

**PSYCHO-SOCIAL CHALLENGES FACED BY CAREGIVERS OF CHILDREN
WITH CEREBRAL PALSY IN DZIVARASEKWA SUBURB, HARARE, ZIMBABWE:
IMPLICATIONS FOR SOCIAL WORK PRACTICE**

By

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DECLARATION

I, Adam Tafadzwa Mukushi hereby declare that this dissertation submitted to the University of Limpopo for degree purposes has not been previously submitted to any other institution of higher learning. I further acknowledge that the work presented in this study is entirely my own work except where sources are acknowledged.

Signature:.....

Date:.....

DEDICATION

I dedicate this research project to my dear parents Krispen and Ivy Mkushi, your presence gives a comforting shadow in my life.

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Every good gift and every perfect gift is from above (James 1 Verse 17). I would like to thank God for the good and perfect gift of life and good health which allowed me to complete my research even when times were difficult. If not for God I wouldn't have come this far.

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ABSTRACT

Disability is most prevalent in low income countries and communities. Cerebral palsy is one of the disabilities that is affecting a sizeable number of children in low income countries. This study sought to explore the psycho-social challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa Suburb in Zimbabwe. The study had the following objectives: to identify the psycho-social challenges facing caregivers of children with cerebral palsy, to appraise individual characteristics of caregivers which predispose them to stress, social exclusion and other psychosocial challenges, to establish which coping mechanisms are employed by caregivers of children living with cerebral palsy in response to the challenges they are facing and also to suggest possible solutions/ strategies social workers may employ to improve caregiving of children with cerebral palsy.

The study used a qualitative approach in exploring the psychosocial challenges caregivers face. The qualitative approach was useful as participants were able to participate freely giving a more realistic picture of their challenges. The research used an exploratory-descriptive case study design in exploring challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa Suburb. Data was then collected using in-depth interviews and Focus Group Discussions. Participants were caregivers of children with cerebral palsy, a hospital psychologist as well as social workers for a local NGO supporting the rehabilitation work at a local hospital. Data were analysed using the Thematic Context Analysis method.

The research concludes that caregivers are subjected to stressing conditions, lack the financial means of caring for a child with CP; caregivers employ negative strategies to the problems they face which include using the children to beg, prostitution among others. The study recommends that, government should lead initiatives for supporting children with disabilities and their families, formation of support groups for parents of children with cerebral palsy, and continuous training of frontline workers in disability to avoid burn out.

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ACRONYMS AND ABBREVIATIONS

ADLs	-	Activities of Daily Living
AIDS	-	Acquired Immunodeficiency Syndrome
BEAM	-	Basic Education Assistance Module
CBO	-	Community Based Organisation
CP	-	Cerebral palsy
CRPWD	-	Convention on the Rights of People with Disabilities.
CRU	-	Child Rehabilitation Unit
CWD	-	Children with Disabilities
DPA	-	Disabled Persons Act
ECD	-	Early Childhood Development
FBO	-	Faith Based Organisation
HIV	-	Human Immunodeficiency Virus
MICS	-	Multiple Indicator Cluster Survey
NGO	-	Non-Governmental Organisation
PWD	-	People with Disabilities

UNICEF - United Nations Children`s Fund

CHAPTER ONE

GENERAL ORIENTATION

1.1. INTRODUCTION

Caregivers of children with cerebral palsy are critical in the care of children with cerebral palsy but are often left out in many interventions. Social work has for a long time emphasised the importance of families and holistic assessments of clients, but when it comes to incorporating this importance in interventions, it lags behind (Pardeck & Yuen, 1999). (Crisp, 2011) is also of the view that social work interventions should be holistic for them to be effective, taking into consideration aspects like religion. In Zimbabwe, social work interventions for children with cerebral palsy gives much attention to direct interventions to the child, aimed at rehabilitation and for children to reach their maximum potential. However, for this maximum potential to be achieved, caregivers play a pivotal role since children with cerebral palsy largely depend on them.

Cerebral palsy has a high prevalence in the high-density suburb of Dzivarasekwa, with eighty children already receiving services at Harare Hospital. However, services that are being offered in this hospital are mainly focused on physical rehabilitation of the child without really considering the different roles played by caregivers. This study focused on exploring the psychosocial challenges that caregivers of children with cerebral palsy face because of their caregiving roles. Children with cerebral palsy rely on their caregivers for Activities of Daily Living (ADLs), adherence to medicine, development and movement from one place to the other. Therefore, the quality of life of children with cerebral palsy largely depend mostly on the caregiver, the hence need to understand the kind of challenges faced by these caregivers.

Since caregivers are pivotal in the lives of children with cerebral palsy, it is critical to understand them, the communities they live in and the types of challenges they face in caring for their children. Caring for a child with cerebral palsy is a normal parental role which has just been made harder by the child`s condition (Singer, Biegel & Ethridge, 2009). Different cultural and traditional beliefs also play a big role on how

caregivers of children with cerebral palsy manage their roles. Haihambo and Lightfoot (2010) argue that crucial to developing interventions that work, and that are relevant to social workers, it is important to understand the cultural and religious myths and beliefs surrounding the subject.

Different personal characteristics of caregivers were also given attention as it has been noticed that they are key drivers of response systems and coping capacities. The researcher looked at characteristics such as level of education, health conditions, economic status and size of family, all of which proved to have a bearing on the quality of services that caregivers give to their children.

Social workers work with both children with disabilities. The families of these children assist them to access services, to accept and understand the children's condition in order to manage it well, and link them with resources, among many other duties. However, for these social work services to be reliable, meaningful and appropriate, there is a need to employ a holistic approach, which looks at the child and its environment, that is, the community they live in, the family and most importantly, their primary caregivers to whom they largely depend on.

1.2. BACKGROUND TO THE STUDY

The prevalence rate of cerebral palsy in Zimbabwe is estimated to be at 1.55 per 1000 people in rural areas and 3.3 per 1000 people in urban areas (Finkenflugel, Maannen, Van, Schut, Vermeer, Jelsma & Moyo, 1996). (Dambi, Jelsma, & Mlambo, 2015), also reiterates that the prevalence in cerebral palsy is higher in rural areas as compared to urban areas. Differences in prevalence have been associated with different lifestyles in rural and urban areas. High density urban areas, which house the majority of urban dwellers, are characterised by overcrowding, shortage of clean water and proper sewer systems, absolute poverty and high prostitution rates (Finkenflugel et al., 1996). (Manjengwa, Mutema and Tirivanhu, 2016) also point out that high density suburbs house most of urban poverty. All these have brought a completely new form of health concerns, of which disability, cerebral palsy to be specific, cannot be isolated.

The high prevalence rate of cerebral palsy shows that the condition is affecting many families. It is, however, unfortunate that in Zimbabwe, service provision is designed

to meet only the needs of children with cerebral palsy, disregarding those of their caregivers as well as their families even in relation to the caregiving role that they play. The fact that in most cases, children with cerebral palsy do not develop self-care functions, but depend entirely on their caregivers makes the caregiving role a straining and emotional one (Brown, Goodman & Küpper, 2013). Consequently, this puts a strain on both the psycho-social and economic well-being of caregivers. Caregivers of children with cerebral palsy face a difficult task of caring for children, given that there is lack of formal and informal support services.

During the data collection period, there were 80 children who were receiving rehabilitation services at Harare Hospital's Child Rehabilitation Unit. Sixty-eight (68) of these children were cared for by their mothers, and the remaining 12 by their grandmothers.

As a high-density suburb, Dzivarasekwa is characterised by low-income households (Parliament of Zimbabwe, 2006). The fact that caregivers of children with cerebral palsy do not have enough support (both formal and informal), lack financial freedom, and the fact that the caring process is extended to children's adulthood means the costs for caring for a child with cerebral palsy is firstly, a high one and secondly, an elongated one.

The government of Zimbabwe has put in place different laws and policies to improve the lives of people with disabilities. Current laws that apply to disability in Zimbabwe include the Constitution of Zimbabwe (Amendment number 19), Chapter 17.02 of the Disabled Persons Act and Chapter 15.12 of the Mental Health Act. Zimbabwe has also rectified the United Nations Convention on the Rights for People with Disabilities. Important to note however, is that all the laws focus on ending discrimination towards people with disabilities, and less attention is given to other problems that caregivers of people with disabilities face.

Thus, looking at the interventions that are being provided by experts, the laws that the government has put in place lack sensitivity to the challenges faced by caregivers. This necessitated the study of this subject by social workers in pursuit of more suitable intervention strategies. This issue has also been neglected over time; yet it warrants a thorough understanding so that feasible interventions and laws are formulated.

The study explored challenges faced by caregivers of children with cerebral palsy given the socio-economic conditions that they experience, the lack of support systems and the poor coping mechanisms that they are employing. The study also investigated possible solutions to improve on the overall caregiving to children affected by cerebral palsy.

1.3. OPERATIONAL CONCEPTS

In this research, the following terms were used as defined.

1.3.1. Psychosocial

The term 'psycho-social' means the relationship between social factors in relation to other people within the community and individual behaviour, thought and emotional state. (Merriam Webster dictionary, 2010) define it as "involving both psychological and social aspects".

1.3.2. Cerebral palsy

In this study cerebral palsy is going to be interpreted as a severe intellectual and physical disability. It is a neurological disorder caused by a non-progressive injury to the brain or deformity when the brain of the child is still developing (Rosenbaum et al., 2007). As a result, the child develops a disability where communication between the brain and muscles is limited. The disability affects movement, posture and growth.

1.3.3. Caregivers

Caregivers will refer to people who are primarily and directly responsible for the wellbeing of children on a day-to-day basis (Merriam Webster dictionary, 2010). Their responsibilities include, but not limited to, feeding, toileting, bathing and general guidance given to children. In this research, these people happen to be mothers and grandmothers of children with cerebral palsy.

1.3.4. Children

The research adopted the definition provided for by the Children`s Act Zimbabwe. According to section 2 of the Children`s Act (Chapter 5.06) of Zimbabwe, a child is “Any individual who is below the age of 16 years”.

1.4. RESEARCH PROBLEM

With Zimbabwe`s ever increasing economic woes and underdevelopment, it is very difficult to find appropriate day care facilities for children with disabilities. This is especially the case because many families who have children with cerebral palsy are poor and cannot afford specialised care for their children. Again, specialised rehabilitation is provided on an irregular basis with the caregiver getting support from Harare Hospital CRU for 10 minutes the whole month. Even those who can afford it will not find this consistently useful, leaving the immediate family to do their best to ensure that children with cerebral palsy develop all the necessary skills such as toileting, feeding and dressing, among others. The caregiving role is made even harder and stressing given that cerebral palsy is a lifelong disability.

Many caregivers go through many emotional phases because of the caregiving role, and yet most available services deal with the wellbeing of the child and not the caregiver.

Providing care to a child is a parental responsibility. This responsibility can be harder than it normally should when the child has cerebral palsy (Singer, Biegel & Ethridge, 2009). In some cases, the child may not develop full self-care functions, and will constantly depend on the caregiver for daily living. Normally, children are expected to develop full self-care abilities once they reach a certain age. However, children with cerebral palsy may experience intellectual deficiencies, which might affect communication and sensory functions until adulthood (Rosenbaum et al., 2007). In some incidents, epilepsy may also be present, thus making the situation worse. In addition, caring for a child with a disability is very expensive and emotionally subduing (Almeida & Sampaio 2007). This is so because it comes with discrimination and loneliness as most community members distance themselves from the immediate family of a person with a disability. This reaction by the community to the condition of the child is disturbing to caregivers and close family members. As a result, the caregiving role is made even harder.

Dzivarasekwa is a low income suburban area with a very high unemployment rate where most families survive on vending, of which balancing the demands of earning and caring for a child with cerebral palsy has proved to be difficult (Parliament of Zimbabwe, 2006). The community segregates immediate families of children with cerebral palsy. In most cases, organisations focus on providing rehabilitation services for children so that they are able to reach certain functional levels, forgetting that by virtue of caring for the child, caregivers are affected socially and psychologically. This necessitates the need for psycho-social support. Caregivers of children with cerebral palsy are then faced with a challenge of managing their child's condition alongside providing for the entire family. The pressure is so much that at times, caregivers have little time for proper rest and sleep, let alone playing the parental role to other children without cerebral palsy (Chambers & Chambers, 2015). In light of this, psycho-social challenges faced by caregivers of children with cerebral palsy should be studied in social work in order to come up with intervention strategies that do not leave out their (caregivers) needs. Thus studying challenges faced by caregivers of children with cerebral palsy is a relevant subject of study in social work, as the profession is not only concerned with the wellbeing of children, but of caregivers as well. Besides, the wellbeing of children depends on that of caregivers.

1.5. ROLE OF THEORY IN THE STUDY

This study was influenced by the Family Caregiving Model by McDonald, Gregoire, Poertner and Early (1997) as its theoretical framework. This model focuses on issues relating to the understanding of stress and coping strategies among caregivers of children with disabilities. This theory influenced the study because in most cases, people are mainly concerned with the provision of material and monetary help, disregarding the psychosocial wellbeing of caregivers. The model suggests that the caregiving process consists of three different stages namely, antecedents, mediators and outcomes.

Antecedents consist primarily of child, family and caregiver characteristics, including those of the community in which the family lives (McDonald et al., 1997). This stage helps to identify the present problems. These range from the extent of the child's

disability and dependency level on caregivers, to how supportive the family members, friends and the community at large are to the caregiver.

The model also posits that these antecedents are mediated by both internal and external factors related to the family caregiver (McDonald et al., 1997). External factor mediators include the availability and use of formal social services and informal social support systems (McDonald et al., 1997). In fact, this refers to anything coming from outside the caregiver to influence smooth caregiving. Internal factors include both cognitive and behavioural coping strategies used by the caregiver. However, many organisations have failed to provide interventions that take note of how mediators affect the outcomes.

Possible outcomes include both positive and negative effects on caregivers' health and wellbeing, together with family and child functioning (McDonald et al., 1997). Negative effects to both psychological health and psycho-social well-being of the caregiver affect the quality of care that the child ends up receiving. For instance, if there are no strong social support systems, the caregiver might develop stress-related conditions, and this is a negative outcome. Consequently, the quality of caregiving is somehow compromised.

For this reason, this research was influenced by this theory on the basis that cerebral palsy is a family experience that can be psychologically and socially damaging to all members of the family, especially the caregiver. The theory was instrumental in looking at individual characteristics of both caregivers (antecedents) and mediators of children with cerebral palsy. These antecedents are mediated by external factors. The research took social support systems or programmes being offered by NGOs and the government as external factors. The research also looked at how these external factors relate to individual characteristics of caregivers and the extent of the child's disability. Lastly, it suggested the possible outcomes.

1.6. PURPOSE OF THE STUDY AND RESEARCH OBJECTIVES

1.61 Purpose of the study

This study sought to explore and describe the psycho-social challenges faced by caregivers of children living with cerebral palsy and to find lasting solutions to the challenges that they face in Dzivarasekwa.

1.6.2. Objectives

1.6.2. 1. To identify the psycho-social challenges faced by caregivers of children with cerebral palsy.

1.6.2.2. To appraise individual characteristics of caregivers which predispose them to stress, social exclusion and other psychosocial challenges.

1.6.2.3. To establish coping mechanisms that are employed by caregivers of children living with cerebral palsy in response to challenges that they are facing.

1.6.2.4. To suggest possible solutions/ strategies that social workers may employ to improve the caregiving of children with cerebral palsy.

1.7. RESEARCH METHODOLOGY

1.7.1 Research Approach

The research was qualitative in nature. Yates (2004) claims that a qualitative approach seeks to achieve a deep understanding and exhaustive description of a certain aspect of an individual. (Babbie & Mouton, 2011) also reiterates that qualitative approaches seek a deep understanding of phenomena. The psycho-social challenges and coping strategies employed by caregivers of children with cerebral palsy are expressive and subjective, cannot be quantified, and therefore, require an in-depth understanding.

Mack, Woodsong, MacQueen, Guest and Namey (2005); (Babbie & Mouton, 2011). postulate that qualitative researches seek to understand phenomena from the perspective of the local people. With this view in mind, the qualitative research approach was seen to be the best approach to understand the psychosocial challenges faced by caregivers of children with cerebral palsy in a specific community (Dzivarasekwa High Density suburb in Harare, Zimbabwe and what it means for social work practice).

The qualitative research approach mainly focuses on describing and understanding as opposed to explaining human behaviour or phenomena (Babbie & Mouton, 2011). This suited the aim and objectives of this research, that is, to understand the kind of psychosocial problems faced by caregivers and to describe these challenges.

1.7.2. Research design

The research employed an exploratory-descriptive case study design. Descriptive case studies are in-depth studies of a certain situation, and in this case, circumstances that caregivers of children with cerebral palsy are facing, and the challenges that come with them are to be investigated (Yates, 2004). Explorative-descriptive case studies focus on unfolding specific behaviours and circumstances in a particular case. They are used to systematically narrow down wide-ranging topics such as disability to one researchable aspect such as psychosocial challenges of caregivers of children with disabilities, as was the case in this study.

Babbie and Mouton's (2011) explorative researches are mainly done to research on relatively little known research subjects. This research focuses on a holistic view of cerebral palsy, that is, the rights and welfare of children with cerebral palsy are only protected through their parents and caregivers since they (the children) depend on them (their parents). Researches on disability for some time have focused on either the challenges faced by people with disabilities and the loopholes of disability policies while leaving out the caregivers of children with disabilities. This study therefore sought to address the gap as observed by Babbie and Mouton (2011) that there are study areas that are little known, and explorative research best addresses these study subjects.

1.7.2 Population and Sampling

Rubin and Babbie (1989) define a population as an aggregation of all the elements in a study location. (Explorable, 2018) define population an entire number of elements of a research, participating or not. For example, all the people in the area under investigation. This study targeted caregivers of children with cerebral palsy in Dzivarasekwa high density suburbs. According to Harare Central Hospital's Child Rehabilitation Unit's Records, there are 80 children with cerebral palsy in Dzivarasekwa suburb, of which 68 are cared for by their mothers, while 13 are cared for by their grandmothers. Stratified systematic sampling was used. Two strata were formed, one represented the 'mother caregivers', and the other represented the 'grandmother caregivers'. After the strata formation, every 9th caregiver from the register of 'mother caregivers' was selected to be a part of the sample, and every 4th caregiver from the 'grandmother caregivers' was also selected. This gave rise to a

sample of 10 participants. Two social workers from J.F. Kapnek Trust and a therapist from Harare Central Hospital Children Rehabilitation Unit were interviewed as key participants. These were selected through purposive sampling, which is a non-probability sampling technique. The J.F Kapnek Trust`s disability programme is running a national programme focusing on the rehabilitation of children with cerebral palsy. In Dzivarasekwa area, they work together with Harare Central Hospital Child Rehabilitation Unit, hence their choice as key participants of the study.

1.7.3 Data Collection

The researcher used in-depth interview guides and focus group discussion guides to collect data from the sample. The researcher administered interview guides to caregivers of children with cerebral palsy. Yates (2004); (Bhattacharjee, 2012) defines in-depth interviews as objective conversations between the researcher and participants for the sole reason of acquiring information from the latter. This data collection method enabled the researcher to get first-hand information on the challenges faced by caregivers. Facial expressions and other non-verbal cues also enriched the information from the participants. In-depth interviews had the advantage of monitoring non-verbal cues, which helped a lot in getting the true picture of the situation from the respondents. In-depth interviews also allowed rapport building and further probing on seemingly difficult questions. Apart from the above, the researcher recorded a 100% response rate from interviews, which is not the case with other data collection tools (Yates, 2004); (Bhattacharjee, 2012).

Focus group discussions were also conducted with the interview participants. Walliman and Appleton (2009) describe focus group discussions as groups of people who discuss particular topics in a research with the guidance of the researcher. Two groups comprising five people each were formed. This was done because other respondents seemed comfortable to talk in a group setting with people that they knew are facing the same challenges as themselves. The researcher used them with much success and was able to confirm and support responses from in-depth interviews. By grouping people of similar experiences and backgrounds, they develop a sense of belonging, which in turn helps them to articulate how they feel, and deal with difficult situations (Walliman & Appleton, 2009). Some people feel comfortable discussing sensitive issues around others of similar backgrounds. In this

research since disability is a sensitive issue in Zimbabwe, focus groups that were held by the researcher were helpful in bringing people of similar circumstances together to discuss experiences that they all face on a daily basis.

In-depth interviews were also be used to collect data from two (2) social workers from a local organisation which is running the rehabilitation programme (The J.F Kapnek Trust) and one (1) therapist from Harare Central Hospital Child Rehabilitation Unit, totalling the key informants to three. This helped in getting a professional view on the psychosocial challenges faced by caregivers, and challenges faced by professionals in assisting these caregivers, leading to viable recommendations.

1.7.4 Data Analysis

According to (Bhattacharjee, 2012) and Punch (2005), data analysis is about working with data, grouping it, breaking it into manageable units, searching for patterns, discovering what is important and what is to be learned, and deciding what needs to be revealed to others. The researcher used Thematic Content Analysis, which is a descriptive presentation of qualitative data. Qualitative data may take the form of interview transcripts collected from the research participants (Punch, 2005). Interview transcripts and field notes were systematically arranged into themes for interpretation and analysis. Data from both interviews and FDGs was grouped according to themes, and from these themes it was analysed (Punch, 2005). The research had two data sets but they were analysed individually and on the basis of themes.

1.7.5 Quality Criteria

Research studies must have a particular degree of trustworthiness for them to be worthy, commendable and valid. In most cases, the validity of qualitative research designs is drawn from a four-pillar model, and these are credibility, transferability, dependability and conformability.

1.7.5.1 Credibility

Credibility involves establishing that the results of the research are believable from the perspective of the research participants (Punch, 2005); (Alabbasi and Stelma,

2018); (Bhattacharjee, 2012) in this research, credibility was achieved by triangulating interviews with focus group discussions. In conducting both the interviews and FDGs, the researcher tried to build an atmosphere of free participation. One of the strategies that the researcher used was for the participants to sign informed consent forms, clearly indicating that their participation in the study was voluntary and that they were not coerced. This ensured that they were free, and hence they were able to freely discuss real issues that they were facing. Because they were able to freely communicate their real experiences, the resultant research outcomes became credible.

1.7.5.2 Transferability

Transferability is about how safe it is to use the study findings in generalising the same aspect under study in different locations or settings (Punch, 2005); (Bhattacharjee, 2012). The researcher fully described the context in which the study was carried out. That is, the economic activities being undertaken in the community, social values, and level of education of caregivers, religious views and cultural practices. All the assumptions that the research was conducted under were also documented to inform future researchers. This ensured that if the findings were to be transferred, there would be comparisons between Dzivarasekwa community and where the results will be transferred. This study ensured transferability of results since the researcher interviewed social workers from J. F Kapnek Trust (a local Non-Governmental Organisation offering rehabilitative services to children with cerebral palsy countrywide). The researcher also interviewed a therapist from the Child Rehabilitation Unit (a government department offering a joint programme with J.F. Kapnek Trust in rehabilitating children with disabilities). One characteristic that will guide transferability in the future is the presence of services from both an NGO (Kapnek Trust) and a government entity (CRU).

1.7.5.3 Dependability

Dependability is about consistency and repeatability of the study findings (Punch, 2005); (Alabbasi and Stelma, 2018). In this research, the study findings were measured by the standard in which the research was conducted, analysed and presented. Each process in the study was reported in detail to enable an external researcher to repeat the inquiry, and to achieve similar results. The researcher also

accounted for any bias that could affect the study results. These biases include personal researcher bias, sampling bias and changes in the study setting.

1.7.5.4 Conformability of the study

Conformability focuses on the degree to which the findings could be confirmed, authenticated or validated by others in the future. The investigator documented measures for checking and rechecking the information throughout the study. After the study had been completed, the researcher conducted a data audit that examined the data collection and analysis measures, and made judgments about the potential for bias or distortion. There was no bias or distortion and all this ensured that the final outcomes of the study were authentic and can be corroborated by other researchers.

1.7.5.5. Limitations of the study

The limitations of the study are those characteristics of design or methodology that impacted or influenced the interpretation of the findings from your research. They are the constraints on generalizability, applications to practice. The study was conducted in one high density suburb and therefore it will be difficult to generalise to other areas. There is also a critical shortage of recent and relevant literature on cerebral palsy and disability in general in Zimbabwe. The sample size might also be too small to generalise for the whole of Zimbabwe especially considering that they were taken from a single high density suburb.

1.8. SIGNIFICANCE OF THE STUDY

Various studies such as challenges of caring for a child with disability in general (Fishwick, 2009), challenges for caring for children with mental handicaps (Ambikile and Outwater, 2012) and family coping studies (McCubbin, 1979) have been carried out on the challenges faced by caregivers of children with disabilities. However, it appears that there are no known studies that have focused on the psycho-social challenges experienced by caregivers of children with cerebral palsy in Zimbabwe. Ambikile and Outwater's (2012) study examined the challenges of caring for children with mental handicaps in Tanzania. Fishwick (2009) carried out a study on the challenges of caring for a child with a disability in general. Most studies have, in the past, focused on challenges of caring for children with disabilities or other types of

disabilities. None paid specific attention to challenges of caring for children with cerebral palsy. Studies that focused on challenges experienced by caregivers of children with cerebral palsy were done in developed countries (Button et al., 2001; Almelda and Sampaio, 2007). In light of this, there is a need for more inquiries on psycho-social challenges faced by caregivers of children with cerebral palsy in Zimbabwe, and the resultant economic implications that come with caring for children with cerebral palsy in a developing country.

The findings of this research are going to be useful to the government, communities, families and organisations working with children who have cerebral palsy because the determination of the challenges faced by caregivers is important in the process of finding ways to support them. The results of the study will be of benefit to organisations as they will direct interventions relating to the strengthening of family systems. Accordingly, children with cerebral palsy will also benefit. Good practice is most likely to be ensured through an integrated approach that takes into consideration both the problem and its surroundings, using best practice in terms of both social and medical terms. The key to ensure the best use of scarce resources is to listen to caregivers of children with cerebral palsy, and to take full account of their views during decision-making, as well as tackling negative attitudes in society as a whole. As a result, this study brought together challenges and views of caregivers of children with cerebral palsy which can inform NGOs and government enterprises.

1.8. ETHICAL CONSIDERATIONS

This researcher considered a number of ethical issues to maintain acceptable standards.

1.8.1. Permission seeking

Permission to conduct the study was obtained from the University of Limpopo Turfloop Research and Ethics Committee. Data collection did not start before the researcher was granted ethical approval. Furthermore, permission was sought from the Director of J. F Kapnek Trust, the organisation which is running the rehabilitation programme together with Harare Hospital's Child Rehabilitation Unit.

1.8.2. Informed consent and voluntary participation.

The researcher put into practice the principle of informed consent. Nachmias and Nachmias (1990); (NASW, 2018) define informed consent as a method used to make sure that all the necessary information about the study has been shared with the prospective participants before they decide to participate or not to participate in the study. The researcher explained to the participants that the research is purely academic. According to Mupedziswa (2005); (NASW, 2018) social workers have an obligation to inform the participants of their right to participate willingly, and the lack of restriction to withdraw from the investigation if they so wish. The participants were made to sign consent forms. Caregivers of children with cerebral palsy were interviewed at the most convenient time to ensure that the research activity did not affect their provision of care to their children. This ethical principle is based on the right of persons to self-determination. In the event that the participants wanted to withdraw from the study, they were free to do so, and this too was in the consent forms.

1.8.3. Privacy, Confidentiality and Anonymity.

The respondents' right to privacy and confidentiality was well respected. Walliman and Appleton (2009) argue that privacy and confidentiality must be maintained in all stages in the research process, and individuals must be kept anonymous in the thesis. Privacy was guaranteed through anonymity, and personal identity was not linked to responses during interviews. The participants' voices were quoted using pseudonym identities such as caregiver Y and caregiver X. No names came out during and after the research, thus, privacy and anonymity were maintained. Anonymity was upheld throughout the research. Even if the research is published, the identities of the participants will not be published unless there is a signed statement of their consent.

1.8.4. Non Maleficence

Researchers should defend participants from psychical and mental distress, deprivation or any kind of harm (Mupedziswa, 2005); (Beauchamp and Childress, 2008) In light of this, the researcher made sure that no participant was hurt either physically or emotionally as a result of their participation in the study. The researcher made a personal evaluation of the participants, assessing any possible harm that

may have been caused because of the research, and none was found. The research guaranteed no physical harm to the participants as the research was entirely based on interviews and FDGs.

1.8.5. Debriefing and Aftercare

After the completion of the study, the researcher provided the participants with the necessary information to complete their personal understanding of the research and the subject matter. The researcher also discussed with the participants their experiences of the research. The main aim was to monitor unforeseen negative results or effects of the research (Walliman & Appleton, 2009). Since the research was a sensitive one, the researcher sought the services of Dr. Vincent Mabvurira (social worker) to provide free counselling to caregivers who displayed severe signs of stress and depression. However, there were no cases of that nature. The researcher had previously said: "If need be, the researcher will also refer caregivers to other professionals such as J.F Kapnek social workers, CRU therapists and Social Welfare Officers for counselling and linkages to other social protection services", but this need did not arise.

The researcher, in accordance with the provisions of the Children`s Act (Chapter 5.06) of Zimbabwe, made sure that everything was done in the best interests of the children. This involved not upsetting their daily routines to suit the research. However, during the course of the interviews, the researcher realised that one child was not feeling well, and facilitated for the child to be examined at the main hospital. It also brought out a key finding about the ability and capacity of caregivers in actively seeking and accessing health services for their children.

CHAPTER TWO

PSYCHO-SOCIAL CHALLENGES AND EFFECTS OF CARING FOR CHILDREN WITH CEREBRAL PALSY

2.1. INTRODUCTION

This chapter focuses on reviewing literature related to cerebral palsy, disability in general, effects of caring for a child with disability and the role of social work in disability issues. It also focuses on the potential of improving the role of social work based on past research and experiences, and explores observed weaknesses of the services on offer and the general disability situation. This lays the platform for the researcher to set the stage for proper and well-informed data analysis and discussion.

2.2. Cerebral palsy

Becker and Yalcin (2010) define cerebral palsy as a disturbance or disorder of posture and movement that usually develops during infancy or early childhood. It is usually caused by damage to the brain at birth, or in some cases, before and shortly after birth. Cerebral palsy should be manageable because brain damage is not progressive, However, with many challenges such as lack of proper management knowledge or understanding, it proves difficult for many, especially those from poor and low income backgrounds (Berker and Yalcin, 2010). The damage to the brain is not progressive but is permanent, which means it cannot be cured, but the effects can be minimised and reduced. Cerebral palsy therefore affects coordination between the brain and other body parts. Children with cerebral palsy are generally slow in developmental milestones and usually face mobility challenges, as they are less active. Some find it hard to master and to do activities of daily life (ADLs).

Cerebral palsy is believed to have a prevalence rate of 2-3 cases per 1000 live births in developed countries, and 5-8 per 1000 of live births in developing countries (Dambi, Jelsma, & Mlambo, 2015). It is however, saddening to note that cerebral palsy is rated among the most disabling conditions for children around the world

(Surveillance of Cerebral palsy in Europe, 2000). Previous literature reported that cerebral palsy impacts on physical and psychological performances of caregivers. Therefore, some children with physical disabilities, including those who have cerebral palsy, may consider dealing emotionally with their disability. This is a major problem that, in turn, poses a major barrier which sometimes hinders their success (Boeraerts & Roeder, 1999). One of the problems that some children with cerebral palsy face is to maintain peer relationships and a sense of belonging to a group, which seems difficult for them when they find themselves obliged to leave the classroom to have supportive services and feel anxious about fitting in at schools (Heward, 2006); (Morgan & McGinley, 2013)

Heward (2006) adds that children with cerebral palsy might experience fear and anxiety from others' view, the sense of being different, frustrations caused by poor control over one's body, inability to communicate their thoughts and needs, and inability to feed themselves. Moreover, because of the visibly noticeable physical symptoms of cerebral palsy, such as incontinence, these children might also feel embarrassed in any setting, and social interaction with peers or adults could be at risk because of their easy emotional pain. In addition, different treatments that they take could reinforce their feeling of being different by reducing their abilities to carry out certain activities at school or in their community (Heward, 2006); (Morgan & McGinley, 2013).

In terms of many researchers' points of view, there are other conditions forcing such children to experience the suffrage of social and emotional behavioural problems, that is, cerebral palsy being associated with a spectrum of developmental disabilities such as mental retardation (Heward, 2006).

2.2.1. Types of cerebral palsy

There are several types of cerebral palsy as described below:

2.2.2. Spastic cerebral palsy

King, Teplicky, King and Rosenbaum (2004) argue that spastic cerebral palsy is the most common type of cerebral palsy, and it is a result of stiffness or tightness of muscles. Body muscles become stiff because the synaptic messages to the muscles

are relayed incorrectly from the affected parts of the brain. When they normally perform a movement, some muscles contract whilst the antagonistic groups of muscles relax in order to perform the movement. According to King et al. (2004), in children with spastic cerebral palsy, all the muscles may contract together, thus making movement very difficult.

2.2.3. Dyskinesia cerebral palsy

King et al. (2004) argue that dyskinesia cerebral palsy is a type of cerebral palsy with abnormal involuntary body contractions and movements. This type of cerebral palsy is sub-divided into two types of movement problems, and these are dystonia and athetosis. Dystonia refers to sustained muscle contractions that frequently cause twisting or repetitive body movements or abnormal postures. Athetosis refers to uncontrolled extra body movements that occur particularly in the arms, hands and feet and around the mouth (Odding, Roebroek and Stam, 2006). The lack of control of body muscles is often most noticeable when an affected child starts to move. For instance, when a child attempts to hold something. In addition, children with athetosis cerebral palsy feel floppy when carried.

2.2.4. Ataxic cerebral palsy and mixed types

Ataxic cerebral palsy and mixed types of cerebral palsy is not common. It refers to unsteady, shaky body movements or tremors (Odding et al., 2006). Children with ataxia have problems with balance. However, many children do not have just one type of cerebral palsy, but a mixture of several of these movement patterns.

2.3. Rights of People with Disabilities

The position of disabled people in society has been discussed internationally for many years. Zimbabwe ratified the United Nations Convention of the Rights of people with Disabilities. The principles related to equality and non-discrimination in the general human rights conventions also apply to disabled people (Gable & Gostin, 2004); (Mugumbate and Nyoni, 2013). For instance, 'equal before the law' means that people with disabilities may require special treatment to achieve equality with other citizens (Article 26 of the International Covenant on Civil and Political Rights). According to the International Covenant on Economic, Social and Cultural Rights, everyone has the right to education that enables them to participate effectively in a

free society, and the right to work, which includes the right to the opportunity to earn a living by work (Articles 6 and 13). Such are some of the rights that relate also to people with disabilities, even though they are not specific to them and they do not focus directly on children with cerebral palsy (Gable & Gostin, 2004). Notable is their focus on the person with a disability. It is a fact that children with cerebral palsy depend on their caregivers, hence efforts should look at both the child and the caregiver.

According to Wajid, Javead, Parvez and Shafat (2006), the year 1981 was the International Year of Disabled Persons whose theme was 'equalizing opportunities and full participation'. To ensure effective follow-up, the United Nations adopted the World Programme of Action Concerning Disabled Persons in 1982. This defined handicap for the first time as a function of the relationship between disabled people and their environment. In 1993 the United Nations adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Even though they are not legally binding, the rules are politically and morally binding. The United Nations appointed a Special Rapporteur, Bengt Lindqvist, from 1994 to 2002 to monitor the implementation of the Standard Rules in cooperation with governments, the United Nations and non-governmental organisations (NGOs) (Walid et al., 2006). Whilst the history of the disability movement at international level highlight a commitment, critical to note is the implications of placing focus on the individual with a disability and not on them and their caregivers, especially for children, (Mugumbate and Nyoni, 2013)

Lindqvist (2002) concluded that the majority of countries had a welfare approach to disability, meaning that they mainly emphasise rehabilitation and prevention, and pay less attention to accessibility and non-discrimination. Looking at Lindqvist's conclusion, it is important to note that the welfare approach does not capacitate the caregiver either to prevent future disabilities or to manage the current disability, as such the under capacity derail management of disability often comes with challenges.

2.3.1. Disability policy in Zimbabwe

Zimbabwe was once viewed as a model country for disability rights in Africa and the world over (Chimedza & Peters, 1999). It was one of the first countries to adopt

disability related legislation through the promulgation of the Disabled Persons Act of 1992. This was a progressive development considering that for many years, PWDs were saddled by the absence of disability legislation. According to Manatsa (2015), apart from the DPA, Zimbabwe now boasts other statutes that address disability in both general and specific terms. The enactment of the DPA in 1992 broadened the horizons of disability rights activism in Zimbabwe, with disability organisations advocating opportunities for PWDs on an equal footing with their non-impaired counterparts (Chimedza & Peters, 1999). Although there are good policies regarding disability, implementation is still a challenge in Zimbabwe. There is the inclusive education policy for children with disabilities to access education, but the physical environment at schools is not friendly. Children on wheelchairs cannot access the classrooms; there are no specialised teachers at schools; and caregivers mostly have to bear the burden and pain of seeing their school-going age children with disabilities at home.

However, it is pertinent to note that such activism did not yield much as the rights of PWDs were not formally recognised under the erstwhile Lancaster House Constitution. It was not until 2005 that the Zimbabwean legislature saw it fit to amend section 23 of the Lancaster House Constitution to include disability as a ground upon which discrimination could be prohibited (Choruma, 2006); (Mugumbate and Nyoni, 2013).

However, even with this amendment, it could still be argued that this Constitution was weak as it only prescribed physical disability as a ground upon which discrimination was proscribed, thereby not encapsulating other forms of disability enunciated under Article 1 of the Convention on the Rights of People with Disabilities (Choruma, 2006). Amendment number 19 of the constitution of Zimbabwe has, however, improved its recognition of disability in Chapter 4 on Declaration of Rights. These laws are universal, for example on Chapter 7 on Elections, people with disabilities are also entitled to vote like their counterparts without disabilities. However, looking at the supreme law document, it still lacks on addressing the real and everyday challenges faced by people with disabilities in general. More so for children with cerebral palsy. One because they are children and are vulnerable, and two because they largely depend on their caregivers.

With the formulation and entry into force of the Convention on the Rights of People with Disabilities in 2007, it was hoped that Zimbabwe would ratify the Convention and implement its provisions (Manatsa, 2015). However, it took more than half a decade for Zimbabwe to ratify the CRPD. The ratification signals the birth of a new era as it signifies more recognition for the rights of PWDs in the country. As posited by Mandipa (2014), Zimbabwe also adopted a new Constitution in 2013, which embraces a human rights based approach to the concept of disability. This represents a great leap forward in the right direction, and demonstrates the country's willingness to protect, promote and fulfil the rights of PWDs. The need is only in recognising that with some disabilities like cerebral palsy, it is not possible to empower or capacitate the child with the disability excluding the caregiver.

2.3.2. The Disabled Persons Act (Chapter 17: 01) / DPA

The DPA is the major law that addresses disability in Zimbabwe. As noted by Mwalimu (2003); (Mugumbate and Nyoni, 2013) the DPA covers two main areas prohibiting discrimination against PWDs namely, access to public premises, services, amenities and employment. The DPA also establishes the office of Director for Disabled Persons Affairs, and constitutes the National Disability Board. In the years of its inception, the DPA was hailed by PWDs and disability organisations as a great landmark in terms of furthering the rights of PWDs (Chimedza, 2000). With the passage of time, the DPA morphed into a subject of debate in the disability rights discourse, with concerns being raised that the Act was becoming a liability and should be consigned to the trash bin and be replaced with an entirely new Act that addresses disability in the modern context (Chimedza & Peters, 1999).

The Disabled Persons Act can be criticised for its failure to provide for the participation of PWDs in disability issues. In other words, the DPA ignores the clarion call of the disability movement that: "nothing without us about us, concerning us". Moreover, the Act has no formal policies, strategies and agreed standards to monitor its implementation (Manatsa, 2015). With the DPA in place, service providers are still providing services in a fragmented manner. All this speaks volumes about how the DPA has been overtaken by events. Basing on the above, it may be argued that there is a strong case for replacing the DPA with an entirely new Act that addresses disability issues in the modern context and at par with the provisions of the CRPD.

From the foregoing, one can conclude that the DPA is incompatible with the provisions of the CRPD.

2.3.3. The Mental Health Act (Chapter 15:12)

This Act governs the care, detention and aftercare of the mentally impaired in Zimbabwe. According to Manatsa (2015), the Act also provides for the establishment of the Mental Hospital Board, which is tasked with the treatment, rehabilitation and general welfare of mental patients. It also provides for the establishment of the Special Board, which makes reports in relation to mental patients detained in various institutions, and the Mental Health Review Tribunal, which primarily hears applications and appeals made by or on behalf of mental patients detained in institutions (Manatsa, 2015).

The care, detention and aftercare of persons who are mentally disordered or intellectually handicapped as advocated for by the Mental Health Act is appreciated in so far as it assists in the realisation of the right to the highest attainable standard of health without discrimination on the basis of disability (Manatsa, 2015). Accordingly, this is in line with the best standards recognised at international level under the CRPD. The Mental Health Act can also be commended for its provision for the care and rehabilitation and aftercare of persons with mental disorders. This is in harmony with Article 25 of the CRPD, which also stresses the need for State Parties to take all appropriate measures to ensure access for PWDs to healthcare services, including health-related rehabilitation.

However, it should be pointed out that there is a fundamental weakness exhibited by the Act. This is so because it uses pejorative language when referring to persons with mental impairments. It is recommended that when calling a PWD, a person must be put first before the disability. Mandipa (2003); (Mugumbate and Nyoni, 2013) notes that terms such as mentally disordered and intellectually handicapped should be discarded in favour of terms like 'persons with a mental disability'. Furthermore, it should be remembered that such terms like 'demean' and 'degrade' stigmatise PWDs and can be regarded as disempowering, which is the reason why they should be removed from the Mental Health Act. Looking at the policies and Acts of Parliament discussed above, it is important to note that their focus and scope is limited. Firstly, there is no acknowledgement of the contribution of family members

and caregivers of people with disabilities. Secondly, when there are amendments, policy makers consult people with disabilities. But it is a fact that for some disabilities like cerebral palsy only, the caregivers of such people can contribute meaningfully to those debates.

2.4. CULTURAL AND TRADITIONAL BELIEFS REGARDING PEOPLE WITH DISABILITIES

Haihambo and Lightfoot (2010) argue that understanding the cultural and traditional beliefs surrounding disability is a key to influence meaningful disability programming because these beliefs control attitudes and cooperation of the public towards disability issues. They go on to argue that cultural and traditional belief systems may have both negative and positive impact on disability and the strengthening of the positive side, whilst challenging the negative side will have a long way in disability issues.

Indigenous knowledge systems and beliefs on the causes of disability are key in determining the attitudes of people (Miles, 2006). In Namibia, most people think that disability is caused by supernatural forces or inappropriate sexual relations within the family (Haihambo & Lightfoot, 2010). Various scholars like Haihambo and Lightfoot (2010) and Mupedziswa (2005) observed that most people in Africa believe that disabilities are caused by witchcraft, punishment from God, avenging spirits or promiscuity on the part of one parent. It is important to note that these traditional beliefs play a role in how communities support caregivers of children with disabilities in general. Parents who believe that disability is caused by witchcraft may start to fight with relatives and other family members, accusing them of bewitching their child. Lack of acceptance for the condition of their child might also trigger stress-related emotions, as a result their psychological state and social interaction with others within the community and family may also be affected.

For Christians who comprise the major religious group in Zimbabwe, there are mixed attitudes and perceptions concerning disability. Miles (2006) posits that Jesus said that disability is not a punishment from God, but rather, it is an opportunity for God to demonstrate his power. Miles (2001), however, also notes that the same Bible in Exodus seems to present children with disabilities as suffering because of the wrong deeds of their parents. This alone creates divided support for children with

disabilities and their families. Miles (2007) argues that Christianity, Judaism and Islam do not seem to offer enough support for people with disabilities in as far as their day to day life and their real needs. Disability is considered as punishment from God, and in some cases, the bible discriminates against people with disabilities (Leviticus 21 verses 16 to 23). According to the above mentioned verses, disability is a curse, and like the verses say, people avoid association and interaction with people living with disabilities and their families.

In a study conducted by Nimbalkar, Raithatha, Shah and Panchal (2014) in India, parents of disabled children reported that relatives made many derogatory comments about the child, which the parents found to be very disturbing to them and the child. At times, they felt that very few people supported them and that society was against them as a whole. They narrated experiences in which they experienced ignorance from society due to attitudes and beliefs that society holds on their situations. One parent in the study explained that some time back when children of a similar age in the same area began speaking, there was more attention towards him as compared to their child (Nimbalkar et al., 2014).

At times, a direct comment could be made that their child seems to be mentally retarded. On accompanying a child for physiotherapy, a few parents reported being asked some very disturbing questions by society members, and even their in-laws failed to understand their situation, and continued to have negative thoughts towards them as they believed that the parents did something and they were being punished by God (Nimbalkar et al., 2014). However, one of the parents pointed out that society will continue to behave in this manner, and that it would be pointless to attempt to manage their attitudes, beliefs and thoughts. According to Nimbalkar et al. (2014), instances wherein the parents were appreciated for the good care they took of their child were also reported, but they were very few and were from professionals whom they interact with when they sought medical attention.

2.5 PSYCHOSOCIAL EFFECTS OF CARING FOR A CHILD WITH A DISABILITY

Children with disabilities and their caregivers are mainly vulnerable to stress and stress related illnesses (Freeman, 2006; UNICEF, 2011). Stress levels seem to relate to the severity of the disability. When the disability is more severe, both the

person with a disability and the family are more likely to be more stressed if they are living in the same house (Barratt and Penn, 2009). This observation clearly shows that caring for a child with a disability is a difficult task which drains caregivers emotionally.

Caring for a loved one with a chronic illness or a long term disability at home comes with its own benefits as compared to care in institutions and nursing homes (Barratt and Penn, 2009). However, caring for a child with cerebral palsy at home also comes with its own challenges. Section 2 (l) of the Children`s Act (Zimbabwe) defines children in need of care as those who suffer from a mental or physical disability and require treatment, training or facilities that their parents or guardians are unable to provide. Among these children are those with cerebral palsy. Usually, there is lack of proper knowledge and information concerning caring for children with cerebral palsy on the part of caregivers (Barratt and Penn, 2009), who lack the basic knowledge and understanding of conditions of children with disabilities in general, more so those with cerebral palsy. Without understanding the conditions, parents and caregivers are more likely to face challenges mastering routines of children and what may be meant by certain changes.

One other serious observation from different researchers is that cerebral palsy is more prevalent in low income families, where the level of education is relatively low, and exposure to current human rights discourses is highly limited. This exposes children with cerebral palsy who suffer. Their rights are abused as they are taken as different children with needs and possibly, rights different from other children. There are several laws and pieces of legislation which have proved to be considered laws of the rich by poor communities, and in cases where children with disabilities face challenges, it is very difficult for them to be treated fairly and with consideration as they are already treated like a burden.

Cerebral palsy affects activity and body movement of children (Berker & Yalcin, 2010). In most cases, children with cerebral palsy cannot do Activities of Daily Living (ADLs), which now require that the caregiver is always around for their needs. Children with cerebral palsy may constantly need assistance in eating, bathing, toilet training and putting them to sleep. Whilst these duties may seem normally less complex, they take a whole new different shape when the child has a developmental

disability like cerebral palsy. This lifetime commitment of caring for a child with cerebral palsy changes the life of the caregiver and of the family as a whole. If the caregiver has other children living in the same home, they may begin to feel like their needs are being taken for granted, and the other spouse who is not the main caregiver may also start spending less time with his/her spouse, who is spending much time with the child (Button et al., 2001; Almelda & Sampaio, 2007).

The change in family or spouse time change has multiple effects; the family begins to feel less of a family and, as a result, this support keeps people going even through hardships disappear (Davey & Paolucci, 1980). Families shape an individual to become who they are, their belief systems, how happy they are and how they interact with other people (Davey & Paolucci, 1980). The fact that caregivers of children with cerebral palsy are mostly occupied with caring for these children have no time to guide and spend time with other children and their spouses means that their families may experience divisions, little bonding and a sense of togetherness. This naturally worries a mother. The stress of caring for the child with cerebral palsy and the stress of keeping the family well and together affect caregivers` wellbeing. Kropf and Timothy (1995) argue that continued caregiving to children with developmental disabilities affect the caregiver`s own health and wellbeing as it is a highly demanding and frustrating task. Caregivers are constantly reminded of their children`s conditions during milestones time like at the age when children are expected to talk, sit, and eat on their own, and especially when their counterparts or younger ones are able to perform these activities.

Willacy (2012) argues that caring for a child with a learning disability is a family experience which affects many facets of the family. Caring for a child with cerebral palsy requires resources. Disability can be understood in terms of the physical or intellectual deformity by scholars, but the family of a child with a disability may understand it from a financial, economic and medical perspective (Yeo, 2011). This observation simply shows that disability is very demanding financially. For children with cerebral palsy, it is even more demanding because they grow up to be adults with the condition and they may not develop self-care functions.

Yeo (2011) argues that the link between disability and poverty have been discussed for decades. It creates a vicious cycle of poverty as it limits the participation of

caregivers in meaningful economic activities. On top of this, it drains every little resource for the wellbeing of the child with a disability. Yeo (2011) goes on to argue that there is an interrelationship between poverty and disability. Poverty is a major contribution to disability as it limits healthy diet or delivery in safe hospitals. On the other hand, disability itself contributes towards poverty as the family of the person with a disability now channels resources towards the disability. Critical to note also is the fact that the family becomes limited in participating or engaging in meaningful economic activities because of the disability.

Caregivers and family members may get the support and assistance from hospitals and home care services (Moster, Wilcox, Vollset, Markestad and Lie, 2010). The responsibility of caring for a child with cerebral palsy is very demanding. Considering the fact that support from the formal support systems like hospitals is periodic and focuses on specific issues caregivers need other support mechanisms. Disability is considered as punishment from God, and in some cases, the bible discriminates against people with disabilities (Leviticus 21 verses 16 to 23). As a result, families and friends of children with disabilities rarely want to be associated with the immediate family of children with disabilities. Churches and other religious groups rarely provide meaningful support to families of children with cerebral palsy as there are verses which seem to discriminate against children with disabilities, and they the churches do not understand the causes of disabilities. As a result, caregivers suffer from discrimination as well as lack of support from close friends and relatives.

Religious institutions are also another support systems for parents of children with cerebral palsy. Caregivers get support like counselling and prayer sessions from church members. This is a really helpful strategy for caregivers as it plays a significant psychological role in accepting and managing their child`s condition. It is important to note that for many caregivers, it is also another source of frustration as much as it intrigues emotional unpleasantness. The spirituality of people with disabilities in general has been largely ignored by spiritual groups (Avery-Wall, 2006). This is especially the case with children because in churches and other religious gatherings, people usually associate themselves with those who are almost of the same age with them. For immature children, it is easy to discriminate against children with disabilities without even feeling guilty. Therefore, in as much as the church is a support system for the caregiver, realising that their child is not enrolled

into the Sunday school, for example, the bible study group is a harsh reminder to the caregiver of the child's condition.

Caregivers usually experience strain on their physical health, psychological as well as social wellbeing (Rosenbau, Brehaut, Walter, Russell, Swinton, Zhu & Wood, 2005; Moster et al., 2010). They go on to say that caring for a child with a disability requires more dedication, commitment and efforts, as compared to caring for a child without developmental or physical delays. This is especially the case with children with cerebral palsy because they, in most cases, grow to be adults who are dependent on others; they do not have independent self-care abilities. Providing care to a child with a disability has shown that caregivers are exposed to strains which cause stress, depression and anxiety, which are again of long periods as compared to the rest of the population (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis & Donelan, 2002; Brehaut, Kohen, Garner, Miller, Lach and Klassen, 2009; Davis, Waters, Cook & Davern, 2009; Cheshire, Barlow & Powell, 2010; Sawyer, Bittman, Angela, Nina & Raghavendra, 2011). This is usually caused by the fact that due to lack of support, caregivers are basically doing everything by themselves. Children without disabilities grow older with their own responsibilities. Some get married and others go out to study or to work away from home. Caregivers are left with children with disabilities, hence they cannot cope with the pressures of caring for a child with disability.

The other stressful aspect to the caregiver is the financial cost of cerebral palsy (Timothy & Kropf, 1995); Moster et al., 2010). Apart from other needs such as clothing, food and accommodation which every child needs, children with cerebral palsy need specialised devices such as wheelchairs, specialised therapy and reviews, which come at a cost. For those who go to school, they also need specialised schools which are expensive. Even those who do not go to school want to be caregivers twenty four hours a day. Whichever way it is, it gives a lot of pressure to the caregiver.

Cerebral palsy can nurture numerous problems for patients, families and health care service providers. It repeatedly includes depression and anxiety (Almeida & Sampaio, 2007). Stress and stress related symptoms are evident in 70% of families of people with chronic disabilities, cerebral palsy not excluded. In addition to

sadness, people with depression regularly experience feelings of hopelessness as well as worthlessness (Neufeld et al., 2001). Depression and anxiety related to disability are often devastating, subjecting individuals to disturbed emotional functioning. Disability related depression and anxiety are often devastating, and can affect individuals' emotional functioning and reasoning abilities (Navaie-Waliser et al., 2002). Caring for a hopeless child is similarly depressing to the caregiver, and once the functional well-being of the caregiver is compromised, the services they give are also compromised.

Children with cerebral palsy have a lot of limitations that can result in requirements for long-term care that far exceed the usual needs of normal children (Odding et al., 2011). The difficulties faced by children with cerebral palsy result in their parents experiencing a higher level of stress, which has an adverse effect on their physical health and social well-being. Changes in healthcare systems and societal attitudes have resulted in most children staying at home in the care of family rather than in an institution. Moreover, in western countries, greater emphasis is laid on family-centred care, wherein the focus of attention is the entire family, rather than just the child, and this has been found to be highly effective. According to King et al. (2004); Moster et al., 2010) the family, together with service providers, are able to make informed decisions about the services and support that the child and family shall receive. In order to develop a family-centred care practice, it is imperative to understand and address psychosocial problems experienced by caregivers of affected children. Several studies of this kind have been undertaken in western countries but very few are reported in India.

2.6. SOCIAL PROBLEMS EXPERIENCED BY PARENTS AND CAREGIVERS

One common problem reported by almost all of the participants was that their participation in social gatherings such as marriages and other ceremonies was reduced (Nimbalkar et al., 2014). They preferred to avoid going out during summers, as they perceived going out of station to be difficult. Interactions with relatives were limited to their own homes, as they could not visit relatives' houses. If the guests came to their home, attention to them was limited, as priority was required to be given to the child's routines such as feeding and going to sleep. Many families

suffered from lack of understanding from society as a whole, which resulted in adversely affected social and family relationships. One of the participants reported that if the child's father was involved in the care of the child, then his peers did not approve of him.

According to Nimbalkar et al. (2014), parents were subjected to constant questioning from friends and peers, with the questions being related to duration of treatment and prognosis of the child. The questions only served to exacerbate the stress and worries of the parents. Many mothers informed that care of the child was overly time-consuming and often clashed with other household duties. Upon inquiring about the effect of the child's condition that had affected their marital life, all parents maintained that it did not affect their marital lives significantly. One of the participants reported complaints from siblings of the affected child regarding excess attention bestowed on the affected child.

2.7. Problems Experienced in Caring for the Child

Nimbalkar et al. (2014) found that in caring of the child, the parents experienced many problems. The child kept them continuously busy. The other problem reported was that they had to carry food and water everywhere they went with the child. One of the participants complained that their child was not able to tolerate heat as he/she cried on exposure to this. Managing the children was made more challenging as there was more difficulty by the child in expressing their needs. The children desired playing and interacting with their peers, but as this was often not possible, parents felt that the children had negative emotions, which often could not be expressed.

It was agreed by most parents that money played an important role in the upbringing of the child (Nimbalkar et al., 2014). These costs ranged from the doctor's consultation, medicines to transport of the child. In some cases, as the child was more disabled, parents had to hire a separate vehicle in order to bring the child to and from the hospital. Many of them had to travel almost daily for physiotherapy treatment of the child. For those who ran their own businesses, the impact was seen. One of the parents was a school teacher and had to leave early from work in order to take care of the child. Parents pointed out that in order to match financial requirements for the care of the child, compromises had to be made elsewhere.

2.8. Psychological Problems Experienced by the Parents.

Nimbalkar et al. (2014) found that parents experienced a wide variety of negative emotions that ranged from mild anger to tiredness and frustration. One of them said that at times she got very angry to the extent that she beat up her child. Another parent went to the extent of saying that at times she feels that it would have been better if she had died so that the problems would end.

Most parents were worried about the child's future (Nimbalkar et al., 2014). They were concerned about who would take care of the child in their absence. Looking at the child developing and learning things, they experienced a sense of relief as it created a hope in their minds that the child would be able to learn something like how to use a computer and how to earn a livelihood. In order to overcome their worries about the child's future, they left it to destiny and were resigned to the fact that whatever is going to happen is bound to occur, and nothing is in their control.

2.9. Response of Caregivers (Caregiver Coping Mechanisms).

According to Nimbalkar et al. (2014), in order to respond to the repeated queries of neighbours and society, a family offered the explanation to others that the mother works at the hospital where they take the child for treatment. Parents also attempted to convey that caring for the child is part of life, and they have to do a bit more than others do. One of the participants in the FGD was the grandmother of the affected child since the mother was staying abroad. The presence of additional family members in the home was helpful in caring for the child. One of the participant's nieces had come to stay with them, and she took care of the child in their absence.

To overcome the negative feelings and thoughts about their child, parents sought explanations which invoked God (Nimbalkar et al., 2014). One said that she felt that it would have been better if God had bestowed them a child with polio or a physically challenged child rather than such a difficult child. Another felt that God was testing them as a result of sins committed in the past. One felt that God had this destiny in store for them. One mother was confident that putting in more efforts towards the care of the child would give improved results. In this way, she could ensure that her daughter would never complain. The child's hazy future worried all of them, especially the fact about responsibility for care of the child when they would not be around. All participants indicated that they felt very happy when they noticed

improvement in their child such as rolling on his own, trying to walk, or attempting to vocalise a few words.

At the same time, they would get upset about their child when they saw other children rolling on the bed or floor or playing (Nimbalkar et al., 2014). Mothers felt helpless when their children did not improve. A mother who had been looking after her child for the last 13 years commented that normal childcare by itself is difficult, and caring for an affected child is even more difficult. Some of them were resigned to the fact that they will continue to do whatever was possible until they were alive, and that there was no point in having negative thoughts in their minds.

2.10. Support Services

The participants reported lack of training facilities for their children (Nimbalkar et al., 2014). They were ready to support any institution that had educational and vocational training facilities for their children. The existing and available schools for training of children with cerebral palsy did not admit children until they were toilet trained. The majority of participants raised objections about the lack of special schools that would take care of their children in an appropriate manner. This was the main reason for their children not to attend school. The participants also inquired about whether the hospital was going to start a special crèche, where a nurse would be available to help and teach their child, and about whether there was any other way that the hospital could help them. They wanted society to understand that by helping the affected child, the entire family would be helped.

2.11. Social work and cerebral palsy

Social workers work with individuals with disabilities, including those with cerebral palsy, and with families who have a child or family member with a disability (Matsukura, Marturano & Oishi, 2007). Their work and responsibilities in these spheres encompass direct practice, group work, community development, policy practice, research and advocacy (Zastrow, 2000). Social workers advocate for a family-centred therapy that appreciates both the importance of the caregiver in rehabilitating the child, and the caregiver's own wellbeing (Dubois & Milley, 2005). On a practical level, social workers are regularly placed to advocate for, and to execute, family-centred studies and interventions that recognise the central role that

families play in the life of children with cerebral palsy (Zastrow, 2000). By placing a child with cerebral palsy in the context of the family, social workers understand that challenges and personal growth opportunities become a truly shared family experience. Mupedziswa (2005) argues that problems cannot be fully solved when approached in isolation without taking into account all relevant factors. In this case, the quality of life of a child with cerebral palsy as well as that of surrounding family members is a priority.

The wellbeing of caregivers to social workers comes with many faces. Wellbeing ranges from material things such as income and consumption to health, political voice as well as social connections (Creswell, 2009). Many policies have ignored the role of caregivers in disability, which increases the challenges of caregiving, especially to children with cerebral palsy. As a result, social workers advocate for inclusion of caregivers of children with cerebral palsy into mainstream community activities and disability policies as they are key constituents regarding the rights of people with disabilities (Zastrow, 2000).

Social workers play a critical role in developing laws and policies that are anti-discriminatory in supporting people with disabilities, and creating disability programmes (Zastrow, 2009; Mupedziswa, 2005). They work with people with disabilities and their families in pursuit of social inclusion, employment opportunities as well as rehabilitation (Dubois & Milley, 2005). However, due to factors such as lack of financial support and policy prioritising disability issues, many disability programmes are secondary to other programmes, of which little attention is given to the caregiver. This makes researching on the resultant psycho-social challenges facing caregivers a necessary topic of study in the profession of social work.

In the past, people with disabilities were institutionalised (Weiner, 2003). The situation is different now because of disability rights movement (Zames & Fleischer, 2001); Mugumbate and Nyoni, 2013). Before the disability rights movement, people with disabilities lived away from their families, and usually treated as objects to be fixed. The medical model to disability regarded this group of people as sick people who can only be healed through the use of medicine (Zames & Fleischer, 2001). However, even inclusion has been fought, for most families with children with cerebral palsy are poor families, therefore, providing financial needs to children both

with and without cerebral palsy has proved difficult for many. Braithwaite, Carroll, Mont and Hefley (2008) argue that many people with disabilities in the developing world live on less than US\$1 per day. Therefore, social workers need to study the kind of challenges faced by caregivers, refer them to institutions and professionals who can make the caregiving process an easy one, as well as increase their wellbeing. The wellbeing of a caregiver results in improvement in the quality of the caregiving role that they play, and hence cannot be ignored.

Traditionally, social work has played a key and fundamental role in disability issues generally. Over the years it has adapted and readapted to new developments, legislations and discourses to provide a more holistic and meaningful intervention though with some challenges. In the past the profession focused on gathering information and sharing with clients together with counselling, making referrals or linking with resources and advocacy roles (Kailes, 1988); (Zastrow, 2009). However, these traditional roles have come to be mistrusted by clients who want a more considerate and holistic approach, which also empowers people with disabilities (Kailes, 1988); (Zastrow, 2009). This observation shows that the profession needs to shift from the traditional social work approach which does not necessarily empower people with disabilities. Children with cerebral palsy need to be considered through their caregivers and families, especially with the consideration that their movement and activities are limited by their condition.

Disability scholars and academics have long argued that many rehabilitation and medical workers view disabled clients as passive clients and operate on a doctor-patient level of operation (Kailes, 1988; Mupedziswa, 2005; Zastrow, 2009). Sadly, most social workers who work with children with disabilities operate in hospitals or medical settings, where children are again treated as passive beneficiaries of the services provided. The challenge with this approach is that the main goal is to try to reach maximum normality possible in terms of physical capacity of children with disabilities. This leaves out their psychosocial normality, which largely depend on the family and caregivers.

The disability Rights Movement takes a whole new different form to the traditional one. It emphasises client self-determination and the incorporation of other factors in the plan, other than just the physical capacity of the client (Simcock & Castle, 2016).

They go on to argue that social workers have a more important role to play in impacting real positive change in the lives of children with disabilities. Mupedziswa (2005) argues that social work interventions should target the real sources of problems or challenges, and they have to be holistic if these interventions are to impact any real change. As highlighted above, cerebral palsy is a permanent condition. Therefore, targeting only cerebral palsy will not bring about a lasting solution. Social workers can also target caregivers with capacity building programmes, making them understand the condition.

Unless social workers shift focus from the child to both the child and the caregiver, the latter will not develop best parental skills as they themselves are a vulnerable group that experience emotional and social strain as a result of their caregiving role to children with cerebral palsy.

2.12. Social support for families of children with cerebral palsy.

Disability within the family can impact different reactions, depending on the characteristics of that family (Turnbull & Turnbull, 2001; Zastrow, 2009). An example of such a reaction is stress. Opportunely, a regular and reliable social support system has been proven to assist in mediating stress (Beckman, Newcomb, Filer, Brown & Frank, 1991; Dunst, 2000; Beckman, 2002). The above researchers found that social support is one effective way of reducing stress both on the child and the family or caregiver.

Family coping studies have shown that relationship with others is a distinct factor in stress management (McCubbin, 1979). McCubbin highlights the fact that the strength of these relationships reduces vulnerability, and positively impacts on family recovering power (McCubbin, 1979). This idea has been proven in different situations such as poverty, psychiatric and physical illness, passing away of a close relative and job termination, among many others. A personal social network such as family members and relatives, friends, self-run parent support groups and support from professionals has been acknowledged as the “primary coping resource” for families (Turnbull & Turnbull, 2001). The above studies emphasise the role of social support systems in mediating stress.

Dunst (2000) has reported on the relationship between social support systems and personal, family and child consequences. The study consisted of 137 parents of Early Childhood Development (ECD) children with mental retardation, physical complexities or at risk of a disability enrolled in an early intervention programme. The results indicate that without social support, stress levels increase in the whole family while there are evident behavioural problems for the children with developmental delays. One of the essential reasons for assessing the effects of social support on family and caregiver well-being is that it has been proven to positively impacts on parenting practices, which in turn facilitates child development (Dunst et al., 1986). Giving parents and caregivers support can help in defining and outlining parental styles, and can improve instructional practices and chances that have enhancing effects on development (Dunst, 2000).

Caregivers' social support networks then become a feasible tool that may simplify caregivers' adjustment process from the time of diagnosis of their children throughout the period that they will be providing care to the child, which is likely to be longer (Ones, Yilmaz, Cetinkaya & Caglar, 2005). Button, Pianta and Marvin (2001) argue that such support usually comes from immediate family members, husband/wife, children and siblings. Even though primary caregivers are usually mothers of children with cerebral palsy, fathers are very important in supporting mothers in the day to day caring of the child (Button et al., 2001).

Disability has been regarded as punishment from God. According to Raina, O'Donnell, Rosenbaum, Brehaut, Walters, Russell and Wood (2005), disabilities, impairments and epilepsy are often interpreted religiously. Most communities regard impairment as punishment, usually resulting from one's or a family's sins. Having a relative with a disability is, therefore, usually regarded as disgraceful and a source of shame for the whole family, sometimes leading to divorce as one partner blames the other (Chitereka, 2010). This means that having a child with a disability may aggravate misunderstandings and quarrels between spouses as one will be thinking that it is the other's dark past which has caused the disability to the child. This, in turn, may increase stress levels, especially to the mother who, in most cases, is the primary caregiver and thus, usually falls victim for such blames. This means that the support systems that a caregiver should have in caring for the child will be affected, hence the accompanying unbalanced loads and stress.

2.13. CONCLUSION

This chapter focused on illustrating the possibility and opportunity of introducing holistic social work intervention for disability programmes. As indicated by the researcher, current programmes focus mainly on the children themselves. But considering cerebral palsy and the fact that children rely on caregivers for daily living, these caregivers are most important in reaching the needs of children. Different researches and publications highlighted challenges faced by caregivers, implications to children, current efforts and legislations surrounding disability and the opportunities for better programming going forward.

CHAPTER 3

PRESENTATION, ANALYSIS AND INTERPRETATION OF FINDINGS

3.1. INTRODUCTION

In this chapter qualitative data which was gathered through interviews and FDGs will be presented, interpreted and discussed. Interviews and FDGs were done with the caregivers of children with cerebral palsy from Dzivarasekwa suburb in Harare. Child Protection social workers from JF Kapnek Trust (a local organisation) were also interviewed as they interact with both the caregivers and the children. A counsellor /psychologist from Harare hospital who works with both the children and their caregivers was also interviewed for more detailed and holistic information. In this chapter again, there is a brief outline of characteristics of caregivers and their economic and household statuses. Subthemes are discussed in relation to the objectives of this study, but there are other themes which came as a result of data, which came out from the interviews and FDGs.

3.1.1 Summary of themes.

The research findings were grouped into themes which had different sub themes. Below is a table of the themes and subthemes.

Table1. Themes, sub-themes, and categories derived from the findings (Caregivers of children with CP)

Themes	Subthemes
Theme 1.Caregiver capacity	Subtheme 1.1.Minimum Level of Education
	Subtheme 1.2 Emotional and physical state of caregivers
	Subtheme 1.3. Religious and cultural affiliations of caregivers guiding and informing caregivers
Theme 2.The psychosocial challenges	Subtheme 2.1. Discrimination
	Subtheme 2.2. Social exclusion
	Subtheme 2.3. Unhealthy relationships with family members
	Subtheme 2.4. Anger
	Subtheme 2.5. Harmful cultural practices

	Subtheme 2.6. Communication challenges
Theme 3. Financial difficulties	Subtheme 3.1 Failure to provide for the needs of a child with CP
	Subtheme 3.2. Failure to provide for self and family.
Theme 4. Support systems	Subtheme 4.1. Non formal support systems
	Subtheme 4.2. Formal support systems
Theme 5. Coping strategies	Subtheme 5.1. Avoiding intimidating environments
	Subtheme 5.2. Seeking faith healing
	Subtheme 5.3. Prostitution and drug selling
	Subtheme 5.4. Using children to beg

3.2 DEMOGRAPHIC CHARACTERISTIC OF CAREGIVERS

The sample consisted of thirteen participants in total. Of these participants, ten were caregivers of children with cerebral palsy, and three were key informants. Out of the ten caregivers, three were grandmothers of children with cerebral palsy and seven were biological mothers of the children. There were two social workers from J.F Kapnek Trust, a local organisation working with children with cerebral palsy, and one psychologist from Harare Hospital Children Rehabilitation Unit, who served as key informants.

3.3. EDUCATION, EMPLOYMENT AND RELIGIOUS BELIEFS

This section looks at the characteristics of caregivers of children with cerebral palsy. Their level of education, employment status, religious beliefs, marital status and the number of children under their care. These were sought because they are believed to have a bearing on the caregiving process, challenges faced by caregivers and as a result, the coping mechanism employed.

3.3.1. Education

All the ten caregivers reached Ordinary level of education, and only two progressed to Advanced level education. None of them attended tertiary education. Of the eight that left school at Ordinary level, three indicated that they did not even go as far as seating for their final exams due to early marriages and financial constraints. All these were seen to have an impact on how caregivers were resilient and adaptive to the caregiving role that they provide to children with cerebral palsy.

3.3.2. Religious beliefs of caregivers

Seven caregivers were members of apostolic sects, while the other three either went to main line or Pentecostal churches like Salvation Army and Methodist Church in Zimbabwe. The religious beliefs of caregivers were more skewed towards the apostolic sects. Both the psychologist and social workers who participated as key informants were in agreement that religious affiliations of caregivers and of those communities where they stay have a great impact on the challenges that they face as well as the coping strategies that they employ.

3.3.3. Caregiver Marital Status

Four out of ten participants were married whereas two were divorced, and only one participant was never married. Notable is that all grandmother respondents were widowed. The marital status of caregivers was seen to have a great impact on the lifestyle of these caregivers, and subsequently, on the caregiving role.

3.3.4. Children under the care of caregivers (With and without cerebral palsy)

All the participants were taking care of more than one child at the time of interviews. In total, all the caregivers took care of fifty children and, on average, it was five children per caregiver. The caregiver who had the highest number of children under her care had nine children, whereas the one who had the lowest number had two children. The number of children under a caregiver proved to have an impact on the average coping capacity of the caregiver.

3.4. EMOTIONAL AND PHYSICAL STATE OF CAREGIVERS

3.4.1. Health problems of caregivers

Four out of ten caregivers reported to have health and physical chronic conditions that also had an impact on the caregiving role. These chronic conditions included AIDS, asthma and persistent headaches. This is in line with observations by Rosenbau et al. (2005) and Moster et al. (2010) that caring for a child with cerebral palsy put a strain on the psychical and psychological health of caregivers. One respondent highlighted the fact that she had minor physical health concerns which interfered with her caregiving role, and five (5) respondents reported being free from

diseases or infirmities. However, all the respondents reported that they at times suffer from stress and physical conditions that are a result of giving too much attention to children with cerebral palsy. A mother caregiver said:

“Maproblems emadzimai anevana vanehurema ndeechokwadi, pandiri pano ndineAIDS, and vanhu vanoziwa nezvehutachiona hwangu vanondiblamer nekuti havazivi kuoma kwakaita kuchenegeta mwana anehurema”.

(Problems faced by caregivers of children with disabilities are real. As I am I have AIDS and people who know about my status may blame me but they haven't experienced the hardness and difficulties of taking care of a child with a disability).

Another caregiver, this time a grandmother said:

“Hakuna zuva rinodoka ndisina kunzwamusoro, kana uchingova musoro wega zvirinani mamwe mazuva nezino rinondirwadza zvekuti ndinokonewa kugadzirira mwana”.

(No single day passes without me suffering from a headache, if it is only a headache it is better, sometimes it is a headache and a toothache and I usually fail to prepare for the child when I am suffering from pain from both my head and tooth).

The social worker also highlighted that caregivers resemble symptoms of sickness. He said:

“...most of the caregivers you do not need a doctor's diagnosis to see that they are experiencing health problems...i remember one caregiver who would vomit occasionally and sadly the caregiver passed on”.

3.4.2. Social Exclusion and Emotional susceptibility.

The participants highlighted the fact that despite their original and natural emotional states, the caregiving role itself is an emotional journey which leaves them more emotionally exposed. This is so because on a daily basis, they are reminded of the conditions of their children either through duties such as toiletry or through comments from community members or strangers. This is in line with Chitereka's

(2010) observation that disability is usually interpreted religiously and spiritually, of which families feel ashamed to be associated with the disability.

This affects how caregivers relate to the community and family members as well as their personal health and wellbeing. This directly concurs with a study by McDonald et al. (1997), who found that the caregiving role affects both the social relations of the caregivers with others as well as their own wellbeing.

All participants from both FDGs agreed that once in a while, they received derogatory comments from strangers, and this affects their emotional state for days. A young mother caregiver said:

“Ndakamboti ndichibva kutown ndakabereka mwana wangu, ndakabata grocery zvikanzi nevamwe baba chakosha chii grocery kana mwana hamuoni here kuti mwana haana kurara zvakana apa munobereka chembere chaiyo”.

(I once had an incident when I was coming from town with my child on my back carrying groceries with my hands when an elderly man approached and said so what is important the child or the grocery, she is not sleeping well and you carry an old woman on your back).

This was corroborated by another mother caregiver, who said:

“Mvura yedu tinoichera pachibhorani everyday nekuti meter yakavharwa vekanzuru. Kana nguva yekunochera mvura yasvika ndinonzwa kuremerwa mupfungwa nekuti munhu wese pachibhorani anenge achingonditarisa zvekushora nekusada kuvapadhuze neni. Izvi zvinondibata zvakanyanyisa zvekuti kazhinji ndichiti pandinodzokera kumba ndinombochema”.

(We fetch our water from the borehole since the local authority have closed our meters. When it's time to fetch water, I am stressed because everyone at the borehole will be looking at me in an insulting manner, and no one wants to be closer to me. This is really painful and most of the times I cry once I get home).

The same sentiments were also echoed by another grandmother caregiver, who said:

“ndakamboshanya kwanga kwakaroorwa mumvana wangu mazuva akabarwa mwana. Vatezvara vacho vakanditi mbuya vechirema vasvika isu munzinza medu hatina akambozvara chirema”.

(I once visited the family which my daughter was married into. Her father in law said the grandmother of the disabled child is here now, in our family we don't have a history of disability).

Family members and the community at large do not understand disability, instead they rush to insult caregivers. Haihambo and Lightfoot (2010) argue that many African societies attribute disability to spiritual causes. This observation was also made by Chitereka (2010). Miles (2006) argues that indigenous knowledge systems on disability are vital in determining people's attitudes towards people with disabilities. These views and observations by scholars were supported by the caregivers, who argue that disability is not understood by many members of the community. In some incidences, people throw insult without even noticing that the needs of the particular child will be completely different from those of other children without disabilities. In other incidences, family members completely show that they blame the maternal side of the child. Incidents like these to caregivers are difficult to handle as they trigger emotional breakdown, and at times such comments seem like contempt which always spoils their mood for days. Almost half of the participants labelled such comments as turn-offs of which they claim they are almost common.

3.4.3. Psychological state and cognitive effects

In the study, almost all respondents reported having been affected mentally by the disability of the child in their care. In other words, the disability had an effect on their mental health. This is similar to the observation made by Rosenbau et al. (2005) and Moster et al. (2010), that caring for a child with a cerebral palsy put a strain on one's psychological health. Freeman (2006) argues that caregivers of children with disabilities are exposed to stressful conditions which affect their psychological wellbeing. This observation is similar to what caregivers were highlighting. One caregiver said:

“Kazhinji ndinogona kukaruka ndavakuita hashu dzekuti pandinopengenuka ndinozvibvunza kuti njere dzangu dzichakanaka here”.

(I usually suddenly get angry to the extent that when I calm down I doubt my own sanity).

Another caregiver was also in support and agreement of the fact that caring for a child with cerebral palsy may affect the psychological well-being of caregivers. She said:

“Rangu dambudziko rava rehanganwa. Ndichikura ndaisava nehanganwa uye njere dzangu dzanga dzakanaka”.

(My problem is being forgetful. When I was growing up, I wasn't forgetful and my mind was sound).

The effects of the caregiving role to mental stability was also echoed by a social worker who said:

“...Unoona kuti maCaregivers ese atinoshanda nawo they show maSigns ekukanganiswa psychologically and this is a result of a lot of factors which come with the disability. Some of the issues have to do with the amount of financial problems and even social problems. These create stressful situations for these caregivers and affects their mental health....”.

(...You will see that almost all the caregivers that we work with show signs of being affected psychologically, and this is a result of a lot of factors which come with the disability. Some of the issues have to do with the amount of stress that that is created by the financial and social problems they encounter and this affects their mental well-being).

The researcher even noted that one thing that mostly drained these caregivers is balancing responsibilities of caring for a child with cerebral palsy as well as other responsibilities in the overall household. This evidently has an impact on their health and general wellbeing.

3.5. CAPACITY FOR CARING FOR A CHILD WITH CEREBRAL PALSY

Caregivers of children with cerebral palsy have a limited capacity to care for their children. This is so because caring for a child with special needs requires much knowledge and resources as compared to children without special needs.

3.5.1. Financial capacity

In terms of economic status and financial means for caring for a child with cerebral palsy, caregivers are not employed, and because of their caregiving roles, they cannot engage in any meaningful or gainful economic activity. This is similar to an observation by Braithwaite et al. (2008), who noted that most families of children with disabilities are living on less than a dollar a day. Caring for a child with cerebral palsy, according to the caregivers, is not only about the physical attention that children require, but also about financial support that they require. This is exactly the same as observed by Yeo, (2011) and Timothy and Kropf (1995). To many, disability is a physical condition, but to the immediate family and caregivers, it is also viewed financially as it is costly. A grandmother caregiver said:

“Mumba munoda kudyiwa, mwana anoda kuCRU every month, ini ndakafirwa nemurume. Zvimwe zvacho zvinoita sekuti handina hanya nemuzukuru asi ndinenge ndisina pekutangira, apa ndinevamwe vazukuru haasiye ega”.

(We want food in the home. This child needs to go to CRU every month, I am a widow myself. Sometimes it seems like I do not care about my grandchild but I do not have anywhere to start from and I also take care of other grandchildren too).

Children with cerebral palsy go to rehabilitation programmes and this require transport, lunches and prescriptions. Considering that their caregivers are not employed, this financial need is hard to bear. The majority of unemployed Zimbabwean nationwide engage in some activities like buying and selling, but caregivers argue that they cannot engage in these activities mainly for two major reasons. One being that their children require a lot of time with them, and the second reason is that when they try buy things and sell them, people will prefer going to buy in far way places than at a home from a person with a disability, which again is

indication of discrimination. This is a sign of discrimination against families of children with cerebral palsy.

3.5.2. Understanding cerebral palsy and relevant legislation

Cerebral palsy is a condition which needs deep understanding for parents and caregivers to be able to provide the best caregiving role to the child. It was evident that caregivers of children with cerebral palsy do not fully understand the condition. This observation was also made by Barratt and Penn (2009), who argued that caregivers of patients of chronic illnesses/disabilities usually lack deep understanding of the condition of their loved ones. A mother caregiver said:

“Patakaona mwana achinonoka kufamba hatina kumbonetseka nazvo nekuti sekuru vake vakazofamba vave nemakore matatu. Patakazoti pengenu kuona kuti hurema uhwu ndopatakazotanga kufamba muzviporofita. Ndingangoti kusvikira parinhasi ndinopinda positori nekuda kwehurema hwemwana wangu”.

(When we noticed that the child was taking long to walk, it did not bother us since her uncle started walking at three years. When we realised that this was actually a disability, that’s when we started seeking faith healing from the apostolic prophets. In fact, until today I go to the Apostolic sector because of my child’s disability).

The psychologist at CRU also highlighted the fact that most caregivers do not understand cerebral palsy at all. She said:

“Macaregivers havanzwisisi kuti cerebral palsy inokenzerwa nei. Kazhinji unotoona kuti mhunhu avanetime achiuya kuCRU anenge anakunzwisisa karinai kekuti cderebral palsy inokonzerwa nei as compared nemunhu achangouya. Vazhinji vanotendera kuti cerebral, palsy akana dzimwe mhando dzese dzehurema ingozi kana kuroiwa, sakani muchiona percentage hombe vachiita zvechipoitori”.

(Caregivers do not understand the causes of cerebral palsy. Most of the time you realise that a caregiver who has been coming to CRU has a better understanding of the causes of cerebral palsy as compared to new clients.

Most believe that cerebral palsy and any other forms of disability are caused either by an avenging spirit or witchcraft. That's why most are into apostolic churches).

However, failure to understand the condition comes with many effects, and compromises the quality of care and protection of the child. When most caregivers were asked about the causes of cerebral palsy, they said that it is caused by witchcraft and supernatural forces. This supports what other researchers like Raina et al. (2005) have observed, that disability in general is often interpreted religiously. The researcher observed that the deeper the belief of the causes of cerebral palsy being witchcraft or foul play, the more the parents seem to be socially disengaged, resulting in failure to accept the condition of the child. In as much as they make efforts to try and help their children to reach their maximum possible potentials, but because of their belief in witchcraft, caregivers end up abusing their children. As highlighted above, caregivers are turning to the apostolic sect, highlighting that they joined the church seeking prophetic powers so that their children will be healed. In as much as this could be helpful to some extent, it shows the limited nature of the solutions from caregivers.

The researcher also observed that caregivers have little knowledge about child protection issues as well as social protection programmes available in Zimbabwe. This is a huge hindrance to proper caregiving role to children. In this study, it was observed that all children of the participants with cerebral palsy are not attending school. This is partly because of the financial constraints and partly because of lack of knowledge, illustrating the importance of education to caregivers. If caregivers know that it is every child's right to attain education, and that there are some social protection programmes like BEAM (Basic Education Assistance Module), which pay fees for children who are unable to access education because of poverty, of which those with a disability are being given preference, maybe some would be in school. When asked about social protection programmes, one caregiver said:

"Maprogramme acho anopiwa here vana vakaremara".

(Are the programmes for children with disabilities?)

When asked about BEAM (Basic Education Assistance Module), the caregiver said:

“Tichikura BEAM taingoziwa ndeyevana avakafirwa nevabereki manje ini ndini mubereki wemwana uyu ndirimupenyu, baba vake kunmyange takasiyana vachirivapenyu futi saka anozopinda muBEAM sei”?

(Growing up we knew BEAM was for orphans. I am the mother of this child and his father is also still alive even though we are divorced. How then will the child benefit from BEAM meant for orphans?)

The caregivers were also asked about the child protection laws and programmes that they know. Apart from showing that they do not know any child protection laws and programmes, they also showed little interest in the programmes. One elderly grandmother said:

“Handina mutemo wandinoziwa wekuchengetedzwa kwevana asi nyangwe iriko mitemo yacho handinei nayo nekuti Muzukuru wangu avanemakore gumi nematatu asi hakuna mutemo wakambouya ukandibikira sadza kumba kwangu”.

(I do not know any child protection laws. Even if the child protection laws exist, I do not care about them because my grandchild is not thirteen years but I have been taking care of him not the laws).

These accounts by the caregivers show that they feel neglected by the government. They expected that the government was supposed to be offering some monetary or material assistance for the care of children with disabilities. But instead they formulate programmes and policies that do not add value to them. This was also echoed by a social worker, who said:

“Looking at the realities of disability in general and the programmes on offer from the government most people with disabilities and or their caregivers feel insulted, neglected and even discriminated against. The reality of disability is more bills to be paid, less time spent working and fewer opportunities. Most caregivers are of the view that government was supposed to be meaningfully assisting with either financial or material help”.

3.6. THE PSYCHOSOCIAL CHALLENGES

People with disabilities in general face a lot of psychosocial challenges from discrimination, stress, exclusion, harmful cultural practices, and communication challenges, among others. Caregivers of children with disabilities, especially those with developmental disabilities like cerebral palsy are at the receiving end of these psychosocial challenges. This is partly because children with disabilities rely on caregivers for their daily living. Willacy (2012) went on to argue that disability is a family experience with challenges being experienced by all family members, especially to primary caregivers who, in most cases, are the mothers and grandmothers of children. This argument by Willacy, (2012) is well supported by findings of this study. Disability is indeed a family experience that affects the whole family psychologically and socially. The following emerged from this research study.

3.6.1. Discrimination

Children with cerebral palsy are discriminated against right from birth. The participants highlighted that discrimination targeted at children themselves also affects caregivers directly as these children rely on them. However, discrimination happens at different levels.

- **Discrimination at family level**

As observed by Willacy (2012), disability is a family experience. This means that the family is the first and primary support system both for the child with cerebral palsy and for the primary caregiver, who is usually the mother or the grandmother of the child. The participants highlighted that some family members (especially extended family members) avoid interaction with the immediate family of children with cerebral palsy. Caregivers indicated that they are not invited to most family gatherings, and in those few events where they are invited, the treatment clearly shows that the family does not want to associate with them. One grandmother narrated how caregivers of children with disabilities are treated at family level. She said:

“Ndakamboshanya kwanga kwakaroorwa mumvana wangu mazuva akabarwa mwana. Vatezvara vacho vakanditi mbuya vechirema vasvika isu munzinza medu hatina akambozvara chirema”.

(I once visited the family which my daughter was married into. Her father in law said the grandmother of the disabled child is here now, in our family we don't have a history of disability).

Another caregiver also narrated how the family discriminated against her and the child, saying:

“Pakazvarwa mwana uyu baba vake vakanga vazvitambira vachitondisimbisa. Nyaya yakazovapo hama dzake padzakatanga kuita mitambo vasingamuudzi vachiti tanga wasiyana nehure rako nechirema charo. Ndiko kwakava kurambana kwangu nemurume wangu baba vemwana iyeyu”.

(When I gave birth to our child, the father accepted it and was my strongest support mechanism. Things started changing when his relatives started hosting functions without informing him, and whenever he asked why they were doing that, they would say get rid of your “lose” wife and her disabled child. This is how I ended up divorcing my husband, the father of this child).

- **Discrimination at community level**

Caregivers highlighted the fact that of all the psychosocial challenges that they are facing, discrimination is the highest challenge. One younger mother caregiver said:

“When you are carrying a child with a disability, even people who know you and the child keep staring at you like they do not know you, like you are carrying faeces...”.

Another caregiver had this to say:

“Ini handifariri kuenda panenge pakaungana vanhu vazhinji. Kazhinji ndikaenda pakaungana Madzima ega ndinobvapo ndichitonzwa kuda kuchema. Kana ndine zvimwe zvandinoda senge huni, mvura, kana kunotenga kuzvitoro ndinowanzoenda nguva dzandisingasangane nevanhu vakawanda”.

(I do not like being at a place with many people. Usually when I get to a place with many women I end up crying. Even if I have something I want like buying

firewood, fetching water or getting something from the shops I usually go when I am sure I won't meet many people).

From the above accounts, it is important to note that caregivers of children with cerebral palsy feel inferior to their communities mainly because of the treatment that they receive from the community. This limits caregivers' participation in social events. This is similar to Nimbalkar et al.'s (2014) observation that caregivers' participation in social events is low mainly because the questions asked by relatives and friends make them feel inferior and uncomfortable. In this case, caregivers argue that they avoid social events and other settings where people gather.

- **Discrimination at institutional level**

Caregivers were in consensus that even medical staff like nurses started treating them differently the moment they realised the 'abnormality' of the child. Caregivers went on to say that when they compare the friendliness before the delivery of the child and after, and comparing how nurses related to them and to other mothers of children with disabilities, they could see the harsh reality of discrimination against people with disabilities. This is similar to the observations made by Yeo (2001) that children with disabilities are discriminated against from birth, and this goes on for a lifetime. There is exclusion from community social activities, and they are treated as outsiders in their own hometowns. One caregiver said:

“Pandakaenda kuzorindira manurses airatidza kundifarira zvakanyanya semunhu wechidiki anga akatsvinda tsvinda. Pandakazvara mwana wangu vakatanga kuratidza kusema sema nekuti wangu mwana akangozvarwa achiratidza kuti anedambudziko musoro wake wakakura kura”.

(When I went to labour, nurses were very friendly to me because I was young and smartly dressed. When I gave birth, they started distancing themselves from me because from birth my child resembled signs of disability. His head was too big).

Apart from discrimination at medical facilities, discrimination also comes from institutions like schools. Caregivers highlighted that children are often denied entry and access to school, with authorities citing that their school do not have facilities suitable for children with cerebral palsy. This is contrary to the government policy of

inclusive education. In explaining how discrimination at institutional levels happens, one mother caregiver said:

“Ndakamboenda kuchikoro kunodzidza vamwe vana vangu ndichiti uyu anehurema aoindewo chikoro. Headmaster wepo akanditi hapana nzvimbo yemwana akaita saye nekuti chikoro hachina kugadzirirwa chakanangana nevana vanehurema”.

(I once visited the school where my other children are learning with the intention of enrolling my child with cerebral palsy at the school. The headmaster said we cannot enrol your child because this school has no facilities for children like these).

Contrary to this, another caregiver highlighted that the school head had agreed to enrol the child, but evidently without comfort. She said:

“Ini pandakaenda kuchikoro head vakanga vatio mwana ngaauye asi hatidi mwana anozotadzisa vana vedu kudzidza. pandakadzokera kumba ndakagara pasi ndikati zvirinani kuti mwana angu agare atorega kuenhda kuchikoro kwacho.”

(When I approached the headmaster, he had agreed to enrol my child into school. However, he then said: “we hope your child won’t disturb our children to learn”. When I got home, I made up my mind and said it is better for my child not to go to school).

The above accounts were also supported by the social worker, who said:

“Vana vazhinji vanemadisability ese zvawo kusanganisira cerebral palsy havasi kuenda kuchikoro. Hongu vamwe vabereki havatodi kuti vana vaende kuchikoro nekuti vanotyira kuti vanogona kunosangana neabuse but kazhinji inyaya yesystem irimuzvikoro macho. Semuenzaniso vana vane cerebral palsy vazhinji vanogara pamawheelchair, handei pachikoro pachoma class akavakwa zvekuti wheel chair haipinde, matoilets anongova mablair toilets, mateacher chaiwo haasi maspecialist teachers. I think the system itself in our schools is discriminating against children with disabilities”.

(Most children with disabilities, including cerebral palsy, are not in school. Sometimes it is the parents who are not comfortable of sending the child to school, assuming that they will get abused. But in most cases, the school system is the biggest contributing factor to this. For example, children with cerebral palsy usually use wheelchairs, but there are no wheel chair ramps to access the classrooms, toilets are just Blaire toilets, the teachers are not specialist teachers. I think the system itself in our schools is discriminating against children with disabilities).

The above accounts from both caregivers and the social worker show that indeed there is discrimination at schools. Discrimination is coming from both the education system as well as education officers. From the system, the schools are not disability-friendly as they lack the necessary infrastructure to accommodate learners with disabilities. They also lack specialist teachers who are able to make the children benefit from coming to school. On the part of education officers at school, usually because of their lack on knowhow of dealing with children with disabilities, they often insult people with disabilities by how they refer to them. If a learner with a disability is enrolled, they do not benefit much because of this again.

3.6.2. Social exclusion

Linked to discrimination is social exclusion. In most societal events, families of children with cerebral palsy are treated as if they do not exist. Caregivers argued that there are programmes meant for people with disabilities, where they actually participate, but when it comes to cerebral palsy, it is a different story. One middle aged mother caregiver said:

“Chinonyanyanyondirwadza ndechekuti masope anopiwa malotions nemagirazi asi isu vana vedu ava havana chavanowana. Kune iya yekumodela futi zvaana Miss Albinism asi hakuna zvakadero kuvana vedu ava”.

(What pains me is that children with albinism are given spectacles and lotions, whilst children with cerebral palsy do not get anything. There is also this modelling competition, Miss Albinism, but for cerebral palsy, there is nothing like that).

Another caregiver agreed that children with cerebral palsy are usually left out in many societal functions. She said:

“Muraini medu munemwana wevamwe mbuya akaenda kuAmerica kwaanoita zvekudzidzisa vana veECD. Pese paanouya anoita party achitamba nevana vadiki achivasiyira matoy nehembe asi ini mwana wangu haasati ambonzi auyewo kunyangwe tirimuraini rimwe. Chinondishamisa ndechekuti vamwe vana vakaremara vanotosheedzwa asi nekuti hurema hwemwana wangu wekuchururuka rute nekungobvunda pamwe anenge achisema kuzotamba naye”.

(In our street there is an old lady with a son who is teaching ECD in America. Every time he comes he hosts small parties with children and he donates toys and clothes to children. What surprises and pains me is that my own child has never been invited to these parties even though we are from the same street. Other children with disabilities are invited but I think due to the condition of my child of having saliva flowing all the time with a shaky body, maybe the host feels he is too smart to interact with such children).

The community in general does not understand the condition, with some fearing contamination. As a result, families are excluded from social and even economic activities.

3.6.3. Unhealthy relationships with family members

Caregivers highlighted a significant change in their relationships with extended families. Davey and Paolucci (1980) attribute this significant change of family relations to the busy schedules that are associated with caring for a child with a disability; caregivers now have less time for social events and gatherings. Yeo (2011) attributes the change to poverty. When there is a person with a disability at home, everything changes because the family begins to earn less and spend more. As a result, social events are counted as luxury. The researcher observed that this is one of the most emotional topic to most participants. The participants said that before members of the extended family realised that the child has a condition, they all loved the child, requesting visits and sending gifts. But the moment the condition

was visible, family members started making excuses to avoid visits and stopped sending gifts for the child. One mother caregiver said:

“Mwana wangu haana kuzvarwa achiratidza kuti anehurema. Pese pandaisangana nezvehukama vaiunganira mwana vangu vachida kumubata. Pakazoti mwana avakuratidza hurema hwake, hapana kana mumwe aida kumubata. Vana vadiki vaimubata vaitosheedzwa nanamai vavo irinzira yekuti vabve chete pamwana wangu”.

(My child did not show signs of disability at birth. Each time I would meet family members they would all come close to hold my child showing affection. When the child was now showing signs of disability, no one wanted to hold my child. Other children would come and hold him trying to play with him but their own mothers would call them, clearly showing their discomfort).

Some caregivers even went on to say that some family and community members directly approached the mothers to express their blame for the child`s condition. If they are not blaming, they are asking insulting questions. This is in line with Nimbalkar et al.’s (2014) observation that family and friends ask a lot of question relating to the treatment, which in most cases are insulting or straining to the caregiver. One mother caregiver said:

“Ndakaenda kumusha ndichinoona vanamai vangu. Muvakidzani wedu akanditaurira direct kuti zivi zviya zvopfuka ka, ndozvazvinoita ukapa mwana kumunhu asiri baba vake. Kazhinji ndinotozosimbiswa nehama dzangu dzekwandakaberekwa, vanamai nehazvanzi dzangu nanasisi”.

(I went to our rural home to see my mother. Our neighbour came face to face and said these are the sins you committed, you cannot give someone a child who is not his child, this will happen. I usually get support from my family (my mother, brothers and sisters).

In as much as there is obvious discrimination in the above account, this is not only a social issue, but also affects caregivers and their immediate families emotionally. This is in line with Mupedziswa (2005) and Chitereka’s (2010) argument that disability is often associated or interpreted traditionally and religiously, of which the family may feel ashamed to associate with the immediate family of a child with a

disability. However, it is important to mention that these researchers left out another important aspect, that the family of the mother is usually very supportive to the caregiver. Caregivers who participated in the FDGs agreed that their families back home accepted that they have a child with cerebral palsy. Except maybe a few, generally they were receiving support from their families. It is therefore the extended family from the father`s side which makes accusatory comments towards the primary caregiver mother.

The participants highlighted the fact that the source of confidence and emotional strength comes from the way siblings of children with cerebral palsy display love and care for other siblings with cerebral palsy. All participants indicated that in as much as the relationship between themselves, extended families and the community in general is bad, siblings of children with cerebral palsy show great affection and this gives them hope and courage. This is contrary to the researcher`s assumption that other siblings may display hatred or no affection to the one with cerebral palsy. A caregiver said:

“Chinotondipa zororo nekudekara inyaya yekuti madzikoma emwana uyu anehurema vanoratidza rudo kwaari. Izvozvo zvinoita kuti ndizive kuti kunyangwe ndikanzi ndafa nhasi anosara anevanhu vanenge vachimubatsirawo kuti aende mberi nehupenyu hwake”.

(What gives me hope and rest is seeing elder brothers of this child with cerebral palsy showing him love. This shows me even if I die today the brothers will still help my child to survive).

Contrary to this mother caregiver, a grandmother caregiver said:

“Ndinochengeta vazukuru vanosvika vapfumbamwe vabatanidzwa. Mumwe chete ndiye anehurema. Pavasere vasina hurema mumwechete ndiye ega anotaridza rudo nemuzukuru wangu asina hurema, pada nekuti vari vaviri ndevamai vamwe. Asi nekuda kwekuti achirimudiki chaizvo chero akavanerudo haana zvizhinji zvaanobetsera nazvo. Nguva zhinji ndikagara ndega ndinenge ndichifunga kuti kurikunzi ndati dhii apa Muzukuru wangu anehurema hupenyu hwake hunosara hwakamira sei. Ndangariro idzodzo dzinodya moyo pamwe nepfungwa dzangu zvakanyanyisa”.

(I take care of nine grandchildren altogether. Only one of my grandchildren has cerebral palsy. Out of the eight without cerebral palsy, only one shows love and affection to the one with cerebral palsy. Maybe this is because they have the same mother with this one, they are blood siblings. Considering that he is so young, even if he is loving and caring, there is little he can do. When I sit alone I am usually wondering how life will be like to my grandchild with cerebral palsy if I was to die. This is very stressing and disturbing).

The above two accounts suggest that love and affection for children with cerebral palsy mainly come from primary caregivers who are usually mothers and grandmothers as well as their blood siblings. This suggests that discrimination and ill treatment begins at the immediate family level since most of these families are characterised by the extended family model, where one or more of the family members is not a blood sibling, aunt or uncle.

However, caregivers argued that when their other children are not home, or are busy with things like homework, they also feel depressed and hopeless about their children with cerebral palsy. Considering that the other children usually spend most of their time at school, it means most of the time of caregivers is spent alone with the child with cerebral palsy. Due to continued stress and emotional negativity that comes with this for a long time, caregivers have noticeable physical outlooks of stressed people. A mother caregiver said:

“Kana ndirindega pamba nemwana wangu anehurema ndinonzwa kuremerwa nehupenyu. Kuvepo kwevamwe vana kunoreva kuti ndinowana nguva yekuitawo zvimwe zvinhu ndakasununguka kuti mwana wangu anevakamutarira”.

(When I am at home with my child with cerebral palsy, I am overwhelmed and stressed. The presence of other children make things easy for me. It means I can do other things knowing that my child with cerebral palsy is being looked after by the other children).

3.6.4. Anger

The participants indicated that they have observed that during the weeks, they spend much time only with the child with cerebral palsy, and they are easily provoked. They

are not patient, and feel like they do not want anyone`s help even though it is evident they could do better with someone assisting. One mother caregivers said:

“Kazhinji ndinombobatwa nehasha dziriserious espeacilly pandinenge ndaita nguva yakati ooo nemwana tiritega kan kwemazuva kana vhiki”

(Most of the time I get very angry especially if I spend some days alone with my child with cerebral palsy).

The same was echoed by another caregiver who said:

“Kazhinji ndinogona kukaruka ndavakuita hasha dzekuti pandinopengenuka ndinozvibvunza kuti njere dzangu dzichakanaka here”.

(I usually get angry suddenly to the extent that when I calm down I doubt my own sanity).

The above accounts suggest that caring for a child with cerebral palsy is a frustrating experience which needs a lot of support. This is so because caregivers are of the view that when they spend days with the child alone, that is where they usually experience serious levels of anger. When there are other people at home who can assist with household chores and look after the child with cerebral palsy, caregivers usually feel relaxed. These findings are in harmony with observations by other scholars. Caregivers usually experience strain on their physical health, psychological as well as social wellbeing (Rosenbau, Brehaut, Walter, Russell, Swinton, Zhu & Wood, 2005; Moster et al., 2010).

The participants further argued that they are often forgetful, especially on days when they have to care for the child. They will instead do something important like paying rentals or go to the market to buy weekly supplies. A young mother caregiver said:

“Ini Hanganwa dzinowanzondibata madays andinenge ndine pressure. Semazuva ekuti rent ikudiwa, mari yacho haisati yakwana apa mwana nerimwe divi anondidawo. Ndinopedzisira dzimwe nguva ndavakukanganwa zvandanga ndichida kutaura kana kutsvaga foni yandakabata mumaoko”.

(During the days when I am under pressure, I am usually forgetful. Like during the days when I have to pay rent, and I haven’t raised enough money for rent.

On the other side, the child needs me. I sometimes end up forgetting what I wanted to say or searching for a cell phone I am holding).

This is a clear indication that caring for a child with cerebral palsy puts the caregiver under pressure and has a strong negative mental effect on them. This compromises the quality of caregiving as continual stress, forgetfulness and anger leads to a bitter person who might end up abusing the very same child they are trying to protect. Despite the dangers of abusing or endangering the child, caregiving is also related to the wellness of the caregivers.

3.6.5. Harmful cultural practices

Disability is interpreted culturally in many African societies. This is in sync with an observation by Haihambo and Lightfoot (2010), that disabilities are often interpreted culturally. Caregivers argued that during the time when it was identified that the child has cerebral palsy, different cultural interpretations were made with regard to why the child was born with the condition. The participants also indicated that they were accused of infidelity or witchcraft by close family members. One caregiver narrated how such interpretations have been made to her. She said:

Ndakaenda kumusha ndichinoona vanamai vangu. Muvakidzani wedu akanditaurira direct kuti zvivi zviya zvopfuka ka, ndozvazvinoita ukapa mwana kumunhu asiri baba vake”.

(I went to our rural home to see my mother. Our neighbour came face to face and said these are the sins you committed, you cannot give someone a child who is not his child, this will happen).

Another caregiver also narrated her ordeal with cultural practices, saying:

“Pakaonekwa mwana wangu kuti anehurema ndakakumbira vatezvara kuti vandiperekedze kuchipatara. Vakaramba kuenda neni vachiti wakamboona ndereka dzichirapwa kuchipatara here, mwana anoda kupiwa Mushonga. Pakapiwa mwana Mushonga akaita infection kusvikira ndazongoenda naye kuchiptara zvakare”.

(When we discovered that my child has cerebral palsy, I asked my father in-law to accompany me to the hospital, he refused. He argued that the form of

sickness did not want western medicine but rather needed African traditional medicine. When my child was given the medicine, he caught some infection and I ended up taking him to the hospital again).

Apart from obviously souring the social relationship between them and family members, caregivers also highlighted that it was mentally and emotionally disturbing, with some going as far as saying that when they think of how it was said and how everything turned up after that, it makes them cry.

3.6.6. Communication challenges

Most challenges faced by caregivers are caused by the reaction of society to disability. However, it is also important to note that communication between parents/caregivers and their children with cerebral palsy is one of the social challenges that they face, which also has a psychological effect. A Caregiver said:

“Pamwe pachu ndinotoona kuti mwana arikutaura chimwe chinhu neni asi ndichitadza kunzwisisa kut arikutii. Kazhinji tinenge tichingova vaviri pamba zvekuti ndinenge ndichida chaizvo nyangwe kungotaurawo nyaya asi pandinooona kuti shuviro dzekuita nyaya naye dzinonetsa kuzadzisa ndinoyerekana ndakungobuda musodzi”.

(Sometimes I see the child trying to say something to me but I fail to read the message. Most of the time we will only be myself and the child. So I will actually be feeling like having a social talk but when I realise that the dream of meaningfully talking with my child is hard to fulfil, I end up crying, it just breaks my heart).

The above account is a clear example of how stressful caring for a child with cerebral palsy is. It is also a good sign of lack of capacity on the part of caregivers to provide care to children as they do not have the necessary skills like communicating with the children.

3.6.7. SUPPORT SYSTEMS

Support systems are individuals and entities that offer emotional, physical, mental and spiritual support to caregivers. As highlighted above, caregivers of children with cerebral palsy face different challenges. Societies and communities have systems

that support caregivers. These support systems come in many forms like non-formal systems such as family and friends, and formal systems such as official rehabilitation programmes by government and its partners.

3.6.8. Non formal support systems

Many caregivers agreed that support mainly comes from the immediate family, that is, the husband for those who are married and other siblings. This is a reflexion of what is provided for in the family caregiving model by McDonald et al. (1997). In this model, the antecedents are the child with cerebral palsy, the caregiver and the family at large. As propounded in the model, antecedents look at the severity of the disability, of which this study used severe cases of cerebral palsy, the support coming from the family and friends, highlighted as non-formal support systems. Other relatives and friends distant themselves the moment they realise that there is a child with a disability in the family, especially when they realise that the child suffers from cerebral palsy, which is a permanent condition. A middle aged mother caregiver said:

“Pakutanga tanga baba venmwana vaitoratidza kuda mwana wavo. Asi munongozivawop zvinoitika nehama. Vakatanga kundipa mhosva ini kusvika baba vacho vatozondipa gupuro”.

(At first the father of this child was showing love and affection to the child, but you know what happens with relatives. They started accusing me and in the end my husband divorced me).

Another caregiver indicated that support from siblings of the child with cerebral palsy is the strongest support mechanism. She said:

Chinotondipa zororo nekudekara inyaya yekuti madzikoma emwana uyu anehurema vanoratidza rudo kwaari. Izvozvo zvinoita kuti ndizive kuti kunyangwe ndikanzi ndafa nhasi anosara anevanhu vanenge vachimubatsirawo kuti aende mberi nehupenyu hwake”.

(What gives me hope and rest is seeing elder brothers of this child with cerebral palsy showing him love. This shows me even if I die today the brothers will still help my child to survive).

The other important support systems for the caregivers are the mother of the child's family. Many have highlighted that they received stipends and hand-outs, advice and social support from the family of the mother, saying:

'Ini hangu rubatsiro ruzhinji ndinotoruwana kubva kuhamu dzaekumusha kwandakaberekwa. Mai vangu nehazvanzi dzangu vanopota vachindibatsira nemari nezvimwe zvinodiwa pakuchengeta mwana wangu.'

(Most of my help comes from my family (where I was born). My mother and brothers usually send me money and other material things that I use to take care of the child with).

The above accounts show that caregivers mainly rely on support that comes from their childhood families as opposed to the families they are married to. However, the cultural rule that a married person has at least to spend some time without visiting her own family presents a serious challenge as they cannot depend on the family that they see few times a year. This means that the real support system for the caregiver shrinks right in front of them as they can only approach their families when things are really bad with a serious need, but considering the needs of children with cerebral palsy, to which they are committed on a daily basis – the therapy which needs bus fair, the medication, the pumpers and diapers, the special food and even the time you spend with the children – it is important to note that the social support system for caregivers becomes very small and less meaningful.

The church has also emerged as another source of support for caregivers of children with cerebral palsy. One mother caregiver said:

'Kazhinji kacho mharidzo dzinopiwa kuchechi sekuti matambudziko pano pasi mufaro kudenga dzinondisimbisa. Asi pakurerwa kwemwana zvishoma zvinoitwa nechurch nekuti mwana wangu ndinongochengeta ndega pasina rubatsiro runobva kuchurch.'

(Most sermons from church give me a positive mind. For example, they say earthly troubles are peace and happiness in heaven. This strengthens me. However, looking at the needs of the child I secure those without the help of the church).

However, caregivers seemed to be divided in terms of how helpful the social support that comes from churches is really to them. Psychologically, they all believed the church is the greatest, especially from teachings and counselling by pastors and elders. Socially, it is not the same. Caregivers highlighted that the same people who segregate against them in communities are the same people with whom they attend church. Only few can display affection for the children. The majority who clearly show dislike and not ready to associate with them or accept them break their hearts every time the church members meet. A grandmother caregiver said:

Kuchurch kunobatsira pakuti mharidzo dzinoitwa dzinosimbisa. Asi chinongobhowera kuchurch inyaya yekuti vaya vatinogara navo munharaunda vachiratidza kusema vana vedu ndozve vatinopinda navo dzichurch. Vashomasa vanhu vanoratidza kuda vana vedu.

(The church is helpful especially when it comes to sermons. It is however discouraging because the same people who discriminate against our children in the community are the same people we attend church with. Very few show affection to our children).

3.6.9. Formal support systems

The most reliable support system for caregivers is the Kapnek supported CRU. Again, this reflects the provision of the family caregiving model by McDonald et al. (1997). The model posits that the antecedents discussed as informal support systems are mediated by external factors. These factors include how the formal support systems work, which include the CRU as an institution. Caregivers highlighted that after counselling from the CRU and Kapnek staff, they started to gradually accept the condition of their children and to understand their needs more. A young mother caregiver said:

“CRU yakandibatsira chaizvo kubva pakutanga kugamuchira kuti mwana anehurema. Kana machengeterwe anoitwa vana vanecerebral palsy vanomboedza. Chinongozosvota ndechekuti kuCRU kwacho tinonzi tiuye kamwe chete pamwedzi dzimwe nguva unosvikopiwa 10 minutes chete”.

(CRU really helped me by accepting that my child has a disability. Even on how children with cerebral palsy are taken care of, they really try. What is

disparaging however is at CRU we usually attend once a month and one is given around ten minutes).

Another caregiver, this time a grandmother, also said:

“Ini ndinonyanyobatsirikana kuCRU nekutikanandichiona vamwe vana vakaita semuzukuru wangu ndinoziva kuti handizi ndega. Asi kunyangwe kuCRU kuchindibatsira kunorwadza nekuti kunoendwa nemabhazi. Kana tikanyorerwa mishonga yekutenga tinozvitengera zvake saka zvinhu zvinenge zvakangooma”.

(I see CRU as very helpful to me. Seeing other children with the same condition is comforting as I realise I am not the only one. As helpful as CRU is, it is costly because we use buses to go there. Even if the doctors prescribe some medicines we buy them ourselves, times are hard).

The above accounts are testimony to the value caregivers place on CRU. Ranging from the official services offered at CRU to the social support that comes from other caregivers, CRU is a cornerstone for caregivers. However, there are a number of challenges that they also highlighted with a passion that comes with attending therapy sessions at CRU. The sessions are conducted once a month, with many caregivers believing that these sessions are not enough as they would have forgotten how to do some home therapies by the time they visit CRU for the next session. Considering that all caregivers did not go past ordinary level education, this is a very important point.

Apart from the issue of time, there are also issues of access costs like transport and medication costs. Caregivers cannot engage in economic activities because they need to be with their children all the time. This means that the monthly bus fare to the hospital and other costs that come with travelling are hard to meet. In as much as all caregivers believe that one visit a month is too little, it is important to note that they all agree that they have missed at least 3 sessions in the past year because of shortage of bus fare. Both negative and positive aspects that come with accessing formal services at CRU are a reflection of the provisions of the family caregiving model (McDonald et al., 1997). Antecedents are mediated by both internal and external factors to produce positive and negative results. In this case, the

antecedents are the caregivers and the child's conditions which are mediated by external factors such as formal services at CRU. Positive results include increased coping capacity for caregivers, and negative ones include ill treatment from health officials and increased access costs.

3. 7. COPING STRATEGIES

Caregivers have employed different coping mechanisms in an effort to curb challenges that they are facing. It is, however, important to note that some of the coping mechanisms are even harmful to the child and the whole family.

3.7.1. Avoiding intimidating environments

Caregivers have resolved to avoid intimidating environments. Respondents were all in agreement that they avoid areas and places where they receive silly comments from strangers and members of extended families. A mother caregiver said:

“Pandakangoona kuti hama dzemurume wangu hadzidi mwana wangu uye vanotaridza kusema ndakabva ndangoregawo kuvafambira”.

(When I realised that my husband's relatives were not comfortable around my child, I stopped visiting them at all).

Another caregiver also indicated that she has stopped going to places where there is intimidation. She said:

“Ini ndakaona kazhinji kuti pakaungana vanhu ndopaunonyanyonyeiwa nevanhu. Kana kuchibhorani ndinoenda nguva dzakusingawandi vanhu. Kunowungana vemhuri handinyanyofarira kukuenda nekuti treatment yaunopiwa yakatosiyana neinenge ichipiwa vamwe vezera rako”.

(I realised that when there is a gathering, that is where people begin to talk from your back. I usually fetch water from the borehole when there are not many people there. I do not like family gatherings because the treatment I get is different from the one my age mates receive).

Caregivers were in agreement that they had to stop visiting members of the extended family, avoid going to public places during busy days, and generally cut themselves out of the entire social life of the community. However, avoiding

emotional suffering by avoiding provocative comments also affects them as they become lonely, which again has emotional effects on them. This supports Chitereka's (2010) observation that disability in general is associated with shame and sin. As a result, strangers and family members insult primary caregivers of children with disabilities, and they themselves withdraw from daily societal activities.

3.7.2. Seeking faith healing

The majority of caregivers believe that their children are in the condition they are because of witchcraft and supernatural forces. As a result of this belief, caregivers have joined the apostolic sector, hoping to use the prophetic power to cure their children. This supports the observation by Chitereka (2010) that disability is generally interpreted religiously. Whilst this interpretation has its own effects, joining the apostolic sect in search of cure is also dangerous to the child. Some caregivers confidently said that they do not adhere to prescriptions because of their apostolic beliefs. This endangers the child as withdrawal from daily routines that are medically proven may worsen the disability. A grandmother caregiver said:

“Dzimwe nguva zvatizonzi tiite kuno kuCRU zvinopuikisana nezvatinenge takaudzwa nemutumwa waMwari”.

(Some of the times what we are told at CRU is different from what we would have been told by God's Messenger).

Another caregiver (a young mother) also indicated that she went to the apostolic sector because of the child. She said:

“Ini ndakakura tichipinda Roma. Asi pandakaita mwana uyu ndichingonzi nevanhu endai kumadzibaba ndakatozopedzisira ndavakupinda madzibaba. Nguva zhinji tinopiwa nhombo dzekuzvidzivirira ende zvinotibatsira streki”.

(I grew up going to the Roman Catholic Church. When I gave birth, people were advising me to go to the apostolic sect, I ended up being a full time member of the sect. Most of the times we are given holy stones for protection and this really helps us).

The above accounts show the influence of religion on disability issues. As propounded by Chitereka (2010), disability is interpreted religiously. When the

causes of disability are aligned to religious and spiritual forces, even the coping strategies employed will also be religious and spiritual. Whilst the caregivers believed and emphasised that it works for them, the social worker believed that it works psychologically. He had this to say:

“Macaregivers vazhinji vanoenda kumapositori sezvamakaona. Asi ukanatsotarisa condition yemwana hapana aimprovement. I think that hope yavanowana ikoko is important psychologically but kunatsoti munhu awana something hapana”.

(Like you have noticed, most caregivers go to the apostolic. But when you look at the child`s condition, there is no improvement. I think that the hope that they get from the prophets is important psychologically, nothing else).

3.7.3. Locking up children in houses

Both the caregivers and the key informants highlighted that the financial statuses of families of children with cerebral palsy act a major barrier to quality caregiving for their children. It is, however, disheartening to note that in trying to curb this challenge, caregivers have, in a number of ways, abused their children and exposed them to serious emotional and behavioural threats. Children with cerebral palsy have a lot of limitations that can result in requirements for long-term care that far exceed the usual needs of normal children (Nimbalkaret al., 2011). This observation is correct because the findings of this study suggest that one of the care requirements of children with cerebral palsy is constant watch. However, caregivers are not able to provide this much needed constant watch to their children. Every caregiver has other economic activities that they try to engage in so that they can feed the child. For those who do urban farming, they leave the child locked inside the house when they go to the fields. A grandmother caregiver said:

“Tinezvimunda zveduwo zvatinerima. Pamwe pachokuti utakure mwana sewangu uyu zera rake harichaita. Kazhinji ndinotosiya ndamuvharira mumba nekuti ndikasadero haazowani chekudya”.

(We have our small fields that we farm. Sometimes for me to carry the child to the fields with her age is not possible. Most of the time I lock her inside because if I do not do this she won't have food on the table).

For those who try to buy and sell, they leave the child either locked or with a neighbour when they go to the market. They, however, admit that if their children soil themselves, people are not comfortable to attend to them and, as a result of this, they usually find their children with stools. Locking the child and leaving them in the care of someone who does not understand their needs or care exposes them to serious emotional harm. A young mother caregiver said:

“Ini ndinoita zvekamusika hangu. Mazuva ekutanga ndaimbosiya mwana namai vepanext door. Asi ndaiwana mwana angora netsvina yake dzimwe nguva karesva kurara. Ndakatozoono kuti kungomusiya kumba kurinani sezvo pasina Rubatsiro rwaaiwana kubva kunevandinenge ndamusiyira”.

(I have a small vegetable market. During my first days, I would leave my child with my next door neighbour. I would find my child unclean. Even when he soiled himself, I would find him like that, and all the time, I would find him lying down uncomfortably. I then realised that it was better to just leave him home since he was not getting any help from the neighbours).

3.7.4. Prostitution and drug selling

Prostitution has also come up as another way that caregivers have put in place to raise money for the child`s supplies. However, the researcher observed that the caregivers who said once in a while they exchange sexual favours for monetary gains seemed evidently troubled and stressed. This was especially the case when they tried to narrate what goes on in their minds when they are alone digesting what they do in order to take care of the child, and the child seemed not to get better as expected. Considering the fact that caring for a child with cerebral palsy does not only involve guidance and support, but is more physical because the child cannot do ADLs and self-care activities, an emotionally broken down caregiver is a risk to the child. If they cannot harm the child emotionally, verbally or physically by beating them, the caregiving quality is reduced.

It is important to note that caregivers resort to commercial sex work as a means of financing the needs of their children. Due to the financial strain that they come across, they resort to transactional sex. They do this so in order to put food on the table for their families, and in the process, they end up getting illnesses and

infections that are associated with these sources of income. One respondent admitted to resorting to prostitution soon after the death of her husband. Her account is recorded below:

“... kubva pakashaya murume wangu muna 2008, ndakashaya kuti ndingararame sei. Hama dzese dzakandirasa and hapana zvandaiita. Ndakaedza kumbhodha ndichitengesa but 2008 yacho hapana business raikwanisa kuitika zvakana because zvinhu zvainge zvakaoma. Saka ndakatanga kutsvagawo mari nedzimwe nzira ndikapedzisira ndaenda pachirongwa...”

(... After the passing on of my husband in 2008, I had no source of livelihood and all our relatives deserted us. I tried to become a vendor but as you know, the year 2008 was not good for any kind of business because of the then poor economic climate. I then resorted to making a living from other unconventional ways and I ended up getting HIV/AIDS).

This account is a good example of the summary of problems faced by caregivers of disabled children in general. After the death of their husbands, family members desert the family (discrimination and social exclusion). The caregiver tries to do vending but cannot balance the demands of running a business and caring for the child. As a last resort, they engage in transactional sex in order to survive. Social work interventions therefore have to look into the dangers of focusing on providing therapy and rehabilitation to the child, ignoring other real and relevant issues that affect caregivers, which also affect children directly since they rely on these caregivers.

3.7.5. Using children as beggar

Children with disabilities are also being used as beggars in the streets. Older caregivers (grandmothers) argued that they do this as a last option to at least ensure that food is served. The mother caregivers also admitted that from time to time, they use the child to assist in some form of begging. This is similar to Yeo's (2011) argument that children with disabilities can be used as beggars. The conditions on the streets, however, are a risk to the children. One caregiver narrated how she ended up using the child to become a street beggar. She said:

“Ini ndinogara nevazukuru ndirishirikadzi. Wakanditarisa ndakura hapana zvimwe zvandichagona kuita. Handitodi kuti Muzukuru wangu aende paroad kunokumbira asi nguva zhinji ndikaomerwa kutomotuma nemukoma wake dzimwe nguva vanotodzoka nemari inokwana upfu”.

(I am a widow who stays with her grandchildren. Looking at me you can see I am old enough there is nothing meaningful I can do. I do not enjoy to send my grandchildren to begging but sometimes I have no option. When I am stranded, I send him together with his older brother as a beggar, sometimes they even bring enough money to buying mealie meal).

A young mother caregiver also claimed that she uses her child as a beggar. To her, begging is more profitable than her normal vegetable selling business. She had this to say:

“Ini ndinoita zvemusika ndinotokwira kombi kuenda kutown ndokwandinoitira musika wangu. Kana munin`ina wangu aripo ndinoenda naye nemwana, ini pandinenge ndichitengesa iye anenge achifamba nemwana achitsvaga Rubatsiro. Dzimwe nguva ndinomboti handichadi zvekutsvaga Rubatsiro nemwana asi kazhinji mari yavanouya nayo yekupemha inenge yakawanda kudarika yandinowana pakutengesa”.

(I have a small vegetable market in town. If my young sister is at home, I usually go with her together with the child. Whilst I am selling my vegetables, they will be begging. Sometimes I tell myself that I have to stop using the child as a beggar, but the money they bring at the end of the day is usually more than I get from selling vegetables).

3.7.6. Abandoning Family

Disability is associated with negativity in many societies. As a result, caregivers resort to running away, abandoning their families altogether. Willacy (2012) argues that disability is a family experience. Some family members who cannot cope with the pressure resort to running away. The participants highlighted that they were either abandoned by husbands, or they experienced marital problems because of criticisms from family members as well as the financial needs required for children to survive. Mother caregivers also indicated that before joining the CRU programme,

they had thought of migrating to South Africa, leaving the child more than once, but changed their minds after receiving counselling. All the grandmother caregivers also indicated that the biological mothers of the children had abandoned them, leaving them in their care. A mother caregiver said:

“Ini ndakatizwa nemurume paakangoona kuti tazvara chirema. Ini pachangu ndakambopindwa nepfungwa yekunosiya mwana wacho kuvabereki vababa vake ndoenda kuJoni asi ndakabatsirwa neveCRU kuti ndizvigamuchire”.

(My husband abandoned me when he realised I gave birth to a child with disabilities. Even myself I once attempted to leave the child with her father`s parents and run to South Africa. This, however, changed when I received counselling from CRU).

The same view was also emphasised by a grandmother caregiver who said that she is taking care of the child because the biological mother ran away. She said:

“Ini kugara kwandirikuita nemuzukuru wangu uyu handitozivi nekuti mai vemwana uyu varipi. Chaakangogona kusauraya mwana. Asi kuti azive kuti adyei apfekei ndini, iye akatya hurema akatiza...”.

(I am staying with my grandchild because the mother ran away, I do not even know where she is right now. At least she did not kill the baby. But I take care of every need of this child without the help of the mother. She feared the disability and ran away).

The same view about abandoning families and children with cerebral palsy were also echoed by the psychologist. She highlighted that most of her clients report being alone with the whereabouts of the other spouse unknown. She said:

“Vazhinji vatinoshanda navo vanenge vasina varume kudzimba. Kana vari vana mbuya vanenge vasingatozivi kuti vanasikana vavo varipi. Vazhinji vacho pavanongoona kuti mwana akaremara vanobva vatizira iko kuJoni kunongoendwa uku. Even vacho vanosara patinenge tichiita counselling unotoona kuti ukasanatsotaura naye pfungwa dzekutiza nadzowo vanadzo”.

(Most of our clients have no husbands at home. If they are grandmothers, they usually do not know where their daughters are. When they realise that

the child has a disability, most run away to South Africa. Even the ones who remain behind, who are part of our CRU programme, I realise when we are doing counselling that the idea of running away is also there).

3.8. IMPLICATIONS FOR SOCIAL WORK PRACTICE

The research had an opportunity of engaging two social workers from a local organisation working with both children with cerebral palsy and their caregivers. The following issues pertaining to implications to social work practice emerged.

- a) Caregiver capacity.
- b) Discrimination at different levels.
- c) Financial problems and strategies employed.

Table 1.1 Social Workers' Accounts: Emerging themes and social work issues

Emerging themes	Social work practice issues
Caregiver capacity	Minimum Level of Education
	Caregiver difficulties accepting the condition of the child
	Religious and cultural affiliations of caregivers guiding and informing caregivers
Challenges (Discrimination)	At family level
	Community level
	Institutional level
Financial difficulties	Failure to provide for children
	Negative coping strategies

3.8.1. CAREGIVER CAPACITY

- **Level of education**

The majority of caregivers are less educated. This contributes to the depth of their understanding of cerebral palsy, the challenges they face and the coping strategies that they employ. Social work interventions are aimed at strengthening human functioning and capacity (Dubois & Miley, 2005). However, considering the complex nature of cerebral palsy, and the level of education of caregivers, social workers

opined that they face difficulties in effectively engaging these caregivers. One social worker said:

Most caregivers are not very progressive. They are adamant to what they know and think is best for the child even when research has shown the dangers and risks involved.

In support of the first social worker, another one said.

Working with caregivers is very difficult. Cerebral palsy needs to be understood first and this is the part where we face difficulties. Caregivers are slow to comprehend some of the issues. After understanding the condition and its causes another important aspect is mastering its management. Most caregivers need support in this and considering many problems like the logistics of ongoing support this is a big practice issue for social workers.

The above accounts by social workers show the impact of the level of education of caregivers present to then social work practice.

- ***Religious and cultural influences***

The majority of caregivers are members of the apostolic sect. They believe that their children`s conditions were caused by a spiritual force, either witchcraft or an ancestral and evening spirit. They also believe in faith healing. Social workers highlighted the fact that most members of the apostolic sect show faith in the belief that one day their children will be healed. This presents a challenge for social workers because cerebral palsy is a permanent condition which needs to be managed for life. Another issue are challenges that come with faith healing. Caregivers stop giving children their medicines and stop attending rehabilitation sessions because they regard faith healing as a better alternative. One social worker said:

Working with the caregivers that are members of the apostolic church is the most difficulty challenge we have. They are very secretive and they do not share even the most important information which can help our work. It is also very difficult to convince them to adhere to stipulated rehabilitation routines. Some of them even use dangerous unproven methods in trying to lessen the

impact of the disability. As social workers it is always difficult to raise awareness within the church to abolish some dangerous practices.

The communities in which caregivers live have their own beliefs regarding disability. The community and the families of children with disabilities interpret disabilities in terms of culture. This presents a challenge to social work practice as it has to deal with the effect this has on caregivers and challenges some of the cultural practices. A social worker said:

For caregivers who are members of the apostolic sect there is a conflict between them and their families. As a social worker I have to make sure that the caregiver's interests are defended, however it is difficult because these apostolic interests are also presenting a risk to the child. For caregivers that are not apostolic as a social worker challenge is on engaging the family to convince them how important it is to support the caregiver in accessing rehabilitation services.

3.8.2. DISCRIMINATION OF CAREGIVERS AND THEIR IMMEDIATE FAMILIES

Discrimination is also a key challenge faced by caregivers of children with cerebral palsy as presented above. This presents a threat to the social work profession as the gains of other interventions like support groups are demotivated by comments and antics from the community in which caregivers live.

- **Discrimination at family level**

Social workers agreed with the caregivers that discrimination faced by caregivers begin at the family level. The extended family is an important support system in the Zimbabwean society, and its disassociation with the immediate family of the child with a disability affects the family to a large extent. Social workers face the difficulty of engaging the extended family since they are scattered all over the country.

- **Discrimination at community level**

Social workers indicated that Dzivarasekwa is multi-tribal community. Its populace comes from different parts of the country. Engaging the community is always difficult, yet the need to raise awareness in the community is evident. Social workers posited that strategies to challenge discrimination at community level always

come short as the community comprised different cultural and religious beliefs. Engaging different groups separately proves to be effective. However, they argued that this strategy is a bit more expensive.

- **Discrimination at institutional level**

Whilst there has been some progress towards challenging discrimination at institutional level in terms of legislation like the DPA, the Education Act, Inclusive Education Policy and the UNCRC among other legislations institutions remain discriminative to people with disabilities in general. Social workers posit that the major problem that they face from institutions is the disconnectedness within government institutions. Whilst they (social workers) make every effort to challenge discrimination, government workers present an attitude that they do not report to social workers, and the government itself does not take social workers seriously. They further argued that in terms of advocacy for policies and legislative intervention, they have effected change through the introduction of policies like the inclusive education policy. But in terms of implementation, institutions are still discriminative.

3.8.3. FINANCIAL DIFFICULTIES AND STRATEGIES

- **Financial difficulties**

Caregivers of children with cerebral palsy face a remarkable number of difficult challenges. One of these challenges is meeting the financial requirements for caring for a child with cerebral palsy. Social workers were of the view that in responding to this, they try to assist their clients to access basic social protection services from government institutions like Basic Education Assistance Module (BEAM), Harmonised Social Cash Transfer (HSCT). But securing these service is a difficulty considering the lack of or partial functioning of government institutions and programmes.

- **Strategies employed**

In response to this, the majority of caregivers employ negative strategies like prostitution and locking children inside homes as presented above. The differences in these coping strategies imply that social workers have to use different methods for different caregivers. This is one way of upholding the social work principle of

individualism. Social workers can take advantage of the casework method to work on caregiver specific needs as it helps to make sure that each caregiver's concerns are addressed, and that the caregivers reach their maximum possible potential as individuals (Palmer, 2014). However, social workers indicated that it is difficult to effectively engage caregivers to avoid these negative coping strategies. One challenge highlighted was the non-functionality of the social protection services available.

3.8.4. WAY FORWARD

Looking at the practice issues raised by social workers, social work practitioners have to look for a holistic way to include all aspects of the problem. In doing so, there is a need for collaboration with other professionals like colleagues in the education department, nursing and medical staff as well as community leaders. There is also the opportunity to utilise both group work and casework as social work methods since there are individual and group aspects that affect disability in general. It is, however, critical to note that social work practice is also affected by other factors like the availability of resources and support from the government in terms of legislation and prioritisation. In this regard, social workers have to put effort to advocacy for better funding from government, and the alignment of laws to the constitution so that people with disabilities and their caregivers benefit.

3.9. CONCLUSION

The aim of this chapter was to present and analyse/interpret data which were collected through interviews and FDGs. Data were analysed in themes using Thematic Content Analysis. The analysis used three themes namely, characteristics of caregivers, their challenges and coping mechanisms employed. Under the first theme, characteristics of caregivers of children with cerebral palsy, discussions were around their levels of education, employment statuses, religious beliefs, health problems faced, psychological state and cognitive effects, as well as their capacity to care for children with cerebral palsy. The major challenges observed under the second theme were discrimination against children with cerebral palsy as well as their immediate families. Linked to discrimination is social exclusion of both children and their caregivers, unhealthy relationships with family members, harmful cultural

practices and beliefs, communication challenges between the caregivers and their children, unexplained anger and forgetfulness as well as shrinking support systems. On the theme of coping strategies, caregivers have reported not to visit intimidating environments. They use children as beggars; they attend sessions at CRU; they lock children inside their homes when they are doing some economic activities; engage in prostitution; they sell drugs and seek faith healing.

CHAPTER 4

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

4.1. INTRODUCTION

This chapter gives a summary of the major findings of the research. It also gives conclusions and recommendations.

4.2 RESTATEMENT OF AIM AND OBJECTIVES

The aim of the study was to describe psycho-social challenges faced by caregivers of children living with cerebral palsy in Dzivarasekwa Suburb as well as their implications for social work. The research achieved this aim through a number of objectives.

- To identify the psychosocial challenges faced by caregivers of children with cerebral palsy.

The researcher collected data through interviews from caregivers of children with cerebral palsy in Dzivarasekwa Suburb. From the data collected through both interviews and focus group discussions, the research found that the major challenge affecting caregivers is discrimination by the community, which can be experienced in government departments, with nurses treating children and their caregivers differently the moment they realise that these children have the condition. Apart from discrimination, other challenges include lack of knowledge or proper understanding of cerebral palsy; meeting the financial needs of the child; meeting other family needs; and lack of physical strength to care for the child who requires all-time attention. The researcher, together with the participants, noted the challenges.

- To appraise individual characteristics of caregivers which predispose them to stress, social exclusion and other psychosocial challenges.

In a bid to achieve the aim of the study, the research also inquired about the personal characteristics of caregivers, especially those that contribute to the challenges mentioned earlier. The researcher noted that the participants seem withdrawn from everyday life of communities and they are less educated.

On the demographic details, it is also important to note that the majority of participants are members of apostolic churches. Whilst religion seems to be an integral part of the Zimbabwean culture, it is essential to note that the participants showed great trust and reliance on faith healing. Whether faith healing works or not falls out of the scope of this research. But it surely has a bearing on the consistency that caregivers give to medical attention required for their children. Caregivers do not adhere to set daily therapies, drug intake and going for checkups. Instead, they focus on alternative strategies given by prophets, such as morning prayers and use of holy stones.

Another key issue relates to the marital status of caregivers. More than half of the participants were single mothers whilst all the grandmothers were widows. This presents two issues, namely the lack of man/fathers participation in the raising of children with cerebral palsy. And another issue being the social impact of disability

within a family which leads to breakdown of relationships and marriages. This is usually as a result of stigma and discrimination that come from cultural and religious interpretations of disability respectively.

Caregivers have at least one health condition, which derails them from performing their role. They also take care of other children as well. The participants openly disclosed their HIV status, indicating that the hardships associated with the management of HIV is also a challenge in terms of caring for a child with cerebral palsy. Other notable physical conditions that highlighted by the participants are headaches. The researcher linked this to stress since the participants also highlighted that these headaches are usually severe when they try to strike a balance between caring for the child and meeting other responsibilities as mothers and wives.

The issue of education was again an important issue, especially about service seeking and adhering to the specialist's guidelines. Less educated participants recorded a higher number of missed monthly appointments at CRU. The less educated the caregiver, the more the days they missed at CRU and the harder the taking care of the child due to lack of proper knowledge.

- To establish coping mechanisms employed by caregivers of children living with cerebral palsy in response to challenges that they are facing.

The researcher also noted that caregivers employ both positive and negative coping mechanisms in relation to the above-mentioned challenges. Some of the positive mechanisms involve not going to provocative places, avoiding visiting discriminatory family members, attending therapy sessions at CRU, and setting up selling points at home.

On the negative side, caregivers also involved engaging themselves in prostitution, thereby exposing children to abuse. The participants indicated that at one point, they engaged themselves in transactional sex in order to meet the needs of the children and other general needs like paying rentals, securing food, paying fees and other home expenses.

The participants also used their children as beggars as some members of society feel sympathy for children when they see their condition. In explaining how they use

children as beggars, the participants claimed that this is usually because apart from the obvious daily living expenses, they do not receive any monetary help from the government, the family and the fathers of children with cerebral palsy. Caregivers are left with no choice other than to find strategies to put food on the table, to pay rent and to settle bills. One option for this was using children as beggars.

The participants argued that they lock children in houses while they engage in some economic activities like going to the fields. They said that this is not the best they can do for their children, but every time this has to be done, it will be the last option although they all agreed that often time it is the only option.

Lastly, they highlighted that they ignore the needs of children with cerebral palsy to focus on children without disabilities. They argued that needs of children with cerebral palsy are broader and costly, hence by focusing on meeting these needs will affect all the other issues that are affected by their presence and monetary forms as well. This is one revelation, which is testimony to the fact that caregivers of children with cerebral palsy lack the capacity to care for their children, in this case financial and technical capacity.

- To suggest possible solutions/ strategies that social workers may employ to improve the caregiving of children with cerebral palsy.

From the accounts of key informants and suggestions from the caregivers, the researcher put together possible strategies that social workers can employ to lessen the burden of caregiving for caregivers of children with cerebral palsy. The strategies and recommendations have a basis on strengthening positive coping mechanisms while discouraging the negative ones. There is need for the government to fund therapy sessions for caregivers, that is, transport and other related costs. There is also a need to formulate support groups for parents and families of children with cerebral palsy so that they can support each other, and share experiences as they are excluded from mainstream social activities of the community. Lastly, there is a need to raise awareness in the community.

4.3 SUMMARY OF FINDINGS

The research explored the psychosocial challenges that caregivers of children with cerebral palsy are facing. The sample was relatively small but representative as it

included both mothers and grandmothers of children with cerebral palsy. Social workers from a local organisation and a psychologist who provide counseling services for the caregivers and children were also interviewed. This gave the researcher a detailed set of data with a wider perspective. All the caregivers who participated in the research are not employed to provide care but are either mothers or grandmothers who stay with the children, hence they have the most relevant experiences that answered the objectives of the study.

4.3.1. Personal characteristics of caregivers.

Below are characteristics of caregivers that were discovered through interviews and FDGs. The researcher found these characteristics to be contributing to the state of wellbeing or coping capacity of caregivers as well as the quality of caregiving provided to their children.

4.3.1.1 Level of Education

The researcher found that all the participants reached ordinary level education. However, none excelled, and others failed to sit for examinations because of different challenges. This seems to have a very strong impact on the caregiving role and the challenges it present. Education increases employability of people. Caregivers are not employed, citing the competitiveness of the job market, with one being able to be considered for a position when they at least have a professional diploma or a higher qualification.

Lack of education has also proved to be a causal factor in issues like adhering to therapy programmes, employing unsafe and negative coping strategies to deal with the challenges, and failure to understand their children`s routines. Because of lack of education, some caregivers argued that they never took time to read flyers meant to increase their knowledge of cerebral palsy and ways of managing it. Caregivers were also not aware of national and international laws and policies that protect children in general. They were not aware of the social protection programmes that are available in the country.

4.3.1.2. Age

Both grandmothers and the mothers proved that age is a key factor. The elderly (grandmothers) who are over 50 years cited mobility challenges, especially in attending treatment therapies where they have to carry the child to and from the bus terminus to the treatment centre. Grandmothers were comparatively more affected by lack of resources as they could not engage in serious economic activities which require commitment compared to the younger caregivers. However, it is important to note that in terms of adhering to therapy sessions and general childcare, they showed more commitment and respect compared to the younger caregivers.

The younger caregivers in general displayed lack of patience, with some openly saying that when pressed, they turn to giving sexual favours to people in return for monetary and material gain. Young mothers were more affected by short temper. This clearly shows that being too old or too young is not ideal for caring for a child with cerebral palsy. Two caregivers in their mid-30s displayed composure, maturity and seemed less pressured as they were mature enough but still energetic to work for their children at the same time.

4.3.3. Employment and marital status

Normal family life proved to be the most reliable support system for caregivers. Support from siblings of the child with cerebral palsy and the husband of the caregiver came out to be vital. However, all those who were not married were very bitter with the biological fathers for abandoning them and the child. It affected their own wellbeing, which also affects the caregiving role that they play to the child. Apart from the social support that spouses provide each other, caregivers opined that if the fathers of their children were around, they would have been engaged in some economic activities while they care for the child at home, and financially, the situation would have been manageable.

Employment status and engagement in economic activity

4.3.2 Psychosocial challenges

Different psychosocial challenges that came out from the research are going to be discussed in brief in this section. These challenges are neither exclusively psychological nor social but are intertwined with other aspects such as economic

and religious aspects, but all end up affecting the social and psychological wellbeing of caregivers and their families. Below are the challenges.

4.3.2.1. Discrimination

On its own discrimination is broad and can be displayed in many different forms. It can be displayed through talking or making accusatory comments, refusing to associate with or share opportunities, looking down upon persons or playing down their needs. All these have been found to be obstacles in the lives of caregivers of children with cerebral palsy. The accounts of the social workers and the psychologist suggest that discrimination is the leading challenge faced by caregivers.

These professionals highlighted that when caregivers come for treatment sessions at Rehab, they are reluctant to seek other medical services from the main hospital due to the treatment that they get from the medical personnel themselves and other patients. Apart from the treatment from medical institutions, caregivers indicated that in many educational institutions, they were also refused entry with their children, with the authorities citing that they do not have facilities that cater for these children. Thus in refusing to associate with children with cerebral palsy and their families, the school authorities display discrimination.

The interviews and FDGs with the caregivers also concluded that discrimination is one of the major challenges faced by caregivers on a day-to-day basis. They said that they receive nasty comments from strangers once these strangers notice that the child has cerebral palsy. Some have been separated from their spouses because of comments from relatives, which again is a consequence of being a parent and a caregiver to a child with cerebral palsy.

Identity also came up as another serious challenge. Caregivers argued that their families have completely lost interest in them after their children were diagnosed with cerebral palsy. Family is an important aspect and is cherished among Zimbabweans, but for the immediate families of children with disabilities, the extended family is almost nonexistent.

4.3.2. 2. Anger and Stress

Stress and stress related symptoms like anger came up as common feelings often experienced. However, sources of stress differ from situation to situation and from caregiver to caregiver. The majority of the caregivers highlighted that the most stressful situations are when they cannot provide the material things needed by their children. They said that their anger is visibly strong when they care for children with other responsibilities at the same time.

4.3.2.3. Forgetfulness

Caregivers opined that the pressure associated with caring for the child, as well as other demands of life are too much for them. They said that they are often forgetful, and this is seen as one sign or indication of how this pressure has affected them cognitively. One caregiver even said that she often looked for something that she is holding in her hand. This is something she usually does when she is frustrated by having to provide for the needs of the child but without the means to access them.

4.3.2.4. Unhealthy relationships with family members

For various reasons, family members distance themselves from the immediate family of children with cerebral palsy. Family cycles shrink when one gives birth to a child with cerebral palsy. This is one of the challenges faced by caregivers.

4.3.2.5. Harmful cultural practices

In line with scholars' observation, disability is often interpreted culturally and religiously. The saddening part, however, is that most of these cultures believe that disability is a sort of punishment to parents, with most women/mothers on the receiving end of these accusations. Often times they are accused of infidelity or avenging spirits (*ngozi*), which leaves them traumatised as well as outcasts of the community.

4.3.2.6. Communication challenges

Children with cerebral palsy mostly rely on their caregivers. However, these caregivers are not specialists in caring for children with this condition. They fail to

communicate effectively with their children. This is frustrating to them and also compromises the quality of caregiving role.

4.3.2.7. Social exclusion

Caregivers are not informed of social or economic activities. They usually spend their time at home because of the attention required by their children with cerebral palsy and their inability to always travel with them. Because of this community, members often leave them out especially considering that most do not really understand the condition.

4.3.8 COPING MECHANISMS

Caregivers employ different coping strategies in response to their challenges. Below are coping strategies shared by caregivers with the researcher.

4.3.8.1. Locking up children in houses

As a strategy to find time to do economic activities, caregivers lock up children in their houses. This is an indication of the weaker support system that they have as relatives and friends are not comfortable to offer support in terms of caring for the children. It is important to note that this is abuse to children as they are at risk, especially considering the fact that they are already vulnerable people if their condition is anything to go by.

4.3.8.2. Using children as beggars

Some caregivers use their children as beggars. This is usually because they have no other alternative to meet their living expenses; they end up taking advantage of different individuals who feel sympathy when they see caregivers and their children in the streets. This is a danger to children as it does not empower or capacitate them, rather they are being used as income generating projects for families.

4.3.8.3. Prostitution

Caregivers are also involved in transactional sex to raise money for household needs and to cater for the child's needs as well. These caregivers argued that men

who come to the house for sex without realising that there is a child with a disability at home, when they realise this, they utter all forms of verbal abuse, and then refuse to go ahead with the deal. This is a clear indication that society does not want to deal and associate itself with families of children with disabilities.

4.3.8.4. Avoid intimidating environments

Caregivers have observed places where they are insulted, starved, verbally abused and treated like second-class citizens. All the caregivers decided not to visit those places. This has led to reduction in cohesion with people, especially extended family members.

4.3.9. KEY INFORMANTS` ACCOUNTS

Based on interviews conducted with two (2) social workers and a psychologist, the researcher noted:

- Caregivers of children with cerebral palsy, particularly mothers of these children have suffered divorce as a result of their children`s condition.
- Resources needed to take care of the children are proving to be overwhelming to the caregivers, as they cannot meet basic needs of children with cerebral palsy.
- Children with cerebral palsy, together with their families, are facing stigma and discrimination on a daily basis from the communities in which they live.
- Caring for a child with cerebral palsy is a very big and challenging role, which requires one to be physically, emotionally, financially and spiritually strong.
- Caregivers of children with cerebral palsy cannot engage in meaningful economic activities as they spend much of their time with these children.
- Most caregivers of children with cerebral palsy are in denial. They have not yet accepted the conditions of their children. As a result, they are reluctant to seek proper medical and rehabilitative services for their children.

- Caregivers are also employing negative and abusive coping strategies to their problems. These include prostitution, locking children in houses and using children as beggars.
- Religious affiliations are acting as the strongest psychological support systems of caregivers of children with cerebral palsy.

4.4 CONCLUSIONS

After a careful consideration of the above findings, the researcher carefully put together the following conclusions to sum up the study:

The major challenge caregivers of children with disabilities are facing is discrimination, ranging from family level up to institutional level. Discrimination is caused mainly because communities do not understand cerebral palsy. This is evidenced by the fact that many interpreted it culturally. Consequently, they end up blaming mothers of children with cerebral palsy for the disability, some accusing them of either witchcraft or infidelity. Discrimination is evident through a number of situations, including but not limited to: exclusion from social events and gatherings, insulting comments from the public, and deteriorating family relations.

The research concluded that the majority of caregivers are less educated and come from low income households. Again, the majority are members of the apostolic churches. All these factors have a bearing on how they comprehend disability. It also contribute to different challenges faced by caregivers, and as result, they react to it through different coping mechanisms.

Linked to the level of education, the research has also concluded that caregivers have no enough capacity to care for their children. They lack capacity in terms of technical knowhow, understanding the condition themselves, financial needs as well as physical structures such as wheel chair rumps. The research also concluded that most frustrations of caregivers come from this lack of capacity. Caregivers are often frustrated by their inability to meet the financial and physical needs of their children. This research also concluded that due to pressure that caregivers are facing, they have put in place strategies. However, some of their strategies are harmful to children. Some of the negative strategies include withdrawing the children from

school, locking them up in houses, using children as beggars and engaging in transactional sex.

4.5 RECOMMENDATIONS

To lessen the psychosocial challenges faced by caregivers, there should be efforts from the government, NGOs, and churches communities at large. The following recommendations were made after analysing the findings of the study and realising what is missing in the currently available services for children with cerebral palsy and their caregivers.

➤ Government to lead initiatives for supporting children with disabilities and their families

NGOs and churches are handling most disability work now. Government should be at the forefront and step up as a duty bearer in supporting children with disabilities. NGOs and other Non-State Actors should complement government efforts not the other way round. This is so because unless government places importance to the disability activities, government officials like medical staff and education officers will continue to discriminate against children with disabilities.

➤ Formation of support groups

As it was realised that caregivers feel better days soon after their monthly therapy sessions because they would have met others with the same situation as theirs, the contribution of meeting people in same situation with you cannot be undermined. There is a need to formulate support groups that are supported by government and NGOs to facilitate caregivers to share their experiences, good practices, how they overcome challenges as well as other external services that they received and think can help their counterparts as well.

➤ Introducing holistic strategies

It has been observed that the current programmes are mainly concerned about the rehabilitation of the child. The caregivers and families are left out in these programmes. However, the wellbeing of the caregiver is directly related to the quality that they provide to their children. Strategies like organising counseling sessions for

parents and capacity building workshops on cerebral palsy for caregivers could be useful.

➤ **Continuous training of frontline workers in disability to avoid burn out**

It is also necessary to create a system that allows and encourages continuous professional development for the frontline service providers so that they keep up to date with new policies and new practices of avoiding burn out.

➤ **Issues of further research**

The research observed that there is little literature regarding disability in Zimbabwe. Most studies are international studies. This research therefore recommends that there be research initiatives that look into disability issues.

➤ **Research on child protection issues for children with CP**

The research observed that because of their conditions, children with cerebral palsy are susceptible to different forms of abuse, yet these are not well-documented.

➤ **Religious and Cultural practices harmful to children with disabilities**

The research also observed that most caregivers have turned to faith healing as a strategy to lessen the burden of caring and rehabilitating their children. However, some of the religious practices are harmful and dangerous in a far as the best interests of children are concerned. Therefore, research is necessary on the different religious practices and their contribution to the lives of children with disabilities.

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APPENDICES

Appendix A: Consent Form.

Title of the study: Psychosocial challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa suburb, Harare, Zimbabwe: Implications for social work practice. THE RESEACHER'S CONTACT DETAILS: +263 773 467 203, +263 713 687 847: adammkushi@gmail.com

Dear participant.

My name is Mr Adam Tafadzwa Mukushi. I am studying towards a Master of Arts degree in Social Work at University of Limpopo. The research study on the psychosocial challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa suburb, Harare, Implications for social work practice is part of my Master`s degree programme. As part of the study, I am expected to collect data from identified participants and that includes you. During the data collection, the researcher will make use of an interview schedule for focus group discussions and individual interviews. You are kindly invited to be a participant in this study. The session will take approximately one hour. You are kindly requested to read and sign the informed consent provided to you. The participation in this study is voluntary and anonymous.

Thanking you in anticipation.

Adam Tafadzwa Mukushi

Masters student: University of Limpopo, Turfloop Campus

Signature.....

Date.../...../.....

Appendix B. Declaration of consent by the participant.

I,, hereby give permission to voluntarily participate in this research study with the following understanding:

- Mr Adam Tafadzwa Mukushi from the University of Limpopo (Turfloop Campus) is conducting the research.
- The research forms part of the requirements for Mr Adam Tafadzwa Mukushi`s Master`s Degree in Social Work.
- Information will be collected by means of interview schedules and focus group discussions.
- No payments or costs are associated with participating in this study.
- There will be recording of my voice throughout the interview.

My rights as the participant:

- I cannot be forced to participate in this stud and can withdraw at any time.
- The discussion may be tape recorded if I accept it to be so.
- I have the right to decline to answer any question (s) I am not comfortable with.
- There is anonymous, my name and identity will be kept from public knowledge.
- Any information I reveal during the process of this study shall remain confidential, shall only be used for the purposes of this research and for publication in Mr Adam Tafadzwa Mukushi`s thesis, and relevant or appropriate publications.
- I grant permission for any information I reveal during the interview process, with the understanding that data collected will remain in possession of the interviewer Mr Adam Tafadzwa Mukushi and his supervisor.

Signature Participant:Date...../...../.....

Appendix C: Interview schedule for caregivers

My name is Mr Adam Tafadzwa Mukushi. I am a Master of Social Work student at the University of Limpopo. The research study on the psycho-social challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa suburb, Harare is part of my Master`s degree programme. As part of the study, I am expected to collect data from identified participants and that includes you. During the data collection, the researcher interviews you together with other participants separately. Feel free to answer the questions the researcher will ask you and if there are questions you do not wish to answer you are not forced to answer.

Caregiver personal details and key characteristics.

1. a) Age.....

b) Level of education

Primary

Secondary

Tertiary

d) Religious belief.....

2. Relationship with child, for example, mother or grandmother.....

3. Marital status (tick where appropriate)

Married-----

Divorced-----

Widowed-----

Single-----

4. Employment status

Employed-----

Not employed-----

Informal Sector-----

5. Employment status of spouse if married Employed-----

Not employed-----

5. How many other children do you take care of?

6. Do you employ someone to help you look after the child with cerebral palsy?
Yes----- No-----

7. How does having a child with cerebral palsy affect other roles that you are supposed to perform?

8. Do you have any health condition yourself?

9. What laws and policies (both local and international) that protect and provide for children that you know?

10. How strong are you emotionally and physically?

Psychosocial challenges faced by the caregiver.

11. What are the challenges you face in cooperating with other people because of your role in caring for a child with cerebral palsy?

12. How do members of your community normally treat you when you are outdoors with the child with cerebral palsy?

13. (a) Can you explain the nature of your relationship with your extended family members?

(b) Has the whole family accepted that there is a child with cerebral palsy in the family?

14. Can you describe your initial reactions following the diagnosis of cerebral palsy?

15. Are your other children`s confidence and self-esteem issues been affected by having a sibling with cerebral palsy? If yes, how does that make you feel?

16. Do you ever feel any signs of depression such as hopelessness and worthlessness as a result of caring for the child with cerebral palsy?

17. Due to the caregiving role you play for the child have you noticed any psychological change signs?

a) Forgetfulness

b) Being extremely harsh (harsher than before)

c), impatience

d) Any other sign you think and feel is a sign of psychological change within yourself.

Coping mechanisms employed by the caregiver.

18. What are your support systems in caring for the child and what are their weaknesses?(this includes formal support systems, for example, services provided by Harare Hospital`s Child Rehabilitation Unit)

19. What problems do you encounter in accessing services for your child?

20. Can you describe how you resolved the initial reactions you had following the diagnosis of cerebral palsy?

21. Are you a member of any social support group and how does this help you?

22. How does religion assist you in coping with having a child with cerebral palsy?

Appendix D: Focus Group Discussion (FGD) guide for caregivers of children with cerebral palsy.

My name is Mr Adam Tafadzwa Mukushi. I am Masters Student in Social Work at the University of Limpopo, Turfloop Campus. The research study on the psycho-social challenges faced by caregiver of children with cerebral palsy in Dzivarasekwa suburb, Harare is part of my Master's degree programme. As part of the study, I am expected to collect data from identified participants and that includes you. During the data collection, yourself and other participants are going to voluntarily participate in group discussions about psycho-social challenges you face as caregivers of children with cerebral palsy. Feel free to answer the questions the researcher will ask you and if there are questions you do not wish to answer you are not forced to answer.

Challenges being faced by caregivers

1. The socio-economic challenges you face in caring for your children
2. The most difficult situations of caring for children with cerebral palsy
3. The stressfulness of caring for a child with cerebral palsy
4. The impact of the child`s condition in your daily living
5. How do other family members and friends take cerebral palsy?
6. Can you describe the nature of your relations with members of the extended family before and after your child/grandchild has been diagnosed with cerebral palsy?

Strategies put in place by caregivers.

7. Strategies you put in place to overcome the challenges
8. Support from people close to you in caring for your child
9. What are the changes in the services you would like to see in the services you are receiving now?
10. Support offered by your religion for caring for the child with cerebral palsy.
11. Strategies put in place to provide for yourselves, the child with cerebral palsy, and the needs of other children and challenges faced in this regard.

Appendix E: Interview guide for key participants

My name is Mr Adam Tafadzwa Mukushi. I am a Masters Student in Social Work at the University of Limpopo, Turfloop Campus. The research study on the psycho-social challenges faced by caregiver of children with cerebral palsy in Dzivarasekwa suburb, Harare is part of my Master's Degree programme. As part of the study, I am expected to collect data from identified participants and that includes you. During the data collection, yourself and other participants are going to voluntarily participate in group discussions about psycho-social challenges you face as caregivers of children with cerebral palsy. Feel free to answer the questions the researcher will ask you and if there are questions you do not wish to answer you are not forced to answer.

Challenges being faced by caregivers

1. In your opinion, what are the challenges that are being faced by caregivers of children with cerebral palsy in Zimbabwe?
2. As a practitioner, how do you see the socio-economic conditions of families with children with cerebral palsy affecting the caregiving process?
3. Have you ever witnessed discrimination against caregivers and families of children with cerebral palsy from the community?
4. If yes to the above questions, using your professional expertise, how do you think it affects caregivers and their families?
5. Do you notice any stress signs among caregivers during your sessions?
6. If yes to the above questions what do, you do to improve the stress management strategies of caregivers.

Support to caregivers from your Organisation and other stakeholders

7. What is the role of your organisation in alleviating the problems they are facing? (*Probe to establish the kind of services they are offering.*)

8. What challenges are you encountering in supporting caregivers of children with cerebral palsy?
9. In your opinion, what are the coping strategies that are being adopted by caregivers of children with cerebral palsy?
10. Do you see caregivers receiving support from family and friends in caring for the child?
11. Other than formal support systems from the Government with its partners how strong is informal support system for caregivers of children with cerebral palsy?

Recommendations

12. Can you give recommendations on what should be done to support caregivers of children with CP in Zimbabwe?

Do you have any other issue that warrants discussion?

Appendix F: Gate Keeper's authorization letter.



The J.F Kapnek Trust
OVC Programme
38 Lawson Avenue
Milton Park, Harare, Zimbabwe
20/11/ 2017

To whom it may concern

The J. F Kapnek Trust is supporting the outreach programme for children with disabilities/cerebral palsy in Harare (Harare Hospital Child Rehabilitation Unit) and Bulawayo (Mpilo Hospital Rehabilitation Unit). On behalf of J F Kapnek Trust I am writing to grant permission for Mr. Adam Mukushi at University of Limpopo, to use this outreach platform and conduct his research titled, "**psychosocial challenges faced by caregivers of children with cerebral palsy in Dzivarasekwa suburb, Harare, Zimbabwe: Implications for social work practice**"; I understand that Mr. Adam Mukushi will conduct interviews and Focus Group Discussions in Dzivarasekwa with our clients and will also use our social workers as key informants for this study.

As Kapnek Trust we are happy to contribute to this study as we appreciate that it is part of wider knowledge generation and seeks quality service delivery for children with disabilities and their families.

Sincerely,

H. Tanyanyiwa

A handwritten signature in blue ink, appearing to read 'H. Tanyanyiwa'.

OVC Programme Manager

THE J.F. KAPNEK TRUST
E.C.D/O.V.C PROGRAMME
38 LAWSON AVE
MILTON PARK, HARARE
TEL: 795218, 795320, 730339