"Like walking barefoot on the gravel road": The experience of Caring for a Child with

Physical Disabilities

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By

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Declaration

I declare that **Like walking barefoot on the gravel road: The experience of Caring for a Child with Physical Disability** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Signature   **Date**

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Abstract

The aim of this study was to develop an understanding of the experiences of caregivers of children with physical disabilities and to explore ways of improving this experience. Although there is a considerable amount of international research on the experiences of caring for children with disabilities, the focus of the methods of enquiry has mainly been on knowledge production and there is limited research conducted using an approach like participatory action research. Secondly, in South Africa, there is still inadequate information regarding the experiences of caregivers who are from low socio-economic backgrounds. It is for these reasons that the current study, which employed PhotoVoice, a participatory research data collection tool, to explore the lived experiences of caregivers of children with physical disabilities from low socio-economic backgrounds was embarked upon. The research methodology comprised two main parts: firstly, a study of relevant literature on the subject matter, in order to gain in-depth understanding of the field; and secondly, qualitative data collection, using PhotoVoice.

A sample of six participants between the ages of 22-57 years was selected through purposive and convenience sampling. Cameras were distributed to participants and after processing of images narratives were shared around selected photographs and this was later followed by focused group discussions. This analysis process provided two master themes, which are supported by subordinate themes. The master themes are: 1) The challenges associated with the caregiving experience, 2) The positive side of the caregiving experience. Participants experienced a lack of resources, challenges of mobility, the hopelessness of the situation, loneliness of the experience and the financial burden of caring for a child with physical disabilities as challenges associated with the caregiving role. Whereas the joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel; precious moments shared with the child; and personal growth were associated with the positive side of the caregiving experience. These findings support and expand on the growing knowledge of caring for children with physical disabilities. This research culminated in a sharing of the narratives with stakeholders by caregivers themselves as a way of seeking to influence policy, enhance their well-being and engage in a discussion of exploring ways of improving their experience.

Keywords: Physical disability, caregivers, PhotoVoice, experiences, Participatory Action Research

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1. Introduction

"Keeping up with her needs and activities has been time consuming and exhausting, but has also been extremely rewarding. This is not to say that I did not experience a profound sense of sorrow and loss when, at the age of 1 year, she was diagnosed. That day was without doubt the darkest in my life. I also clearly remember, however, the pivotal moment during the first weeks after Amanda's diagnosis at which I moved beyond my sorrow. One moment I was mired in grief and the next moment I thought: 'I can't waste time over the loss of Amanda because Amanda needs her dinner'. While there have been many emotional highs and lows since that day, and the complexity of her care can often seem overwhelming, the experience of raising my daughter has been both positive and powerful."- Mother of a 21 year-old daughter with severe cerebral palsy (Green, 2007, p.152).

The experience of parenting any child can be stressful, but caring for a child with a physical or mental disability can be a demanding experience as the lifelong care required taxes both the physical and emotional capacities of the caregiver, as well as the material resources of the family (Chirwa & Ndija, 2012). When the parents receive the news that there is something seriously wrong with their child, or receive the diagnosis, they go through a wide range of emotions including denial, anger, frustration, guilt, resentment, depression and fear (Gupta & Singhal, 2004; Marsh, Dickens, Yackovich, & Wilson, 1993, cited in Davis & Gavidia-Payne, 2009). Caregiving for children with physical disabilities can indeed have a momentous impact on the parents or primary caregivers. The above quotation portrays the deep, emotional impact of having a child with severe physical disabilities. The extensive and continuous support required across the child's lifespan may impact on family and social relationships (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, & Wood, 2005). The inadequacy of social support systems and the economic challenges of poverty can exacerbate the problem. Evidence from previous research suggests that long-term caregiving is associated with financial difficulties, physical sickness, psychological distress, fatigue and even mental health challenges such as depression (Bayat, 2007; Heimann, 2004). According to Read (1991, cited in Nelson, 2002) families find that while their expenditure increases as a result of high costs in terms of special diets for the special needs of the child, costs of assistive devices and transport costs, their capacity to earn is reduced because of the additional care involved in bringing up a disabled child, which requires full-time attendance.

Furthermore, parents of disabled children in disadvantaged contexts in South Africa face multiple, unusual challenges and hardships (Saloojee, Phohole, Saloojee & Ijsselmuiden, 2007). These may include, but are not exclusive to: intensive childcare demands which are sometimes unpredictable (Patterson, 1991, cited in Gupta & Singhal, 2004); lack of and/or difficulty accessing services; and poorly resourced service systems (Heah, Case, MacGuire & Law, 2007). Because of lack of resources, many families from low socio-economic backgrounds are negatively affected in their caregiving responsibilities. They may also experience additional problems when attempting to access the mental health system, which means inability to receive the much needed support from mental health professionals.

Whilst the negative side of care-giving has received considerable emphasis in the literature, little attention has been paid to parental ability to see beyond the burdens to the benefits of their caregiving role (Green, 2007). We now have sufficient evidence, that many parents of children with disabilities identify and report positive impacts of their experiences, including personal growth, more self-confidence and self-understanding, and changes in general perspective about life (Gupta & Singhal, 2004; Hastings & Taunt, 2002).

1.1 Significance of the study

Although there is considerable amount of international research on the experience of caring for children with disabilities, the focus of the methods of enquiry has mainly been on knowledge production and the research participants have been relegated to the position of objects to be studied instead of co-authors of 'knowledges' about their experiences. There is limited research conducted using an approach like participatory action research whose aim is not just to produce knowledge, but to bring about transformation at both community and individual levels through the process of empowerment of participants. Secondly, the methods of enquiry that have been used are mainly dependent upon information gleaned from interviews, whereas PhotoVoice, the data collection tool used in this study, relies not just on the voice of the participants, but also on the photographs that capture the reality of their experiences.

This study, which uses PhotoVoice to explore the experiences of caring for children with disabilities, is intended to allow the participants to be co-authors of the knowledge produced about their experiences. PhotoVoice has proven to be a relevant method of data collection when one seeks collaboration and wants to avoid the increasingly critiqued method of

allowing decisions to be unilaterally made by the researcher, which ends up being ineffective in achieving long-term outcomes in communities (Wang, 1999). PhotoVoice is underpinned by the principles of standpoint feminism, a theory built on the premise that feminist social science, or any study into women's subjective experiences should be practiced from the standpoint of women or the particular groups of women under scrutiny, as they are better equipped to understand aspects of their world (Harding, 1990, cited in Foster, 2007). The study therefore aims not just to gather information but to afford the participants an opportunity to be active participants in a study about their experiences whilst at the same time working at improving those experiences. Even though PhotoVoice has been used in South Africa in HIV/AIDS (Mitchell, De Lange, Moletsane, Stuart & Buthelezi, 2005), educational research (Mitchell, 2008) and research with black gay men and lesbians (Graziano, 2004), the area of disability has not been explored much using this approach. There is however study that has been recently published by Rohleder, Hunt and Swartz (2018) using PhotoVoice to reframe understandings of sexuality and disability in South Africa, so this study will add to this small body of research.

Furthermore, the participants in this study are black, IsiXhosa speaking women who have experienced both race and gender oppression, and because of being under-privileged, they are not new to the position of being 'spoken for' and being 'objects' of inquiries. Therefore, this study gives them a unique opportunity to be authors of their stories, allowing them to assume a much more powerful position than the one they are used to. Moreover, it offers them an opportunity, during the focus discussions about their caregiving experiences to take an inventory of their individual and collective strengths, to identify areas of interest and concern, and at the same time be agents for change, through discussion of possible strategies for improvement.

The current research also has the potential to enable local researchers within South Africa to determine whether international literature on the experiences of caregivers of children with physical disabilities is appropriate for the South African context, in particular, for individuals from low socio-economic backgrounds. Finally, the findings of this study could assist policy-makers and other relevant stakeholders such as mental health professionals and organisations for people with disabilities to come up with more appropriate intervention strategies in support of the children with disabilities and their caregivers.

1.2 The purpose of the study

The purpose of the study was to explore and describe the experiences of individuals who are primary caregivers of children with physical disabilities, in Grahamstown, Eastern Cape. The objective of the research was to produce an in-depth understanding of these experiences and to explore how they can be improved. Another objective is to inform policy-makers and other relevant stakeholders of these experiences, so that they can be guided to develop programs and interventions that offer relevant support for the children as well as the caregivers.

1.3 Research question

This study seeks to find answers to the following questions:

➢ What are the experiences of caregivers of children with physical disabilities?

➢ How can these experiences be improved?

➢ How can the findings from this research be used to influence policy?

These are broad research questions which are about an interest in participants' daily experiences, including joys and challenges; the impact of these experiences upon the caregivers' social and occupational functionality and overall well-being; availability of or lack of support as well as coping mechanisms.

1.4 Brief chapter overview

This research report consists of five chapters: literature review, research methodology, findings, discussion and conclusion. The structure of the research is discussed in detail below. The current chapter provides an introduction to the research report and establishes the motivation and purpose of the study. It also provides an understanding of the focus of the study as well as its rationale.

1.4.1 Chapter 2: Literature Review. The purpose of the literature review is to provide an overview of relevant, available research on the experiences of caregivers of children with physical disabilities. The literature review begins by differentiating between impairment and disability and moves on to discuss some models of disability. Subsequently the focus moves on to a discussion of negative and positive experiences of caring for children with disabilities. The chapter ends with the concluding section which is combined with the rationale for the study.

1.4.2 Chapter 3: Research Methodology. This chapter presents the research questions and describes the research approach and method used. This is a research study influenced by principles of Participatory Action Research (PAR) and the focus is to identify issues related to the experience of caring for a child with physical disability and explore ways to improve the experience. This study uses a participatory visual method called PhotoVoice to collect data. The sampling process is discussed and relevant information about research participants is provided. The procedures of data collection as well as how the data was analysed will also be discussed. A section on ethical concerns and methods undertaken to address these concerns is included and the reliability and validity of the study is discussed.

1.4.3 Chapter 4: Findings. This chapter comprises of the presentation of the research findings. The experiences are categorised according to main and sub-themes and photographs that were shared by the participants and that were the focus of narratives and focus discussions by the participants are provided. The photographs are accompanied by verbatim quotes, phrases or narratives from the participants. The photographs are contextualised and discussed in order to give a deeper awareness and understanding of the participants' experiences of caring for physically disabled children. Since PAR advocates for change in the lived experiences of participants, solutions that were the culmination of the brainstorming session to challenges experienced are also presented, as well as the slide show presented by two of the participants, in fulfilment of the PAR's goal of empowerment of participants.

1.4.4 Chapter 5: Discussion. This chapter consists of the discussion of the findings, which is done in the context of existing literature to note areas of similarities and differences.

1.4.5 Chapter 6: This chapter is a conclusion to the study and it includes final comments, summary of the findings and various limitations. It concludes by highlighting the contributions made by the research and makes recommends regarding possible direction for future research.

2. Literature Review

2.1 Introduction

This is a focused literature review on the experiences of caregivers of children with physical disabilities. This study aims to explore and describe, using PhotoVoice, how the primary caregivers of children with physical disabilities experience their day-to-day responsibilities, how they cope with challenges and how their experiences can be improved. For the purposes of this research the term 'caregivers' will be used to refer to the mothers/fathers/grandparents/guardians of children with physical disabilities who serve as parental figures for these children and are responsible for the day-to-day care and maintenance of these children. A child is a person under the age of 18 years (DSD, DWCPD and UNICEF, 2012) and what is meant by disability is discussed in the next section.

Perhaps it is important here to explain the reason behind using the word 'caregivers' as opposed to 'mothers' or 'parents' in this study. In South Africa, especially amongst the 'black' population, one of the lingering effects of apartheid has been the threat to the family structure enforced by the need to migrate to the urban areas in search of employment (Klasen & Woolard, 2009). This has resulted in maternal or parental separation from children leaving grandmothers or other members of the extended family as primary caregivers (Moore, 2013). Even though the apartheid system has now been dismantled, the echo of its evil policies still reverberates and in some cases mothers are forced by circumstances to leave their children in the care of 'others' (Ramphele & Richter, 2006). But it is important to note that in the African context, where the 'other' is a grandmother or a member of the extended family, this is not considered an abandonment of the child, because even in the presence of the mother or parents, other members of the family play a significant role in child care-giving activities (Montgomery, Hosegood, Busza, & Timaeus, 2006).

This chapter begins by differentiating between impairment and disability and then reviews the models of disability as these have been influential in how people understand disability and in shaping public policy on disability matters, which impact on caregivers' experiences. Then the focus moves on to a discussion of negative and positive experiences of caring for children with disabilities. The chapter ends with the concluding section which is combined with the rationale for the study.

2.2 Differentiating between impairment and disability

The number of persons with disability worldwide is estimated at more than one billion, and low- and middle-income countries have particularly high prevalence (Murray & Lopez, 1997 cited in Watermeyer, 2006). In South Africa, it is estimated that the number of people living with some form of disability is 7.5 % of the total population and this does not include the statistics on children under the age of five years or persons with psychosocial and certain neurological disabilities, due to data limitations (Statistics South Africa, 2014). Even though the consequences of disability have received growing attention, the burden of caregiving for persons with physical disabilities remains unquantified.

There are many terms that have been used to speak about people and disability, and from the traditional definitions that were dominant prior to the International Year of Disabled People, in 1981, it is clear that the understanding of disability during that era was based only on medicine and rehabilitation. Historically, disability meant an individual limitation that prevented a person with 'impairment' from performing everyday tasks in what is known as the 'normal' way, which then resulted in a social handicap (Oliver, 1996, cited in Watermeyer, Swartz, Lorenzo & Schneider, 2006). One can understand how any person who 'deviates' from the norm of what is termed 'able' might feel overwhelmed and oppressed just by terminology used to refer to his/her condition. Highlighting the effects of such terminology, Goodley (2017) distinguishes between what he terms ableism and disablism. According to him 'ableism' refers to contemporary ideals on which the able, autonomous and productive citizen is modelled. It is the belief that being without a physical or cognitive disability, impairment or chronic illness is the norm. Disablism on the other hand is defined as the social, political, cultural, socio-economic and psycho-emotional exclusion of people who have physical, sensory, and cognitive impairments.

Various attempts have been made since the 1960's to come up with acceptable and suitable definitions that will distinguish between impairment and disability. The World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps defines impairment as any loss, or abnormality of psychological, physiological, or anatomical structure or function that makes it difficult to perform some functions (WHO, 2011). Disability is any restriction or lack of ability to perform an activity in the manner which is considered normal for a human being and this lack results from the interaction of the person with the impairment and the environment. Depending on how accommodating the

environment is the individual's functioning may be better or worse (Oliver, 2017). The recent revised International Classification of Disability and Functioning (ICF) conceptualises a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors (Levasseur & Desrosiers, 2007). It is a biopsychosocial model of disability, based on an integration of the social and medical models of disability.

Disabled people themselves have looked for words and definitions that distinguish between the physical condition of an individual and the oppressive constrictions experienced by disabled people because of the ways in which society is organised. Many disabled people's organisations reject the term 'people with disabilities' because it implies that the disabling effect rests within the individual, when in actual fact it is the environment that disables the individual (Barnes & Mercer, 2010).

Impairment is the functional limitation within the individual, which is caused by the loss or lack of some functioning part (organ or mechanism) of the body (Anastasiou & Kauffman, 2013). Disability on the other hand is defined as an experience arising out of the interaction between a person with a health condition, such as a physical impairment and the context (environment) in which the person lives. According to The United Nations Convention on the Rights of Persons with Disabilities (Lawson, 2006), disability is an evolving concept which results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others who are considered 'normal'.Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Hendriks, 2007).

People with physical disabilities have impairments that in interaction with the environment hinder their full and effective participation in society on an equal basis with others (Leonardi, Bickenbach, Ustun, Kostanjsek, Chatterji & MHADIE Consortium, 2006).

The organisation, Disabled People South Africa, states that the term 'impairment' should not be confused with the term 'disability', because whilst the former refers to a person's medical condition, the latter is the product of how society fails to include people of difference (Watermeyer, 2006).This dramatic shift in the way of thinking about disability in a social

world is imperative if the focus is to be turned away from locating the problem in people, to tackling the oppression that is experienced by disabled people in society.

The cause of physical disabilities can be grouped using the Uniform Data Set for Medical Rehabilitation as the following: neurological conditions such as multiple sclerosis and cerebral palsy; neuromuscular disorders such as polio, transverse myelitis, and muscular dystrophy; brain dysfunction such as traumatic brain injury and cerebrovascular accident; spinal cord dysfunction such as spinal cord injury and spina bifida; sensory disabilities such as blindness and deafness; arthritic and orthopedic conditions; and other conditions (Austin, 2001).

In this research, the phrase 'physical disability' will be used to refer to the limitation on a person's physical functioning due to impairment and an environment that is not accommodating of the health condition (Masala & Petretto, 2008).

People's perceptions and ideas about people with disabilities are shaped by models of disability and these models also serve other important purposes such as providing definitions, shaping identity of people with disabilities, guiding the formulation and implementation of policy etc, (Retief & Letsosa, 2018) and this has an impact on the lives of the people with disabilities, which directly and indirectly impacts the caregivers' experience.

2.3 Theories/Models of Disability

The three models of disability that will be discussed in this section are: the medical model, the social model and the critical disability theory.

2.3.1 The medical model

Historically, research on disability has taken a medical model perspective which focuses on the biological, often pathological, aspects of disability (Rothman, 2010). According to this model, initially proclaimed in a World Health Organisation definition from 1980, disability is seen to be the result of an abnormality that manifests itself as changes in the structure of the body and problems in body functioning which disable persons from performing certain actions or engaging in certain activities (WHO, 2011). The medical model views disability as a feature of the person, which is caused by some disease, trauma or another health condition and requires medical care in the form of treatment by a professional (Jette, 2006). From this

perspective disability is rooted within the individual's deviance from a healthy norm and is closely linked to the idea of assistance, which can be described in the form of charity and the perception of persons with disabilities as patients, rather than persons (Fin & Asch, 1988 cited in Tarusarira, 2016). As discussed above, until the latter part of the 1900s, disability was understood to be a problem of the individual and the focus of intervention was solely on the specific individual with the intention to 'correct' the problem (Ptyushkin, Vidmar, Burger & Marincek, 2010). This deficit model, does not view a child with a disability in a holistic manner, but focuses instead on the child's inability to function in a so-called 'normal' way. This conveys the message that disabled children are 'incomplete' or 'defective' which in turn causes mothers of disabled children to feel that their children will never be good enough (Mantey, 2015**).**

The medical model has been severely criticised for adopting a narrow view of disability, labelling individuals in a negative way and failing to take into account the broader context in which the individual exists. Its implication, that having a disability is a deficiency and therefore the person must be cured or fixed by the medical profession, has encouraged an attitude which has often led to the individual person being labelled and therefore excluded on the basis of being not 'normal' (Watermeyer, 2006). Barnes, in her book 'The Minority Body: A Theory of Disability' (2016) argues that to be "physically disabled is not to have a defective or broken body, but to have a minority body" (p.6). Even though having a physical disability may make one different, this difference is not in and of itself a negative or bad difference. Some would argue differently though and state that physical disability can have a negative impact on well-being and render one vulnerable by challenging one's capabilities to perform some functions in a world that is programmed to accommodate certain people and not others (Ridley & Watts, 2013)**.** One of the models that arose out of the criticism of the medical model is the social model.

2.3.2 The social model of disability

The social model of disability, which began in the United Kingdom in the 1970s, arose as a critique of the traditional, individual understandings of disability (informed by the medical model of disability) which were viewed as oppressive in that they tended to locate the origin of disadvantage within bodily difference (Priestley, 2006). Inspired by the activism of the British disability movement in the 1960s and the 1970s, the social model of disability developed in reaction to the limitations of the medical model which saw disability as a

medical problem that resides in the individual (Retief & Letsosa, 2018). The social model supporters rejected the medical model outright and called for disability to be acknowledged as a form of structural oppression (Coleridge, 1992,cited in Tarusarira, 2016). The social model, by contrast, aims to understand and challenge the condition of disablism. One of the ways it attempts to do this is by rejecting the notion that disability is a product of bodily pathology and locating it instead in the social, cultural and economic world (Barnes & Mercer, 2010). Within the social model, disability came to be understood as a result of disability barriers imposed on persons with impairments by a society bent on censorship of what it considers a 'misfit' (Oliver, 2017).The emphasis was no longer on individual deviance from a medical norm as observed in a given society, but on the social perceptions attached to that difference, which, it is argued, render impairment a disability (Barnes & Mercer, 1996).

Disablism, according to the social model, reflects a society that discriminates, disadvantages, and excludes people with impairments, by giving preference to those without impairments and failing to make accommodations for those with impairments (Barnes, 1999, cited in Anastasiou & Kaufmann, 2013). The social model is thus concerned with the personal and collective experiences of disabling social barriers and how its application might influence personal practice and shape political action (Barnes & Mercer, 1996). At the core of the social model arguments is the belief that it is society which disables people. So disability is not at all an attribute of the individual, but is a socially created problem. It is not a medical condition but is rather determined by the limitations in carrying out activities of daily living as well as the barriers to participating in the social, economic, political and cultural life of the community that is structured in a way that caters for a certain group of people (Banks & Polack, 2014). Lack of opportunity (e.g. no poolside wheelchairs in swimming pools) and discriminatory behaviours (e.g. teasing and exclusion) are what limit the people with disabilities, not necessarily the impairment.

Some restrictions that are experienced by people with disabilities are attributable not just to social attitudes, but to the socially constructed barriers to self-determination of people with disabilities and to appropriate services such as medical care, counselling services, education, resources etc (Anastasiou & Kauffman, 2013).This sentiment is shared by Watermeyer where he states that "our society has been designed and constructed with only the interests of a portion of South Africans - the so-called nondisabled - in mind" (2006, p1). However, to deny the fact that impairments present special challenges and to construe disability as solely a

creation of social exclusion and social oppression is being reductionist and can result in denial of the assistance that persons with disabilities need due to their impairment (Baglieri, Valle & Connor, 2011). Furthermore, in ignoring the differences and the diversity resulting from the variety of impairments and degrees thereof, the social model risks being labelled as adopting an idealistic stance (Smith-Chandler, 2011). Therefore there is a need to acknowledge the fact that some of the challenges faced by people with disabilities have also to do with the physiological impairment rather than only societal barriers. One theory of disability that offers a balanced conceptualisation of disability is the critical disability theory.

2.3.3 The critical disability theory

The critical disability theory offers an understanding of disability that is a synthesis of the medical and social models (Martin, 2013). Disability is conceptualised as an outcome of some form of impairment, personal responses to the impairment and the barriers imposed by the social environment to the concept of disability (Hosking, 2008). This theory acknowledges both the bio-medical and social aspects of disability. The individual's medical condition, such as not being able to use one's legs, is not the only source of disadvantage experienced by disabled people, impairing though it may be to a certain extent. But neither is society's failure to accommodate the person. Therefore, according to this model for any intervention to be successful it has to incorporate the bio-medical techniques such as prevention, treatment and rehabilitation, as well as the social model interventions of changing the socially constructed environmental barriers (Barnes & Mercer, 2010). Anastasiou et al, (2013) posit that the meaning of disability lies in both biology and society and to deny the role of biology in disability is also to deny the daily experiences of people with disabilities.

The World Report on Disability is in agreement with the critical disability position as it also construes disability as neither a purely medical or social phenomenon, but as an umbrella term that refers to activity limitations *and* participation restrictions with regards to interaction between an individual and that individual's contextual factors, encountered as a result of impairments or certain health conditions (WHO, 2011). In agreement with the tenets of the critical disability model which advocate for an account of disability that views it as socially constructed, yet emphasizes the significance of objective realities of disabled individuals, the phrases 'physically disabled' and 'children with physical disabilities' will be used interchangeably in this research report.

The theories/models discussed in this section do not just provide definitions, shape identity of people with disabilities and inform policies, but they influence people's perceptions about disabled people and also impact the caregiving experience to the point of determining the presence or absence of, as well as the nature of support received by the disabled people and/or their caregivers. Both positive and negative experiences have been noted when it comes to caring for a physically disabled child (Hastings & Taunt, 2002) and the subsequent section will focus on what these experiences, as elaborated in the literature, are.

2.4 Caring for a physically disabled child: burden or joy?

For most parents, the birth of their child is both a joyous time and a time for celebration. However, from as early as giving birth, many parents receive distressing news about their child's health. This news may be the fact that their child has a serious chronic illness, a health defect, disability, sensory impairment or intellectual impairment (Barnett, Clements, Kaplan-Estrin & Fialka, 2003). This has been described as a very challenging time as the parents have to deal not just with the disappointment of letting go of 'what might have been', but facing the possibility of a future that is filled with struggle and sadness of dealing with what is yet 'unknown' (Fisher & Goodley, 2007).

It is a fact that diagnosing disability in children is inherently much more difficult than in adults, due to the fact that children go through a natural development process as they grow, thus making the task of assessing and distinguishing limitations from variations in normal developmental processes a complicated and complex one (Halfon, Houtrow, Larson & Newacheck, 2012). Because children are developing and changing constantly, knowing when to apply a diagnostic label to a developmental concern can be particularly difficult. Using the Washington Group (WG) Short Set of Questions, which ask survey respondents about difficulties experienced in seven domains of functioning e.g. hearing, walking, remembering, concentrating, self-care and communication, the Statistics SA Annual General Household Survey 2009 classified nearly 2.1 million children as disabled (Department of Social Development/ Department of Women, Children and People with Disabilities/ UNICEF, 2012). This is 11.2 per cent of the total child population.

2.4.1 The challenges associated with caring for a child with a physical disability

The experience of parenting any child can be stressful (Cameron, Dobson, & Day, 1991 cited in Watson, 2011), but researchers have suggested that families generally respond well and adjust in order to maintain stability and manage life's challenges (Minnes, 1988 cited in Groce, Kett, Lang, & Trani, 2011).The presence of a child with a physical disability in a family, however, is a huge responsibility that has its own unique challenges and it has an immense impact on the way the family functions (Seligman & Darling, 2009). Caregiver burden is conceptualised as a multi-dimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience (Oh & Lee, 2009; Resch, Mireles, Benz, Grenwelge, Peterson & Zhang, 2010). Researchers have proposed that families of children diagnosed with disabilities are negatively impacted and therefore experience more instability and dysfunction than families with typically developing children (Green, 2007; Watson, 2011). This strain is usually determined by the nature and severity of the child's physical disease or disability (Wallander, 1995 cited in Green 2007) and may be exacerbated if the family lives in an under-resourced area (Dambi, Jelsma, & Mlambo, 2015). Besides the usual parenting responsibilities, caring for a child with a physical disability usually brings disability-specific demands such as maintaining treatment and care regimen, social and financial constraints and maintaining family responsibilities (Groce, Kett, Lang & Trani, 2011). Seligman and Darling (2009) have written extensively on childhood disability and its effects on family life based on their research, and they provide a vast amount of information on the processes of adapting to the presence of a disabled child, including aspects such as the stages of mourning for parents, the different attitudes parents develop when they have a child with a disability and the challenges of endless care for the child and factors that affect the family, such as stress and finances. Many studies that have been conducted in both affluent and financially constrained communities, and in different cultures, on the experiences of caring for children with physical disabilities have reported diverse challenges associated with this task (Monsen, 1999; Mpontshane, 2017; Smith, Cheater & Bekker, 2015;Stabile & Allin, 2012; Wiart & Darrah, 2002). The following have been associated with the experience of caring for a child with physical disabilities: coming to terms with the loss, activities of caregiving, time spent on activities related to caregiving, psychological burden, role restriction and the social impact on caregivers, the financial implications as well as communication problems. Each of these will be discussed in turn below.

2.4.1.1 Coming to terms with the loss

The impact of the diagnosis on the parent brings a range of emotions such as disbelief, confusion, anxiety, fear, guilt, turmoil, grief and a loss of identity (Johnson, 2000; Monsen, 1999). According to research, the initial grief that parents experience is related to losing the 'child of their imagining' (Moses, 1988 cited in Barnett et al. 2003). Smith, Cheater & Bekker (2015) conducted a rapid structured review of primary studies written in English describing parents' experiences of living with a child with a long-term condition. One of the commonly reported issues in the 34 studies that met the criteria for inclusion was that parents experience stress, disappointment and grief when their child does not meet their hopes and expectations for a healthy child. This grief can later turn to chronic sorrow and depression as one continually searches for reasons for the child's condition, whilst also being confronted with feelings of self-blame and guilt. One of the strengths of this review was that it covered a wide range of contexts and was inclusive of studies conducted in both rich and poor resource settings.

Parents have to learn to adjust their expectations and hopes for their child in the face of substantial uncertainties inherent in the child's medical, motor, intellectual and social prognosis (Bowlby, 1980 cited in Barnett et al. 2003). Nelson (2002) conducted a metasynthesis of twelve studies conducted in the U.S., focusing on the experience of mothering other-than-normal children. The nature of the child's disability, the demographics of the study populations and specific qualitative methodology used varied widely. One of the common emotional themes inherent in the accounts of the mothers was the shock and disappointment at the news of having a disabled child, confusion and anxiety related to a delay in diagnosis and confusing, inconsistent medical diagnostic opinions. In the cases of delayed diagnosis, the mother not only faces the loss of the child she had previously known but has to transition to the next step in the mothering experience, that of negotiating a new kind of mothering (Boydell, 1996 cited in Nelson, 2002). Similar findings were confirmed in a systematic review of available literature on paediatric cerebral palsy in Africa by Donald, Samia, Kakooza-Mwesige and Bearden (2014) where they found that in poor resourced communities, there is lack of resources to support the mother to emotionally process the situation, which means she has to deal with the devastating news all by herself and this can later lead to other mental health problems such as depression.

2.4.1.2 Activities of caregiving

Adaptation and coping has been identified as a prominent feature of living with a child with physical disabilities, and this is a dynamic process because the child's condition changes with time and other developments, such as increase in height or weight, bringing other challenges when it comes to taking care of such needs as bathing and mobility etc (Davis & Gavidia-Payne, 2009; Davis, Shelley, Waters, Boyd, Cook & Davis, 2010). Providing on-going care is a main challenge resulting in what is termed functional care strain, especially in the absence of effective support. A child with physical disability needs more assistance with some if not all activities of daily living which include bathing, dressing, toileting and eating. Even though all children, depending on their age need assistance with these, with a child with physical disability this is an on-going chore and despite the age of the child, he/she may never get to the point of doing these activities without assistance (Thrush & Hyder, 2014). Transition to independence and self-sufficiency is a dream that is never realised in cases where the disability is severe. Chiarello et al. (2016) conducted a study involving 585 parents or guardians from 6 Shriners Hospitals for Chidren around USA. The purpose of the study was to identify family priorities for activity and participation in children and youth with cerebral palsy and what they found out is that 68.7% of the parents identified mobility most often as a priority and expressed concerns about dressing, toileting, self-feeding and play. These parents identified self-care as a primary focus of rehabilitation, as they felt that if the children could be brought to a level where they can take care of their basic needs this would lessen the caring responsibility. The challenge of mobility is further exacerbated by lack of wheelchair accessible transport, which is a particular challenge for families with older children.

Providing physical assistance such as lifting, carrying or helping to walk has been cited as a challenge that results in physical strain on the caregivers (Geere, Gona, Omondi, Kifalu & Hartley, 2013) .Some of the symptoms associated with the physical burden of caring include: fatigue, tiredness or exhaustion and sleep deprivation. These symptoms sometimes lead to chronic back pain, hypertension and resultant sickness for the carers themselves (Geere et al., 2013). Even in contexts in which there may be support available, caring for a child with physical disabilities may have a negative impact on the health and well-being of caregivers (Makela, Birch, Friedman & Marra, 2009).This is because physical disability is associated with multiple impairments resulting in activity limitations as well as participation restrictions. According to the findings from research conducted by Mpontshane (2017) in the Uthungulu

District municipality, Zululand, due to activity limitations of their children, mothers are sometimes forced to carry their child on their backs whilst doing house chores or travelling long distance to access services. This finding however may not be applicable to other contexts where there are assistive devices such as wheelchairs or access to transportation.

2.4.1.3 Time spent on activities related to caregiving

Caring for a child with physical disability can be a time-consuming responsibility and depending on the severity of the disability, it can be a full-time responsibility (Brotherson, Goldstein, 1992, cited in Thrush & Hyder, 2014). Besides the amount of time spent on activities of daily living, there is the time spent frequenting health-care facilities for check-ups, medication and other support (McCann, Bull, Winzenberg, 2012). Most parents of children with physical disabilities indicate that everything they do revolves around their children and most of their days are spent in caregiving responsibilities. For example, in a study by Murphy, Christian, Caplin and Young, (2007) who distributed questionnaires to forty parents/caregivers of children with disabilities residing in urban, suburban and rural regions of Utah, the majority of the caregivers stated that the daily caregiving responsibilities occupy most of their time, even to the point of them neglecting self-care and other duties to other members of their families. As a result of having no time for rest, especially where one lacked respite care this often led to burnout, physical pain and emotional challenges. Chirwa and Ndija, (2012) conducted a study of the experiences of mothers caring for their school-going children with physical or mental disabilities in low-income communities, conducted in Cloetsville, an Afrikaans-speaking, mostly Coloured community in the Western Cape report an interesting finding. They reported that despite the fact that caring for a disabled child is time consuming and even though there was support available in terms of family and a special needs school, some of the parents were reluctant to leave their children as they were not sure of the quality of care they would receive. These caregivers stated that even time away from the child was spent thinking about the child and imagining the worst case scenario.

2.4.1.4 Psychological burden

Caring for a child with physical disabilities can be emotionally draining and some studies which screened caregivers found them to be at risk for clinically significant mental health problems (Raina et al. 2005; Dunn, Burbine, Bowers &Tantleff-Dunn). Some of the psychological burdens that have been reported include denial, projection of blame, guilt,

depression, anxiety, despair and lower levels of happiness amongst others (Thrush & Hyder, 2014). Sometimes the emotional trauma, paralyzing disbelief and confusion begin right in the delivery room as the mother watches the silent responses of birth attendants as well as the sound and sight of efforts of resuscitation (Monsen, 1999). According to Oh and Lee (2009) mothers of children with disabilities experience greater stress than other mothers and this is because of the daily tasks that take their time away from adequately taking care of themselves. Depression has been associated with the gruelling, daily care-giving activities; whereas anxiety has to do with 'worry' about the quality of child care, lack of resources and concern about the future of the child should the parent not be available to take care of their needs (Chiarello et al, 2016). Some caregivers have cited despair in relation to the hopelessness of the situation as one is confronted daily with the reality that their child will never fit into what is normal (Nelson, 2002). In addition to the prevalence of significant health challenges, caregivers who are from poor-resourced areas and low socio-economic backgrounds hardly receive any psychological treatment or related support (Van Der Mark & Verrest, 2014). Saloojee, Phohole, Saloojee and Ijsselmuiden (2007) conducted a study, using a descriptive study design, exploring unmet health, welfare and educational needs of disabled children in Orange Farm, an impoverished South African peri-urban township. One of their findings was that the sense of despair and helplessness felt by caregivers of more severely disabled children was unmistakable, and what was even more discouraging was the fact that none of the caregivers interviewed belonged to a support group or disabled people's organisation, which meant the only form of emotional support at their disposal was from their immediate family.

Lack of collaborative working between parents and health professionals perceived inhumane treatment of the child as well as insensitivity of the health care providers can also add to the feelings of despair and helplssness (Alex & Whitty-Rogers, 2012). Lack of support in relation to managing their children's long-term condition, service provision that lacks coordination as well as inability to retain and assimilate information were cited as some of the challenges contributing to psychological distress in a rapid structured literature review conducted by Smith et al. (2015). This review included a wide range of data from countries such as USA, UK, China, Finland, New Zealand and Sweden. One limitation of the review is that it was too general as the requirement for inclusion was that the study must be about the experience of caring for a child with a long-term disease and as such, parents' accounts of disease-specific challenges may not have been captured.

2.4.1.5 Role restriction and the social impact on caregivers

The inability to pursue one's personal interests due to the responsibilities involved in raising a child with physical disabilities is one of the challenges reported for caregivers and this restriction affects not just social activities, but other areas such as homemaking, participation in community affairs, education and career (Wallander, 1995 cited in Makela et al, 2009). Caring for a child with physical disability can result in changes in personal plans, which influences one's social life as well as their social connections (Chirwa & Ndija, 2012). It means less freedom, a restricted social life and withdrawal from activities such as church, hobbies, outings etc (Mpontshane, 2017).

One of the challenges faced by parents of children with disabilities is that they must raise their children within the context of powerful societal discourses that devalue people with disabilities and, therefore, hold low expectations for the ultimate success of parenting children with disabilities (Prilleltensky, 2004, cited in Chiarello et al., 2016). It is such discourses and beliefs that sometimes negatively influence the parents' attitudes and responses towards having a child with disability. In some countries such as India, disability is still viewed in terms of a 'tragedy' with a 'better dead than disabled' approach (Gupta & Singhal, 2004). The high levels of social stigma toward children with neurological disorders have been stated as some of the reasons for families failing to seek treatment even when it is available (WHO, 2006). According to Gona, Mung'ala, Newton and Hartley (2011), this social stigma can extend to the condition of the child being viewed as resulting from evil spirits, which leads to isolation and exclusion not only for the child but also for the caregiver. In her book *'The forgotten tribe: People with disabilities in Zimbabwe'*, Choruma (2007, cited in Chirwa & Ndija, 2012) states that in some cultures disability is also surrounded by myths concerning witchcraft, curses and God's punishment for maternal promiscuity. This was confirmed in a study by the two researchers which was conducted in Mutare, Zimbabwe's third largest town, using various qualitative and quantitative methods. According to findings in this study, caregivers of disabled children suffer from prevalent stigma associated with beliefs of witchcraft, maternal failure and evil spirits, on a daily basis. Cultural beliefs as to the cause of the disability have also been cited as contributors towards this stigmatization and subsequently social isolation and emotional problems for the caregivers.

In some studies, caregivers are reported to have experienced negative reactions such as gossiping, avoiding contact, showing disgust and/or fear for the child with disability (Lang & Chadowa, 2007, cited in Lang, 2009; Marongwe & Mate, 2007). Children with disabilities are sometimes seen as objects of shame who should not be seen and the child gets excluded and misses out on the opportunity to play or engage with others and this can be a very sad experience for a parent (Dowling & Dolan, 2001). There is also family conflict and less stability in relationships (Mailick Seltzer, Greenberg, Floyd, Pettee, Hong, 2001).

2.4.1.6 The financial implications

The financial or economic impact of caring for a child with physical disabilities has been reported in several studies as one of the challenges of the experience (Davis et al 2010; Green, 2007). Anderson, Dumont, Jacobs, Azzaria (2007) conducted a review of the literature published from 1989 to 2005 for articles that examined the economic burden incurred by families as a result of caring for a child with disabilities. The articles reviewed were mainly from the U.S. and the U.K. Their analysis indicated that the burden incurred by these families can be substantial, especially among families who care for a child with a severe disability. But what the analysis failed to discover was what the magnitude of this cost was and to account for factors such as the country where the study was conducted, the races studied, variables of ages of children, family income level, severity of the disability and the different methods of enquiry.

Due to the demands of the daily life activities, caregivers report loss of income or productivity, either through reducing hours of work or stopping altogether so as to focus on the caregiving role (Stabile & Allin, 2012). Some caregivers struggle to retain meaningful employment and in turn, an adequate standard of living due to a lack of reasonable workplace accommodations and/or inclusive childcare arrangements (Warfield, 2001, cited in McConnell, Savage & Breitkreuz, 2014). This was confirmed in a study by Dambi et al. (2015) to establish the well-being of caregivers of children with cerebral palsy, living in high density areas of Harare, Zimbabwe. According to data collected in this study which used a descriptive and analytical longitudinal design, caregiving may lead to compromised working conditions due to the conflicting demands of caregiving and employment, which ultimately results in limited opportunities to enter gainful employment. In addition to loss of income, provision of care usually involves significant financial expenditures related to medical expenses, assistive devices, special foods, endless visits to doctors etc (Elina, 2012).

In resource-poor contexts like some communities in South Africa, limited access to health-care facilities and specialists, and lack of adaptive equipment and other ambulation aids aggravate the situation (Donald, Samia, Kakooza-Mwesige & Bearden, 2014). Caregivers find the financial costs attached to medical care, rehabilitation, assistive devices and transportation to be significant barriers to seeking care and improving the experience of caring for these children (Patterson, 1997, in Stabile & Allin, 2012). Both child's and caregiver's health are compromised when there is lack of resources to assist in caring for the child (Wiart & Darrah, 2002). Lack of inclusive child care as well as educational options also puts a strain on family finances, because it means only the most affluent can afford to take their children to private school (Heah, Case, & MacGuire, 2007). A study by Saloojee et al. (2007) revealed the fact that an alarming gap exists between the needs of those, and the services available in, resource-poor settings and despite the fact that there is state-funded assistance available for children with disabilities, less than half of the children in their study were recipients of this grant. Secondly, lack of money was listed as one of the major reasons why caregivers were not utilising available services, since they needed to travel long distances and could not afford transport money.

Lack of financial resources has also been linked with difficulty in finding a suitable school for the child with disability by parents of children with disabilities in a study conducted in the Uthungulu District municipality, Zululand by Mpontshane (2017).

2.4.1.7 Communication problems

Parental sensitivity, emotional attunement and responsivity with young children largely depends on parents' ability to accurately recognise, understand and interpret their children's behaviour, body language, facial expressions and speech (Howe, 2006). However, in the case of children with disabilities, there may be a range of conditions that affect motor and cognitive development, which compromises their ability to communicate with clarity their thoughts, needs or feelings. This failure to understand the child's mental states is one of the things that contribute to the caregiver's frustration, emotional strain and helplessness (Goubert et al. 2005). But this frustration is not felt by the caregivers only, as was revealed in a study to develop an in-depth understanding of how Ugandan families cope with their disabled children, conducted by Hartley, Ojwang, Baguwemu, Ddamulira, Chavuta, (2005). In this study, which used a qualitative phenomenological design, carers mentioned that communication problems often limited the child's ability to express his/her needs and

feelings, leading to frustration resulting in the child becoming withdrawn. Not being certain of what need the child is communicating frequently leads to a trial and error approach, where different things are tried out with the child and the resultant responses estimated (Gona et al, 2011). Fonagy, Steele, Steele and Moran (1991, cited in Howe, 2006) state that failure to mentalize and be attuned to the child's emotional state sometimes result in anger which leads to ignoring the child, which later may lead to feelings of guilt and heighten the helplessness of the situation. Because most of the children with cerebral palsy suffer from communication difficulties, 'excessive crying' may be the only viable means of communicating, which leads to more frustration for the caregiver (Dambi, et al, 2015).

Although we have explored negative experiences of caring above, caregivers have also described positive experiences that have resulted from caring for their children with physical disabilities. The subsequent section will now focus on this.

2.4.2 Focusing on the positive aspect of the experience

The negative side of care-giving for a child with physical disabilities has received considerable emphasis in the literature on the social experience of parenting children with disabilities, (Boerner, 2004, cited in Green, 2007). Little attention has been paid to parental ability to see beyond the burdens to the benefits of their caregiving role (Green, 2007). We now have sufficient evidence that many parents of children with disabilities identify and report positive impacts of their experiences, including personal growth, more confidence and self-understanding, and changes in general perspective about life (Gupta & Singhal, 2004; Mpontshane, 2017). Scorgie and Sobsey (2000), conducted a two-phase study in order to explore transformation in the lives of parents of children with a wide range of impairments, such as hearing impairment, visual impairment, severe multiple disabilities, Down syndrome, rare genetic conditions etc. The participants included families members recruited via an agency in Western Canada and parents who resided in Alberta. The first phase was qualitative and was designed to determine how some parents of children with disabilities who are managing life successfully would describe the positive aspects of their experience. The second phase was quantitative and intended to determine the proportion of other parents of children with significant disabilities who agree with the statements made by the former parents. All the parents who were interviewed and a large majority of the parents surveyed reported some positive transformations associated with parenting their children with special needs. These perceived transformations were reported in personal growth, improved relations

with others and changes in philosophical or spiritual values. Bayat (2007) reports similar findings from a survey study of 175 parents and other primary caregivers of children with autism. In a study of parents of infants in neonatal intensive care units, Affleck, Tennen, and Gershman (1985, cited in Green 2007), found that even at this early stage over half of study participants perceived benefits arising from their experiences.

It is sad however to note that there are studies that have suggested that parents who hold positive attitudes towards raising a child with disability are sometimes referred to by some researchers, health professionals and some community members as being unrealistic and in denial of their children's conditions and are depicted as failing to accept their tragic circumstances (Ferguson, 2001 & Read, 2000, cited in Green, 2007). These studies suggest that at most, the experience of caring for a child with a long-term condition is much more complex and nuanced than the current body of literature suggests (Groce et al 2011). Some of the benefits associated with caring for children with physical disabilities are: personal growth, focusing on the child, the relationship and the child's achievements and support system. These will each be discussed in turn.

2.4.2.1 Personal growth

Even though research literature has been written extensively about the stress associated with caring for children with disabilities, what has been discounted is the fact that the stressful experiences can result in acquisition of new coping skills and resources, perception of growth and spiritual or religious transformation (Gupta & Singhal, 2004). According to Johnson (2000), caring for a child with a long-term condition provides opportunity for personal development such as increased knowledge about the child's condition and treatments, managing the child's unique needs and improved communication and organizational skills. This was confirmed by findings from the phenomenological hermeneutic study conducted by Monsen (1999) in Arkansas on the lived experiences of mothers of children with spina bifida. Caucasian and African-American mothers of children with spina bifida, aged between 12 and 18 reported that one of the areas in which they had grown was in learning to work collaboratively and share responsibility with health professionals, to negotiate terms and conditions related to managing the child's needs and assume the role of advocating for their children. One limitation of this study is the fact that the sample was too small for it to be generalisable to other contexts.

Another study by Green (2007), which included a survey of 81 mothers with disabilities in Florida, USA, and follow-up interviews with 7 of these mothers, found that most mothers of children with disabilities become experts in navigating the health care and social delivery services and this makes them a point of reference and they become the "go to" people within their families whenever a crisis arises. These skills and the accompanying confidence can spill into other areas of life and the caregivers' self-image is boosted and they become more assertive. Exposure to the world of disability also increases one's level of comfort with other people with disabilities, makes one more compassionate and less self-focused, and teaches one to see beyond the disability (Ambikile & Outwater, 2012). According to Heimann (2002), parents of children with disabilities are able to arrive at this more positive state through the need to form a new identity, attempts to derive meaning from the situation, development of a sense of personal control and being in charge of the situation.

2.4.2.2 Focusing on the child, the relationship and the child's achievements

The pleasure and satisfaction gained through the relationship with the disabled child is one fundamental reason why parents feel able to continue to care for their child. In a survey of 81 mothers of children with disabilities in Florida, USA conducted by Green (2007), in the composite measure of nature and extent of perception of benefit, all the participants stated that watching the pride and joy the child feels with each accomplishment made all the work worth the effort. Green, concurs with this finding on the basis of her own lived experience as a mother to Amanda, a young woman who lives with severe cerebral palsy. She claims that she has experienced immense pride at her daughter's achievements which include enrolling in a post-secondary commercial photography program and selling her own work in local shops and art festivals. This perceived benefit of pride and joy at the child's achievements is also recorded in a South-African study which reported on an 8-week randomized controlled trial of a strength training program for adolescents with cerebral palsy. In this rehabilitation programme mothers worked in collaboration with health professionals and the results, which reported improvement in gait and body image perception (Unger, Faure & Frieg, 2006) were regarded by the mothers as an important milestone for both mother and child. It is such achievements, resulting from collaborative work with caregivers that motivate parents and caregivers to stay positive and celebrate even the smallest improvements. After the initial stage of grief for the loss of the 'child of one's dreams', research suggests that some parents experience a shift when they pull themselves together and focus on the child who needs them

and this attitude change and focusing on 'this' child enables one to open up to new possibilities (King et al.,2006).

2.4.2.3 Support system

The availability or unavailability of support has been reported as having a huge impact on some of the challenges experienced by caregivers and this theme was found to be common to all the families involved in the study of Ugandan families conducted by Hartley, Ojwang et al. (2005). Social support may serve as a coping resource in optimising caregiver well-being and health outcomes (Seligman & Darling, 2009). A non-critical family network has been associated with low psychological distress in mothers and having a social network predicts positive family adjustment (Gupta & Singhal, 2004). Social support networks, including family and other household members, provide emotional, financial and practical support, especially where institutional facilities are absent (Oh & Lee, 2009). In instances where the caregiver has some support and shares caregiving duties with some adults, the negative impact on social relationships is reduced (Raina et al, 2005). This theme of availability of support in the form of baby-sitting, from family, friends and neighbours and its positive impact in lessening the physical burden and allowing for time for personal and social activities was highlighted in the systematic review of literature on paediatric cerebral palsy in Africa conducted by Donald et al. (2014). One of the strengths of this review is the fact that literature from different countries, using a wide variety of tools was consulted, making the findings more generalisable to various contexts. Some mothers have also reported that caring for a child with a disability can strengthen existing social bonds and important familial relationships as it has potential to bring members closer as they learn to support each other (Chirwa & Ndaji, 2012).

Hospitals, clinics and health workers provide professional support usually in the form of information that enhances the management of the child, enabling the carer to access services and benefits meant to ease the task of raising their child (Pain, 1999, cited in Johnson, 2000). The role played by health professionals can sometimes shift from that of just a care prescriber and information dispenser to one of collaborator, working in partnership with parents (Smith et al 2015). Davis and Gavidia-Payne (2009), in their study of the impact of child, family and professional support characteristics on the quality of life in families, recruited and administered questionnaires to families of 64 children with a developmental delay or disability from 14 Early Childhood Intervention Centres in the northern, western and eastern

suburbs of Melbourne, Australia. What they discovered from their study is that parental perceptions and experiences of family-centred professional support was one of the strongest predictors of family quality of life. Support from extended family members was listed as a significant contributor.

The presence of community-based rehabilitation programmes has been reported as being effective, not only in terms of support, but in increasing access to education and assistive devices (Donald, et al, 2014). It is this expertise and contribution that is valued by parents of children with disabilities. What transpired in a phenomenological qualitative research exploring the experiences of parents of children with disabilities in Zululand, conducted by Mpontshane (2017), is that even in the absence of formal rehabilitation programmes to offer support, the availability of extended family members, as well as support structures in the caregivers' communities did contribute towards the positive experiences.

Other forms of support from the state or private organisations has been linked to perceived benefits and this may include respite services, financial services such as cash subsidies, in-home support such as personal assistance, assistive technology, adaptive medical equipment, health and professional services, family counselling, parent support groups, transportation, specialised clothing and dietary services (Rizzolo, Hemp, Braddock, Schindler, 2009). In South Africa, there is a government assistance programme in the form of a disability grant which can be very useful in allaying some of the costs of caring for a child with disabilities. The disability grant, which is called the Care Dependency Grant is awarded to the parent, primary care-giver or foster parent of a child who is under the age of 18, provided a medical or assessment report confirming that the child is severely disabled and requires permanent care or support services (South African Social Security Agency, 2005).

2.5 Conclusion

The purpose of the literature review in this chapter was to explore how the developments concerning the experiences of caregivers of children with physical disabilities have been evolving over time. The review first looked at definition of terms pertinent to the study, then three models/theories of disability were discussed and lastly current and historical literature to contextualise the study, and local and international sources were consulted. Caregivers of children with physical disabilities may have both positive and negative experiences of their

responsibility. They may experience the families, community structures and mental health system as not providing the essential support for better care to take place. However, when this support is available they may experience the lessening of the burden. Furthermore lack of resources and financial constraints contribute to the negative side of the experience, whereas focusing on the relationship with the child and the child's achievements have been seen as positive factors.

Although there is considerable amount of international and local research on the experience of caring for children with disabilities, the focus of the methods of enquiry has mainly been on knowledge production and the research participants have been relegated to the position of objects to be studied instead of co-authors of 'knowledges' about their experiences. In this current research however, photovoice, a participatory action research data collection tool, is used to give a platform to primary caregivers of children with physical disabilities to share their lived experiences and brainstorm ways and means of improving these experiences.

3. Research design and methodology

3.1 Introduction

The purpose of the current study is to develop a deeper understanding of the lived experiences of caregivers of children with physical disabilities in Grahamstown, South Africa, explore how these experiences can be improved and take the necessary steps aimed at bringing the desired change. It is hoped that through the sharing of narratives the participants will not only benefit from social support but will also be empowered through learning from one other.

This is a qualitative study, situated within an over-arching framework of action research, in particular, participatory action research. As noted by Merriam (2009), qualitative research is interested in understanding the experiences people have in their world and the meanings they have constructed about these experiences. Action research aims to help people investigate reality in order to change it (Kemmis & Wilkinson, 1998). It seeks to produce practical knowledge that is useful and relevant to individuals in their everyday lived experiences (Bradbury & Reason, 2003). Participatory action research involves different stakeholders who have an interest or concern in the outcome of the study, from its beginning to the end (Wagner, Kawulich & Garner, 2012). These may include the researcher, the participants, policy proponents, Non-Governmental-Organisations and government departments.

In this chapter PAR and the PhotoVoice data collection strategy will be discussed in detail, including the sampling process, the method of recruitment of participants, a description of participants and the data analysis process. It is vital that every research project be based on ethical considerations, and this is essential especially in this study which uses PhotoVoice, an intrusive data collection method. So the ethical guidelines which informed this study and which were implemented will also be highlighted. A section on the validity and reliability of the methodology used in the study will also be provided.

3.2 Research questions

This study seeks to find answers to the following questions:
- ➢ What are the experiences of caregivers of children with physical disabilities?
- ➢ How can these experiences be improved?

➢ How can the findings from this research be used to influence policy?

These are broad research questions which are about an interest in participants' daily experiences; including joys and challenges, the impact of these experiences upon the caregivers' social, occupational functionality and overall well-being, availability of or lack of support as well as coping mechanisms. As a participatory action research project, the aims of the research are also to empower participants through their engagement with the research.

3.3 Research design

This is a qualitative research study that is informed by principles of Participatory action research (PAR). PAR principles are appropriate for this project as its core tenets are complementary to the aim of this research, which is exploring the experiences of caregivers of children with physical disabilities, with the purpose of sharing their narratives with other stakeholders as a way of seeking to enhance their well-being and engage in a process of transformation where necessary.

Participatory Action Research (PAR) is different from the traditional 'expert' research models in that planning and execution of research is a process of collaboration between the researcher and the members of the community or organisation under study (Kemmis & Wilkinson, 1998). PAR seeks to bring about transformation in living conditions at both community and individual levels through the process of empowerment of participants (van der Reit, 2001). It draws on critical social theory, a multi-disciplinary knowledge base whose implicit goal is to promote human liberation and advance the liberating function of knowledge by promoting the role of criticism in the pursuit of knowledge, understanding and emancipation (Leonardo, 2004). Critical social theory promotes the cultivation and nurturance of an ability to critique institutional as well conceptual predicaments, particularly those that lead to domination and oppression in their many forms (Shapiro & Hassinger, 2007).

Being particularly concerned with social justice, PAR is famous for its principles of inclusivity, empowerment, support and relationships, as well as learning and democracy (Townsend & Wilcock, 2004). PAR methodologies are used to increase participation through the utilisation of creative methods and by engaging in a collaborative process between the researcher and the participants (Bray & Moses, 2011). The appeal of PAR is that in claiming to empower, it has the potential to address the profound inequalities in power between the

participants and the researcher, by getting them involved in the process of co-construction of knowledge (White, 2005). Research is not done on people, but by and for people. Even though there are methodologies in the other disciplines under qualitative research which are sensitive to and which acknowledge these views, these have been used mainly to inform the research design, but the process used in designing still ascribes to and reflects many of the qualities of the traditional approaches where the participants still assume the role of 'subjects' to be studied (Borrel-Carrio, Suchman, & Epstein, 2004). Studies of caretakers of children with physical disabilities have been conducted, but there is a need to use a design that allows for them to be active participants in constructing knowledge about their lived experiences. The data collection method that was employed allows not just for this gap to be filled, but for the participants to assume the superior role of being agents for change, instead of playing the usual role of receiving 'hand-me-downs' from someone 'up there' who thinks they have an answer to the challenges articulated. Data collection for this research was done through photovoice, an arts-based research method grounded on insights drawn from the following theories; the feminist standpoint theory, Paulo Freire's 1970 approach to empowerment education and critical consciousness theories, and a participatory approach to documentary photography (Wang & Burris, 1997). Each of these theories will now be discussed in detail to provide an outline of the theoretical basis of the methodology.

3.3.1 The feminist standpoint theory

There are two central understandings that have shaped the feminist standpoint theory; that knowledge is situated and subject to perspective, and that there are multiple viewpoints from which knowledge is produced (Intemann, 2010). The positivist research paradigm has always claimed universal knowledge with its assumption that the scientific method is the only way to establish truth and objective reality, and that its objective methodologies are value-free, based on precise observation and measurement that is verifiable (Wagner et al., 2012). But the feminist scholars' and researchers' illumination of women's previously invisible experiences as well as exposing the under-representation of these experiences within this paradigm disputed this claim (Brooks, 2007). Subsequently, feminists produced research that posed a serious threat to the positivist claim about the so-called value neutrality of positivist social science (McGlish, & Bacon, 2003). Knowledge building has never been value-free, social reality is not static and there is no social scientific inquiry that exists outside of the social world (Hruby, 2001). According to Hartsog, (1975, cited in Intemann, 2010) reality as

perceived by different segments of society is varied, and therefore subjective experience should be respected because it offers an insider view into the understanding of a certain phenomenon.

Feminist standpoint theories date back to the 1970's/ 80's and challenged the relations between the production of knowledge and the practices of power (Harding, 2004). Standpoint feminism is a theory built on the premise that feminist social science, or any study into women's subjective experiences should be practiced from the standpoint of women or the particular groups of women under scrutiny, as they are better equipped to understand aspects of their world (Harding, 1990, in Foster, 2007). Even though the researcher for this study did not set out to specifically recruit female participants, all participants turned out to be women and this suggests that primarily, caregivers of children with physical disabilities are predominantly women. It is befitting therefore that a study that seeks to pursue a deeper understanding of women's experiences should be under-pinned by a theory like the feminist standpoint theory. This theory encourages use of research methods where women are not just positioned as subjects, but are actively involved in data collection, meaning-making as well as advocating for change.

According to the standpoint epistemology, the status of the oppressed as the bearer of authoritative knowledge is supreme over the procedures of science (Ganote & Longo, 2015). Thus, when there is a conflict between two 'knowledges', the perspective of the oppressed is to be preferred, in the cases where the matter of dispute is about their experiences (Walby, 2001). This is based on the fact that direct experience is more objective and less distorted than the assumptions made by an outsider. A standpoint is the point or place at which a person stands to view something and this determines what the person focuses on but also what is hidden from the person's view (Capous-Desyllas, 2010).

For a very long period women, like members of other oppressed groups, had long been the object of inquiries of their oppressors (Learner, 1975 cited in Harding, 2004). The traditional methods of research did not permit any conceptual framework in which women as a group could become subjects or authors of knowledge (McCall, 2005). It did not matter what the race, clan, age, educational level, socio-economic level was, or whether that knowledge was about their lived experiences (Harding, 2004). Rooted in the Marxism ideology that the poor can be a source of societal knowledge, the feminist theories hold the assumption that those who are socially oppressed, such as women, have a fund of knowledge that is often under-

valued and undermined by the traditional approaches to research (Faisal, 2011). These theories have proven to be valuable as a way of empowering groups, valuing their experiences and pointing towards a way of developing other alternative oppositional 'knowledges' (Collins, 1989 in Harding, 2004).

Understanding the experiences of caregivers of children with physical disabilities from their own standpoint is important as it provides an opportunity for collaborative knowledge creation of crucial issues in order to enhance social service delivery and advocate for social change. People of low socio-economic status are used to being spoken 'for' instead of 'to' and are usually the objects of research rather than subjects of and authors of their stories. So this research aims to contribute to a different approach.

Standpoint theories have been severely criticised for claiming epistemic privilege of women and other marginalised groups, and some scholars have challenged this viewpoint stating that reducing all women to a group that shares one experience and one single point of view based on that experience is problematic (Brooks, 2007). Women are diverse, so the critics claim, and being positioned on various dimensions socially, economically, racially and so forth, they do not share sufficient commonality on which to base their perspectives, regardless of a similar experience (Reinharz, 1992, in Capous-Desyllas, 2010). However, this inquiry into women's realities carried out by and with women has potential to empower people to honour women's intelligence and value knowledge grounded in experience, no matter how diverse or common the meaning-making turns out to be. How transferable to women of other races, socio-economic backgrounds etc., this knowledge turns out to be remains to be seen. The standpoint theory, which seeks to validate knowledge that is produced by women about their lived experiences and their efforts to cope with circumstances that are sometimes created by a society that is oppressive, in addition to mobilising collective action for change is appropriate for this study. The participants in this study are black, IsiXhosa speaking women who have experienced both race and gender oppression, and because of being under-privileged, they are not new to the position of being 'spoken for' and being 'objects' of inquiries. This study gives them a unique opportunity to be 'subjects' and authors of stories, allowing them to assume a much more superior position than the one they are used to.

3.3.2 Freire's approach to empowerment education

Paulo Freire was a Brazilian educator whose ideas in democratic and empowering education came from an educational background in Catholic liberation theology and an adherence to Marxist ideology (van Gorder, 2007). Freire believed that before change can be externalised, it has to start within the oppressed, with their quest to be liberated and with their desire to take an active role in their own liberation (Freire, 1996). One of his most original and significant contributions to the liberation movement is the concept of conscientization, which is the process by which human beings (more so the oppressed) become more aware of their sources of oppression and begin to collaboratively think critically about their situation and what actions are open to them to improve it (Blackburn, 2008). Conscientization is a precursor to challenging inequalities of treatment or opportunity with regards to not just social and/or structural obstacles, but also psychologically limiting factors (Freire, 1996).

Freire's approach triggered a process where oppressed people examined, as individuals, their potential roles as self-liberators and worked together in community efforts towards social change (Capous-Desyllas, 2010). He put an emphasis on organizing at the individual, organizational and community level. Empowerment education theory emerged around the 1960's as a result of group deliberations of the Brazilian Institute of Higher Studies (Hoops, 2011). It was developed from his teachings and writings and it involves individuals working together in group efforts to develop a healthier society by identifying their problems, finding solutions, and working together to develop strategies to overcome the barriers in achieving their goals (Wallerstein & Bernstein, 1988 cited in van Gorder, 2007). The goal to be attained therefore is not to achieve power to dominate others, but rather power to work with others towards influencing change.

Candy (1989, cited in Mitchell, 2008) argues that there is an urgent need to move beyond the dualist paradigm of the qualitative-quantitative dichotomy which has for centuries traditionally informed research, and move towards alternative ways of knowing, such as critically interpretive approaches which are characterised by an acceptance that understanding is greatly influenced by individual systems of meaning. Another such alternative way of knowing is documentary photography, which Freire promoted.

3.3.3 Documentary photography

According to Freire (1970, cited in Weeks, Liao, Li, Dunn & Wang, 2010) the visual image is an important tool that enables people to think critically about their communities and it reveals the reality of their everyday social and political existence. Documentary photography has been described as the portrayal in visual imagery of the social and mental wellness of both the subjects and the society of which they are part (Wang & Burris, 1997). The use of visual images is a potent way of building an in-depth awareness of one's community and encouraging dialogue and construction of knowledge (Petheram, Stacey, Campbell, & High, 2012). Photographs have an ability to fuel critical consciousness and collective action by making political statements about the reality of people's lives and this is due to the fact that whilst what one says is subjective and can be disputed, it is difficult to argue against what is seen (Franz, 2005). To 'show' and 'tell' is more powerful than to 'tell' only and this is a significant difference, bearing in mind the fact that this is an action research study and one of its aims is to inform and influence policy-makers.

According to Wang and Burris (1997) documentary photography is the portrayal of the social and mental wellness of the society as well as the subjects who are part of it. In documentary photography ordinary people are given cameras and they capture images of what represents the reality of experiences and these are used to dialogue not just between themselves but with other stakeholders such as policy makers. This creative and powerful tool not only allows participants to draw attention to the realities of their lives but promotes the well-being of the photographers as well as their communities and ignites public interest and curiosity (Wang & Burris, 1997). Some have questioned the wisdom of giving cameras to amateurs, instead of allowing experienced photographers to capture expert images. However, if one really thinks about it, people are experts in their own lives and documentary photography using the method of PhotoVoice (see below) allows people to initiate change within their communities, instead of being passive subjects of other people's intentions and images, however well-meaning those people may be (Wang, Cash, & Powers, 2000). It is this perceived lack of 'expertise' that makes PhotoVoice data potent and original.

3.3.4 PhotoVoice

PhotoVoice is a community based participatory research method that was developed in the mid-1990's by Caroline Wang and her colleagues (Chio & Fandt, 2007; Wang, 1999; Wang & Burris, 1994) and it has proven to be a successful way of empowering groups that have traditionally been under-represented, labelled and stigmatised. It has received growing attention not just in health education and social issues, but in international business (Novak, 2010), as well as negotiation & conflict management (Chio & Fandt, 2007; Purdy, 2012). PhotoVoice can be defined as "a process by which people can identify, represent, and enhance their community through a specific photographic technique" (Wang, Cash, & Powers, 2000, p. 82). These ordinary members of the communities who are usually the objects of research and who spend time under the lens are empowered to be subjects of research and given an opportunity to be behind the camera lens and be authors of 'knowledges' about their lives (Wilson, Green, Hayworth-Brockman, & Green, 2007, cited in Beh, Bruyere, & Lolosoli, 2013).

Whilst documentary photography uses line drawings or photographs usually captured and produced by 'experts' to represent realities, PhotoVoice takes this a step further by allowing members of the communities or participants themselves to take the photographs, thus assuming authorship of the information. The use of photographs (visual imagery) and stories (personal insights) are a powerful combination that can give voice to participants despite their race, gender, age, ethnicity and level of education or social status. This is what enhances the ability of the researchers to accurately capture the meaning of an experience from the participant's point of view and it is what makes PhotoVoice unique (Drew, Duncan, & Sawyer, 2010).

In traditional research methods, the distinction between the researcher and the participants is vast and the power dynamics are conspicuous, but PhotoVoice limits the tendency of experts and decision makers to assume ahead of time that they know the problems and corresponding solutions (Chio & Fandt, 2007). The researcher is therefore forced to assume the 'non-expert' stance. According to Booth and Booth (2003), the process challenges the established politics of representation by shifting the means of documenting lives from the powerful to the powerless, the expert to the lay person, the professional to the client, the bureaucrat to the citizen, the observer to the observed. PhotoVoice therefore advocates for 'another way' of knowing. It is based on the assumption that people are experts in their own lives and any

change that has to be sustainable has to elicit their direct involvement and participation (Carnahan, 2006). This is in line with the principles of PAR whose creative and visual methods are used to increase participation through utilisation of creative methods and by engaging in a collaborative process between the researcher and the participants (Bray & Moses, 2011).

This active engagement of community members in the research process demonstrates to participants that they are valuable members of the research team (Mitchell, De Lange, Moletsane, Stuart & Buthelezi, 2005), and may contribute to a sense of community ownership through participation in a project that will help draw attention to important community issues (Wang & Burris, 1997).

 PhotoVoice has been used successfully in a variety of projects and in many studies such as those involving children with autism (Carnahan, 2006), as well as with urban youth in a literacy programme (Zenkov & Harmon, 2009). Data collection in both of these studies was focused on visual imagery as a means of increasing engagement and attention as a powerful tool in helping autistic children and helping youth with learning difficulties write analytical and descriptive paragraphs. In South Africa researchers have successfully used PhotoVoice in different fields to address numerous challenges and solutions in areas such as HIV/AIDS in rural communities (Mitchell, De Lange, Moletsane, Stuart, & Buthelezi, 2005); exploring gender (Taylor, De Lange, Dlamini, Nyawa & Sathiparsad, 1997) and poverty (Olivier, Wood, & De Lange, 2007).

According to Wang & Burris (1997), PhotoVoice has three goals: (1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and (3) to reach policymakers. But how does the process unfold? Wang & Burris (1997) have clear recommendations sequencing activities in the PhotoVoice method and these and how they were applied in this study are discussed under data collection and analysis.

3.3.4.1 PhotoVoice limitations

It is important to mention that no research method is one hundred per cent effective and PhotoVoice also does come with challenges and limitations. As a qualitative research method it is subjective in nature and depends upon the information which participants want to share, which means it can be biased and easily manipulated to report or withhold information (Jurkowski, 2008). Its results therefore cannot be quantified nor confirmed scientifically (Capous-Desyllas, 2010). Secondly, it is an intrusive method and not all participants in a PhotoVoice project may be willing to discuss their thoughts, feelings and attitudes or open themselves up to public scrutiny (Moletsane, 2012). Even though there is an assumption that PhotoVoice results will ultimately stimulate change by influencing decisions and policies, sometimes all it does is to raise awareness and expectation among participants and other community partners (Wang & Redwood-Jones, 2001). Moreover, change is a slow process and therefore it is difficult to quantify the degree that PhotoVoice has impacted program improvements or policy change within a set timeframe (Wang & Pies, 2004). However, just the fact that the participants get to critically think about their individual and collective challenges, as well as to work collaboratively towards improving their lives marks a significant shift in the right direction. This is in line with the principles of Freire's approach which posits that before change can be externalised, it has to start within the oppressed, with their quest to be liberated and with their desire to take an active role in their own liberation (Freire, 1996).

3.4 Research participants and sampling procedures

The recruitment of participants was determined by the criteria outlined by the research question which is; exploring the experience of caring for children with physical disabilities. PhotoVoice is commonly conducted with marginalised populations and there may be potential challenges in accessing participants, therefore convenient strategies, such as partnering with community groups are usually required (Sutton-Brown, 2014). This was the case in this study, in which the researcher had to consult with The Association for People with Physical Disabilities (APD), a local NGO. This proposed research required that participants reflect certain characteristics- firstly, they are primary caregivers of children with physical disabilities. Secondly, they come from a low socio-economic background and reside in Grahamstown East in the Eastern Cape.

The sampling methods that were utilised were purposive and convenience sampling. The purposive sampling method is used in exploratory research and it involves the researcher selecting cases with a specific purpose in mind, i.e. caregivers in disadvantaged contexts (Wagner, et al, 2012). The participants were selected because of their convenient accessibility and proximity to the researcher. In order to encourage in-depth conversations and to develop rich data, Wang (1999) suggests a sample size of seven to ten participants, even though smaller groups have also proven to be effective (Sutton-brown, 2014).

The sample in the current study consisted of six participants. The participants were all 'black', isiXhosa speaking women from the township of Joza, which is in Grahamstown East in the Eastern Cape. I purposely focused my recruitment in this area which is of a low, socio-economic status and whose residents are affected by high rates of unemployment and absence and scarcity of resources. The reason for this was the fact that people who are from disadvantaged and impoverished backgrounds are usually objects of research and rarely get an opportunity to own a project and participate more actively in the process of knowledge production. It was not the intention of the researcher to select women participants, but all the caregivers whose contact details she received from APD were female and since photovoice is about allowing the disenfranchised populations an opportunity to be co-authors of the stories about their own lives; this became a valuable opportunity for gender-empowerment as well.

3.5 Participant recruitment

The sample was recruited through collaboration with the Association for People with Physical Disabilities (APD), an organisation that offers services and support to people with disabilities and their families. A relationship between the Rhodes Psychology Department and APD exists already, so I did not encounter any challenges in enlisting assistance from the APD personnel. I approached APD and after explaining the project, she requested their assistance in accessing caregivers who are looking after children with physical disabilities.(See Appendix 1). This request was approved. (See Appendix 2).The initial plan was to recruit on-site with an APD employee, at the developmental clinics during specified dates when the caregivers attend monthly clinics with their children and receive services and support from the Occupational Therapists from Settlers Hospital and staff from APD. After visiting one site and speaking to two caregivers, I found this exercise very distressing and insensitive. My observation was that the session with the OTs was an emotional and

distressing one for both caregiver and child. As the child underwent a routine physical check-up which included being massaged, put through some physical exercises she/he would scream as if in discomfort/pain and the caregiver who stood helplessly would at times be close to tears too.

For me, after this emotional and distressing experience, to approach the caregiver with a request for a few minutes of her time whilst I explained the project and its objectives, seemed not just ill-timed, but insensitive and devoid of empathy. So, after speaking to two caregivers I decided to abandon this exercise and think of another strategy of recruiting the participants. I later discussed my feelings with the APD employee and the OTs who were at the health centre. After this discussion, a new strategy was formulated. The Occupational Therapists and APD employees compiled a list of caregivers who visit their centre once a month and the APD Administrator agreed to call them telephonically and ask for consent for the researcher to contact them on their cellphones. I was then given a list of the caregivers who had indicated an interest and had given verbal consent to be called on their cellphones. I contacted each of these caregivers telephonically, explained what the study was about, and enquired whether they would be interested to participate. I then proposed the date and venue for the first meeting where all the participants would meet to receive more information on the project, sign the informed consent form, receive cameras and training on how to use them, as well as the procedures of taking pictures.

3.6 Participants

Table 3.1: Characteristics of participants*

Name	Age	Background information	Child Diagnosis	Child's name
Mandisa	35	Grandmother to the child. Currently unemployed but used to work at a developmental centre but resigned to take care of her grand-son who is 3 years old.	Not sure of the child's diagnosis.	Lenki
Phili	25	A single mother to a child who is 2 years. She is an ex-university student who is left with two modules into a BA degree. She	His diagnosis is still tentative. Initially she was told he has	Luna

		fell pregnant in her final year and had to abandon her studies when she gave birth to her son who has physical disabilities.	cerebral palsy, but later it was said he has neuro-regression.	
Thandi	22	Mother to a 5 year-old boy. She dropped out of high school after completing Gr 11 due to falling pregnant. She grew up in an orphanage and when she fell pregnant she was expelled.	Her son was diagnosed with Radinopathy of prematurity (ROP), epilepsy and Cerebral Palsy.	Enni
Lethu	57	Widowed grandmother to a 2 year-old girl. The biological mother stays in the same house with the child, but she distances herself from the child, so the grandmother has taken the responsibility of caring for the child.	Cerebral Palsy.	Nunu
Sindi	29	Single-mother to an 11 year-old girl. Did not finish high school due to the pregnancy and giving birth to a child with physical disabilities.	Cerebral Palsy	Tiny
Pamella	32	Single mother to a 12 year-old boy. She has not been working for the past 11 years due to the responsibility of taking care of her son.	Cerebral Palsy.	Athi

*Pseudonyms have been used for both caregiver and child.

3.7 Data collection

Even though one approaches this phase of the study with a plan on how to proceed it is important to be aware that in qualitative research the process may unfold in a different manner and one needs to be flexible enough to make adjustments along the way. In this study, I tried to adhere as closely as possible to the activities of PhotoVoice method recommended by Wang and Burris (1997). But while using the suggested stages as a guide, my own process of implementing the PhotoVoice method with the caregivers of children with physical disabilities was flexible in order to meet the unique circumstances and needs of the participants. The data collection stages of this PhotoVoice research study involved:

- Recruiting a group of participants and introducing the PhotoVoice methodology.
- Distributing cameras and reviewing how to use them. Initially I had planned to meet with all the participants in one venue for the purpose of distributing cameras, training on how to use them and the procedure of asking for consent. This plan had to be adjusted because of the weather conditions. It was a rainy, cold weekend and since all the participants rely on public transport I felt that it would have been insensitive and inconsiderate to expect them to take their children out on the cold weather and attend the meeting. So I decided to spend the day visiting them at their places of residence. Although this was a time-consuming and expensive exercise, it afforded me an opportunity to meet with the carers in their comfort zones and I was able to connect with each of them on a personal level. Building rapport is very important in action research and this gesture was appreciated by the participants as it was an indication that I was sensitive to the challenges they are facing. I explained the purpose of research and gave the caregiver a consent form to sign (See Appendix 3) agreeing to participate in the study. I then explained the data collection method, ethics around camera usage, how to ask for consent to take a picture, how to operate the camera, when to use the flash, camera handling when taking photos and this also included a demonstration. Beyond the research question and stated purpose of the study, training and ethical guidelines, no direction was given to the women regarding the specific content of what to photograph. Disposable cameras which allow for a maximum of twenty pictures were given out and participants were given blank consent forms to use when they were taking photographs of other people.(See Appendix 3, 4 & 5)

- **Allowing time for participants to take pictures.** The researcher and the participants mutually agreed that three weeks would be allowed to take pictures. After the set time I collected the cameras and dispatched them for printing. This process took two weeks.

- **Meeting to discuss photographs.** Initially, the proposal was to have a series of 4, one-hour group meetings to hold discussions and then the 5th one to plan an exhibition, but five of the participants felt that this was too much for them due to the challenge of using public transport whilst travelling with a child who is physically disabled. So it was agreed that there would be two, 2-hour-long meetings for discussions and another meeting to plan an exhibition would be scheduled later. So two meetings were eventually held, the first one lasting two hours and the second one three hours.

- **Selecting and recruiting a target audience of policy makers or community leaders.** The caregivers felt that there is a need to inform, educate and sensitise communities, Ward Councillors, APD and the Department of Health workers about the challenges of caring for a child with physical disabilities. These were therefore identified as the target audience for an exhibition presentation. The caregivers reasoned that some of the challenges they face can be attributed to ignorance about the situation and if these stakeholders can be given an opportunity to hear the story they may show support. They also stated that even APD can advocate better for their needs if informed about the exact nature of those needs and which ones need to be prioritised.

- **Plan with participants a format to share photographs and stories with policy makers or community leaders**. In PhotoVoice, the researcher assumes the role of a facilitator and she is accountable to the group or community and openly committed to certain kinds of social change (Wang, 1999). This is one of the characteristics of PhotoVoice that renders it its uniqueness. Unlike the traditional data collection methods, this method requires that the researcher not just assume a position of an enquirer, but that of an ally in the quest for some improvement of the experiences of the participants. The researcher and participants agreed that they would plan a Power-Point presentation/ slide show to present to their target audience which is APD, Ward Councillors, Department of Health workers (nurses and OT's) and community members. The slide show was later planned and presented by two participants in

collaboration with the researcher to a group of stakeholders that included a Councillor from Makana Municipality, representatives from APD and researchers from Rhodes University. This small group met at the Psychology Department, Rhodes University on the 4th of May, 2018.

3.8 Data analysis

In PhotoVoice, the participants themselves are central to the data analysis as this research method draws on participatory analysis (Palibroda, Krieg, Murdock, & Havelock, 2009). It is important to highlight the fact that the process of data analysis overlaps with that of data collection. During this stage a lot depends upon the facilitator's understanding of PhotoVoice as a Freirian process of discussion and action, and he/she must have the ability to facilitate a dialogue not just about the women's visual images, but the social and political context and action and strategies for change (Wang, 1999). There are three ways to carry out the participatory analysis of data (Wang & Burris, 1997) and all three were drawn on in this research:

- **Selecting photographs**; which involves selecting five to seven favourite photographs that each participant wants to present as evidence and which they feel are representative of their experiences. This session began with the researcher handing over the photographs to the participants and allowing them time to go over them and select those that are meaningful to them, most accurately reflect their experiences and that they wanted to share with the group.

- **Contextualising** involves telling stories about what the photographs mean to them. Each participant was asked to describe the content and context of each of their photos and once finished with each photo she would paste it on the wall and move on to the next one until she had added her voice to all she had selected. During this time, as the facilitator, I would pose some questions if the participant was uncertain about what to say and at the same time I was taking short notes as each person presented. Above each photograph pasted on the wall I wrote a caption/word/phrase taken from the narrative about the photo. Each participant was also asked to select two or three images that were the most significant to them in terms of what they portrayed. What was interesting was how as these narratives were shared themes began to automatically emerge and as each participant shared,

she would paste the image next to the one that had a similar or related story/experience, so that at the end of the discussion, some photographs were grouped together and some were in isolation, if the participant was the only one who had shared that experience or had captured an image with a unique story. At the end of the session a photograph of the images as they were arranged on the wall was taken by myself, as the facilitator, and I took them off the wall and packed them as they were grouped. These images were going to inform the content of the next stage of discussion and each participant was given a consent form releasing the photographs to the facilitator. (See Appendix 5)

- **Codifying** entails identifying issues, themes or theories that emerge. A week later the group met again and it was during this discussion that the participants dialogued and discussed their photographs, voicing their individual and group experiences. Even though this meeting had been scheduled to take two hours ended up taking three hours because time was also spent in discussing ways of improving the experiences of the caregivers and brainstorming solutions to some of their challenges. The photos were discussed in the way they had been grouped and the themes and issues that emerged out of the stories and discussions were contextualised and grouped into codes and themes. Wang (1999) suggests that to guide the discussions questions that spell the acronym SHOWED be asked. So during these discussions the participants were guided by the following questions:

A. What do you **S**ee?
B. What is really **H**appening here?
C. How does this relate to **O**ur lives?
D. **W**hy does this situation, concern or strength **E**xist?
E. What can we **D**o about it?

So in this study there were two levels of data analysis. The first layer involved the participants selecting photographs and sharing their narratives around them. During this stage the facilitator used key words and phrases from the participants' stories. These were later developed into categories and overarching themes during the second level of meetings which involved a focus group discussion based on the photographs shared. Whilst I facilitated the group discussion, I also wrote key words, quotations and short notes from the narratives which I later integrated into the identified themes that have been written up in the findings chapter of this research. Due to the fact that I was a novice to the PhotoVoice method, this

was a challenging experience for me, because not only was I required to multi-task, as mentioned above, but as soon as I arrived at home I had to spend time reflecting on the process and writing process notes, personal reflections, recording information collected whilst it was still fresh in the memory and consolidating. A reflexive section on my experience of conducting this PhotoVoice project is included in the research findings chapter. Because this was a participatory action research project, it would not have been enough just to have a discussion about the challenges experienced by the caregivers, but the caregivers also got involved in a session of discussing ways of improving their experiences and brainstorming solutions to the challenges. These are also discussed at length in the findings section and they culminated in the slide show presentation to stakeholders, mentioned in the data collection section.

3.9 Ethical considerations

PhotoVoice is an intrusive data-gathering method as it involves invading people's private space; therefore ethical considerations are crucial (Mitchell, 2008). Anonymity cannot be guaranteed as some of the photographs taken have to be used in the data analysis, discussion and publishing of the findings. It becomes crucial therefore that participation in the research is voluntary and to ensure this, three types of written consent forms (for participation, being photographed and release of photos) were issued and these can be found in the Appendix section (Appendix 3, 4 & 5 respectively). Wang (1999) also suggests that an information brochure explaining the purpose of the study and what participation will entail be supplied and this can be found in Appendix 7.

Issues of responsible use of a camera, how to minimise potential risks, respect for people and transparency were discussed with the participants during training. The researcher personally trained the participants on how to use the camera responsibly and how to obtain consent from the subjects. She also explained to the participants for what purpose the information provided would be used and assured them that their personal identity would be protected by using pseudonyms. To further ensure that the photographs are used just for the purpose of this research she personally delivered the cameras to the photo shop for processing and collected the photographs herself. All the negatives were handed back to the participants with all the photographs before the discussions and the participants signed the release form for all the photographs shared (See Appendix 5). Even though the participants had been given blank consent forms and had been informed how to use them when they take pictures of people,

some could not produce signed copies giving consent to use photos, but claimed to have obtained oral consent and in such cases I still included the photos but veiled the faces to protect the identity of the persons in the photographs. Ethical clearance for the study was obtained from the Research and Ethical Review Committee of the Department of Psychology at Rhodes University (Appendix 6).

Because the topic is a sensitive one I anticipated the fact that sharing narratives around their lived experiences might be an emotional exercise for some of the participants and I informed them of the option for counselling at Rhodes Psychology clinic should a need arise and as a student psychologist I was well equipped to assess throughout the sessions whether this was necessary.

3.10 Validity and reliability

Photovoice is a qualitative-based research method and reliability and validity of the findings are achieved by increasing the methodology's credibility, authenticity, transferability and consistency (Appleton, 1995 cited in Fade, 2003). The method's transferability is increased through triangulation of data collection methods through the use of photographs, focus groups and member checking (Appleton, 1995, cited in Wagner, 2012). One limitation of this study is the fact that only one method of data generation was employed, therefore there was no triangulation. Photovoice however relies on the participation of the target population, in this study, the primary caregivers of children with physical disabilities, and the fact that the photographs taken represent their lived experiences attests to the authenticity and credibility of the method. Engaging caregivers of children with physical disabilities may improve the validity of the research because it also fosters a more authentic analysis of their beliefs and knowledge related to the research questions. The data are more accurate with regard to the social reality of the caregivers and the findings can be used to develop more effective programmes of support for both child and caregiver. However, Evans (1999) has suggested that the photographs themselves can also present challenges in the sense that the results may be a consequence of participants' subjective experiences being influenced by their personality or mood at the time of data collection. One limitation with this study is the fact that even though the number of participant was enough to yield credible information, all the participants are 'black' women who come from one socio-economic background and whether these results would be transferable to people from other races and people from a different background cannot be guaranteed.

3.11 Reflexivity

Reflexivity may be defined as both a central component of being human (i.e., the capacity to position the self) and as the ability to reflect on and consider intersubjective dynamics between researcher and data (Finlay & Gough, 2003). Owning one's perspective, as reflexivity is described by Fisher (2009), helps the reader evaluate the researcher's perspective and interpretation of the data. As a mother of so-called 'normal' children, I understand and am aware of the responsibilities that surround being a mother, but as a person who spends time in doing voluntary community work, I lack understanding of what it is like to raise a child with 'special needs.' In my volunteering activities I have been exposed to families caring for children with physical disabilities and from my personal observations, it has often appeared as though they struggle in their role to meet the needs of these children. I have observed a lack of resources such as wheelchairs, financial restraints as well as what appears to be lack of social support for both parent and child. So doing this research allowed me an opportunity to gain an in-depth knowledge about their experience, but also possibly opens up a platform for intervention. A section on my personal reflections can be found in the results chapter and this is where I discuss the challenges I encountered during this project as well as the highlights of the experience.

3.12 Conclusion

In conclusion, the current study was a Participatory Action Research study which utilised the PhotoVoice method of inquiry as it is consistent with the research question framing the study, which is how individuals experience caring for a child with physical disability/ties. PhotoVoice, is an arts-based research method grounded on insights drawn from the following theories; the feminist standpoint theory, Paulo Freire's 1970 approach to empowerment education and critical consciousness theories, and a participatory approach to documentary photography. In this chapter I have endeavoured to clearly set out all the methodological procedures that were followed in line with PhotoVoice requirements including the sampling, recruitment, data collection and data analysis procedures.

4. Findings

4.1 Introduction

This chapter describes the findings of the study generated from the data analysis process that was conducted with the participants. In this study there were two levels of data analysis. The first layer involved the participants selecting photographs and sharing their narratives around them. During this stage I used key words and phrases from the participants' stories to create headings of themes. These were later developed into categories and overarching themes during the second level which involved a focus group discussion based on the photographs shared. The analysis process produced two master themes and seven subordinate themes (see table 1 for the list of themes) which address the over-arching research question of the study "What are the experiences of primary caregivers of children with physical disabilities in Grahamstown, Eastern Cape?" This was a study informed by the participatory action research principles and it aimed to explore, using photovoice, the lived experiences of caregivers of children with physical disabilities and how their experiences can be improved. A list of the themes and subthemes in table form is provided, photographs to substantiate the themes and an analysis of the photos conducted with the participants. Furthermore, I will report on the suggestions by participants on how to improve their experiences and finally I will provide s section on my personal reflections of the process/action aspect of the research.

TABLE 4.1: List of themes

The challenging side of the caregiving experience	The positive side of the caregiving experience
1.1 Lack of resources	2.1 The joy brought about by support from family, the health service providers and the Association for People with Disabilities personnel.
1.2 Challenges associated with mobility	2.2 Special precious moments shared with the child
1.3 The hopelessness of the situation, the	2.3Personal growth

pain and despair that accompanies it	
1.4 The loneliness of the experience	
1.5 The financial burden associated with caregiving.	

4.2 The challenging side of the caregiving experience

This master theme captures the challenges experienced by participants in relation to caregiving and the photographs taken were backed up by narratives shedding more light into the nature of the challenges. Under the theme of challenges there are five subordinate themes namely: lack of resources, challenges of mobility, the hopelessness of the situation, loneliness of the experience and the financial burden of caring for a child with physical disabilities.

4.2.1 Lack of resources

The challenge of lack of resources is an experience shared by the participants and it is reported as one of the main reasons behind the experience of caring for a child with physical disabilities being so difficult. The participants experience hardship when it comes to feeding, bathing and carrying the child around and this becomes even a bigger challenge as the child grows older and becomes heavier to carry. Of the six participants, four are caring for children who have been diagnosed with cerebral palsy and are unable to control their motor functions which means they are completely dependent upon the caregiver for the fulfilment of most needs. Even though the children have been supplied with wheelchairs, prams, feeding chairs etc, with time they outgrow these and they are not supplied with age-appropriate ones. The following pictures, were taken by the caregivers and they depict the lack of resources, specifically related to the lack of assistive devices and/or lack of age appropriate assistive devices.

Figure 1: Sindi's photograph reflecting lack of resources. "This is Tiny's sleep couch but she is now taller and it no longer fits her length."

Figure 2: Mandisa's photograph reflecting lack of resources. Lenki is 2 years old but he cannot yet walk. Sometimes he is able to pull himself up and propel himself on the table as shown in the picture above, and his grandmother expressed the wish that if he had a walker he would be able to move around using his legs and that would probably strengthen his leg muscles.

Figure 3. Sindi's Photograph reflecting lack of resources, She spoke about the picture showing that the feeding chair has become too small for Tiny and as a result her mother struggles to balance the act of feeding her whilst supporting her with one arm, using one hand to hold the plate, the other hand to feed her. This can be a painstakingly slow process as she

sometimes has to force Tiny's mouth open in order to feed her. Tiny's mother reported how frustrating this is and how sad it makes her because feeding times should not be a struggle but precious times of bonding with her child.
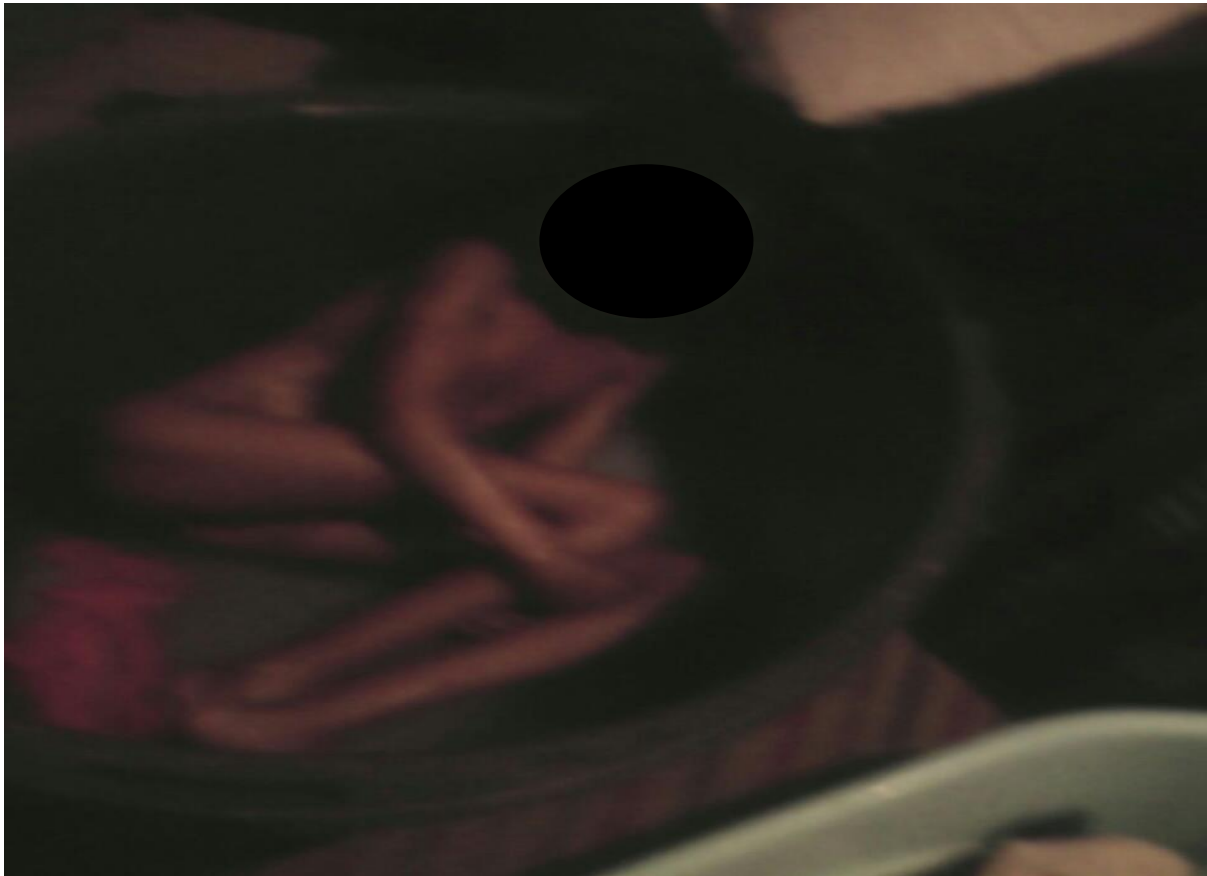
Figure 4: The photo above was taken by Pamella and it reflects a lack of resources. "Bath time is a challenge as I am forced to squash him in this washing basin."
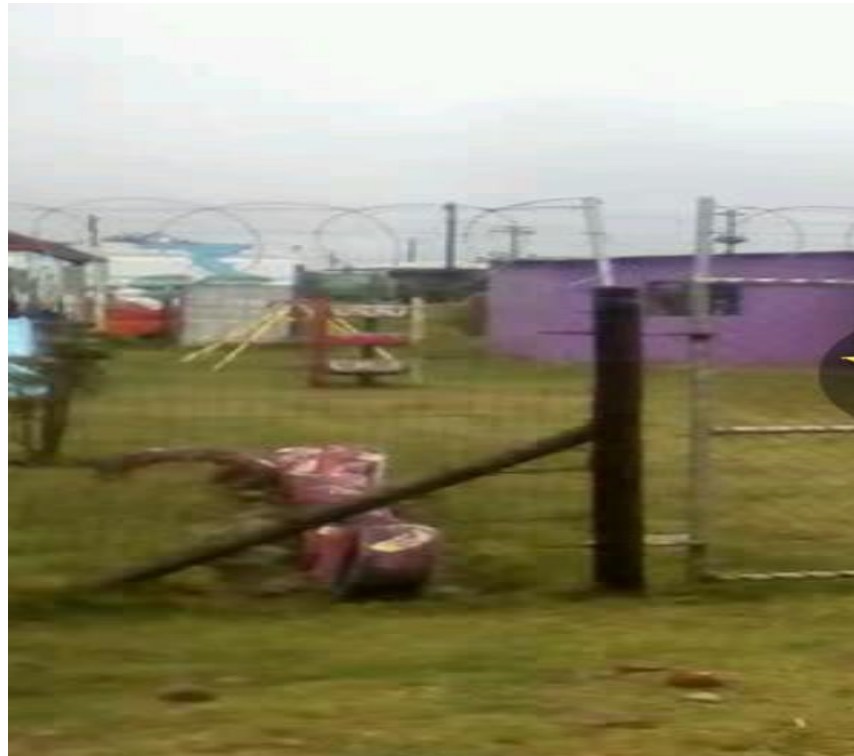
Figure 5:

This is a photo of a local pre-school that is next to Luna's home and the picture was taken by Luna's mother. She stated that she feels sad because her child cannot attend pre-school like other children in the area. In Grahamstown there is no pre-school that specifically caters for children with physical disabilities, so the caregivers have to care for the children around the clock.

All the caregivers in this study agreed that lack of resources is one of the main challenges they face and it interferes with their ability to execute their role in a fulfilling way.

4.2.2 The challenges associated with mobility

None of participants in this research have their own private transport and none of their family members have either. Therefore, a shared experience for the caregivers was challenges associated with mobility. Caregivers spoke about how it becomes challenging to take their

child for monthly check-ups at the local health clinic or to go somewhere to run errands such as shopping or attending church services. This has to do not just with prams that are not age-appropriate, but with infra-structure challenges which make it difficult to push the pram in and out of the house. The challenge is also exacerbated by the fact that the caregivers have to use public transport and at times they are denied access into the taxis because the wheelchairs cannot be accommodated, which means the caregiver either has to walk long distances or hire private transport.

Figure 6: Thandi's photograph reflecting the challenge of mobility

"This is the gravel road I push Enni's pram on when I need to go to the taxi rank. Sometimes I walk long distances with Enni strapped on my back."

Even when they can use public transport, the caregivers are often required to travel to the taxi rank/bus stop which is a long way, particularly with an assistive device, that may not even be suitable to the age or condition of the child.

Figure 7: Pamella's photograph reflecting the challenge of mobility.

"Athi is now 12 years old but he is still using this pram which is too small for him, but I am forced to use it when taking him somewhere because he is too heavy to carry."

Moving the child from one place to another was found to be a challenge by caregivers and they claimed this ended up restricting their social lives as it wasn't easy to take the child with them outside of the home.

4.2.3 The hopelessness of the situation and the pain and despair felt

Participants reported that they were frequently on an emotional roller-coaster alternating between sadness, anger, guilt, frustration and helplessness. Perhaps it is important to mention that four of the six participants are single women who were still schooling at the time they conceived and two are grand-parents whose daughters also conceived whilst still at school. Three of the mothers stated that during the early days of discovery that there was something drastically wrong with their children, they were experienced feelings of anguish and fear for the future, anger towards self and God, and guilt and self-blame. The participants stated that they felt guilty because they had become pregnant outside of wedlock and felt that their

child's disability was a punishment from God, whilst at the same time they felt angry towards God for allowing this to happen to them. One participant mentioned that for a long time she blamed herself, feeling that she had probably eaten something during pregnancy or done something that caused harm to the foetus. She recalled a time during the pregnancy when she used to fasten herself with a tight belt to hide the growing stomach and wondered whether that may have harmed the foetus.

The other factors that were reported as contributing to the bleakness of the situation include the frustration of the diagnostic process and even up to the end of the data collection phase some participants had not yet had the diagnosis of their child confirmed. Not having a firm diagnosis means that the caregiver has to frequently take her child to the public hospital for more tests, has to deal with the long queues and the curious stares and questions of people about what is wrong with her child. One participant stated that it is during such times that she despairs to the point of shedding tears. Other participants described how it was not the strangers who inflict most pain but family members who are not supportive, but are resentful towards the single mother who, they claim, is responsible for putting the whole family through this ordeal. Some of the participants did not have any family or social support increasing their sense of isolation. For many participants, their child's impairment also meant giving up on dreams of furthering their education and pursuing their goals because caring for their child is a full-time job.

One participant also stated that the child's paternal family rejected him from the onset saying in their family they do not have a history of anyone suffering from cerebral palsy, so this could not be their son's child. Thus they ended up turning the boyfriend against her and he subsequently ended their relationship. She stated that the anguish for her was so great and the experience in the earlier days so dark and gloomy that she wished her child had died, and even contemplated suicide.

Figure 8: This photograph was taken by Lethu and she stated it reflects how dark the experience is and how hopeless she feel most of the time.
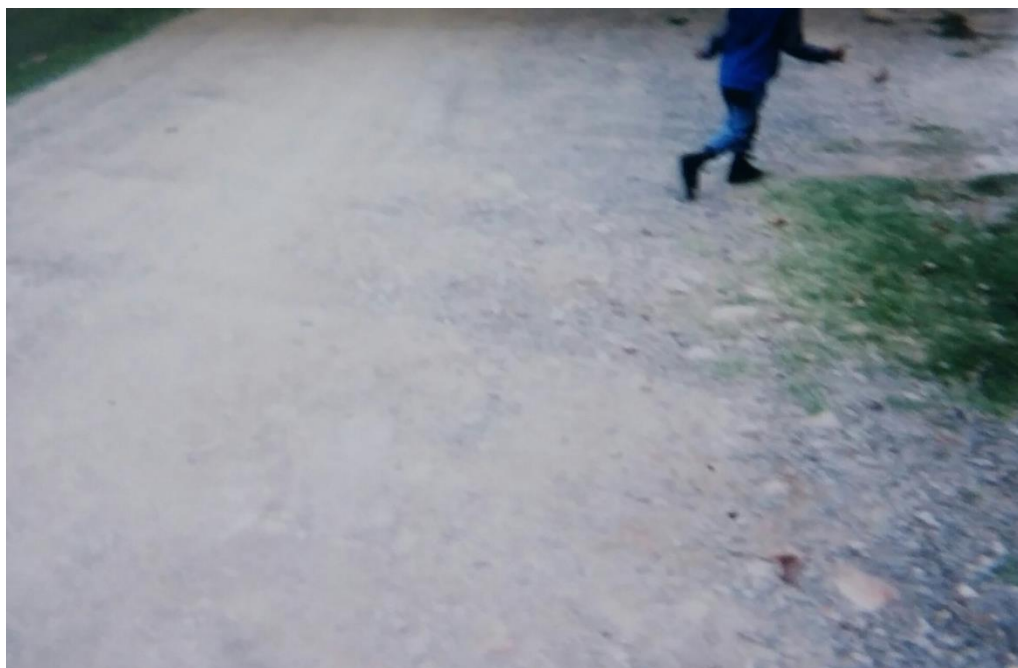
Figure 9: Mandisa's photograph reflecting how challenging the experience is. "It feels like running barefoot on the gravel road."

Figure 10: Pamella's photograph reflecting the sense of hopelessness that accompanies the experience. "I will never complete my education and wear a graduation gown."

4.2.4 The loneliness of the experience

Figure 11: Thandi's photograph reflecting the isolation she feels from the community. "It is a lonely experience. I feel alone as if I live in a deserted place."

Figure 12: Sindi's photograph reflecting the loneliness of the experience.

The experience of isolation is shared by both the mother and daughter. When Tiny's mother took this picture, she stated that it was during mid-day and it was quiet in the neighbourhood because most children were at school. She reported that she was feeling very lonely and as she looked at her daughter, she realised that the daughter seemed lonely too. "Tiny lives in her own world and other children are scared of her and when they see her outside they usually peep from a distance."

4.2.5 The financial burden associated with caregiving

Caregivers reported that provision of care for a child with physical disabilities has significant financial implications due to the fact that besides the usual daily expenses associated with caring for a child there are additional costs such as medical expenses, endless visits to the doctors or hospitals, daily supplies of diapers, special foods etc. The carers who participated in the study are from low income families and are unemployed and completely dependent upon the government disability grant of R1 600. The caregivers depend on this amount to provide not just for the basic necessities of their children, but also to take care for their own needs which include rent, electricity, food etc. This means there is barely enough money to make ends meet and they reported that they find themselves sliding towards poverty.

Figure 13: Pamella's photograph reflecting financial struggles. "Sometimes there is not enough food to give to Athi because the grant is not enough to see us through the month."

Figure 14: Phili's photograph reflecting financial struggles. "If I need to go somewhere I have to pay for a private car because it is difficult to use public transport."

Figure 15: Lethu's photograph reflecting financial difficulties. "Nunu has CP and I cannot afford buying right things to help him."

All the participants in this project regarded the caregiving experience as financially burdening, especially because they are all unemployed and depend upon the children's disability grant.

4.3 The positive side of the caregiving experience

This master theme captures the positive experiences reported by participants in relation to caregiving for their children with physical disabilities. The participants reported that their experiences are not entirely doom and gloom, but there are positive moments associated with the responsibility. This theme contains subordinate themes namely: the joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel; precious moments shared with the child; and personal growth.

4.3.1 The joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel

The caregivers expressed how the availability of support from their families goes a long way towards lightening the burden and the participants reported that knowing that they are not alone but have people who are supportive in one way or the other is indispensable. Caregivers narrated that family members do not just provide practical help such as babysitting but

provide emotional support as well. One participant stated that despite the fact she knew how disappointed her parents were with her pregnancy, they supported her and when her child was diagnosed with cerebral palsy, they stood by her all the way and she believed as a result they are now stronger as a family and more united. The caregivers also mentioned that the training and support they receive from health services providers (i.e. Occupational Therapists and Physiotherapists) is indispensable and here they described not just getting skills and demonstrations around exercising and massaging the child, but also receiving encouragement and getting an opportunity to discuss any challenges they are facing. This is very important to the caregivers who often do not have anyone to talk to about the child's condition. The personnel from the Association for People with Physical Disabilities provides practical assistance such as help with accessing the disability grant and facilitates other forms of necessary support to the caregivers and their children. This support was identified as very important to the caregivers.

Four of the caregivers are young people who have no formal education beyond Matric and they are not well equipped to deal with bureaucracy and systems and they stated that were it not for the intervention of APD they probably would not even have the little they have in terms of resources. It is this expertise and contribution that is valued by the parents of the children with disabilities.

Figure 16: Lethu's photograph reflecting family support.

Assistance with baby-sitting provides relief and allows for the much-needed time for self-care

Figure 17: Pamella's photograph reflecting family support. "Athi's cousins come to play with him. His face always lights up"

Figure 18: Nunu's photograph reflecting family support.

Figure 19:Phili's photograph reflecting the support from health-care providers and the personnel from APD.

This is one of the health clinics where the caregivers and the children receive support from the health-care providers and APD personnel. Luna's mother took the picture because she appreciates the support she receives from the Occupational Therapists, who meet with the caregivers and their children once a month. This was confirmed by Mandisa who mentioned the fact that the relationship that she has with one of the Therapists has grown and she now looks upon her as a big sister who takes time to listen to her and whose role is not just to monitor her child's development, but to acknowledge her efforts as a mother.

Availability of support was seen by the participants as useful in lightening the caregiving responsibilities.

4.3.2 Precious moments shared with the child

The caregivers reported that though the activities of caregiving can be time-consuming and challenging, they can also be rewarding. The precious moments that they share with the children are priceless to them and even though their child is unable to express affection the caregivers reported feeling the love their child has for them.

Figure 20: Sindi's photograph reflecting the precious moments spent with Tiny.

Figure 21: Lethu's photograph reflecting the precious moments shared with Nunu. "She enjoys being bathed and I take my time when I do it."

The time spent feeding, bathing or just spending time with the child was mentioned as precious, and one participant stated that during the odd moment when she is away from home, she feels restless when the time for a scheduled activity with her daughter comes and she is only at peace when she is physically there. Even though she is missing out on

opportunity to further her studies and has received an offer from the paternal grandmother to actually leave her daughter, she claims she is very reluctant and knows her mind would always be back home, wondering whether she was receiving the quality of care she is accustomed to.

Figure 22: Mandisa's photograph reflecting the moments spent with Lenki. "I read bedtime stories to Lenki."

Figure 23: Lethu's photograph reflecting precious moments with Nunu

Caregivers value the precious time they spend with their children, feeding, bathing or just spending time with them.

4.3.3 Personal growth

The caregivers reported that through this experience they have grown personally in ways they feel would not have been possible had they not been exposed to caring for their 'special' children, whom they referred to as 'iziphiwo' meaning 'gifts'. They have become more loving and patient, no longer as vain and selfish as they used to be, were more grounded in life and more appreciative of the skills they have acquired through caring for their child. One participant also mentioned that she used to be bitter and angry, but she has learned to forgive and move on, and this has given her peace and she is now able to take care of her child without complaining.

Figure 24: Pamella's photograph reflecting personal growth. **"Taking care of Athi has taught me to be more appreciative of life and not take people for granted because I don't know what they are going through. I have also learned more about CP and have learned new skills about

how to care for my child."
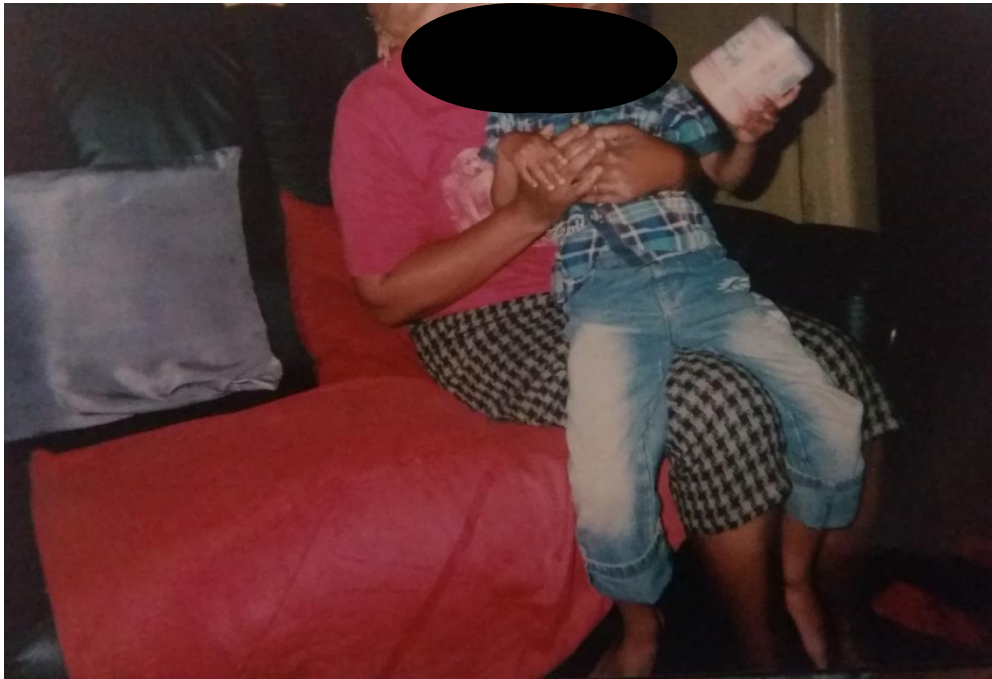

Figure 25: Thandi's photograph reflecting personal growth "I have learned to accept my life and to be responsible. I had to let go of bitterness towards Enni's father and his family."

Figure 26: Phili's photograph reflecting personal growth. "I now spend more time at home than I used to and I am proud of how I am handling the responsibility of taking care of my special child."

Being a mother or caregiver of a child with physical disabilities has resulted in personal growth, and the participants stated that they are better people for having been exposed to this situation.

4.4 Brainstorming solutions and ways of improving the experience

Since this was a participatory action research project using photovoice, the aim of the project was not only to find information and produce knowledge, but also to find ways of improving the experiences of the research participants. Photovoice is different from the other traditional methods and its purpose is not just to gather information, but it is meant to be a tool of empowerment for those participating in the project. This point was highlighted by the research participants themselves in one of the discussions as they reflected on the experience of participating in a study using this approach. Four of the participants have previously participated in a study exploring their experiences using the interview method. They stated that even though they enjoyed participating and sharing their experience the interview study did not add much value to their personal lives, as it did not impact their lives in any way.

Secondly, they reported that participating in a study of this nature made them feel like they were in control of the process, since they did not have to follow the lead of somebody else as in the case of interviews, but decided what to photograph. But more than this they were challenged to think about ways of improving the experience, instead of just relying on Non-Governmental-Organisations, such as APD and the state. This underscores the importance of PAR as a research method that not only seeks to gather information, but to bring transformation as well. It also highlights the relevance of the data collection tool, which offers the caregivers an opportunity to be catalysts for change instead of passive complainers.

Below are the recommendations suggested by the participants on how their experiences could be improved:

4.4.1 Emotional support during the initial phase of the diagnosis

The participants reported that the time when it was discovered that there was something wrong with their child was one of the darkest periods for them. They reported that when they received the devastating news they did not receive any form of counselling and more often than not there was no one to help them process the information. What made it worse was the

fact that since they are single parents there was no partner who was there to offer comfort. Thus the availability of some form of support in hospital, e.g. counselling, was cited as a necessity.

4.4.2 Improving the process of diagnosis

They further stated that the diagnostic process itself was lengthy and unsupportive as there was no transparency and most of the time they were kept in the dark as to what was exactly wrong with their child. Even up to now some of them are not sure of their child's diagnosis. The participants felt that the Department of Health needs to improve their services by speeding up the process, being transparent with information regarding the child's condition and offering ongoing counselling services to the families of the children diagnosed with disabilities. The caregivers further stated that it is very sad that when caregivers gets discharged from hospital with the child, she fees on her own and has to teach herself how to handle activities such as bathing the child.

4.4.3 Planning a power-point presentation of the findings

The caregivers felt that the reason why they were not adequately supported could be due to the fact that the Health services providers, the Association of People with Physical Disabilities Personnel, the Ward Councillors and community members probably were not aware of what they were experiencing or did not know about the nature of support expected from them. Hence the participants decided to plan, together with the researcher, a power-point presentation where they could share the photos and their narratives with the hope of making people aware of their experiences.

4.4.4 Starting a support group

The participants appreciated the time they had spent together sharing with others going through the same experience, claiming it was a supportive environment where they felt contained. Their wish was to start a supportive group where they will meet to socialise and offer and receive support. A 'What's App' group was opened for the participants to have a platform to further communicate and discuss ways of being there for one another. They also planned to meet once every 2nd month to socialise and share tips on how to improve their experiences.

4.4.5 Starting a Home Business

Because caring for a child with physical disabilities is a full-time job, none of the participants was working or studying at the time of the data collection, and the caregivers discussed the idea of studying short courses such as in baking, pastry-making, curtain-making etc. that would allow them to start home businesses.

4.5 A meeting between the caregivers and stakeholders to present a slide show of the photos and share narratives about their experiences

Since one of the main goals of photovoice is to influence policy makers (Wang, 1999) it was important for this project to culminate in a session involving some policy makers. During the brainstorming session the participants had indicated that they would like to present a slide show to the Local Councillors, APD personnel and community members. On the 4th of May 2018 a small group of stakeholders which included a Councillor from Makana Municipality, representatives from APD, a representative from the Social Services Department, the researcher and her supervisor met with two of the caregivers in the Psychology Department of Rhodes University.

Although this was an anxiety-provoking experience for the participants, it was however empowering, because they had previously never been afforded an opportunity like this, where they shared their narratives, let alone to an audience such as this one. Together with the presentation of the photographs, they gave the audience key insights into the joys and challenges experienced by caregivers of children with physical disabilities in the East Grahamstown area of Eastern Cape. The presence of the representatives of APD was siginificant because they are the ones who advocate for the rights and needs of people with disabilities and the caregivers had expressed a desire for them to hear about the nature of the challenges the caregivers face in their caregiving role. The local Councillor from the local municipality was able to share information about available services from the Mayor's office with contact details, offered some suggestions concerning challenges of accessing services and promised to share the knowledge and information he had received with the board comprising other Councillors. The photos below were taken during this meeting.

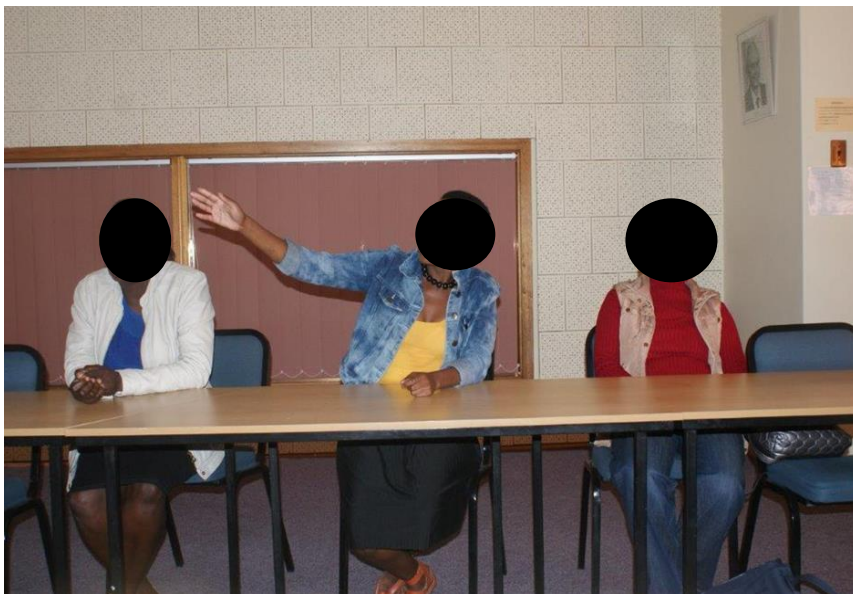Figure 27: Meeting between the researcher, care-givers and stakeholders.

Figure 28: Sindi presenting during the meeting.

4.6 My reflections on the process

Participatory Action Research involves collaborative work between the researcher and the participants and seeks to bring about transformation in living conditions at both community and individual levels through the process of empowerment of participants (van der Reit, 2001). Putting this project together was both challenging and fulfilling, with exciting and frustrating moments and below are some of my reflections regarding the challenges as well as the highlights of the experience.

The reflection below serves to provide further information on the actual process/participatory action aspect of the research, to support the findings reported above. The reflection process started right from the beginning of the research and I kept a journal where I dutifully recorded my experiences after each meeting with my supervisor and research participants. This is where I wrote notes from supervision, insights gained, thoughts and feelings during data collection, as well questions to take to supervision.

4.6.1 The challenges experienced

4.6.1.1 Setting up the first meeting

During the first one-on-one meetings I observed the eagerness of the caregivers to share with me the challenges encountered in the caregiving experience and this placed me in an uncomfortable position because besides not having time, this was not the purpose of the visit and I was not prepared for the role of containing emotions and offering support. But to have brushed the caregiver aside might have seemed dismissive and could have been detrimental to the relationship I was trying to build. The first meeting should have taken only two hours if all had gone according to the plan, but I ended up spending the whole day on Sunday and a few hours on Monday doing home visitations. This indicated to me how overwhelmed the caregivers were and how much they needed a safe space to talk about their experience to someone who is supportive. Locating the houses of the participants was also a struggle because the township of Joza is big and I am not familiar with the place and the person who had promised to escort me had informed me of his unavailability that very same morning.

4.6.1.2 The process of taking photographs

Once the cameras had been collected, I expected the processing of the photographs to be an easy one, only to discover that in Grahamstown, the photo-shops no longer process film from disposable cameras and the nearest shop was in Port Elizabeth. But it turned out that shop no longer had the equipment to separate the film, so I had to wait for two weeks for it to be sent to someone else to separate and return the film. This was very frustrating as I found myself having to frequently make adjustments on the research timeline.

4.6.1.3 Meeting to discuss photographs.

Initially, the proposal was to have a series of 4, one-hour meetings to hold discussions and then the 5th one to plan an exhibition, but five of the participants felt that this would be too challenging for them since they would be using public transport to travel with children who are physically disabled. So it was agreed that there would be two, 2-hour-long meetings for discussions and another meeting to plan an exhibition would be scheduled later. The challenge of transport challenge was later confirmed by the caregivers when they shared their photos and narratives.

The discussions themselves presented another challenge as they were quite emotionally laden and sharing about the photographs triggered painful memories for the caregivers and some of them shed tears when they shared the narratives around their photographs. It became obvious to me that the caregivers carry some unprocessed emotions regarding their experiences.

Another challenge I encountered was the fact that I did not audio-tape the discussions, so I relied on taking notes and writing captions/phrases of the narratives on the board, whilst at the same offering containment to the caregivers. Even though I did consider audio-taping the sessions, I decided against the idea because the main focus was on the shared narratives and discussions of the experiences rather than on the individual narratives. I wanted to guard against conducting my own analysis of recorded data and rather focus on facilitating the participants' own analysis of their stories. However, it became clear during data collection that there was data that I could not capture because I was making short notes and did not have audio tapes to refer to after sessions.

4.6.1.4 Organising the meeting with the stakeholders

Getting the stakeholders together for the powerpoint presentation was another challenge. The caregivers had proposed to do two slide shows; one for APD and another one for the local councillors of Makana municipality, but it proved to be almost impossible to get them together and we finally had to settle for a presentation to a few members from both groups. Organising this meeting successfully was crucial because one of the main tenets of photovoice is to make policy makers aware of the challenges communities face and these two stakeholders had been selected by the caregivers for the presentation.

On the day of my arrival in Grahamstown for the meeting I was confronted with yet another challenge. During my telephonic conversations with the caregivers, three of them had assured me of their availability, but a day before the meeting, one called to excuse herself as she had another important appointment she needed to attend. This would not have been a challenge had this not been the participant who was going to actually lead the presentation during the slide-show. Once the other two caregivers heard that she was not coming then they stated that they would not be able to attend, because they felt that they were not confident enough to talk to the group especially because they are not fluent in English. The fact that the venue for the meeting was at Rhodes University did not help either in allaying their fears, because they now imagined a room filled with Professors asking them questions and so on. To convince them otherwise was a struggle and I had to drive at night to meet with them so that they could familiarise themselves with the slides. This is one area where I saw the goal of empowerment being fulfilled and through PhotoVoice the participants had an opportunity to 'speak' and not be 'spoken for'.

4.6.1.5 The emotional toil of the data collection process

The project put a lot of pressure on me emotionally. Being a mother of two children myself I am aware of the challenges of parenting, but working with these young mothers, watching their children lying helplessly in their cots, beds or wheelchairs and hearing about their struggles provoked sadness and helplessness in me. During the meetings I had to fight hard to distance myself emotionally and focus on my role as a researcher, but after the meetings I struggled a lot with these unprocessed emotions.

4.6.2 The highlights of the experience

4.6.2.1 Empowerment of participants

Through this project, the caregivers were offered an opportunity to be catalysts for change instead of passive complainers. They not only discussed challenges but brainstormed solutions to their challenges, shared care giving tips with one another, started a support group and when the opportunity to share their stories with a group of stakeholders was presented, they faced their fears and were assertive enough to do what needed to be done.

4.6.2.2 The value of supervision

Working under a supportive supervisor helped a lot in ensuring the success of the project. When I encountered some challenges that were beyond my capability, my supervisor assisted me to find solutions. One of those times was when I was struggling to convince the APD personnel about the significance of allowing the caregivers an audience to present the slideshow. The funding she organised also had a very positive impact towards the success of the project. Besides transport money, there were refreshments during all the meetings. Availability of funds also enabled me to travel from Durban to Grahamstown to facilitate the meeting to present a slide show. Supervision also gave me a safe space where I could process the thoughts and emotions I had been forced to suppress during the meetings with the caregivers.

4.6.2.3 The personhood of the researcher

The fact that I am a 'black', isi-Xhosa speaking mature female was an advantage because it played a role in creating a conducive environment for rapport building and allowed communication to flow freely without a need of a translator. Secondly, the fact that I am also a mother made it easy for me to empathise with the caregivers and also assisted me in forming an alliance with them.

Secondly, during the data collection phase I was registered as a student Psychologist, which was an added advantage because sharing their experiences was an emotional exercise which triggered pain, sadness, resentment and despair at times and at times I had to adjust my role

from that of a researcher and offer containment and normalise what that particular caregiver was feeling.

4.6.2.4 The excitement of being a part of a project that seeks to bring positive change in people's live

I consider it an honour that I was allowed by the caregivers to be a part of their lives even if it was for a brief period. What I observed was a group of determined women who are faced with a challenging task but are doing the best they can for their children. I also saw unconditional love for the children. I treasured the research relationship, as I saw myself being trusted with private, personal information about the experiences of the caregivers. It was exciting for me to see the bond that developed between the caregivers which has continued until now and some of them still contact me with some news about the changes in their lives and their children's lives which they attribute to their participation in this research. The project achieved some of its goals and one of those was the empowerment of the caregivers, which saw them becoming courageous enough to address a group of educated professionals and share narratives about their experiences during the presentation of the slideshow to some of the stakeholders.

4.7 Conclusion

This chapter has reported the findings of the study which aimed to explore the experiences of primary caregivers of children with physical disabilities. The findings indicate that caregivers have positive and negative experiences in relation to their responsibility. The findings shed some light into the nature of the challenges they experience and how their experiences can be improved. The findings also suggest that the caregivers felt empowered by the research process and experienced it as a source of support which they plan on continuing.

5. Discussion of findings

5.1 Overview

Although there is considerable amount of international research on the experience of caring for children with disabilities, the focus of the methods of enquiry has mainly been on knowledge production. This research, which was a Participatory Action Research project using photovoice sought to gain an in-depth understanding of these lived experiences and how they can be improved. The participants were not positioned as objects of study as is usually the case, but they were engaged in a collaborative relationship with the researcher and became co-authors of the knowledge produced. Even though contribution to existing knowledge is important, empowering the caregivers and looking at how their experiences can be improved was the primary goal of this study. The research participants were 'black', isiXhosa speaking women from Grahamstown in the Eastern Cape.

The data analysed cover what emerged from the photographs shared by the participants, the narratives around the photos, as well as the focus group discussions involving all six participants. Master themes as well as the subordinate themes mentioned in the previous chapter will be discussed in relation to the existing literature as presented previously in chapter two. Therefore, this chapter will include a discussion about how the current research findings relate to, extend, confirm or contradict the literature.

5.2 Discussion of the main findings

The participants' experiences will be focused on by discussing the main findings of the research. There were two dominant themes that arose from the analysis; there are challenges associated with the caregiving experience, but there also is a positive side to the experience. Under the main theme of challenges, the following subordinate themes emerged: lack of resources; challenges associated with mobility; the hopelessness of the situation, the pain and despair that accompanies it; the loneliness of the experience; and lastly the financial burden associated with caregiving. The subordinate themes that emerged under the positive side the experience included: the joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel; precious

moments shared with the child and personal growth. The challenges associated with the caregiving experience will now be discussed in relation to existing literature.

5.2.1: The challenges associated with the caregiving experience

5.2.1.1 Lack of resources

The challenge of lack of resources is an experience shared by all the participants and it is reported as one of the main reasons behind the experience of caring for a child with physical disabilities being so difficult. Grahamstown is known as a semi-rural area, and as alluded to in chapter 1, most of its residents are isi-Xhosa speaking and are from a low socio-economic background. The participants reported that lack of resources makes their responsibility harder when it comes to feeding, bathing and carrying the child around and this becomes even a bigger challenge as the child grows older and becomes heavier to carry. In the cases where there were resources, these were age inappropriate and were therefore not functional. Of the six participants, four are caring for children who have been diagnosed with cerebral palsy and are unable to control motor function, which means they are completely dependent upon the caregivers for the fulfilment of every need. These experiences of the challenges posed by lack of resources have been reported in other studies such as the one conducted by Chiarello et al. (2016), who further stated that the anxiety that is reported amongst the caregivers has to do with 'worry' about the quality of child care as a result of lack of resources.

Additionally, this theme of lack of resources is consistent with studies reporting the similar challenge in South Africa. A study conducted in SA within a rural context by Mpontshane (2017) showed that all the mothers focused on hardships of caregiving due to the lack of resources. Resch et al. (2010) mentions that the well-being of the caregiver is compromised when the resources to meet the needs of the caregiving role are unavailable or inadequate. Traditionally, modification of factors external to the child for the purposes of achieving successful movement was not valued as much as changing the factors within the child, which often turned out to be an illusory goal. The importance of ambulation and other assistive devices in the rehabilitation and management of children with physical disabilities is now encouraged as an intervention strategy (Wiart & Darrah, 2002).

Lack of resources however does not just refer to aids and assistive devices but the participants also mentioned that lack of schools or places where they can safely leave their

children means that this is a twenty-four hour job without any break, especially where there is also absence of social support. The government schools are not equipped to accommodate children with physical disabilities, which means they are not catered for in the system. This is consistent with what Olkin (1997 cited in Resch et al., 2010) reported when he stated that for some parents school and community inclusion is a fight for basic human rights.

Literature reports that in resource-poor contexts like most communities in South Africa, limited access to health-care facilities and specialists, and lack of adaptive equipment and other ambulation aids have been reported as factors that aggravate the situation (Donaldet al., 2014). Indeed, because of inadequate health-care facilities, two of the participants still had not received confirmation of the diagnosis of their children and each time they make an enquiry they are told the results of the blood tests are still not available.

5.2.1.2 Challenges associated with mobility

All six participants mentioned the challenge associated with moving the child from one place to the next in order to access services such as monthly check-ups at the local health clinic or to go somewhere to run personal errands. This has to do not just with prams or wheelchairs that are not age-appropriate, but with infra-structure challenges which make it difficult to push the pram or wheelchair in and out of the house. Previous literature has written about mobility as one of the factors that have a negative impact on the caregiving for children with physical disabilities (Saloojee et al., 2007). Their study revealed that even where there are available state facilities caregivers were still not utilising these services because they needed to travel long distances and they depend on informal public transport that does not accommodate children with disabilities. This compels the caregivers to either use expensive public transport or carry the disabled children to the services by themselves. Seligman and Darling (2009) also elaborate about the challenge of mobility which they state is further exacerbated by lack of wheelchair accessible transport, which is a particular challenge for families with older children. In support of this, Chiarello et al. (2016) confirmed that mobility is often seen as a priority by parents and lack or limitation of mobility does not only lead to limitations in participation but also robs the child of an opportunity to explore the environment, engage in play, interact with peers and thus gain pleasure and a sense of mastery.

The participants reported challenges associated with moving the older children around the house to bathe him/her or carry him/her outside for much-needed fresh air and sunlight. Due to the age and weight of the child, one caregiver narrated that at times she has had to drag her son because she can no longer lift him up. Providing physical assistance such as lifting, carrying or helping to walk has been cited as a challenge that results in physical strain on the caregivers (Geere et al., 2013).

5.2.1.3 Feelings of hopelessness, pain and despair

Participants reported that from the moment one receives the news, there is a dark cloud that seems to be engulfing one and during the following days one is frequently on an emotional roller-coaster alternating between sadness, anger, guilt, frustration and helplessness. This extreme psychological distress is associated with the frustration caused by slowness of the diagnostic process, lack of transparency and lack of co-ordinated service delivery where caregivers felt unsupported in the experience. None of the participants received support in the form of counselling following the news about the condition of the child. These findings confirm what Donald et al. (2014), found in a systematic review of available literature on paediatric cerebral palsy in Africa that in poor resourced communities, there is lack of resources to support the mother to emotionally process the situation, which means she has to deal with the devastating news all by herself and this can later lead to other mental health problems such as depression. This is probably why the participants emphasized the need for counselling services to be made available as a form of support to the mothers. In addition to this, support in learning how to do ordinary tasks of motherhood such as feeding or bathing the child is required.

The frustration associated with the lack of provision of appropriate health care is confirmed in other literature which states that mothers sometimes feel that the medical personnel, including nurses and doctors can sometimes be insensitive, negative and disrespectful of the humanity of the child (Alex & Whitty-Rogers, 2012). One participant mentioned her exasperation with the long queues and having to move from one queue to another without finding relevant information or sufficient help.

Feelings of despair were expressed and in the early days there was a wish that the child had died, confirming findings by Gupta and Singhal, (2004) that in some countries such as India, disability is still viewed in terms of a 'tragedy' with a 'better dead than disabled' approach.

These thoughts and feelings were accompanied by a sense of guilt and self-blame. The participants stated that they felt guilty because they had fallen pregnant outside of wedlock and felt that their child's disability was a punishment from God, whilst at the same time they felt angry towards God for allowing this to happen to them. Choruma (2007, cited in Chirwa & Ndija, 2012) in the study he conducted in Mutare, Zimbabwe also found that disability is surrounded by myths concerning witchcraft, curses and God's punishment for maternal promiscuity. Previous research has confirmed the experience of being confronted with feelings of self-blame, guilt and anger towards God as one continually searches for reasons for the child's condition, and this can later turn to chronic sorrow and depression especially in the absence of emotional support (Smith, Cheater & Bekker, 2015).

5.2.1.4 The loneliness of the experience

Another challenge cited by the caregivers is the fact that being a caregiver of a child with physical disability can be a lonely experience where one feels isolated from the community and unable to participate in church, recreational and social activities. Wallander (1995, cited in Makela et al., 2009) confirms these experiences of isolation in his discussion of parenting a child with disability. He specifically agrees that the inability to pursue one's personal interests due to the responsibilities involved in raising a child with physical disabilities and the restriction affects not just social activities, but other areas such as homemaking, participation in community affairs, education and career.

Literature has confirmed high levels of social stigma toward children with neurological disorders, with the belief that the child is cursed resulting in exclusion of the family (Choruma, 2007, cited in Dambi et al., 2015). Such cultural beliefs have been stated as some of the reasons for families failing to seek treatment even when it is available (WHO, 2006). According to Gonaet al. (2011), this social stigma can extend to the condition of the child being viewed as resulting from evil spirits, which leads to isolation and exclusion. In some studies, caregivers are reported to have experienced negative reactions such as gossiping, avoiding contact, showing disgust and/or fear for the child with disability (Lang & Chadowa, 2007, cited in Lang, 2009; Marongwe & Mate, 2007).

5.2.1.5 The financial burden

The financial or economic impact of caring for a child with physical disabilities has been reported in several studies as one of the challenges of the experience (Daviset al., 2010; Green, 2007). This was confirmed in this study. As stated in chapter 3 of the study, all the participants are women who are not employed and are mainly dependent upon the disability grant which is provided by the government. The sub-theme of financial burden as one of the challenges was derived from the photos and narratives of all the six participants. Taking care of a child with physical disability involves not just the usual daily expenses associated with caring for the child; there are additional costs such as medical expenses, constant visits to the hospital or health clinic, daily supplies of diapers, special foods etc. Since the caregivers are not employed, they also depend upon the disability grant to meet necessities such as rent, bills, food etc. Stabile and Allin (2012) reported that due to the demands on the life schedule, caregivers report loss of income or productivity, either through reducing hours of work or stopping altogether so as to focus on the caregiving role.

The participants also reported that there are additional costs involved in the care of the child such as assistive devices like specially fitted wheelchairs which they have to do without because of lack of money. Additionally, participants expressed that they often faced financial barriers to accessing services due to high costs of medical and support services, or lack of money for public transport. In support of this Donald et al, (2014) suggests that in resource-poor contexts like South Africa, financial costs attached to medical care, rehabilitation, assistive devices and transportation are significant barriers to seeking care and improving the experience of caring for these children.

5.2.2 The positive side of the caregiving experience

Being a parent of a child with physical disability is not a unilateral experience filled with only hardships and previous research has indicated that raising a child with a disability can be as fulfilling as raising one without (Green, 2007). This was confirmed in this study as all six participants reported that despite the turmoil concerning difficulties such as financial strain and lack of resources, they do experience positive aspects of having a child with physical disabilities.

5.2.2.1 The joy brought about by support from family, the health service providers and the Association for People with Disabilities personnel

One of the factors that the participants mentioned as contributing to the positive side of the caregiving experience is the availability of support from their families, which they stated made them feel that they are not alone in this. According to them family members do not just provide practical help such as babysitting but provide emotional support as well. Seligman and Darling (2009) agree that social support may serve as a coping resource in optimising caregiver well-being and health outcomes. Moreover, a study conducted by Gupta and Singhal (2004) reports that a non-critical family network has been associated with low psychological distress in mothers and having a social network predicts positive family adjustment. This is possibly because social support networks, which include family and other household members, provide emotional, financial and practical support, especially where institutional facilities are absent (Oh & Lee, 2009). In previous literature it has been reported that mothers state that caring for a child with a disability can also strengthen existing social bonds and important familial relationships (Chirwa & Ndaji, 2012), and this was confirmed by some of the participants in this study. This support from family members becomes crucial in under-resourced communities where there are no respite care facilities, formal rehabilitation programmes or special schools (Mpontshane, 2017).

The other form of support the caregivers mentioned as being crucial and beneficial to their overall functioning is the support they receive from the Occupational Therapists who are either working for the Department of Health or for the NPO (APD). These health practitioners offer training on practical skills of caring for the child, give demonstration of exercises to improve the functioning of the child, assess the development of the child and if necessary do referrals to the hospital. This is touched on by Pain (1999, cited in Johnson, 2000) who maintained that hospitals, clinics and health workers provide professional support usually in the form of information that enhances the management of the child and enables the carer to access services and benefits meant to ease the task of raising their child. The role played by health professionals can sometimes shift from that of just a care prescriber and information dispenser to one of collaborator, working in partnership with parents (Smith et al 2015). Acknowledgement of maternal effort and knowledge, plus a willingness to listen have been cited as characteristics that lead to the relationship with the health provider being regarded as valuable and supportive by the caregivers (Nelson, 2002).

The findings drawn from this theme further highlight and add to the literature that reports the importance of the role that is played by community-based organisations as well as by primary health care facilities (as most of these mothers were referring to the clinics they attend). Donald, et al, (2014) have reported that the presence of community-based rehabilitation programmes is effective, not only in terms of providing rehabilitation support, but in increasing access to education and assistive devices. The support from the personnel from the Association of People with Physical Disabilities (APD) was mentioned as indispensable by all the participants. APD is a Non-Profit Association based in Grahamstown and they offer practical support such as assisting the caregivers to quickly access the disability grant as well as the role of advocacy for resources.

One of the significant findings of this current study relates to how the women used the process of this research for support for one another. Listening to each other, validating one another, communicating through a newly-formed 'What's App' group and sharing parenting tips was cited as having been one of the advantages of participating in the study. Photovoice gives the participants an opportunity to form social relations and learn to be a source of support to others experiencing similar challenges (Wang & Burris, 1997).

5.2.2.2 Precious moments shared with the child

The caregivers reported that though the activities of caregiving can be time-consuming and challenging, they can also be rewarding. The special precious moments that they share with the children are priceless and even though the child may be unable to express affection the caregivers claimed that they can feel the love from the children. Hastings and Taunt (2002) in their review of published research on positive perceptions of families with children with development disabilities found out that the parents reported pleasure/satisfaction in providing care for the child and this was seen as moments of sharing love with the child. Previous research has indicated that even though the caregivers found caregiving less rewarding when there was no reciprocal communication with the child, they still found value in the relationship and had great love and commitment to their children (Larson, 1988, cited in Green 2007). Heiman (2002) in his study reported that the parents in his study concluded that their initial negative reactions and feelings of disappointment later turned into positive and optimistic feelings of love, joy and acceptance as they developed a special bond with their children.

5.2.2.3 Personal growth.

Despite the fact that previous literature has written extensively about the challenges encountered when raising a child with disabilities, we now have sufficient evidence, that many parents of children with disabilities identify and report positive impacts of their experiences, including personal growth, more confidence and self-understanding, and changes in general perspective about life (Gupta & Singhal, 2004). This was confirmed by all the six participants who claimed that through this experience they have grown personally in ways they feel would not have been possible had they not been exposed to caring for their 'special' children. This growth covered a wide range including becoming more knowledgeable about the disability, more skilled in providing special care to the child, confidence in one's ability and being more assertive as caregivers finds themselves playing the role of a defender, protector and advocate for the rights of the child . Monsen (1999) also reported that one of the acquired traits that was rated highest by participants in their study was the ability to speak out on behalf of their children, to negotiate terms and conditions related to managing the child's needs and assume the role of advocating for their children. This was often done to fight discrimination and difficulties associated with accessing services, a fact which was confirmed in the current study.

May (1997, cited in Nelson, 2002), describes mothering a child with special needs as mothering that comes with extras and these extras include needing to learn many aspects of caregiving either through self-education, trial and error, or education provided by health care personnel and all this results in personal growth. This finding, that caring for a child with physical disability can lead to personal growth is not new, as Johnson in his study in 2000 concluded that caring for a child with a long-term condition provides opportunity for personal development such as increased knowledge about the child's condition and treatments, managing the child's unique needs and improved communication and organizational skills. One of the participants in the current study reported growth in terms of facing challenging situations, an attribute she feels she has developed out of this experience of caring for her child. This is in line with what Ambikile and Outwater (2012) reported in their study, that exposure to the world of disability makes one more compassionate and tolerant towards others who are disabled and less self-focused.

One participant mentioned the fact that before she had her child with disability, she was self-centred and did not care much about anyone's needs except her own, but from this experience she has noticed that she is always putting her child's need before her own and there is no sacrifice she is not prepared to make if it will be to her child's advantage. Behr, Murphy and Summers (1992, cited in Hastings, 2002) found that indeed taking care of a child with disability can be a stimulus for personal growth and development.

5.2.2.3.1 Growth as a result of participating in the study

Even though the existing body of literature confirms the finding of personal growth as a result of caring for children with physical disabilities, the current study, using photovoice, added to this growth through empowering the participants. Because of the participatory nature of the study the participants had an opportunity to brainstorm solutions to their challenges. This is one of the reasons why PAR is such a potent research design. It allows people who are used to be subjects of research and to depending on other people for solutions to their challenges to be active participants in finding solutions their challenges, thus assuming positions of agents of change (Kemmis & Wilkinson, 1998). The participants in this study learned how to use a disposable camera, the skill of asking for permission to take a photo and were also given an opportunity of sharing with other caregivers facing similar or related experiences. This confirms the fact that involvement in a photovoice project can make the participants feel empowered and enriched (Wang, 1999).Through participation in the project, the participants were given a voice through an engagement with the decision makers, which was done through a slide show and through this the experts had an opportunity to match what they think is important to what the people living the experience think is. Thus the caregivers assumed a stance of being 'experts', which is something they are not really used to. This has hopefully opened up a critical dialogue about what theirs and their children's needs are, which will in the future hopefully inform policy.

5.2.2.4 Conclusion

In this chapter, the findings of the current study were discussed as they relate to, extend, confirm or contradict the existing literature. Master themes and subordinate themes mentioned in the findings chapter were discussed in relation to existing literature and those findings that relate to the unique participatory nature of this project were highlighted.

6. Conclusion

6.1 Overview

The aim of this study was to develop an understanding of the experiences of caregivers of children with physical disabilities in low-income communities using a participatory visual method called PhotoVoice. The rationale for this research was a gap in the existing literature regarding the experiences of caregivers of children with physical disabilities in low-income communities, using a research method that is aimed at not just acquiring knowledge, but contributing to improving these experiences. A small sample of six participants was given cameras to take photographs that capture the significant moments of their experiences and later, narratives and discussions regarding these photos were held. Even though this research does not in any way claim to provide an exhaustive understanding of participants' experiences of caring for children with disabilities, some rich data was gathered. Two major themes were identified across the experiences of the six participants, namely; there are challenges associated with the caregiving experience, but there is also a positive side to the experience. Participants brainstormed solutions to their challenges and they had an opportunity to share their experiences with stakeholders which included representatives from social welfare, the local municipality and APD. In this chapter the two main themes will be discussed briefly, together with the participatory aspect of the findings and then implications for policy interventions, study limitations and recommendations for future research will be discussed.

6.2 Brief review of the main findings

Under the theme of challenges there were five subordinate themes namely: lack of resources, challenges of mobility, the hopelessness of the situation, loneliness of the experience and the financial burden of caring for a child with physical disabilities. The themes of lack of resources and the financial burden of the caregiving experience were strongly noted in the experiences of all the participants. All participants noted the two sub-themes to be a challenge and a stumbling block to their caregiving responsibility. This was consistent with the literature, for example a study conducted in SA within a rural context by Mpontshane (2017) showed that all the mothers focused on hardships of caregiving due to the lack of resources. Furthermore, the participants also experienced caregiving burden associated with

challenges of mobility, which makes it difficult to access health and other necessary services for the child. The participants also expressed that this is a lonely experience where both mother and child feel isolated and this is also consistent with literature which confirms high levels of social stigma toward children with neurological disorders, with the belief that the child is cursed resulting in exclusion of the family (Choruma, 2007, cited in Dambi et al., 2015).

However, the participants also claimed that not all is gloom and doom, but there is a positive side to their experiences which was consistent with what Green (2007) in her study of parents of children with cerebral palsy discovered, i.e. parenting a child with physical disability is not a unilateral experience filled with only hardships. On the positive side, the caregivers reported the following: the joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel; precious moments shared with the child; and personal growth. It was clear from the narratives shared and the discussions that support, whether from family, health professionals or the Association of People with Disabilities goes a long way towards lightening the burden of the caregiving experience. This is consistent with Seligman and Darling's research (2009) who found that social support may serve as a coping resource in optimising caregiver well-being and health outcomes as it provides emotional, financial and practical support, especially where institutional facilities are absent. The special precious moments that they share with the children were reported to be a major contributing factor to the positive side of the caregiving experience. This was found to be consistent with what Hastings and Taunt (2002) in their review of published research on positive perceptions of families with children with development disabilities found; that the parents reported pleasure/satisfaction in providing care for the child and this was seen as special moments of sharing love with the child. Finally, all the participants mentioned personal growth as a result of caring for their children, which include more confidence and self-understanding, and changes in general perspective about life. This was consistent with what Gupta and Singhal (2004) found that indeed taking care of a child with disability can be a stimulus for personal growth and development.

Participating in this photovoice project was perceived to be beneficial by all the six caregivers and they reported that the social aspect of the project which exposed them to other caregivers going through similar experiences, leading to the idea of a formation of a social support What's App group was beneficial, and the opportunity to brainstorm solutions to their challenges was empowering. Further development was demonstrated when two of the

participants who had previously never presented to anyone were able to do a slide-show presentation for a group of stakeholders.

The findings in this study provided a contribution to an understanding of individuals' experiences of caring for a child with physical disability in a low-income environment.

6.3 Limitations of the research

The researcher acknowledges a number of limitations of the study. Firstly, since recruitment was done through APD, this means only the participants who are registered in their database and attend regularly at the clinic with their children were considered for participation. This means some caregivers who may have been interested in participating were excluded. Secondly individual interviews with each participant could have been utilised before gathering all the participants to share collectively as this may have allowed participants to share about more photographs and in the private space of just the researcher. Also, the fact that participants were allowed to select and share about a handful of photographs means there was some subjectivity in the choices made and therefore some rich data may have been lost from those images that were not selected.

Thirdly, the current study had a homogenous sample, and consisted of 'black' isiXhosa speaking women, which means that the findings of the study cannot be generalised to other populations, however the findings are transferrable. Furthermore, another limitation was the fact that the researcher is a novice to photovoice methodology, and a wide range of skills is necessary to complete a photovoice research and project activities. In order to adapt the method to this particular study context I had to make adjustments along the way and there is a possibility that those adjustments may have impacted the research findings. A chief limitation of the study is that the discussions were not audio-taped and the researcher had to play multiple roles at the same time; facilitating discussions, arranging photographs on the wall and writing headings underneath, making short notes of narratives including quotes etc. This means I may have missed some important information that was shared during the discussions. Additionally, some participants had trouble presenting abstract ideas through photographs, and wanted to share some experiences which were not backed up by photographs and stated that they had been unable to capture photographs that expressed the experience. But this information could not be used because the research method is about a 'photo' and a 'voice.' Finally, how much of a change will be brought about as a result of this photovoice project

remains to be seen. In order for some change to take place at policy level, more advocacy work would need to be done by the NGO's representing people with disabilities, e.g. APD. Even though the Councillor who attended the slide show presentation indicated that the Mayor's office has an office that deals with issues pertaining rto disability, it seemed as though this information is not known by the public and therefore there is a need to make sure that those who are community leaders ensure that the people on the grassroot level are aware of services available to them. Although the research has limitations, the findings do present certain implications for practice and policy. These will be discussed below.

6.4 Implications of the findings

In light of the findings of the current research, there are a number of implications for practice and policy. Firstly, regarding the finding of lack of resources and the financial burden of caregiving, the government may have to consider increasing the disability grant so that it can meet the needs of the child. The Department of Health (DOH) needs to work hand in hand with the Non-Profit Organisations, such as APD in provision of services such as the supply of age-appropriate assistive devices for the children. Secondly, regarding the diagnostic process and emotional support, the DOH has a role to play in ensuring that the process does not take too long, and that parents are supported emotionally not just during the diagnosis, but throughout the experience. To offer emotional support is not just the responsibility of the DOH, but NPOs, churches and other welfare organisations can facilitate and promote support groups for mothers who are providing full-time care for their disabled children. The Department of Education has a responsibility to cater for the educational needs of physically disabled children and a special school, with adequate resources is a need in Grahamstown. This would also provide the caregivers with the much needed relief from the caregiving activities. In cases of severe disability, where a child is not in a condition to attend school, then a community respite centre can be built to provide short periods of breaks from caretaking.

Secondly, even though social exclusion and stigma may not be abolished completely, creating awareness in society about disability might have a positive impact on people. This can be in the form of holding an exhibition of the pictures depicting the experience, presentation of slide shows at community meetings and educational campaigns involving caregivers and where possible children with disabilities. It was one of the wishes of the caregivers that their

experiences be also shared with community members to make them aware, with the hope that they may offer some support.

Finally, the local businesses could sponsor Short Courses and later equipment for the caregivers to operate small businesses from home as this would enable them to make earnings whilst working from home. The next step here is to work collaboratively with APD and local councillors to assist the caregivers in approaching local businesses with a request to provide sponsorship.

6.5 Areas of further research

As pointed out in the rationale for this study, there is a gap in the literature regarding the experiences of caregivers of children with physical disabilities in South African low income communities. Furthermore participatory action research within this context is almost non-existent. While this study can be seen as a successful step towards filling this gap, it has its limitations, such as the small sample, time and space constraints, so there is a need to do further extensive research on this topic, using the same research methodology in order to further validate and compliment the findings. Since this is cycle one of this PAR project, cycle two should then focus on taking action to implement the solutions and recommendations from the group discussions and meetings with the stakeholders.

Further research is also needed on how welfare services and NPO's coordinate their services in order to identify and meet the needs of those caring for children with physical disabilities. Another area that could benefit from further research is how the government can improve the access and process of assistance for families of children with disabilities, through its various departments such as health, education, social and welfare services. Lastly, research is needed on how the government can develop and implement policies that focus on meeting the different needs of families caring for children with disabilities.

6.6 Concluding remarks

The primary aim of the current study was to gain an in-depth understanding of the experiences of caring for a child with physical disabilities. The findings suggest that the participants experience challenges that are associated with lack of resources, mobility challenges, financial burdens, the loneliness of the experience as well as the hopelessness of the situation. The findings further reveal that there is a positive side to the experience, which is linked to the joy brought about by support from family, the health service providers and the Association for People with Physical Disabilities personnel; precious moments shared with the child; and personal growth. A brainstorming of solutions session was planned and the caregivers discussed ways of improving their experiences, which included presenting the findings to stakeholders including policy makers, (which was done by two caregivers), starting a support group and working towards starting a home business. So the project was empowering to the participants.

Limitations of the study and areas of future research were explored and implications for practice and policy were provided.

Hopefully, in the not so-distant future the experience of caring for a child with physical disabilities will be transformed into walking on the gravel road, but this time wearing perhaps something like sneakers.

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APPENDICES

Appendix 1: Letter requesting Gatekeeper Permission
Chairperson

Association for Persons with Disabilities

Grahamstown 6139

12 July 2017

Dear Pasha Alden

RE: Permission to recruit through APD for research purposes

I am writing to request your permission to recruit caregivers of children with disabilities as research participants for research that will be conducted as part of the requirements for my Masters degree at Rhodes University. These research participants will be recruited from amongst those primary caregivers who form part of your clientele and who utilize your services. The research aims to explore, using photovoice, the experiences of the caregivers, including their challenging and joyous moments, how their well-being is affected, the support they receive or lack thereof and will culminate in the sharing of the narratives to invited community members and leaders, as well as policy makers.

The findings of the research will also be used to provide feedback to your organisation. Ethical approval for this research has been granted and I attach a copy of this for your information. I also attach the information sheet and the informed consent forms that will be shared with the caregivers for your information. These will be translated into isiXhosa and communicated verbally to participants by myself, as the researcher.

The research is supervised by Prof Lisa Saville-Young, an Associate Professor at Rhodes University, whose contact details are : 046 603 8047 (phone no) and L.YOUNG@RU.AC.ZA

Please do not hesitate to ask me any questions that you may have about the research. I look forward to receiving your response.

Yours faithfully

Nokanyo Ndlovu

078 881 7183

Nokanyondlovu68@gmail.com

Appendix 2: Email granting permission to recruit participants through APD

-----Original Message-----

From: Pasha Alden [mailto:vanishaspice@vodamail.co.za]

Sent: Monday, August 21, 2017 10:41 PM

To: l.young@ru.ac.za

Subject: RE: Request for permission to conduct research

Good day Lisa,

I think it would be in order to go ahead.

-----Original Message-----

From: Lisa Saville Young [mailto:L.Young@ru.ac.za]

Sent: 21 August 2017 09:44 AM

To: vanishaspice@vodamail.co.za

Subject: Fwd: Request for permission to conduct research

Appendix 3: Consent to Participate in Research (Caregiver)

The purpose of this form is to provide you with information that may affect your decision as to whether or not to participate in this research study. The person performing the research will describe the study to you and answer all your questions.

I, _____ (name) agree to participate in the research project of _____(researcher's name) to share my experiences of caring for a disabled child, using photovoice.

   I understand and agree on the following: 1. The researcher is a Rhodes University student who is conducting the research as part of the requirements for a Masters degree in Psychology.

2. The researcher may be contacted on _____ (cell phone) or _____(email). The research project has received ethical approval and is being supervised by Lisa Saville Young, an associate professor in the Psychology Department at Rhodes University who may be contacted on 046 603 8047 (office) or at l.young@ru.ac.za (email).

 3. The researcher will give me a camera to use to capture my experiences and will arrange group meetings to hold discussions and sharing narratives about the photographs. I also understand that some of the photographs may include my child and I give consent for their use in the research

4. My participation is voluntary and I am free to withdraw from the study at any time.

5. I am invited to voice to the researcher any concerns I have about my participation in the study.

6. The report on the project may contain information about me, but the report will be designed in such a way that pseudonyms will be used to protect my identity. Findings of the report will be made public.

7. Feedback will be provided to me based on the research. This feedback will be provided by the researcher. If I feel I need additional support due to the effects of the research, the researcher will refer me to the appropriate psychological support.

Signed on (Date): _____

Participant:_____   Researcher:

_____

Appendix 4: Authorization for Taking of Photographs for research purposes

I, _____ (*Name of Individual*), by signing this consent form, authorize _____(*Name of participant*) to take photographs of myself and/or my child for research purposes.

I understand that before the images are used, my permission will be sought out and I will sign a form giving my acknowledgement of the images and releasing them for use in research.

I have read this document and understand its contents.

Signature of individual (or parent or guardian) _____

Relationship to individual _____

Date _____

The authorization must be signed and dated and a copy provided to the individual completing the form.

Appendix 5: Authorization for Release of Photographs

I, _____ (*Name of Individual*), by signing this release, authorize

_____(*Name of student*) to use photographs of

myself and/or my child for the following purposes:

1. Use in the data collection, analysis and publication of MA thesis studied through Rhodes university.
2. Use in print or electronic form in informing community members and leaders as well as policy makers for the purpose of improving the life and health of those affected in the community.
3. I understand that the images described above may be included in, copied and distributed by means of various print or electronic media. I understand that my and my child's name will not be included with the images.

I understand that this Authorization can be revoked at any time to the extent that the use or disclosure has not already occurred prior to my request for revocation. In order to revoke the authorization, I must notify the Department of Psychology in writing at the following address:

       Prof Lisa Saville Young

        Department of Psychology

       Rhodes University

       Box 94

       Rhodes University

       6140

If I cancel this Authorization after publication of the materials outlined above, I understand that my cancellation may not be able to be honored. If I revoke this Authorization, the University and Department of Psychology shall not engage in any new uses or disclosures of the images or testimonials.

The University and (*Department Name*) will not condition treatment, payment, enrollment or eligibility for services or benefits on the execution of this Authorization. I understand that the images and testimonials may be subject to re-disclosure by the person or entity receiving such information and thus will no longer be protected by federal privacy regulations.

This Authorization is given without promise of compensation. The photos specified above become the property of the Rhodes University and I release to the University any right, title and/or interest of any kind that I and/or my child may have in the information or images produced.

I have read this document and understand its contents.

Signature of individual (or parent or guardian) _____

Relationship to individual _____

Date _____

The authorization must be signed and dated and a copy provided to the individual completing the form.

Appendix 6: Ethical Clearance Letter

RHODES UNIVERSITY
Where leaders learn

Psychology Department
1 University Road, Grahamstown, 6139, South Africa
PO Box 94, Grahamstown, 6140, South Africa
T: +27 (0) 46 603 8500
T: +27 (0) 46 603 7614
E: psychology@ ru.ac.za

RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

22 June 2017

Nokanyo Ndlovu
Department of Psychology
RHODES UNIVERSITY
6140

Dear Nokanyo,

ETHICAL CLEARANCE OF PROJECT PSY2017/46

This letter confirms your research proposal with tracking number PSY2017/46 and title, *'Using photovoice to explore the experiences of caregivers of children with physical disabilities'*, served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 14 June 2017. The RPERC notes that this project is supervised by Prof. Lisa Saville Young. Your project has been given ethics clearance.

Please note that should your project require consent from institutional gatekeepers, the RPERC requires that you submit written confirmation of this consent. Kindly also ensure that the RPERC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators.

Yours sincerely

Mr. Werner Bohmke
CHAIRPERSON: RPERC

Appendix 7: Information brochure
THE POWER OF PHOTOVOICE IN CHANGING LIVES

This is a research project exploring the experience of caring for a child with a disability and it consists of:

*Using a camera to capture significant moments; joys, sorrows, challenges, coping mechanisms, etc. *Getting together to share our stories based on the photographs we took.

*Putting out heads together in brainstorming interventions for improving our lives.

 *Making our communities, leaders and policy makers aware.

Researcher Information:

Nokanyo Ndlovu

 Masters in Psychology student (Rhodes University)

 078 881 7183 nokanyondlovu68@gmail.com