

Full Length Research Paper

The plight of people with disabilities and children with cerebral palsy: The role of social work and multi-disciplinary approach

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Disability and cerebral palsy can occur at any time of any individual's life. Conditions such as cerebral palsy affect mostly children and can be seen as one of the birth defects. A study was conducted to investigate the plight of children with cerebral palsy (CP) and their families in Moses Kotane Hospital, Bojanala District. This was done as the area of disability is mostly neglected in the helping profession. To gain insight about the nature, types and challenges of CP, availability of services addressing the problems and needs of children with CP and their families as well as people with disabilities are covered in this study. Another objective of this study was to assess social work services provided to children with CP and their families as well as other disciplines like the occupational therapy especially in outreach services. Qualitative research approach was adopted using semi-structured interviews as a method to collect data. Purposive sampling was employed to identify participants and 10 children with cerebral palsy were recruited. These were sourced from the hospital where they were all receiving medical treatment. Themes and sub-themes were developed. The findings confirmed that children with cerebral palsy experience problems that have a negative and direct impact on their families. Psycho-social challenges were identified, constant medical care, special diet, poverty and unemployment pose also a risk as many are from impoverished background. Conclusions in this study indicate that families of children with cerebral palsy and other disabilities encounter many challenges from socialization to general medical care. Further, a multi-disciplinary approach including occupational therapy is essential as well as the role of social workers.

Key words: Disability, Cerebral Palsy, children, plight, social worker, family.

INTRODUCTION

People with disabilities are the nation's largest minority and tend to be marginalized in all aspects of life. Cerebral palsy (CP) is defined in Shorvon et al. (2011) as a group

of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the

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developing infant brain. WHO (2011) estimated that 15% of the world population have some form of disabilities. According to the statistics from the Department of Social Welfare, the registered number of disabled people is 197,519. CP is the most common physically disabling paediatric condition globally (Gagliardi et al., 2008). Worldwide, there are number of people living with cerebral palsy. Developed countries with sophisticated medical services are also experiencing cases of those having or living with Cerebral Palsy. Donald et al. (2014) continued to say that in Africa CP rates have been found to be even higher, with an estimated prevalence of 2-10 cases per 1000 births. In Malaysia people with disabilities (PWDs) can be considered as one of the most vulnerable of the minority group in the Malaysian population. A total number of 359,203 disabled people were registered with the Department of Social Welfare in December 2012. In their research, Olawale et al. (2013) state that psychological stress associated with cerebral palsy is known to be one of the most pressing conditions of families. Lyons et al. (2010) state that children with cerebral palsy experience much pain and are more likely to have emotional and behavioural difficulties than children in the general population, and that they take part in fewer activities than other children of their age. The view is held by UNICEF (2013) in their report that children with cerebral palsy are often excluded in many activities that other children undergo which serves to render them uniquely vulnerable, denying them respect and dignity, their individuality and often their right to life. Thus, children with cerebral palsy are often marginalized and excluded, experiencing prevalent violations of their rights. Discrimination against CP children arises as a result of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination and cultural views on disability (Cooper, 2002). The views of Islam and Cojacaru (2015) are supported that South Africa as a developing country has a high number of children born with CP which is estimated between 1 and 8%. The researcher brings forth the lack of resources in some rural areas in South Africa which predisposes poor families and more so families where disability is present. The absence of fathers in some instances deprives children of both parents and the much needed father's support.

In this study, the authors hold the view that caring for a child with CP poses many challenges and expenses to the family in terms of visits to the health facility as well as special food that they have to eat. Many of the children with cerebral palsy rely on their mothers/care givers for feeding, bathing, toileting in their daily life. This article deals broadly with people with disabilities and specifically with children with Cerebral Palsy in the Moses Kotane District. A qualitative approach was utilized and interviews with mothers and care-givers of these children were conducted. Statistics on the prevalence and nature

of children with Cerebral Palsy was collected from Moses Kotane Hospital and Job Shimangane Tabane Hospital in Rustenburg, Bophelong Hospital in Mafikeng and Klerksdorp/Tshepong Hospital Complex in Klerksdorp in the North West province. The total number of CP patients from these four hospitals was 547.

REVIEWED LITERATURE

Cerebral Palsy is defined by Ross and Deverrell (2010) as a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances in the developing infant brain. These authors' research showed that the motor disturbances of CP are frequently associated with disturbances of sensations, perception, cognition, communication and behaviour caused by epilepsy, or secondary musculoskeletal problems. There are few opportunities to place young children in appropriate day care facilities particularly those with severe disabilities from families with limited financial resources and South Africa is a good example when it comes to limited resources for children with disabilities and CP. Care centres do not have resources and space to accommodate people with disabilities and parents and caregivers have no means of support as a result.

Prevalence of CP is estimated from 1.5 to more than 4 per 1000 live births or children of a defined age range. About 1 in 323 children has been identified with CP according to estimates from CDCs Autism and Developmental Disabilities (Centres for Disease Control and Prevention, 2016). In Africa statistics shows that CP is the most common cause of physical disability in children worldwide. However, little is reported on this condition in the African context. The prevalence in Zimbabwe is estimated to be at 1.55 per 1000 in rural areas and 3.3 per 1000 in urban areas.

Diagnosis of cerebral palsy

In some black families, cerebral palsy is a rare phenomenon. Zastrow et al. (2019) define CP as a disability involving problems in muscular control and coordination resulting from damage to the brain's muscle-control. According to Ross et al. (2010), the diagnosis of cerebral palsy is based on a clinical assessment, and not on laboratory or neuro-imaging. When possible, neurologic testing and neuro-imaging studies are used to enhance the understanding of the infant's movement or lack of movement and the possible prognosis. A view is held by the researchers that the evaluation of a child with cerebral palsy requires a multidisciplinary approach with a team of professionals comprising a paediatrician or pediatric neurologist, occupational therapist, a physiotherapist, child psychologist and a social worker.

The diagnosis of Cerebral Palsy is made by the doctor. Causes of cerebral palsy differ from one individual to another and may not be connected to brain damage. Some causes occur before (pre-), during (peri-) and after (post-) natal. These include infections like malaria, measles, low birth rate, child asphyxia, implications from premature birth as well as head injury whereas the mother could be exposed to rubella, HIV/AIDS, toxemia, cytomegalovirus, multiple pregnancies etc. (Ross et al., 2010).

Four types of Cerebral Palsy are identified and usually grouped according to the way the condition affects a person's movement or the way it affects a particular body part. Types of cerebral palsies are spastic, athetoid, ataxic and mixed cerebral palsy. They are classified as follows: *Spastic cerebral palsy*. This is said to be the most common type of CP. It affects approximately seventy percent (70%) of children with CP. *Athetoid cerebral palsy* is another type of cerebral palsy. It is characterized by involuntary movement which is uncontrollable, slow or fast, jerky, tremor or rotator patterns. The third type of cerebral palsy is *Ataxic cerebral palsy*. This is the least common type CP characterized by unsteadiness, shaky movements or tremors. Ataxic cerebral paralysis is recognized to reduce muscle timbre. Ross and Deverrell (2010) mention a fourth type of CP known as *Mixed CP* whereby two types of cerebral palsy occur in one body at the same time. In this type, the spastic cerebral palsy and the athetoid cerebral palsy combine and are responsible for various disabilities in a child.

Problems experienced by the cerebral palsied and people with disabilities

People with disability, whether physical or mental, experience problems and challenges. Some of the challenges include discrimination, medical, behavioural as well as exclusion and lack of access to resources, amongst others

Discrimination

People with disabilities are at risk of being oppressed, discriminated against, ignored, ridiculed and denied equal rights (Zastrow et al., 2019). Researchers believe that people living with disabilities, cerebral palsy and other disabilities are affected by stigma from the society. Every person deserves to be treated with respect and a right to live harmoniously in the society like any other human beings. Marumamogae (2012), concurring with the latter statement, believes that discrimination against people with disabilities is one of the worst social stigmas that the society has not been able to overcome. She adds that

women, men, and children with disabilities are often amongst the most marginalized in all societies and face unique challenges in the enjoyment of their human rights

Medical problems

There are many cases reported on the poor medical treatment that children with cerebral palsy receive in the public medical institutions in South Africa. Most reported medical problems extend in pregnant women who get bad medical treatment which later results to children born with cerebral palsy. Medical intervention starts with continuous assessment, diagnosis and diagnostic conclusions and prognosis. Social work intervention relies on the diagnosis made by medical professionals. Zastrow et al. (2019) distinguished amongst the following medical problems namely, hearing, visual, epilepsy and concurrent disabilities.

Behavioural problems

Children with disabilities, by the nature of their disabilities, present with various problems which may affect other areas of their functioning. Where there is speech defect, communication becomes a problem and this can affect their social skills. *Learning* may also prove to be a *challenge* in some instances (Ross et al., 2010).

Exclusion and lack of access for disabled people generally

According to Ross et al. (2010) disability remains one of the most neglected and forgotten development conditions. There are many places and areas where people living with disabilities do not have easy access to compared to non-disabled people. Some institutions and organisations do not have easy access for people living with disabilities like wheel chair ramps and escalators. The blind do not have access to Braille system and feel excluded. People with disabilities in the institutions of higher learning encounter numerous challenges too, but some universities like Mafikeng campus of the North West University has tried to bridge the gap as they have a special disability unit which addresses all forms of disabilities in its campus.

THEORETICAL FRAMEWORK

This study relied on two theories namely *Systems theory* and *strengths perspective*. Systems theory guided the study to understand everyday functioning of the child with cerebral palsy. The study also focused on the strengths that the family had in accepting and coping with the

disability as well as what strengths and coping mechanisms the family of a child with CP are employing to keep the family strong and functioning.

METHODOLOGY

The research is qualitative in nature as it provides an opportunity for participants to express the social and psychological challenges and experiences of living with a child with cerebral palsy. This approach has been defined as phenomenological by Fouche (2002) as it is aimed at understanding and interpretation of participants' meaning that subjects give in their everyday live. This study was exploratory and gave the researchers an opportunity to interpret data, with the intension of providing an in depth understanding of the experiences by linking various data obtained. *Purposive sampling* was utilized as it forms part of the non-probability sampling procedure. Rubin and Babbie (2010) further say purposive sampling involves the selection of a sample for observation that is known to have the potential of providing the most suitable information for the study.

It involves the selection of sample for observation that is known to have the potential of providing the most comprehensive understanding of the subject studied in accordance with Curran and Runswick (2013). The recruitment of participants was done through the local clinic as well as from the social work load in the hospital. These organizations were approached with both the proposal approved by the university structures like the Higher Degrees office as well as the ethical approval. Permission was granted and the researchers were helped through the list of children with CP provided. The sample size of 25 respondents was drawn from the parents and caregivers of children with cerebral palsy from residing in the district selected, Moses Kotane Sub-district. Moses Kotane District is one of the five local municipalities of the Bojanala Platinum District municipality with 107 villages, 31 wards and bordering two formal towns. A total number of 10 participants were selected from the 25 samples as the 14 remaining were not attending or receiving medical care. These participants are children who attend CP lessons in Moses Kotane Hospital in Ledig Village. Thus, they were outside the ambit of the health centre. Semi-structured interview schedule was set up as data collection tool. This method of data collection helped the researcher into the sessions, with a set of predetermined questions on face to face basis. This enabled the researcher to ask follow-up questions which varied among the respondents in seeking in depth experiences, views and perceptions of the participants. This method of data collection also enabled, on the other hand, the participants to relate to their experiences and their thoughts and to answer to the research question. The university granted ethical clearance to conduct this study.

Data analysis

Section A of the study presents the demographical information and the profile of the participants who formed part of the study. Section B provides a discussion of the research findings that the study achieved. The findings are given according to the main themes and formulated sub-themes. Quotes from the interview sessions (in italics) and verbatim, were used to substantiate the findings of the study, and also to give more meaning and understanding on the challenges faced by children with cerebral palsy and their families. Questions for the three (3) professionals, namely the two social workers and two occupational therapists are addressed in the fourth

theme in the results section, and is concluded by the role that the social workers play with regard to children with cerebral palsy.

Biographical information

The study had a vast diversity in demographics of the 10 participants who took part in the study (Appendix Table 1). Participants comprised biological parents and caregivers of children with CP who are the main focus of the study. Two (2) social workers and one occupational therapist who work in Moses Kotane Hospital were also interviewed. From the total number of 10 children who are the main focus of the study, 7 were boys and 3 were girls. The majority (9) of them were black and one (1) was coloured. Four (4) of them came from Setswana speaking families, two (2) came from Sotho speaking families, three (3) came from Zulu speaking families whilst one (1) came from Afrikaans speaking family.

Biographic analysis

The data in this section is of the CP children in question as shared by the parents and care-givers (Appendix Table 2):

Age: Parents and care-givers of children between 1 and 11 years were selected. It was observed that the parents to the older children have accepted their children's condition as they seemed to be coping better with the situation. It may be because they have been living with their children for a very long time and have found ways of dealing with the disability. Only parents and care-givers of children in this age bracket were interviewed.

Race: Children, parents and care-givers of participants (nine over ten) came from the same racial backgrounds. All of them were black, besides one participant who was coloured. Even though they are black, they do not belong to the same tribe, and therefore do not speak the same language. They speak Isizulu, Sesotho, Afrikaans, and the majority speaks Setswana. Their differences did not create any language barrier, because they could all hear the translation of questionnaires in Setswana language.

Gender: Moses Kotane Hospital as a focus area of the study has a high volume of males born and diagnosed with cerebral palsy, and it may be the reason why the study had a high number of males who participated in the study as compared to females.

RESULTS AND DISCUSSION

This section comprises the findings and interpretations or discussions based on the results from the empirical investigation with the parents and caregivers of children with cerebral palsy in Moses Kotane Hospital in the Bojanala District. Ten (10) parents and care-givers, identified as representatives were interviewed. A semi-structured interview schedule was prepared to gather data and some responses are represented in italics (Appendix 3). There was no schedule for the health professionals, that is, social workers and occupational therapist but a brief during the recruitment of possible participants. The thought on their workmanship is derived from this encounter. Four themes and sub-themes (from two to six respectively) were identified and are discussed

Table 1. Identified themes and sub-themes.

| Themes | Sub-themes |
|---|--|
| Psychological challenges experienced by children with cerebral palsy and their families | Feelings and experiences of children with CP, parents and carers Coping mechanisms with CP Labelling and its effects |
| Social and emotional effects of cerebral palsy on the children and their families. | Stigma: Unemployment Educational challenges Sense of belonging Social security and support structure Availability of resources |
| Programs in place to address problems and needs of children with cerebral palsy | Physiotherapy /occupational therapy Community outreach programmes |
| Social Work services to children with cerebral palsy in Moses Kotane Hospital. | Counselling Outreach programmes The impact provided by the social work services in Moses Kotane Hospital to children with cerebral palsy and their families. |

below. Direct quotes from the interviews that were held with the participants' representatives were used as reflected in these themes (Table 1).

Theme 1: Psychological challenges experienced by children with CP and their families

Participants in this study stated that they were negatively affected and disturbed because of the conditions of their children. Participants shared how they were saddened when thinking of the future of their children. What came to the fore was their thoughts and emotions, their children's happiness and worry that they will neither have families of their own nor do anything for themselves. It can be deduced that the condition of their children has affected participants psychologically. Some of the responses are summarized in the following manner:

Feelings and experiences

The following responses were based on the question on how the birth of a child with CP affected parents and what their reaction was to this realization.

P2: *"I had mixed feelings when I started to realize that I have a child with CP. I was sad and angry. I once imagined that life is unfair and that God does not like me. On the other hand, I at times say to myself; whatever that is happening is the will of God and I should accept, even though it is hard at times to cope with the condition".*

P1: *"At times I cry when I look at my child. I sometimes feel like I have done something wrong or offended God*

which is why he ensured that I have a child like this. I cannot talk to her, when I do, she does not respond.

P3: *"I wanted a child who I could be able to pride myself with, I wanted a child who I could walk the streets of my community without any fear of shame or embarrassment. At first I wanted nothing to do with the child, but for some time nothing went well with my life, and I have no choice but to love this child. He is my child, yes, I learned to love him, but he is definitely not what I asked for from God. I am always home based, because of him".*

P5: *At first it was hard for me to accept that I have a child with disability. I was planning to give the babe for adoption after I was told by the medical personnel that I have a child with CP. It is hard for me to have another child, because I always have a feeling that haunts me. I am even afraid to have another child. The fear I always have, is what if I give birth to a child with CP again, what will I do with two kids with disability if I cannot manage with one. At times I feel like my child is a burden. I love my child, but I cannot deny the fact that he is a burden".*

Most of the participants declared that stress is one of the feelings that will never disappear as long as one has child with disability and particularly cerebral palsy in life. This was confirmed by one of the participant about stress:

P4: *"I do not feel comfortable being approached by guys for love. I often turn them down, because I know that should we agree on starting a relationship, I will not have time to give it attention because my child takes all the time I have. It is my wish to find a guy who can love me with my child, because most of the guys I dated did not take well the fact that I have a child with disability".*

This comment displays the parent's feelings which some

of them had no chance to talk about. It was like a platform for expressing inner feelings toward the situation faced. The response was also based on the fact that a single parent with a child with CP finds it difficult to engage in any romantic relationships as assumptions and stigma gain the upper hand. However, researchers did not observe any feelings or hear talk of giving up. Participants use their strengths to cope with adversity and survive.

Labelling and its effect on children with CP and their family

The attitude of the community and the derogative names assigned to CP children is seen as labelling by the researchers. The researchers hold the view that labelling causes harm or pain to one's emotions and leaves them hurt and looking down on themselves. Parents and caregivers explained that their children are called names by the way they look or who they are and have the following to say about this aspect:

P6: *"I remember my child was called (seritsa) and I was addressed as (mmage seritsa), which means a cripple, someone who cannot do anything by himself. Even though the child is disabled, it does not permit a right for anyone to call a person like that. Everyone has a right to a name, and deserves to be called with his or her name".*

P9: *"You know I really know what you are talking about when you talk about labelling. The name that the community used to call my child with rings a bell when you talk about it. I do not even want to say the name, because it makes me sad and angry. You know at times I used to feel like life is unfair, simply because when a mother is raising a child with disability alone, there are many good and courageous names that she can be called for the job well done; this will make her to continue to have the strength and courage to keep doing good. Instead of people doing that, they rather call you names that belittle you and that will make you feel discouraged at times".*

Coping mechanisms of participants

From the participants' point of view and the live experience of the researcher, children with CP find it hard to communicate their needs. They cannot express their felt needs, and therefore most of the times, they cry. At times they do not get attention whenever it is needed. Some of the children who participated in the study can talk but one cannot understand or make sense of what they say. The researcher asked the representatives of the children of participants how they know what the child needs or wants when trying to communicate:

P8: *I try by all means to pay attention to whatever sound the child makes, in order to understand what he is trying to say to me or the other person. After hearing the sounds, I would try to come with something to the child and try to understand if he was asking for that particular thing. If he shows a sad or bored face, I know it is not what he wants. Truly speaking it is frustrating to the child if you do not follow what he is trying to say or what he wants. Even if he is crying, he does not cry like normal, I would see tears coming from his eyes then I would notice he is not happy.*

P1: *"My daughter is 7 years now, I have been looking after her on daily basis, but even today I still find it hard to understand her methods of communications. She cries like any other babe when she needs something and does not get it, or when you give her the opposite of what she want, she cries like nobody's business. At times you would think she want a certain thing and give it to her, she would just stop crying and take it, but you see that it is not what she wanted, but because it is a child she would just accept it".*

P3: *"My son is more severe on physical parts, but he can and hear understand when you talk to him. He can respond, but words coming from his mouth are not clear. He is 9 years; I have learned to understand how he communicates. To other people it is difficult to understand what he says when he talks. When someone keeps asking him to repeat what he said, because of not getting the message clear, he gets angry and throws whatever he sees around him to that person. He has temper issues. I took him for sessions with the psychologist, in Moses Kotane Hospital but there is no change".*

These participants were coping well under the circumstances, which show their resilience. This aspect ties up with the above-mentioned especially with regard to stress. Resiliency is seen by Greene and Conrad (2012) as the ability of an individual, family, community or organization to recover from adversity and resume functioning when suffering serious trouble, confusion and hardship.

Theme 2: Social challenges experienced by participants

Stigma: Stigma is one of the leading factors amongst most of our communities. Stigma is regarded as a pervasive social force that has powerful; consequences for those who are stigmatized and society itself (Patel et al., 2010). They believe that stigma acts to decrease life opportunities among those that it affects by reducing among other things social contacts. Same as it is viewed by the authors above, participants said that the community has a very negative image about them, their

children, and also their families, stigmatizing them.

Participants' views

P 2: *"In my community especially people of the same street I live and some in my neighbourhood used to call my mother a witch. It was well known then in my community that my mother is a witch. The time people find out that I gave birth to a child with disability, they started saying that I am paying for my mother's sins. They regard my child as a punishment. To them my son is paying for the sins committed by my mother."*

P4: *At first it was frustrating to believe that the community regards my son as a punishment. I am no longer participative in some of the activities or rather the ceremonies in my community such as weddings, and funerals because when I try to assist, I get side lined at times, because people do not feel safe and comfortable to eat the food prepared through my assistance".*

"In my community some of the words I hear about my daughter are not said to me directly. I hear them from my friends and other people I associate with around the community. They accuse me of having slept with multiple partners, which is why I gave birth to a child with disability. At first these words used to hurt me, but I have learned to come to terms with them.

I decided not to care anymore as to who says what about me, my family and more especially my child. People use to stare through the windows when I walked with my child. I believe the aim was to confirm whether it is true I have a child with disability or not".

"My child is wheel chair bound. Wherever I go I am with him. He cannot talk, he cannot do anything. I am not working, I am self-employed. I make enough profit out of the business that I run. People who are running the same business that I do in my community do not progress faster than I do".

Researchers are aware that stemming from these responses, it is clear that communities and neighbours are not always supportive or knowledgeable about CP hence the assumptions, stigma, labelling and derogative names these children have to endure. Zastrow et al. (2019) state that a family is a system which finds itself in a broader community with other systems, which the family of a CP child is intertwined with. However, some households are confronted by unsupportive neighbourhood (McGoldric et al., 2011).

Unemployment and education

Unemployment is another significant factor that most of the parents of children with CP are faced with. Those

who are not biological parents but caregivers of children cannot regard looking after the child as employment because they are not earning anything from the work they do. The participants said it is hard for them to go look for work, because they have no one to look after the child, should they work. Many families in South Africa, and the participants in this study, rely on the child support grant and the disability grant for the child as the main source of income.

All the children who were selected in the study do not attend school. The parents and care-givers conceded that education is very important. Parents and care-givers in this study shared the same feelings about special schools. Some stated that they have not made an effort to look for appropriate schools for their children, citing different reasons as indicated below:

P6: *"I have never thought of taking my child to a special school. I am afraid that I am going to give teachers a challenge with my child".*

P8: *"My friend had a child with disability. Her child's condition was severe as that of mine. She took the child to a special school but nothing was changing. The teachers also did not treat her well as compared to those who were not severely disabled. They would leave him for a long time without asking the helper to change her nappies. When I think of taking my child to a special school, I always think of what happened to my friend's child and seriously".*

McGoldrick et al. (2011) bemoan the fact that single parents or household are beset with poverty, limited access to resources especially health care, inadequate housing which researchers agree with and as it does not help household with unemployed single parent households. Working mothers generally would live their offspring to find employment to sustain her family. The emotional bond with the child will be lost and it is what Papalia and Martorell (2015) call 'maternal deprivation'.

Sense of belonging

A sense of belonging is the feeling of connectedness with or involvement in a social system or environment of which a person feels an integral part. Abraham Maslow described a sense of belonging as a basic human psychosocial need that involves feelings of both value and fit (Curran and Runswick, 2013). Researchers agree that kinship is essential; thus, families are defined by an emotional bond and are interconnected to other sub-systems to form a whole.

When asked if the birth of their children have brought changes in their lives, participants admitted that there have been changes in their lives following the birth of the child who was diagnosed with Cerebral Palsy. Some

mentioned that they have lost touch with the society, friends and neighbours as they had other responsibilities and could no longer socialize the same way they did before the child became member of their families. Others said that they were afraid to visit places like churches as most of these places are neither accommodative nor conducive to the child's condition.

Theme 3: Social security and support structure

On the aspect of social security, participants identified poverty as one of the main challenges. Participants have admitted that they receive child support grant and disability grant but that this is not sufficient to accommodate the family's needs. Participants further mentioned that the grant is not always utilized for the things it is intended to cover, which is most important, to care for the child's needs. It was shared by the participants that these children under their care do not have enough clothes or foodstuffs. Most of the children cared for by participants encountered problems with the food that are prepared as some cannot swallow some of the food. They have special meal and the family incurs expenses due to the child's daily health needs. Most of the children need to be taken for routine check-up at the clinic, and sometimes at the hospital.

Participants admitted that raising a child with disability as a single parent is not easy. Experiences of participants were quoted as the follows:

P8: *"I separated from my husband who could not come to terms with the disability of our child and was under pressure from his relative". This is a clear prove that many families tend to blame the mother of the child if it happens that she gives birth to a disabled child".* Only two parents declared their husbands to be supportive and caring to their children. Accordingly, a second source of influence in a child's life stems from the father's role as a source of emotional and instrumental support to the other people, principally mothers, involved in the direct care of the child, according to Stanton (2012). The provision of emotional support from the father is continuously important to enable the child to grow knowing the warmth, love and the support of the father in life.

P9: *"Everything was fine before and when I was still pregnant. I have another child who is the first born, between me and my ex-boyfriend, also the father to the second child who has disability. After giving birth to the second born who has cerebral palsy, things started getting tough at home. "I am still married to my husband, but we are not staying together. After he finds out that we have a child with disability, he started being distant".*

The feelings that participants shared, and the responses they gave to the questions, give credibility to

the plight that children with CP face, including their families. Families provide intimate social environment to other family members which includes nurturing and caring (Zastrow et al., 2019). Where a father is present in a family and provides both material and emotional support, it becomes bearable for parents as well as care-givers to care optimally for the child with CP. Absence of fathers in South Africa is a common phenomenon.

Availability of resources

Most participants believe that there are services and resources for children with disabilities in South Africa, but lamented the fact that they do not have access. This has been proved by McGoldrick et al. (2011) how poor, single families struggle to have access to necessary resources. But the participants believe and agree that most of them do not reach those people who are living in rural areas like themselves. The participants said the government is doing good to deliver these services in urban areas and townships, but there are no such resources in rural areas. Participants believe the conditions of their children would have been better if they had full time physiotherapist and occupational therapist in their clinics. Due to lack of resources, participants are able to take their children for medical treatment only once in a month. They emphasised the need for day care centres for children with special needs, so that they can take them there to socialize with other children with similar disabilities. They believe availability of such institutions will enable them as parents and care-givers to look for jobs, knowing that their children's safety is secure.

Theme 4: The impact provided by the social work services

Social workers in a hospital setting help patients and their families understand particular illnesses, work through the emotions of a diagnosis, and provide counselling about the decisions that need to be made (NASW, 2011). Social workers working in Moses Kotane Hospital also ensure that they help the parents of children with cerebral palsy to understand CP and also to learn to accept the child's condition. This was shared when the researcher was inquiring about the number and frequent visits of children with CP. Social workers admitted that their role is not easy but they make sure that they handle the situation effectively. When intervening social workers said they do the following:

"We help patients to deal with the emotions of a diagnosis, and give counselling. Experience has taught us that our services are very important to the patient, particularly to parents of children with CP. After having counselling

sessions, most of them start to accept the child's condition, though it is always not easy for them to accept the condition and at time the child itself. CP is a life changing condition to each and every family. We therefore help them address their social, psychological and financial needs, so to accommodate the child's special needs which are related to the condition itself. "We make this possible through screening and evaluation of the patients' families during the initial meeting of the referral. We make a psychosocial assessment of the child, and also the parents".

Social workers in the hospital further alluded that "they believe that finding out of the diagnosis of CP comes as a shock to most parents and to the family in general. They further said the diagnosis can be traumatic to other parents and families, and therefore, when necessary they offer in depth counselling to avoid trauma from happening. They said to give them emotional support, hope and to make them accept and recognize that despite the child's physical condition, he or she deserves the love and support from the family. They partner with private and public institutions to ensure that the parents and families receive continued care and support and refer to other institution for further management and support. The following is the reflection of what the social worker's role entails when dealing with children with CP.

The role of social Workers

Social workers should try to learn and understand how the condition occurs; they may also offer continuous support to the family and the individual. They must develop strategies of how to help the family by explaining all relevant medical terms, tests and any assessment done on the child and also try to engage other families with similar problem as well as other methods of intervention like group work. Teaching the family to manage a budget that will include unforeseen medical bills is a role the social worker may play and help the family deal with ostracism and stigma. Community awareness campaigns are not only limited to conditions like cancer and HIV, but disability and cerebral palsy too. Empowerment and education is important as a tool for the social worker to help a family with a child with cerebral palsy. The social worker can help the family learn skills how to regulate the behavior displayed by CP children and alleviate stress levels as a result.

Outreach service: Occupational therapy

Occupational therapists aim to assist children with cerebral palsy with normalisation of their muscle tone, maintaining range in the muscle of the upper limb, development of play, functional and fine motor skills

(Therapies for Kids, 2016). Occupational therapists at Moses Kotane Hospital, pointed out that it takes perseverance and commitment to continue participating on the cerebral palsy sessions that are held within the hospital. Cerebral Palsy Guide (2016) is of the opinion that occupational therapists helps children with CP develop or recover the skills needed to lead independent lives. Paediatric occupational therapy focuses on improving the child's ability to play and learn, encouraging development and independence. Occupational can help to improve physical, cognitive and social abilities, as well as fine motor skills and posture (Cerebral Palsy Guide, 2016). All these children are the beneficiaries of disability grant, but not all of them are budgeted the money to travel every twice a month to the hospital for cerebral palsy lessons. The money is used to look after the whole family. Occupational therapists do community outreach programmes. This is done in collaboration with multi-disciplinary team to ensure maximum treatment and support for these children. Children attending cerebral palsy sessions regularly are recognized by physical developments in their body. Most of them are able to do basic bodily functions such as holding things for themselves and being able to play with others.

Conclusion

Early detection and diagnosis of CP in children is necessary to prepare the parents and any group involved in child care. This will help health care workers like social workers to give the necessary support and information to parents and care-givers through counselling, empowerment and general support. In this way, the social worker can play a role of an enabler, broker, educator and initiator through counselling, information sharing and practical assistance required in the early diagnosis. Herbst and Reitsma (2016) state that family counselling is important for the development of stronger communication between individual family members, especially in traumatic situations as the shock of having a child with disability and cerebral palsy can be traumatic for particularly young parents, or overwhelming to single parents. This results in healthier family dynamics that are able to successfully negotiate the challenges that either one family member may be experiencing that is impacting on the other members, or that of the family as a whole, is facing. This will cushion myriad feelings that families may have and in support from social workers be referred to other resources. These resources may include help with grant application, linking with medical resources like amongst other therapy like occupational or physical, as well as admission to special schools. Dealing with stigma and exclusion can be handled thus. With the child admitted in a special school or some relevant resource,

parents can seek employment and so augment the social/disability grant and combat poverty. The researchers conclude that continued research, services and programmes will benefit children with disabilities and cerebral palsy their families and the communities.

The researchers came to another conclusion that indeed children, aged between one and eleven years, both male and female with cerebral palsy, as well as their families are marginalised and excluded from many of the society's resources.

CONFLICT OF INTERESTS

The researchers hereby declare that there is no conflict of interests.

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Appendix

Appendix Table 1. Biographic data of participants.

| Demographic factor | Sub-category | Number |
|--------------------|--------------|--------|
| Age (years) | 1-3 | 03 |
| | 4-7 | 05 |
| | 8-11 | 02 |
| Total | | 10 |
| Race | Black | 09 |
| | White | 01 |
| Total | | 10 |
| Gender | Males | 07 |
| | Females | 03 |
| Total | | 10 |
| Home Language | Zulu | 03 |
| | Pedi | 0 |
| | Sotho | 02 |
| | Tswana | 04 |
| | English | 0 |
| Total | Afrikaans | 01 |
| | | 10 |
| Religion | Christian | 10 |
| | Muslim | 0 |
| | Hindu | 0 |
| Total | | 10 |

Appendix Table 2. Information of parents and care-givers as representatives.

| Representative | Profile |
|------------------|---|
| Representative 1 | The respondent stays in rural areas where she occupies a 4 roomed shack. She is single and has 2 children, one is attending school and the other one is not. She is unemployed, she was employed at a local clinic as a cleaner, but had to leave her job to take care of her child. The father to the child is not supportive to them, either financially or emotionally. She relies on her mother and her siblings for support. Disability grant of the child is also the main source of income within the family. She said that her religion was very useful, as it was a source of comfort and a pillar that gave her strength during difficult times. She indicated that she believe God is the creator and one has to accept whatever that is created by God. |
| Representative 2 | Respondent number 2 stays in a rural area in a 6 roomed brick house. She is married and blessed with 4 children. 2 of them are of school going age, and the one is working and the last born has CP. She is an Extended Public Works Programme (EPWP) employee, and also a day to day carer of the child. The father to children does not support them financially and emotionally. They are separated but not divorced. She has a partner; he is the one who support them financially and emotionally. Her main source of income is her salary, the child's disability grant and the little she get from the partner. |
| Representative 3 | Respondent number 3 stays in a rural area in a 6 roomed brick house. She is married and has 3 children. She is unemployed and stays home full-time. Being at home full-time enables her to continue to take care of the disabled child. The father to the child does not support them financially and emotionally. The husband is a pastor and he is always supportive. The main source of income is the husband's salary, the child's disability grant, and the money they get from their children. Church is one of the things that she relies on for support and courage. |

Table 2. Contd.

| | |
|-------------------|---|
| Representative 4 | <p>Respondent number 4 stays in a rural area in a brick house. She is single and has 1 child aged 4 years. She is unemployed and it enables her to continue to care for her child. The father to the child does not support them financially and emotionally. She gets support from her mother, father and her siblings. She stays full-time with her parents at their home. The child's disability grant is also a source of income within the family. She indicated that religion was very useful as it came as a source of comfort during difficult times. Church still plays a vital role even today.</p> |
| Representative 5 | <p>Representative number 5 here in a rural area in a 6 roomed brick house. She is single and has no child. She is a day to day carer of her younger brother who has CP. The mother to the child is working as a cleaner at a local clinic and does not have time to look after the child due to work commitments. The family is supportive towards the child. The father is a pensioner; he is supportive emotionally and financially. He still has money he got of his pension funds. The family members are not regular church attendants, but regard church as important and powerful to their lives.</p> |
| Representative 6 | <p>Representative number 6 stays in a 4 roomed mud-house. She stays with her mother and her 3 children. The father is not emotionally and financially supportive. She relies on the child support grants, and the disability grant of the child who has CP. She is a full-time church attendant and regard church as a source of comfort during hard times.</p> |
| Representative 7 | <p>Representative number 7 stays in a rural area in a brick house. She was married and got divorced to the father of her children. She is unemployed and blessed with 4 children. The father to the children is supportive financially due to maintenance of his 2 children, and continuously visits them. The other source of income within the family is the child's disability grant and the salary of 2 children who are working at the mines.</p> |
| Representative 8 | <p>Representative number 8 stays in an informal settlement in a 6 roomed shack. She is unemployed and single. She has 5 children, and depends on their child support grant and 1 disability grant of her child who has CP. She is not a Christian and said she does not attend church as she does not believe in God. All her children have different fathers, and they are all not supportive emotionally and financially.</p> |
| Representative 9 | <p>Representative number 9 stays in a rural area in a brick house. She is single and has 2 children. They are school going age, but the one who has CP is not at school. She stays full-time at home, and is a full-time carer of her child. Both her children have different fathers and all of them are not supportive emotionally and financially. She relies on the child support grant and the disability grant for survival. She also has a small business, selling vegetables to have a sustainable income.</p> |
| Representative 10 | <p>Representative number 10 is unemployed and has only one child. She is not the biological mother to the child with CP, but is a day to day carer of the child. The mother to the child is working as a clerk at a government department and does not have time to look after the child due to work commitments. The mother to the child is married and is blessed with 4 children. Both the husband and the wife are support to the child, the carer and the entire family, emotionally and financially. They regard the role of church in their life as significant. She said church moulds their behaviour and is their source of strength.</p> |

Appendix 3. Semi-structured interviews questionnaire

- Can you tell me about your life and your experiences before you gave birth to a child with CP?
- At what stage did you figure out that you are carrying a child with CP?
- How did you feel after been told?
- Did the medical personnel explain to you what CP entails?
- How did the immediate family members take the news?
- How does the community feel about the child, and the family?
- Do you ever get negative treatment from the community?
- How does the treatment make you and the family feel?
- How do you know what the child needs?
- What challenges are you facing since you gave birth to a child with CP?
- Where is the father to the child?
- Has he been supportive ever since the child's birth?
- How is the relationship between the father and the child?
- Did you ever feel life is unfair? If so why?
- Where you stressed after finding out the child's condition?
- How has having a child with CP changed your sleeping pattern?
- Do you receive assistance from any persons or institution? If so, who?