this study reframed their understanding of disability from a negative to positive picture and being hopeful that their

child still had a chance to be better. This agrees with (Krstić & Oros, 2012) who found that reframing is the most commonly used strategy for coping. In the current study however, parents used institutional support for physiotherapy services. However, beyond this, health professionals should link parents to a network of social support such as other families of children with CP, counselling services, recreation and others places where they can get help. This appeared to be lacking among participants as some parents did not even know where to access support such as the social cash transfer for their children with CP.

Parents' Perceptions of the Life Prospects of their Children Living with Cerebral Palsy

Overall, in Zambia at least, this research has shown that the little social support parents received in form of counselling and physiotherapy raised parental hopes for success in life for their children with CP. Although as explained earlier, initially parents experienced emotional breakdowns at diagnosis stage, they had learnt to accept, support and live with their children with CP, despite the numerous difficulties brought by the condition. It is important to appreciate that what was encouraging from the parents was the positive acceptance of their children with CP after they observed improvement from physiotherapy services at hospitals. In summary, we learnt that emotional support from schools and health facilities helped parents to turn around their negative feelings into positive feelings of hope and success;

I don't know but you know as time goes on they [children with cerebral palsy] tend to choose their own careers. What I want for her is to educate and take her to college. You know I was inspired when I went to Up-task where they make wheel chairs but what inspired me was that those who were helping other people were all challenged in one or the other. So I looked at them and said I hope my daughter will one day work here to help other people and encourage them (Parent PP; Female; 16/09/2019)

I would want her to have the best of education and just to be there for her. I would want her to be educated because I have seen how intelligent she is, the IQ is something else. Even the kinds of comments we have had from the teachers, it's something that is quite encouraging. I would have probably given up at some point if I saw that there was no improvement. For me I must say I am a proud parent and a proud father because my daughter is able to do beyond something that a normal child can do. (Parent VC; Male, 17.09.2019)

Despite the challenges faced, all parents expressed optimism, hope and commitment towards the improvement of the future life prospects of their children with CP in terms of both their education and physical abilities. They were committed to taking their children for psychosocial counselling and physiotherapy at UTH and Bauleni School for Special Needs. Our argument in brief, is that when parents see other children with disability succeeding in school and in life generally, they become motivated and encouraged to support their own children with disability. It is therefore reasonable to conclude that when

services that improve motor movements and manipulative skills are provided, parents become encouraged and regain hope in their children's success despite having CP.

It is important to emphasise that the positive attitude portrays positive perceptions of parents towards their children with CP. In such a context, the parents' perception is enhanced by the improvement seen in the child, thereby raising hopes for the future. What stands out exclusive from the only male parent in the study is that his child with CP was quite intelligent and able to perform academically better than even other children without any disability. He was quite confident about the child's success in education and managed to support the child through physiotherapy at school. According to this parent, the child with CP was like any other child and needed their support. Children with CP can have normal intelligence like any other child. The nature of positivity in this parent is worth noting as a lesson for other parents. Significantly, like this parent, other parents were equally positive about the future of their children with CP. Such findings are not peculiar to this study but are consistent with those of other scholars such as Olawale et al (2013) who in their study revealed that parents were generally positive about their children with CP.

We argue therefore that this realisation of the parents that children with CP can also be intelligent just like any other child, is crucial to encouraging parents to support their children with CP with the understanding that CP as a condition does not necessarily affect intellectual functioning but motor movement and that children can still succeed academically once supported. The above-mentioned case is an example of the widely held view that 'disability is not inability.' Once parents accept the child in this manner, they become devoted to the child and to meeting the child's needs which is likely to positively affect the child's self-image. Experts need to provide such necessary counsel to parents during their journey to acceptance.

This is encouraged by the Ministry of General Education through its policy document *Educating our Future: National Policy on Education*, which emphasizes equality in the provision of education to children with special needs and to whatever extent possible the integration of children with disability into mainstream classrooms (Ministry of Education, 1996). Guided by this policy, Zambia has made tremendous progress in providing education to learners with disability through different modes (Muzata et al., 2019). However, as (Banja & Mandyata, 2018) have observed, measures regarding the integration of pupils with disability into school practices have to be concerted and systematic in order for them to be effective and impact positively on the education of children with disabilities.

In our view, based on the above discussion, and in line with literature on the subject (Kumari et al., 2013; Singh, 2013), it became clear that parents' perceptions towards their children with disability were dependent on many factors. These include the severity of the CP condition, the nature of support the parents receive, the challenges that the child with CP presents to the families and how they cope with these challenges, and on whether the child is making progress or not through rehabilitation.

Conclusions and policy implications

This article has highlighted the challenges of parenting children with CP which included psychosocial difficulties in adapting to the condition, the financial demands of caring for the children with CP, and stigmatisation from the community. Our paper suggests that existing theory, such as the family systems theory, correctly illuminates the fact that problematizing children with CP at the expense of those taking care of these children, unfortunately, neglects to bring to the fore the experiences of parents/guardians and leaves them (parents/guardians) at risk of psychological and problems that result from having a child with CP. The eminently practical issue therefore is that, if children with CP are to receive quality healthcare, it is important to understand the experiences of their parents/guardians who are at the centre of providing for these children and designing family-centred intervention strategies to improve the quality of healthcare. Looking more closely at this scenario, we argue from the findings of this study that, parents need to be provided with knowledge right at diagnosis of CP because lack of parental knowledge of CP condition is traumatic to the caregivers. In addition, negative attitudes towards children with CP mean that the community needs to be sensitized towards the plight of children with CP together with their caregivers.

The article has also shown that some of the needs of parents of children with CP are financial, hence the need for policy formulation that would create a broad-based support system to include financial empowerment of parents of children with CP. Thus said, we suggest that such a system should incorporate the provision of child care services which would allow young parents to get back to school and eventually get a formal or informal job to help support their children. Additionally, such a policy could include educational and other subsidies for families with children with CP to cushion the harsh economic realities under which most of families live. In order to improve parents' resources to cope with demanding situations, interventions should also be aimed at developing their abilities, coping strategies, and strengthening their social networks.

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References

- Arruda, P. & Dubois, L. (2018). A brief history of Zambia's Social Cash Transfer Programme. International Policy Centre for inclusive growth: *Research Brief*, ISSN 2358-1379 62.
- Banja, M. K. & Mandyata, J. (2018). Teachers' situational analysis of the integration of pupils with disability in selected primary schools in Zambia. *Multidisciplinary Journal of Language and Social Sciences Education*. 1(1), 175-205
- Chawla, B. (2007). Prominent psychosocial difficulties that parents of young children with severe disabilities may cope with during their child's early years. <http://www.kapc.or.ke/downloads/2009/TABITHA.pdf> (Accessed on October 5, 2015).

- Chirwa, M.S. (2017). Experiences of Parenting Children with Disabilities: A Qualitative Study on the Perspectives of Mothers of Children with Disabilities in Zambia. Doctor of Philosophy in Social Work and Social Policy- University of Warwick. Available @ <https://pdfs.semanticscholar.org> .
- Cohen, L., Manion, L. & Marrison, K. (2011). *Research Methods in Education*. Routledge Falmer
- Central Statistics Office. (2012). *ZAMBIA: 2010 Census of Population and Housing National Analytical Report*. Lusaka: CSO.
- Dezoti, A.P., Alexandre, A.M.C., Freire, M.H.S., Mercês, N. N.A. & Mazza, V.A. (2015). Social support to the families of children with cerebral palsy. *Acta paul.enferm.* 28 (2)
- Eyong, K.I., Ekanem, E.E. & Asindi, A.A. (2017). Challenges of care givers of children with cerebral palsy in a developing country. *International Journal of Contemporary Pediatrics*, 4 (4), 1128-1131.
- Freeborn, D. & Knafl, K. (2013). Growing up with cerebral palsy: perceptions of the influence of family. *Child: care, health and development*, 40 (5), 671–679, doi:10.1111/cch.12113.
- Guyard, A., Michelson, S.I, Arnaud, C. & Fauconniera, J. (2017). Family adaptation to cerebral palsy in adolescents: A European multi-centre study. *Res Dev Disabil.* 61: 138–150.
- Kirk, S., Gallagher, J.J., Coleman, R.M. & Anastasiow, N. (2009). *Educating exceptional children*. Harcourt Publishing Company.
- Krstić, T. & Oros, M. (2012). Coping with Stress and Adaptation in Mothers of Children with Cerebral Palsy. *Med Pregl LXV* (9-10): 373-377.
- Kumari, R. P. & Singh, S. P. (2013). Stress and Coping among Mothers of Cerebral Palsy Clients with a View to Prepare a Management Protocol. *International Journal of Education and Applied Research*, 3 (1), 9-14.
- Ministry of Justice (2012). *Disability Act of 2012*. GRZ
- Muzata, K.K, Simalalo, M., Kasonde-Ng'andu, S., Mahlo, D., Banja, M.K. & Mtonga, T. (2019). Perceptions of Students with Visual Impairments towards their Inclusion in the Faculty of Education at the University of Zambia: A Phenomenological study. *Multidisciplinary Journal of Language and Social Sciences Education.* 2 (2) 170-210
- Olawale, O. A., Deih, A.N. & Yaadar, R.K.K. (2013). Psychological impact of cerebral palsy on families: The African perspective. *Journal of Neuroscience in Rural Practice.* 4(2): 159–163. doi: 10.4103/0976-3147.112752.
- Pinilla-Roncancio, M. (2017). The reality of disability: Multidimensional poverty of people with disability and their families in Latin America. *Disability and Health Journal.* xxx, 1-7.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D. & Russell, D. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics.* 115:626–636.

- Singogo, C., Mwenshi, M. & Rhodah, A. (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, 71(1): 274. doi: 10.4102/.
- Skok, A., Harvey, D. & Reddihough, D. (2006). Perceived stress, perceived social support, and Wellbeing among mothers of school aged children with cerebral palsy. *Journal of intellectual and developmental disability*, 31 (1), 53-57.
- Wanamaker, C. & Gleniwick, D. (1998). Stress, coping, and perceptions of child behavior in parents of preschoolers with cerebral palsy. *Rehabilitation psychology* 43 (4), 297

Appendix A



THE UNIVERSITY OF ZAMBIA

DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

Great East Road | P.O. Box 32379 | Lusaka 10101 | Tel: +260-211-290 258/291 777
Fax: +260-1-290 258/253 952 | Email: director@drgs.unza.zm | Website: www.unza.zm

Approval of Study

30th September, 2019

Ref. No. HSSREC 2019- SEP - 028

The Principal Investigator
Dr Madalitso K. Banja
School of Education
P.O Box 32379
LUSAKA

Dear Dr Banja

RE: "PSYCHOSOCIAL EXPERIENCES OF PARENTS OF CHILDREN WITH CEREBRAL PALSY"

Reference is made to your request for waiver of ethical approval of the study. The University of Zambia Humanities and Social Sciences Research Ethics Committee IRB has approved the study noting that there are no ethical concerns.

On behalf of The University of Zambia Humanities and Social Sciences Research Ethics Committee IRB, we would like to wish you all the success as you carry out your study. In future ensure that you submit an application for ethical approval early enough.

Yours faithfully

Dr. J. Mwanza

Dip. Clin. Med. Sc., BA. M.Soc., PhD

CHAIRPERSON

**THE UNIVERSITY OF ZAMBIA HUMANITIES AND
SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE - IRB**

cc: Director, Directorate of Research and Graduate Studies
Assistant Director (Research), Directorate of Research and Graduate Studies