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The influence of the Malamulele onward intervention model on caregivers of children with cerebral palsy

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CHAPTER 1

1. INTRODUCTION

1.1 General overview

In most communities family members are the primary caregivers to children with chronic medical conditions and disabilities. Studies worldwide have shown that trying to cope with the burden of caring for their children in addition to other family responsibilities gives rise to high stress levels and reduced quality of life in caregivers (Glen et al., 2008; Ones et al., 2005; Parkes et al., 2011; Rentinck et al., 2006; Sawyer et al., 2011). Using a stress process model, Brehaut et al. (2004) found that stress related to burden of care also adversely affected caregivers' mental and physical health. Unlike caregivers of children with other chronic illnesses, caregivers of children with cerebral palsy have to deal with a range and variety of disabilities that sap their resources (Guyard et al., 2012; Pugin, 2007). Furthermore, looking after a child with cerebral palsy involves long-term commitment on the part of the caregiver that, in turn, prolongs their stress and increases their risk of deteriorating health-related quality of life (Dambi et al., 2015a; Hamzat & Mordi, 2007; Raina et al., 2005).

Regarding the prevalence of cerebral palsy amongst chronic medical conditions and disabilities, a population-based study done in Atlanta, Georgia, in the United States of America (USA) by the Developmental Disabilities Branch of the National Center on Birth Defects and Developmental Disabilities at the Centers of Disease Control and Prevention (van Naarden Braun et al.,

2016) found that advances in obstetrics and neonatal care ensured increased survival rates after birth. In their study, an average of two children with cerebral palsy out of 1000 births survived to 1 year and beyond, which is in keeping with the worldwide prevalence of 0,2 to 0,3 percent. However, prevalence rates for cerebral palsy are higher in poorly resourced countries, often due to inadequate medical care of perinatal and postnatal complications, infections and injuries. In their July 2014 the Newsletter National Council for Persons with Physical Disabilities in South Africa (NCPPDSA) reported that the incidence of cerebral palsy in the country was as high as 1 to 8 percent, depending on the area and access to medical resources.

Mothers and other female relatives usually shoulder the greatest burden of care for children with cerebral palsy, especially in Africa (Gona et al., 2013; Hamzat & Mordi, 2007) and this places them at greatest risk for physical and psychological ill-health. In disadvantaged communities these children are often members of single parent families or are raised by other female relatives, usually grandmothers (Hartley et al., 2004). All too often, caregivers in African countries are unemployed and have to rely on meagre social grants to support their families as well as to provide for the special needs of children with cerebral palsy. The risk of physical and mental ill-health in such caregivers is high, which in turn endangers the wellbeing of their families in general and the child with cerebral palsy in particular.

In addition to providing extraordinary home-based care, caregivers of children

with cerebral palsy need to make provision for specialised medical treatment and rehabilitation that may be necessary. Traditionally, treatment and rehabilitation for children with cerebral palsy was based on acute care medical models focusing on the child rather than the caregivers and families (Rosenbaum, 2011). Over the past few decades there has been a change in approach to rehabilitation, engendering closer collaboration caregivers. Studies in Europe and the USA have shown that caregivers reacted positively to consultation with medical staff and therapists and inclusion in the decision-making processes and implementation of their children's care and rehabilitation (Jeglinsky, Autti-Rämö & Brogen Carlberg, 2012a and 2012b; Schreiber et al., 2011). These findings support the move towards a family-centred service approach to rehabilitation that acknowledges the needs of the family as well as those of the child (King et al., 2004). This approach also recognises caregivers' knowledge and expertise in their children's condition and needs, and provides information, support and skills in coping with their children at home (Rosenbaum et al., 1998). Home-based programmes have been designed with a family-centred service approach in mind (Novak & Cusick, 2006; Novak, Cusick & Lowe, 2007). Gona at al. (2013) described "*some positive transformations in the caregivers' experiences*" (p. 10) of their children and validated their role and expertise in the rehabilitation process. Saeid et al. (2013) reported that proper instruction in home-based care procedures improved caregiver competence which reduced their burden and enhanced their quality of life. Moreover, the health and wellbeing of children with cerebral palsy improved on these programmes, irrespective of the severity of their disabilities (Moore, Mah & Trute, 2009).

There is inadequate access to hospital-based rehabilitation for children with cerebral palsy in various African countries (Gona et al., 2010; Hammutty, 2001; Hartley, 2004). According to the NCPPDSA July 2014 Newsletter, less than 30% of children with cerebral palsy receive adequate rehabilitation. However, the results of the above studies suggest that a family-centred service approach to rehabilitation and home-based programmes may offer viable alternative for treatment of children with cerebral palsy in areas of inadequate access to traditional therapy. Furthermore, it would "*provide supportive interventions for the caregivers to mediate the effects of caregiver burden*" according to Dambi, Jelsma and Mlambo following their Zimbabwean study (2015b, p. 701).

The present study examines the effect of one such family-centred intervention and home-based programme, namely the Malamulele Onward Intervention Approach (Saloojee, 2007; previously known as the Malamulele Onward Intervention Model), on the burden of care and quality of life of caregivers with children who have cerebral palsy in rural areas of South Africa.

1.2 Background to the study

In 2007 Saloojee et al. drew attention to the plight of disabled peri-urban township children in South Africa with respect to access to healthcare and rehabilitation. In line with findings reported in other African countries (Hammutty, 2001; Hartley, 2004), Saloojee (2006) found that caregivers'

experiences of rehabilitation at public hospitals often failed to meet expectations, especially in the rural areas. The Malamulele Onward Intervention Approach (Saloojee, 2007) was developed with a view to addressing this gap in service delivery in poorly-resourced areas of South Africa.

Development of this approach involved a three-year study in the Mnquma sub-district in the Eastern Cape between 2007 and 2010 entitled "*Provision of annual intensive five day blocks of Bobath-based therapy on children with cerebral palsy living in a poor rural area: a longitudinal study to evaluate sustainability and impact*" (Saloojee, 2007, Protocol No. M070520; Clearance Certificate no. R14/49). The resultant Malamulele Onward Intervention Approach was founded on family-centred service principles of consultation, shared knowledge and skills, building confidence and competence and treating caregivers and their disabled children with respect (Malamulele Onward Non-Profit Company [NPC], Annual Report 2011). This rehabilitation model provides information, practical assistance and intensive hands-on home programme training for caregivers from rural areas in South and Southern Africa who lack adequate access to rehabilitation centres in hospitals. Malamulele Onward NPC is now a non-profit company based in Johannesburg that continues to offer intervention and follow-up services to caregivers and their children with cerebral palsy living in rural areas.

1.3 Problem statement

The available literature on the effects of family-centred home rehabilitation programmes on caregivers' lives and well-being is based on studies done in the United States of America, Canada, Europe and Australia (Darrah et al., 2012; Jeglinsky et al., 2012a and 2012b; King et al., 2004). Thus, these studies were done in well-resourced settings and the applicability of their findings to resource-constrained settings has not been described. Probably due to the dearth of such programmes in Africa, little is known about their impact on African caregivers who differ significantly both culturally and socioeconomically to the comparable caregivers in the developed world. Thus, the research questions that arose were: How do caregivers in under-resourced areas of the Eastern Cape experience the Malamulele Onward Intervention Approach and the use of the home programme designed to supplement the rehabilitation of their children with cerebral palsy? Furthermore, would cross-cultural and language differences between therapists and parents pose additional challenges?

1.4 Aim of the study

The aim of this study was to specifically explore how the Malamulele Onward Intervention Approach has influenced the lives of caregivers of children with cerebral palsy in the Mnquma sub-district of the Eastern Cape.

1.5 Objectives

The objectives of this study were to:

- Describe the caregivers' experiences of the intensive five-day course of therapy with the Malamulele Onward therapists and volunteers.
- Describe the caregivers' experiences of coping with their children at home after implementing therapy ideas and suggestions provided during the intervention week and, where relevant, since using the specialised equipment and assistive devices.
- Describe the caregivers' perceptions of changes in their burden of care, family and community support and quality of life.

Based on a review of the literature one assumed that, provided the therapists accommodated language and socioeconomic differences, the caregivers from disadvantaged backgrounds could respond favourably to the Malamulele Onward Intervention Approach and that, once they acquired more knowledge and skills during the intensive training period, they could use what they learned when implementing their children's home rehabilitation programmes.

1.6 Summary of the introduction and preview

Caring for children with cerebral palsy poses multiple challenges for their caregivers, especially in under-resourced rural communities. The resultant burden of care increases stress, negatively affects their physical and mental health, and reduces their quality of life. Various studies have found that the

family-centred intervention and home-based programmes have a positive effect on the lives of caregivers. It was hoped that the caregivers in this study who live in resource-constrained settings could also benefit from a more inclusive approach to rehabilitation for their children with cerebral palsy.

Literature relevant to this study is reviewed in Chapter 2. It begins with a definition of cerebral palsy before exploring the various challenges that face caregivers of children with cerebral palsy. The chapter concludes with a discussion of traditional and family-centred rehabilitation services and programmes.

Chapter 3 covers the qualitative methodology used in this study. It starts with a more detailed description of the 3-year study using the Malamulele Onward Intervention Approach. This is followed by a description of the participants and ethical considerations. Thereafter, the collection, analyses and validation of the data are presented.

The results of the qualitative analyses of the data are discussed in Chapter 4 in terms of the themes that evolved.

This will be followed by general discussion comparing these findings with those of other studies in Chapter 5.

The conclusions, limitations and recommendations for further research are presented in Chapter 6.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

Cerebral palsy is a fairly common developmental disorder in children and is, in the view of Cans (2000), the most prevalent cause of childhood motor impairment. Rosenbaum et al. defined cerebral palsy as "*a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems*" (2007, p.9). Although the definition emphasised the motor disorders it also recognised that they are often accompanied by other developmental disorders that affect everyday functioning and behaviour.

Healthcare systems and societal attitudes have changed in countries, such as Australia, the United States of America and Canada, with the result that children with cerebral palsy remain in the care of their families instead of in homes and institutions (Davis, Mackinnon & Waters, 2012; Sawyer et al., 2011; Raina et al., 2005). Parents are the primary caregivers and, as such, are responsible for the health, wellbeing and development of the child over and above their other family responsibilities (Lin, 2000). The dedication and self-sacrifice required to provide long-term care for these children reduces

their caregivers' overall quality of life (Davis et al., 2010; Guyard et al., 2012; Raina et al., 2005). This has repercussions for their ability to care for their family as well as the child with cerebral palsy.

The same can be said for children with cerebral palsy in African countries, including South Africa. In disadvantaged communities, the burden of care is often left to single parents or other female family members (Hartley et al., 2004), placing them at most risk for physical and psychological ill-health and reduced quality of life. The World Health Organisation (1997) defined quality of life as "*a state of complete physical, mental and social well-being not merely the absence of disease*" (p.1). Davis et al. (2010) emphasised the importance of quality of life for caregivers to provide proper long-term care for their children with cerebral palsy and Shelly et al. (2008) pointed out that a caregiver's quality of life has become an important outcome variable when evaluating the effectiveness of intervention programmes.

The rest of this chapter examines the challenges faced by caregivers in raising children with cerebral palsy as well as rehabilitation options available to them.

2.2 Caregiver challenges

Worldwide, the burden of caring for children with cerebral palsy permeates social and occupational spheres of daily living (Davies et al., 2010). These

demands add to the caregivers' burden of care with negative consequences for their health and quality of life. After reviewing the literature on the impact of caring for children with cerebral palsy Guyard et al. (2012) concluded that caregivers' daily lives were affected in seven areas, namely "*time, finances, work, the relationship with the family, social relationships outside the home, (and) physical and psychological health*" (p.1595). Brehaut et al. (2004) reported similar findings when comparing caregivers of children with cerebral palsy with the general Canadian population, including lower incomes, more time demands, and poorer physical and psychological health. Caregivers in resource-constrained settings have to grapple with these challenges over-and-above their daily hardships associated with living in poverty in rural settings (Fatudimu, Hamzat & Akinyinka, 2013, Gona et al., 2010; Mobarak, et al., 2000; Ones, et al., 2005; Saloojee, 2006).

2.2.1 Home-based care for children with cerebral palsy

Sawyer et al. (2011) highlighted the amount of time caregivers spent on attending to the daily needs of their children with cerebral palsy. Caregivers who reported greater time constraints experienced higher levels of stress and depression. Often, caregivers had little free time to attend to other responsibilities and to hold down a job, or for relaxation and leisure activities, especially when they had little or no support (Davis et al., 2010). Under these circumstances, caregivers were prone to burnout (Tothill, 2010).

Studies done in Turkey and India indicated that time spent on home-care and

attending appointments interfered with family functioning (Ones et al., 2005). Single caregivers experienced more stress and strain than those who had assistance from partners (Pugin, 2007). African caregivers were often housebound and unable to fulfil community obligations, which have marginalised them and lead to loneliness (Gona et al., 2010; Hamzat & Mordi, 2007). In another Southern African study caregivers living in the rural areas in the Eastern Cape considered their children with cerebral palsy to be helpless and dependent on them for all activities of daily living, leaving them no option but to stay at home (Quinn & Gordon, 2011). Even so, the constant struggle to accommodate their children's home-care needs was a source of stress (Gona et al., 2010).

2.2.2 Financial burden of caring for children with cerebral palsy

Long-term care for children with cerebral palsy is expensive. The children require on-going monitoring by medical staff and therapists as well as specialised schooling and equipment (Pugin, 2007). An Australian study revealed that some families purchased out-of-pocket positioning and mobility devices, equipment for toileting, bathing and dressing as well as other technical and medical devices and toys as they weren't supplied by public health care providers (Bourke-Taylor, Cotter & Stephan, 2014). The more assistance the child required the more equipment he or she needed and the more money was spent.

Bearing in mind the costs involved in looking after a child with cerebral palsy,

caregivers often have less time available to work for pay (Brehaut, et al., 2004) and this can lead to problems in sustaining employment (Davis, et al., 2010) and acquiring work (Pfeifer, et al., 2014). Time constraints also interfered with employment opportunities in Kenyan caregivers, preventing them from providing for their families (Gona et al., 2010).

In 2003 the Board of Directors of the American Academy of Pediatrics (AAP) appointed a Task Force with a view to guiding policy and making recommendations for promoting functional families. One area of investigation was financial stability in these families. The findings showed that female-headed families were five times more likely to live in poverty than those of married couples (Schor, 2003). The situation is similar in Africa where female African caregivers are often unemployed and live in poverty. In a study conducted by Pugin (2007) the amount of income correlated strongly with stress levels in caregivers, leading her to conclude that poverty was a major contributing factor to stress. This conclusion concurred with findings of other researchers in well-resourced and resource-constrained countries (Guyard et al., 2012; Mobarak et al., 2000). Even when caregivers of children with cerebral palsy shared similar socio-economic circumstances to matched controls a Nigerian study done by Fatudimu et al. (2013) found that they had less disposable income and demonstrated poorer quality of life than the control group.

2.2.3 Personal consequences of looking after children with cerebral palsy

Tending to the daily needs of children with cerebral palsy is stressful for caregivers (Glenn et al., 2008). When considering negative elements of caregiving, Uren (2009) found that burden of care and stress gave rise to burnout and compassion fatigue. Using a multidimensional model, Raina et al. (2005) found that child behaviour, caregiving demands and family functioning were the most important predictors of caregiver stress. Higher stress levels related to burden of care affected caregivers' mental and physical health according to Brehaut et al. (2004). However, Marrón et al. (2013) commented that caregivers adapted to the demands of looking after a child with cerebral palsy in different ways. In their view, this was due to individual issues, such as the physical and mental limitations of the child and the caregiver, as well as the contextual issues, such as the home environment, and consequences the caring role may have for other family members. Manuel et al. (2003) concurred with this view and wrote that it was important to determine moderating factors, such as caregiver perceptions of the impact of their child's disability, income and support when evaluating caregiver stress.

In 2010 a study by Cheshire, Barlow and Powell showed that caregivers of children with cerebral palsy were more likely to demonstrate psychological disorders than caregivers of children with chronic illnesses. Also, psychological distress showed negative correlation with overall quality of life in caregivers (Davis et al., 2010 and 2012). Most often, this manifested as

depression, in keeping with Manuel et al. (2003) who found caregivers to be depressed compared with controls. Marrón et al. (2012) considered depression to be an important indicator of burden of care and quality of life. This view was supported by the results of a Sri Lankan study done by Wijesinghe, Hewage & Fonseka (2014) that revealed psychological disorders, namely depression and anxiety, in cases where burden of caring for children with cerebral palsy was high.

One would presume that parents of children with milder forms of cerebral palsy would be less stressed that those with children who have more severe disabilities. Surprisingly, studies in various well-resourced (Brehaut et al., 2009; Sawyer et al., 2011; Skok, Harvey & Reddihough, 2006) and under-resourced (Hamzat & Mordi, 2007; Ones et al., 2005; Pugin, 2007) countries failed to show any relationship between severity of the child's physical disability and caregiver stress levels, psychological well-being and quality of life.

Physical health problems related to stress, such as back pain, ulcers, etc., were prevalent in caregivers of children with cerebral palsy (Brehaut et al., 2009). Where little or no assistance is available to caregivers, as is the case in certain African countries, there are complaints related to physical strain, such as backache, especially in caregivers with older and more disabled children with cerebral palsy (Dambi et al. 2015b; Hamzat & Mordi, 2007). Pain was one of the factors contributing to lowered health-related quality of

life in a study by Dambi et al. (2015a). Several caregiver participants in my study resorted to carrying their children on their backs out of necessity, irrespective of the size and weight of the child. Some of the children were teenagers and their caregivers complained that carrying them any distance took excessive effort and gave rise to severe backache and other body pains.

2.2.4 Interpersonal consequences of looking after children with cerebral palsy

In a joint United Kingdom and European study Parkes et al. (2011) identified interpersonal stress in caregivers as originating from their relationships with the child with cerebral palsy, the rest of the family and their social environment.

Several studies draw attention to the important relationship between child behaviour problems and caregiver stress and psychological well-being (Glen et al., 2008; Guyard et al., 2012; Pousada et al., 2013). Children with cerebral palsy have far more behaviour problems than their peers, especially during the pre-teen years (Sipal et al., 2010). According to findings in a Canadian study, Raina et al. (2005) considered behaviour problems to be a foremost predictor of psychological well-being in caregivers. These findings concurred with those of Mobarak et al. (2000) in a Bangladeshi study, suggesting that there was a similar trend in well-resourced and resource-constrained countries. Behavioural problems appear to be worse when cerebral palsy is accompanied by cognitive and communication deficits (Parkes et al., 2011; Vargus-Adams, 2011). Such deficits in children with cerebral palsy impeded

bonding with their mothers and the development of attachment behaviour in studies done in the United Kingdom and in the Eastern Cape (Howe, 2006; Quinn & Gordon, 2011).

Difficulties in coping with a child who has cerebral palsy can have a negative effect on the caregiver's attitude towards the disability (Guyard et al. 2012). Eisenhower, Baker and Blacher (2005) proposed that differences in behaviour between children with cerebral palsy and children with other disabilities, such as autism, could be due to the type of rehabilitation received – the former concentrated on physical, occupational and speech therapies whilst the latter focused on psychosocial and behavioural interventions. Their findings suggest that psychosocial aspects of children with cerebral palsy could be overlooked giving rise to emotional and behavioural difficulties.

There is considerable consensus in the literature about the importance of partner/marital, family and community support for caregivers of children with cerebral palsy. Marital support appears to have a moderating effect on caregiver stress. In a Japanese study parents of children with cerebral palsy nominated their spouses as the person who gave them most support (Hirose & Ueda, 1990). Caregiver stress was found to be low in mothers where there were high levels of support and marital satisfaction (Britner, et al. 2003). Button, Pianta and Marvin (2001) observed that practical assistance and support from partners were better predictors of wellbeing in mothers than perceived emotional support. Factors increasing caregiver stress were poor

spousal support (Glenn et al. 2008) and marital problems (Pugin, 2007). The latter increased stress levels in caregivers as well as the risk of behaviour problems in their children with cerebral palsy (Sipal et al., 2009). There are indications that spousal involvement could interfere with caregiving routines and increase maternal stress (Button et al., 2001). In African cultures support from husbands and male partners could be low as child-rearing is left to women (Dambi et al. 2015b; Gona et al, 2013; Pugin, 2007).

Family cohesion is paramount to caregivers' health and well-being (Raina et al., 2005). Britner et al. (2003) viewed families as "*self-regulating organisational systems*" (p346). Factors contributing to cohesion and resilience in the face of crises and changing demands included the capacity for reorganisation and adaptation within the family and the utilisation of support resources. The results of Lin's study in 2000 produced five factors that assisted with adaptation and coping along similar lines, namely "*positive family appraisa*l", "*support from concerned others*", "*spiritual support*", "*personal growth and advocacy*" and "*positive social interaction*" (p.207). This author emphasised the importance of "*life cycle stages*" (p.204) of both the caregiver and the person with cerebral palsy in terms of ability to cope with, and adapt to, the demands of care.

Cultural differences could account for disparate findings in some of the above studies. For example, family members were supportive towards Japanese parents of children with cerebral palsy (Hirose & Ueda, 1990). In China, on

the other hand, family members often blame the mother for the child's disability and refuse to contribute towards the child's care, leaving the mother to bear the burden of raising the child on her own (Huang et al., 2010; Huang et al., 2011). Similarly, family members of mothers with disabled children in some African cultures presume they have been punished for some deed, cursed or bewitched and want nothing to do with them (Gona et al., 2010).

Low levels of social support were associated with increased stress and depression in caregivers according to a literature review by Pousada et al. (2013). Case-Smith (2004) reported that caregivers often missed out on social events and recreational activities outside the home for lack of a substitute caregiver that could potentially lower depression. Conversely, when caregivers perceived their social support system as satisfactory there was a reduction in their stress and depression (Rentinck et al., 2006; Wanamaker & Glenwick, 2011).

Again, the literature demonstrated cultural differences in social support resources. In a Brazilian study caregivers turned to friends for assistance (Pfeifer et al., 2014). Japanese mothers found solace in sharing experiences and information with other mothers of children with cerebral palsy (Hirose & Ueda, 1990). In African countries caregivers were often marginalised by the community due to superstition and stigmatization (Gona et al., 2010; Hamzat & Mordi, 2007), leaving them feeling isolated and overwhelmed. Whilst technological means of communication, such as cell phones and the Internet,

may be readily available in certain urban areas, this is not always the case in resource-constrained rural areas.

2.2.5 Summary of caregiver challenges

Caregivers of children with cerebral palsy face multiple situational, contextual, personal and interpersonal challenges that reduce their health-related quality of life and give rise to psychological and physical problems. For the most part, these challenges seem to be universal, although cultural practices play a role in social support, which is one of the moderating factors that assist with adaptation and coping. Conversely, factors, such as poverty, single parent families, and a lack of support may increase the burden of care and health-related quality of life.

2.3 Rehabilitation of children with cerebral palsy

2.3.1 Traditional healthcare and rehabilitation services

In well-resourced and resource-constrained countries caregivers are referred to hospitals and/or clinics for treatment once their children are diagnosed with cerebral palsy. In Africa caregivers of disabled children usually rely on public healthcare providers for rehabilitation. Yet there are discrepancies between the services offered by public healthcare providers and caregiver needs and those of their children. A study done in Zimbabwe by Hammutty (2001) revealed notable dissatisfaction amongst caregivers with available services as well as with the absence of outreach programmes for their children. Dambi

and Jelsma (2014) confirm that there has been deterioration in the healthcare services in Zimbabwe. Rehabilitation and treatment options in public hospitals and clinics were found to be unsatisfactory in other parts of Africa. Caregivers in Kenya reported that there was poor understanding of their situation and a lack of medical attention and advice from hospital staff (Gona et al., 2010). In an impoverished peri-urban township in South Africa Saloojee et al. (2007) found that caregivers of disabled children were underutilising available resources and services because of poverty, poor dissemination of information and problems with bureaucracy. These views concur with findings reported by Sloper and Turner (1992) namely that it is the most vulnerable families of children with cerebral palsy who either struggle to find appropriate healthcare or "*take a passive approach to dealing with problems*" (p. 279) as they are overburdened with other responsibilities.

Other problems experienced by caregivers living in rural areas are the availability and cost of transport to the local hospital and/or clinic. Participant caregivers in this study were from the rural Mnquma sub-district of the Eastern Cape so they attend the Cerebral Palsy Clinics at the Tafalofefe and Butterworth Hospitals. The women reported that they traverse vast distances between their dwellings and the Hospital Clinics using public transport along undulating and bumpy gravel roads that become impassable in rainy weather. Bus services are unreliable so most of the caregivers use taxis. Taxi fares are expensive and caregivers miss appointments if they are short of funds and are unable to borrow money.

In the preface to her PhD thesis Saloojee (2006) gave an account of what awaits caregivers when they finally arrive for their children's monthly visit at South African public hospitals. She wrote that queues, checking-in delays due to misplaced files, long waits, limited time to spend with rehabilitation staff for assessment and adjustment to home programmes and language barriers are commonplace. In her words, "*its chaos*", which prompted her to ask, "*Are we really achieving anything here?*" (p.1) and to wonder whether this was making any difference in the lives of the caregivers and their children.

2.3.2 Family-centred rehabilitation services

As early as 1990 McLinden noticed a tendency for medical and mental healthcare professionals to design interdisciplinary programmes and interventions that would encompass the needs of parents and empower families. However, in 1992 Sloper and Turner observed that families still experienced difficulties in dealing with multidisciplinary teams and they suggested that a designated therapist be appointed to assess the needs of individual families and liaise with other members of the team to coordinate services.

For years therapists have provided caregivers with home programmes as an extension of in- and outpatient rehabilitation for children with cerebral palsy. Hinojosa and Anderson (1991) found that programmes were often too complex and/or time consuming, leaving caregivers overwhelmed and unable to comply with suggestions to implement therapeutic activities at home.

Novak and Cusick opined that in Australia this could be due to a lack of "*clinical guidelines*" for therapists when developing, implementing and evaluating home programmes (p. 262, 2006). They proposed a five-phase model based on family-centred service principles as a frame of reference for use by therapists. Using this model a pilot study done by Novak et al. (2007) yielded promising results in terms of therapeutic goals and outcome measures.

Raina et al. believed that "*the development of interventions to reduce the stress experienced by caregivers of children with CP (cerebral palsy) both possible and necessary*" (p. 634, 2005). Accordingly, various studies investigating caregiver involvement in rehabilitation programmes showed that this increased their understanding of their children's disabilities, provided additional skills and competence, reduced stress and improved their sense of wellbeing (Ahl et al., 2005; Cullen & Barlow, 2003; Jansen, Ketelaar & Vermeer, 2003). Ones et al. (2005) considered active parent/caregiver participation to be crucial to their children's management and treatment. In fact, the children of caregivers who were involved in therapy reached therapeutic targets sooner than those who refrained from participation. Caregivers who were involved in setting goals for therapy aimed at improving daily functioning in their children reported a positive change in their view of caregiving (Ahl et al., 2005). Information from caregiver focus groups in Canada provided similar findings in that they were enthusiastic about participating in therapeutic goal-setting for their children with cerebral palsy (Wiart et al., 2010). However, they experienced some difficulties with

implementing complex movement therapies and reported that they struggled to balance therapy with other daily activities.

To improve what Cullen and Barlow (2003) called "*caregivers' self-efficacy regarding the care of their child*" (p. 204) they trained primary caregivers of children with cerebral palsy in the United Kingdom in simple massage techniques. With increased self-efficacy and confidence over time there was improvement in caregiver psychological well-being. On reviewing literature on parental participation in physical therapy Jansen et al. (2003) concluded that parental stress decreases as their confidence in caregiving competence increases. Efficacy and confidence also increase with ongoing training in individualised home-based programmes. This was the case with caregivers in a Taiwanese study (Kuo et al., 2013) and the results showed a reduction in their emotional problems and depression and an increase in health-related quality of life.

Rosenbaum et al. (1998) foresaw that family-centred approaches to rehabilitation in children with cerebral palsy would constitute partnerships between the caregivers and the therapists involving communication and collaboration, bearing the family characteristics, situation and capabilities in mind. However, Jeglinsky et al. (2012b) observed that implementation of the family-centred principle by traditional therapists and/or rehabilitation institutions could be problematic at times when it came to collaboration and open communication with caregivers. These therapists seemed to have

difficulty in adopting a more cooperative approach and viewing caregivers as partners. In a study by Darrah et al. (2012) Canadian therapists were committed to family-centred service programmes for children with cerebral palsy in principle, but implementation tended to be informal rather than formal. Therefore, integration between therapeutic goals and home programmes was lacking. Such integration is vital and Nicolson, Moir and Millsteed (2013) emphasised that caregivers must perceive that the time and effort expended on acquiring therapeutic skills were worthwhile when it came to implementing their children's home rehabilitation programme.

The above studies have been done in well-resourced settings and the applicability of their findings to resource-constrained settings is unknown, especially when there may be cultural and language differences between therapists and parents. In the African context the challenge is to meet the needs of caregivers and their children with cerebral palsy against a backdrop of limited available resources whilst taking the taking the cultural and language differences into account. Family-centred multidisciplinary programmes that educate and involve caregivers in goal-setting and therapeutic intervention are essential in areas where there are significant obstacles to accessing healthcare services on a regular basis. In an attempt to address the issue of access, rehabilitation staff in Zimbabwe introduced outreach community-based programmes linked to hospitals in six major centres (Dambi & Jelsma, 2014). Unfortunately, due to the economic downturn and deterioration in the healthcare system this service is only offered in Harare. Caregivers bring their children with cerebral palsy to

community centres twice a month. There, the children receive individual therapy whilst the caregivers attend group activities and education sessions. A pilot study done by Dambi and Jelsma (ibid) showed there was greater satisfaction with service received and better compliance amongst caregivers whose children attended the outreach community-based programmes than those who continued with institution-based service. Moreover, they observed that caregivers continued to bring their older children with cerebral palsy for therapy.

In South Africa therapists and volunteers associated with NPO Malamulele Onward travel to rural areas in various provinces to offer rehabilitation services and caregiver training to children with cerebral palsy. Each visit lasts five days during which time the children are assessed and receive intensive therapy from a multidisciplinary team based on the Bobath approach, involving observation, analysis and interpretation of task performance (Saloojee 2006). In the meantime, the caregivers undergo education and training. Follow-up visits involve reassessment of the children and reappraisal and adjustment of their intervention programme as well as retraining and follow-up interviews with caregivers. Furthermore, in accordance with the family-centred approach to rehabilitation, the caregivers are considered experts on their children's condition and collaboration with the therapists in developing, revising and implementing their individualised rehabilitation programmes is welcomed.

2.3.3 Summary of rehabilitation of children with cerebral palsy

There is a move away from traditional institution-based (hospital and clinic) rehabilitation services to family-centred services, involving open communication and collaboration between the therapists and caregivers of children with cerebral palsy. Studies into caregivers' experience of the family-centred approach have shown promising results. However, although caregivers support this approach in principle, attention still needs to focus on implementation.

CHAPTER 3

3. METHODOLOGY

3.1 Introduction

According to Silverman (2010) "*research methods should be chosen based on the specific task at hand*" (p. 9). The aim of this study which was "*to specifically explore how the Malamulele Onward Intervention Approach has influenced the lives of caregivers of children with cerebral palsy in the Mnquma sub-district of the Eastern Cape*" (see page 6). Thus, it was important to elicit and to unpack the participants' individual views and experiences of the Malamulele Onward Intervention Approach. It was my opinion that a qualitative research design was best suited to achieve this aim. For this reason I chose this design to capture as much rich personal information as possible from the participants in accordance with the objectives of the study (see pages 5 to 6).

This chapter presents a detailed description of the design of the study, including the participants, ethical considerations, the procedures used to collect and analyse data, and to ensure rigour of the findings.

3.2 Research design

For the purposes of this study, a descriptive qualitative research design (Botma, Greeff, Mulaudzi & Wright, 2010) was used in order to gain insight into the way in which caregivers of children with cerebral palsy experienced

the Malamulele Onward Intervention Approach to training in therapeutic and handling techniques and the use of specialised equipment and assistive devices, and how this affected their daily lives and burden of care.

The study utilised data collected from six focus group discussions conducted as part of the longitudinal study entitled, "*Provision of annual intensive five-day blocks of Bobath-based therapy on children with cerebral palsy living in a poor rural area: a longitudinal study to evaluate sustainability and impact*" (Protocol No. M070520; Human Sciences Ethics Committee [Medical] Clearance Certificate R14/49 Saloojee, 2007).

3.3 Study population

3.3.1 Participants

The participants were selected from a group of caregivers from the remote Nqamakwe Health District in the Eastern Cape whose children attended the cerebral palsy clinics at the Butterworth and Tafalofefe Hospitals.

In accordance with the unique Malamulele Onward Intervention Approach, caregivers accompanied their children to venues at the hospitals (viz., the nurses lecture room at Butterworth Hospital and the nurses dining hall at Tafalofefe Hospital). The children were seen three times a year for three years – the first visit each year was a pre-intervention assessment session,

the second was the five day intervention session whilst the third visit was the follow-up assessment (see Table 3.1 on page 33). During the intervention visit, the children received five days of intensive therapy from a team of experienced volunteer therapists (physiotherapists, speech therapists and occupational therapists) who had specialised in working with children with cerebral palsy. At the same time, their caregivers were educated about the children's condition and trained to continue with the rehabilitation programmes at home. Where necessary, the children were also fitted with specialised equipment and assistive devices free of charge. Three months after each of these five-day intervention visits, the children returned for a follow-up assessment and revision of the home programmes. During the second, third and fourth pre-intervention and the follow-up visits, time was set aside to interview the caregivers and to run focus groups. The participant caregivers were informed in advance of the dates of the focus groups.

The following criteria were used when selecting participants for the focus groups:

- The participants had to feel comfortable to talk freely about their feelings, their experiences and their children in front of others.
- The participants were all primary caregivers and were either biological or adoptive mothers, or grandmothers.
- Their children all had a diagnosis of cerebral palsy, ranging in type and severity, and associated impairments involving, for example, motor function, cognition, vision and communication.

Altogether, 21 participants were included in this purposive sample whose first language was IsiXhosa. Five of the participants were grandmothers and the remainder were mothers. There were focus groups at the Butterworth and Tafalofefe Hospitals. With the exception of the first focus group, which combined participants from both hospitals, participants attended focus groups at the hospital closest to their place of residence (i.e., either the Butterworth or the Tafalofefe Hospital). The focus groups comprised a minimum of five and a maximum of 12 participants (see Table 3.1).

3.3.2 Ethical considerations

As mentioned previously, this study was part of a larger, longitudinal study namely, "*Provision of annual intensive five day blocks of Bobath-based therapy on children with cerebral palsy living in a poor rural area: a longitudinal study to evaluate sustainability and impact*" that was granted clearance by the Human Sciences Ethics Committee in 2007 (Clearance Certificate no. R14/49; see Appendix 1). As a result, the participants in the present study had already given informed written consent (verbal in the case of caregivers unable to read and write) for their participation in the focus groups, for the discussions to be audiotaped and for the information to be used for research purposes. In order to encourage participation in the focus groups the participants' travelling costs were covered and they were provided with refreshments on attendance days. With regard to confidentiality, participants were not identified by name. Also, they were instructed not to discuss what happened in the focus groups with anyone else. However, it

was not possible to ensure that the participants complied with these instructions.

3.4 Data collection

This study utilised data collected from the focus group discussions conducted at intervals over three years. The first focus group was convened in August 2007 and the last focus groups in January 2010 (see Table 3.1).

Table 3.1: Focus Groups – dates, locations, visits and participants

Dates	Hospital locations	Visits	Participants
August 2007	Butterworth	Follow-up /post-intervention	12
January 2008	Butterworth Tafalofefe	Pre-intervention /assessment	10 8
August 2008	Butterworth Tafalofefe	Follow-up /post-intervention	8 8
January 2009	Butterworth Tafalofefe	Pre-intervention /assessment	8 8
August 2009	Butterworth Tafalofefe	Follow-up /post-intervention	9 9
January 2010	Butterworth Tafalofefe	Pre-intervention /assessment	8 5

The first focus group discussion took place at the Butterworth Hospital during the follow-up visit after caregivers and their children with cerebral palsy had attended the first five-day intervention session. It was the largest group and comprised a combination of participants from the Butterworth and Tafalofefe Hospital Clinics. By then, participants had some experience of administering the home programmes and using the specialised equipment and assistive devices with their children.

Thereafter, focus groups were convened at each of the hospitals during the pre-intervention and assessment visits (January 2008, 2009 and 2010) and follow-up visits after intervention (August 2008 and 2009). Four of the participants attended all six focus groups. With the exception of five newcomers in 2009, the remaining participants missed one or two visits and focus groups. The newcomers received the same education and training that was afforded other members of the focus groups.

Throughout the study the same two facilitators, trained in conducting focus groups, facilitated the discussion. Both were fluent in a number of languages, including English and IsiXhosa, and were mothers of children with cerebral palsy. It was assumed that the participants would feel comfortable with these facilitators as they were conversant in their mother tongue and had personal experience in raising a child with cerebral palsy and that this would encourage open discussion more readily than if a professional researcher was employed.

The focus groups took place in quiet rooms within the grounds of the Butterworth and Tafalofefe Hospitals with seating for all the participants. Prior to commencement, the purpose and process of the focus group discussions were explained to the participants and they were invited to ask questions to clarify any misunderstandings. They were then requested to speak openly and honestly during the discussion and were asked to keep the information confidential and not to repeat what was said outside the group.

During each focus group, there was discussion on the following broad topics that were pertinent to my study:

- The caregivers' experience of the full-day sessions with the Malamulele Onward therapists during the five-day therapy intervention.
- The caregivers' experience of coping with their children at home after implementing therapy ideas and suggestions provided during the intervention week and, where relevant, since using equipment.
- The caregivers' perception of changes in their burden of care, family and community support, and quality of life.

The focus group discussions lasted an hour to an hour and a half. They were audiotaped and observations were recorded in writing. Whenever a participant responded, they were required to identify themselves and to give the name of their child or grandchild so that the speaker could be identified when the audiotapes were being transcribed. This was important for purposes of analysing participants' narrative responses. Each question was explored until no new information was forthcoming on that topic. Once all the questions had been explored, the focus group participants were asked whether there was anything else they would like to add. Once everyone had had their say the participants were thanked for their participation and the focus group was adjourned.

I was not present during the focus group discussions in 2007, 2008 and 2009.

However, I was involved in the focus group discussions in 2010 as an observer and note-taker.

3.5 Data analysis

As mentioned above, data used in this study formed part of a larger body of data collected by quantitative and qualitative methods during the longitudinal study entitled, "*Provision of annual intensive five day blocks of Bobath-based therapy on children with cerebral palsy living in a poor rural area: a longitudinal study to evaluate sustainability and impact*" (Saloojee, 2007). I was not involved in planning the larger study. Instead, I carried out secondary data analysis on selected information gathered during the focus group discussions.

Analysis of the collected data followed a series of steps, starting with preparation of the data for analysis and then proceeding with inductive content analysis. The latter involved a process of 'bottom up' analysis to segment the data into codes that were then organised into categories and combined into increasingly abstract subthemes and themes to gain a deeper understanding of the data (Botma et al., 2010; Creswell, 2014).

The first step in analysis of the data was to transcribe the focus group discussions recorded on the tapes verbatim into IsiXhosa, which was done by professional translators. They then translated the IsiXhosa transcriptions into

English, attempting to keep the narrative as close as possible to what was originally said. The English translations of the discussions were printed and bound according to the date of each focus group.

To check the content of the transcriptions and to capture as much linguistic and emotional richness as possible from the original recordings I listened to the audiotapes again in the presence of a Parent Liaison Officer and Therapy Assistant for Malamulele Onward, who was one of the facilitators and who acted as interpreter. In this way, I recovered and made notes of additional audio-information to what was said during the discussion between participants, such as sounds of laughter, sighs, changes in voice volume, etc.

In qualitative research the content of the transcripts are analysed using coding techniques, which Skinner (2008) described as "*searching the data for common themes which can be established as categories into which ideas and information can be collected*" (p. 324). I followed the thematic coding technique outlined by Creswell (2014, pp. 197-200), using a manual colour coding technique. He suggested the following steps in the process of analysis:

- Step 1: Organise and prepare the data for analysis by transcribing the interviews, writing up field notes, sorting data according to the source.
- Step 2: Read through the transcriptions repeatedly to get a general sense of the information and reflect on its meaning. Start making notes

in the margins.

- Step 3: Start coding the data by organising the text into chunks by segmenting the sentences into categories. List the topics and condense into categories and allocate a code.
- Step 4: Use the codes to identify themes and sub-themes emerging from connections between categories.
- Step 5: Represent these themes in the form of qualitative narrative in a detailed discussion (see Chapter 4).
- Step 6: Interpret the data (see Chapter 5).

3.6 Rigour

Botma et al. (2010) noted that "*authors differ when it comes to describing rigour in qualitative research*" (p. 230) so different terms are used. For example, Creswell (2014) referred to qualitative validity and reliability, whilst Lincoln, Lynham and Guba (2011) preferred the term, trustworthiness. In Creswell's (ibid) view trustworthiness and validity were similar.

Trustworthiness (Lincoln, Lynham & Guba, ibid) was established by:

- Using data from various sources to corroborate findings. In this study, I used the English translations of the IsiXhosa transcripts from the taped focus group discussions, my field notes and notes I made whilst listening to the original tapes with one of the facilitators, who acted as interpreter.

- Using rich and thick descriptions of the setting and providing transcripts as close as possible to the language used by the participants.
- Collecting and analysing data until no new information or categories emerged.

In line with Creswell's (ibid) concept of qualitative reliability I took the following precautions:

- The transcripts were checked for accuracy by listening to the original audiotapes with one of the facilitators, who acted as interpreter.
- Cross-checking codes with other researchers. A colleague with a background in psychology familiar with qualitative data analysis and who was not involved in the data collection independently coded the data. There was a high percentage of agreement between the categories, codes and themes that were generated by myself and my colleague. In order to control for possible psychological bias the data were examined by two other professionals outside of the field of Psychology.

3.7 Summary of methodology

Using a qualitative, descriptive and contextual design I analysed data in the form of translated transcripts generated during a series of focus group discussions with caregivers of children with cerebral palsy who are involved in the Malamulele Onward Intervention Approach rehabilitation programme.

A thematic coding technique was used to analyse the data. The original transcripts and the findings were subjected to various methods to ensure trustworthiness and reliability of the findings.

CHAPTER 4

4. FINDINGS

4.1 Introduction

In this chapter themes that were generated by the participant caregivers in response to the broad topics of discussion during the focus groups will be presented (also see 3.4 in Chapter 3).

4.2 Discussion of themes

4.2.1 Introduction to themes

Five main themes were identified from the data collected during the focus group discussions on caregivers' experiences of the Malamulele Onward Intervention Approach and the way in which it had influenced their lives. They were 'validation', 'empowerment', 'wellbeing', 'faith and hope' and 'stress and strain'. These themes as well as their subthemes and categories are presented in Table 4.1 on page 42. A fuller presentation thereof together with examples of supporting data can be found in Appendix B, Tables 1 to 5.

In addition to the above themes a few of the participants mentioned that they were still experiencing various stresses and strains as a result of ongoing hardships in raising their children with cerebral palsy. These include forced resignations for employment, dashed hopes and wishes, other impediments and lack of placement opportunities in facilities, such as Special schools and Day Care and are laid out in Appendix B, Table 5.

Table 4.1: Main themes, subthemes and categories from focus groups

Themes	Subthemes	Categories
Validation	Acceptance from others	*Love and respect from therapists and hospital staff.* *Acceptance from family members and community*.
	Acceptance from caregivers	*Accepting the child and his/her disability.*
Empowerment	Education	*New knowledge and understanding*.
	Self-efficacy	*Practical skills and competence.* *Use of equipment.*
Wellbeing	Reduced caregiver burden	*Reduced physical strain when using equipment.* *Support from the family and community.* *More free time for activities.*
	Relief for the child	*Increased comfort and freedom for the child.* *Improvement in the child's condition.*
	Positive psychological state	*Reduced psychological stress.* *Gratitude.* *Moral support from other caregivers who are part for the study.*
Faith and hope	Uplifting coping strategies	*Wishing for further improvement.* *Spiritual faith.*
Stress and strain	Hardships	*Forced resignations.* *Dashed hopes and wishes.* *Impediments.* *Lack of alternative placement facilities*

4.2.2 Theme 1: Validation

As a psychological construct Linehan (1997) believed that the term, 'validation', incorporated various meanings. In her view, "*when validating the individual, one validates everything there is*" (p.357). In other words, one acknowledges who the person is in their totality without judgement, they are worthy of respect and one's full attention, and their views matter and are taken seriously and accepted unconditionally. With this in mind I chose this term to describe the first theme. It incorporates two subthemes, namely that of acceptance of the caregivers and their children with cerebral palsy by significant others as well as acceptance of these children by their caregivers.

The caregivers in this study felt as though they were treated as “equals” by the Malamulele Onward therapists and volunteers as well as the hospital staff involved with the rehabilitation programme and that, in some cases, they received “special” treatment. One participant remarked, “*You people have treated us as equals. Even the white people treated us like equals. They know the meaning of humanity”* (Participant 8). Of the facilitators another participant commented, *“They are parents like us and that’s what bonds us”* (Participant 9).

Within their communities neighbours treated them and their children with positive regard and started showing an interest in their children’s rehabilitation as well as a healthy curiosity about the equipment they received. One participant said, “*Even my neighbours like me. They treat me very well. They encourage us not to stop what we are doing so that we can see results”* (Participant 7). Attitudes towards the children with cerebral palsy changed as noted by one participant who said, “*When I got these things* (specialised equipment items) *people came when they saw my child was important”* (Participant 14). Neighbourhood children were more inclined to socialise with the caregivers’ children and missed them when they went for their sessions at the hospitals. Said another participant of the social changes, “*He sometimes stands in his standing chair and lets the children push him. It is very nice now. Even the neighbours respect him. They realise that, at least, he is alive. They do not concentrate on his disability any more”* (Participant 2). Neighbours shared in the excitement when children were provided with new equipment as reported by yet another participant, “*Even when they see me*

with the things they rejoice and celebrate. I live in peace with them. My neighbours take care of my child and love him" (Participant 4).

A few participants reported that they were no longer ashamed of their child's disability. In the poignant words of one participant, "*When I meet other people I can talk about my child. Before that, even if someone asked about my child, I could not talk about my child and I would feel tears in my eyes"* (Participant 15). Another participant declared, *"There is change. I am very grateful for this. I am not ashamed"* (Participant 7).

4.2.3 Theme 2: Empowerment

The Online Psychology Dictionary (2016) defines '*empowerment*' as, "*promoting skills, knowledge and the confidence needed to take control of your life".* Central to the Malamulele Onward Intervention Approach is the sharing of knowledge and transference of skills with caregivers of children with cerebral palsy.

As part of the programme caregivers were given the facts about cerebral palsy to dispel misinformation and misunderstandings. According to one participant, *"The fact that I was told that my child had a disability helped me because I was always comparing him with his age group. Those children could sit, but mine could not. It helped me"* (Participant 5). Another participant explained, *"I heard that he has a disability. I was told that each*

step will take time, slowly. He will not be at the same level as his age group. I am now patient with that, he is developing as they said" (Participant 9).

In addition to educating caregivers about cerebral palsy they were trained in the necessary rehabilitation techniques relevant to their children's rehabilitation programme. Caregivers were taught how to feed, wash, dress, and handle their children as well as how to use equipment, such as standing boxes, splints, and special drinking cups. Several participants spoke about their new skills, for example, "*I did not know how to hold him. I did not know how to feed him. They showed me. I was taught many things. He could not even drink and bathing him was difficult for me. Now I can do things"* (Participant 5). Another participant admitted*, "It helped me when feeding him because he used to take a long time to eat. I was taught how to hold his head and turn him when feeding him. Now he takes a short time"* (Participant 3). Yet another participant declared, "*We were here a whole week. They were doing therapy in front of you and then they give you the child to do exactly what they were doing. If you do it wrong, they will keep correcting you till you do the right thing. They also told us to do this even if we are at our homes"* (Participant 8). As summarised by one participant, "*I learned everything that week. I was taught everything. Now the thing lies also with me"* (Participant 10).

4.2.4 Theme 3: Wellbeing

In his chapter on wellbeing Warr (2012) pointed out that the "*construct has*

many possible forms (different ways to be well)" (p.76) and took cognisance of the physiological as well as the psychological and social aspects thereof. He noted that prolonged psychological and social stress manifested physiologically and vice versa. I have incorporated all three aspects in subthemes of the third main theme, 'wellbeing' as they are related to caregivers' perception of changes in their burden of care, family and community support and quality of life.

The first subtheme refers to reduced burden of care. Provision of wheelchairs and buggies allowed for easier mobility for caregivers who were used to carrying their children on their backs. This is particularly important as the children grow and get heavier so the risk of aches and pains and physical injury increases in their caregivers. Improved mobility also made it easier for family members and neighbours to look after the children, allowing the caregivers more free time. As a participant put it, "*She is not my responsibility alone. She is everybody's responsibility. Everyone can sit her in the chair and push her. So that means she is not dependent on one person. We will assist one another"* (Participant 15). Placing children in wheelchairs or in standing frames at home also allowed caregivers time to do chores and attend to other members of the family. According to one participant, "*I go everywhere. He is not in my way*" (Participant 8). Yet another participant was able to leave her child with her neighbours and added, "*When I get back I see that there is nothing wrong. He is fine. He is fed. He is bathed. He is clean"* (Participant 4).

From the feedback provided by participants, their children also enjoyed using the buggies, and wheelchairs, which increased their comfort and freedom as other children enjoyed pushing them around. One of the participants described her child as "*an uncomfortable person*" before he used the buggy. Now it seems, "*He is happy, he claps his hands and sleeps in it*" (Participant 17). Another noted the joy in her child when being pushed by other children. "*He wants to get in when the chair is moving. When they drive him and the chair is running he becomes very happy".* (Participant 5).

I called the third subtheme 'positive psychological state', incorporating reduced psychological distress experienced by caregivers, the gratitude expressed at improvement seen in their children's condition and the moral support they received from fellow participants and other caregivers in the programme. All the participants expressed feelings of happiness. As one participant put it, "*We are very happy about you, all of us as parents, truly inside our souls*" (Participant 11). Caregivers also reported improved relationships with their children due to greater acceptance of their disabilities. One participant eloquently described the situation at home as follows, "*It becomes joyful at home. He hugs me around the throat. I want to say that I see a smile and I am happy"* (Participant 8).

By implementing the home rehabilitation programme and suggestions every participant in this study reported improvement in activities of daily living with their children for which they were grateful. One participant observed, "*He*

could not do many things. Now, he is trying to eat by himself. He is even trying to call others. He knows his name. In a nutshell, there is a big difference ever since I met them (the therapists)" (Participant 8). Of another child another participant stated, "*When I came here she could not stretch when sleeping. She was always curled up. Now she can stretch when sleeping, when waking, like any child*" (Participant 20). Yet another participant reported, "*That chair has helped her a lot. Now she can sit up. Her hands were deformed, but now her hands can function. She is even able to take a glass and drink herself. When she slept I turned her. Now she turns herself. The change is very enormous. Thank you"* (Participant 14).

Because some communities are far from each other many participants reported feeling isolated. However, by participating in the Malamulele Onward programme they became acquainted with other caregivers who were also grappling with caring for children with cerebral palsy. One participant reported that she was the only person in her village who attended the Malamulele Onward programme. She added, "*But now there are many people coming here"* (Participant 13). Another spoke about the change in herself by saying, "*I shall talk about the change in me as a parent. When you have a disabled child you cannot be with other people and enjoy yourself. When I came here I saw I am not the only one who has a disabled child"* (Participant 15).

4.2.5 Theme 4: Faith and hope

The Oxford Dictionary (2016) defines faith as both "*a strong belief based on spiritual convictions"* and *"complete trust and confidence".* Hope is defined as "*a feeling or expectation and desire for a particular thing to happen"* (ibid). As both concepts were based on the individual's trust in their optimistic point of view I grouped them together to describe Theme 4. Certain participants used their faith and hope in the future as uplifting coping mechanisms to deal with the difficulties of raising a child with cerebral palsy.

After seeing some improvement in their children's condition most caregivers expressed the hope that there would be on-going improvement and that this would lead to greater self-sufficiency and independence. In the words of one participant, "*I have hope because I see him crawling that he will walk. The legs that were straight can now bend"* (Participant 11). Others hoped that the therapists would continue working with their children indefinitely. As one participant put it, "*They must carry on the way they can so they can help him"* (Participant 5). Some parents hoped for divine intervention. For example, a participant wished that, *"God will make him crawl because his health is not good"* (Participant 19).

Some grandmothers hoped that God would grant them the strength and/or longevity to continue caring for their children as they did not know who would look after them when they were gone. As one grandmother put it, *"When I think about death or when I am no more, who will take care of him?"*

(Participant 19). Another grandmother disclosed, "*I wish God to give me many more years so that I can bring him up till death do us part".* (Participant 15).

4.2.6 Theme 5: Stress and strain

A few participants reported ongoing problems in raising their children with cerebral palsy. I used the terms "stress and strain" to capture opinions and feelings expressed by some participants with regard to their hardships. In the Oxford Dictionary (2016) stress is defined as "*tension resulting from adverse and demanding circumstances*" whilst strain is defined as "*a severe or excessive demand on resources or abilities of someone or something*".

Many of the mothers were forced to resign from their jobs in order to go home and look after their children. One mother stated, *"When he became sick I was forced to stop working"* (Participant 14). This resulted in loss of income and financial hardship. Another mother who hoped that she would be free to work in the future and confided, "*I wish that he was able to speak so that, if I end up going to work due to financial constraints, He is able to tell the person looking after him that he is hungry*" (Participant 5).

It seemed some mothers still showed signs of residual trauma related to the reality that their children are disabled. Their hopes and dreams for their children's future had been dashed due to the disability and the realisation that

it would have far-reaching ramifications for the rest of the child's life. One such mother told the focus group, *"I wished for a child that I could take care of while he was growing up, take him to school and ask him to do something for me. And then I got a baby and he was disabled".* (Participant 4).

Other caregivers reported that there were ongoing problems in getting from one place to another. For example, wheelchair access posed difficulties when participants have to use public transport to attend appointments at clinics and hospitals. According to one participant, the taxi drivers did not like the wheelchairs that cannot fold. As a result, some participants resort to carrying their children some distance to the nearest taxi rank. Another participant complained that she could not open her child's legs in order to tie him to her back so she has to carry him to the bus stop, which was far from her home.

A few participants felt the necessity to cut short visits to neighbours or trips to celebrations to return home to look after their children. As one participant explained, *"When they have a celebration or anything I cannot stay with them for a long time I have a child who is not right at home, you see".* (Participant 10). A grandmother shared, "*Because I am her grandparent I no longer attend festivities*" (Participant 11). Yet another participant said she stopped growing vegetables because the child cries whenever she goes outside. Sadly, a participant reported that she was still ostracised, "*I am not a people's person to my neighbours because they gossip about me, saying I am selfish and I keep myself indoors. That breaks my heart"* (Participant 10).

Although the study was not specifically designed to assess developmental changes, a comparison of participants' comments over the three years revealed an increased need amongst caregivers for a Special School nearby for those children who were at a school going age, but would not cope in mainstream education. In the words of one participant, "*The one thing I would like to see is to have a school for the disabled like with other places"* (Participant 11). Still other participants whose children were still quite disabled, but had grown and were getting more difficult to manage, expressed the need for Day Care or weekly boarding facilities. "*Because our communities are very far apart it is difficult to carry your child to a place very far away. Yet if the place is nearby you can just visit your child in the weekend or fetch him*" (Participant 3). Participant 4 backed up the previous views by saying, "*I support the idea of us really getting a place where they can live in, even if they will be sent home late".*

4.3 Summary of findings

Overall, the feedback on participant experiences of the Malamulele Onward Intervention Approach programme was positive. All participants reported seeing a degree of improvement in their children with cerebral palsy. The participants also indicated that they had acquired new knowledge and skills in working with their children, which made participation worthwhile. Thus, it appears that the programme had the effect of reducing the burden of care and improving the quality of life in the caregivers.

Whilst most participants were optimistic about the future, there were those that still encountered various hardships. Others whose children had grown since starting with Malamulele Onwards Intervention Approach hoped that schools and centres could be established nearby where their children could be sent during the day or as weekly boarders.

CHAPTER 5

5. DISCUSSION

5.1 Introduction

The aim of this study was to explore the influence of the Malamulele Onward Intervention Approach on caregivers of children with cerebral palsy who live in the remote and under-resourced sub-district of Mnquma in the Eastern Cape. In particular, I was interested in learning whether additional information about their children's condition and improved handling and rehabilitation techniques acquired during the intensive five day intervention sessions, as well as the specialised equipment and assistive devices that were provided had assisted in reducing caregiver burden at home and whether there had been a positive effect on their mental and physical well-being and general quality of life.

This chapter comprises an integrated discussion of the previous chapters and the themes and subthemes that were generated during the caregiver focus groups aimed at eliciting experiences of the Malamulele Onward Intervention Approach with reference to the aims of the study and the existing literature.

5.2 General discussion

From the 1990's there was a move away from the medical model of rehabilitation to a family-centred approach that encouraged communication and active collaboration between therapists and caregivers when it came to

setting rehabilitation goals and developing and implementing rehabilitation programmes (Rosenbaum, 2011). Studies done in well-resourced settings using this approach produced encouraging findings when it came to improving caregivers' knowledge and understanding of their children's condition as well as their skills and competence in dealing with home programmes (Ahl et al., 2005; Cullen & Barrow, 2003; Jansen et al., 2003; Moore et al., 2009; Raina et al., 2005). Moreover, there was a reduction in stress levels and enhancement of health-related quality of life in caregivers (Jansen et al, 2003; Kuo et al. 2013).

Prior to the introduction of the family-centred Malamulele Onward Intervention Approach in South Africa, Saloojee (2005) expressed concern that, in impoverished settings, caregiver involvement in rehabilitation of their children with cerebral palsy may add to their stress and burden of care, thereby adversely affecting their quality of life. With regard to the Mnquma sub-district caregivers she envisaged two possible negative outcomes to implementing suggestions for improved care and involvement in a home-based therapy programme for their children with cerebral palsy, namely:

- Caregivers would experience increased stress and burden of care with deterioration in their well-being and quality of life due to the time and effort required for implementation.
- The time and effort required for implementation would outweigh benefits to their burden of care, well-being and quality of life.

In reviewing the literature it was evident that Saloojee's reservations were well-founded. According to a study done in Europe by Guyard et al. (2012) there are seven areas of daily existence that adversely affected burden of care and health-related quality of life when looking after a child with cerebral palsy. They involve time constraints, increased financial responsibilities, less time for full-time employment, and adverse effects on relationships within the family and outside in the community. Despite cultural and socio-economic differences with above subjects, these results were applicable to participants in this study.

Firstly, many of the participants were sole caregivers, leaving them little or no time for themselves. As a result, full-time employment was out of the question. Several caregivers who were previously employed gave up work to look after their children. Also, those involved in informal money-earning endeavours, such as growing vegetables for sale or running tuck shops, were forced to scaled down or give up their micro businesses to care for their children. Often, this meant their families lived in poverty as was the case in a Kenyan study done by Gona et al. (2010). As determined by Pugin (2007) in a South African study and supported by Guyard et al. (2012) and Mobarak et al. (2000) working in well-resourced and resource-constrained countries, poverty is a major source of caregiver stress.

Secondly, the presence of a child with cerebral palsy in the home often resulted in estrangement from partners and other significant family members. Several of the younger caregivers reported that the children's fathers refused to have anything to do with them (the mothers) or the children, which coincided with findings in other parts of Africa (Dambi et al., 2015b; Gona et

al., 2013). In some areas, caregivers were shunned by neighbours and community members, usually due to misunderstandings about the causes and nature of cerebral palsy, as was reported by Nigerian researchers, Olawale, Deih and Yaadar (2013). This left caregivers with little or no support from partners, family and their community. In their review of the literature Pousada et al. (2013) found that low levels of social support gave rise to increased caregiver stress and depression.

Thus, if one considers the findings of studies in well-resourced settings (Brehaut et al., 2004; Davis et al., 2010 and 2012; Shelly et al., 2008) as well as those in African countries (Fatudimu, et al. 2013; Gona, et al. 2010; Hamzat & Mordi, 2007), caregiver/participants in the current study were at high risk for excessive burden of care, poor quality of life and physical and psychological ill-health. Moderating factors that were shown to lessen the load and aid in adaptation, such as support of a partner, family members and others as well as financial security posited by Marrón et al. (2013) and Manuel et al. (2003), would not apply to them. Consequently, it could follow that involvement in a home-based rehabilitation programme that required consistent commitment from the caregiver could be overwhelming and add to their stress and strain.

Notwithstanding these reservations, Saloojee (2007) chose to use a family-centred approach to treatment and rehabilitation of children with cerebral palsy to address the shortfall in access to hospitalised rehabilitation

programmes in under-resourced areas. In keeping with this approach she embarked on an ambitious project to provide intensive, time-limited assessment and intervention for children and education and training in home-based therapy for their caregivers. This culminated in the introduction of the Malamulele Onward Intervention Approach.

When developing any rehabilitation strategies and home programmes Davis et al. (2010) emphasised the importance of understanding issues affecting the daily lives of caregivers. However, Hinojosa and Anderson (1991) warned that caregiver compliance would be low if the home programme was too time-consuming and complex. In their study caregivers selected what was easy for them and fun for their children. Thus, Brehaut et al. (2004) recommended investigation of whether rehabilitation strategies and home programmes improved the health and wellbeing of caregivers, their children with cerebral palsy and other family members.

With this in mind, ongoing research into the Malamulele Onward Intervention Approach included focus group discussions with caregiver/participants from the Mnquma sub-district in the Eastern Cape. The purpose of these groups was to provide accounts of caregivers' personal experiences over a three-year period of the Malamulele Onward Intervention Approach (what it was like for them), in implementing the home-based rehabilitation programmes (whether they experienced any problems in doing so) and, more importantly, the effect the intervention and programmes had on their daily lives.

5.3 Discussion of the objectives and findings

This study forms part of a larger, long-term study into the Malamulele Onward Intervention Approach providing a time-limited and intensive family-centred approach to rehabilitation and implementation of home programmes in poorly-resourced rural areas of Southern Africa. Information from the focus groups held over three years provided valuable insight into the experiences of caregivers with children with cerebral palsy in the remote Mnquma sub-district of the Eastern Cape. This information can be used to refine the Malamulele Onward Intervention Approach for future use in other under-resourced areas throughout Southern Africa.

Five main themes were identified by means of qualitative analysis of the data gathered during the caregiver/participant focus groups, namely ‘validation’, ‘empowerment’, ‘wellbeing’, ‘faith and hope’ and ‘stress and strain’. The first four signified surprisingly optimistic reactions to the caregivers’ experiences of the Malamulele Onward Intervention Approach. Characteristically, these themes were similar to those reported by researchers working in well-resourced setting where the studies showed that caregiver participation in their children’s rehabilitation programmes was beneficial in various ways. For example, information into their children’s condition, new skills and competence in rehabilitation reduced caregiver stress levels and improved their general wellbeing (Ahl et al., 2005; Cullen & Barrow, 2004). Thus, it appeared that cultural, socio-economic and language differences with the Malamulele Onward volunteer therapists did not interfere with participants’

ability to benefit from this intervention and rehabilitation approach.

The main themes will be incorporated into a discussion of answers to the objectives posed at the beginning of this study as will other information obtained from the data. To distinguish the participants in this study for other studies the term, “Malamulele Onward study” will be used.

The objectives were to:

- Describe the caregivers’ experiences of the intensive five-day course of therapy with the Malamulele Onward therapists and volunteers.
- Describe the caregivers’ experiences of coping with their children at home after implementing therapy ideas and suggestions provided during the intervention week and, where relevant, since using the specialised equipment.
- Describe the caregivers’ perceptions of changes in their burden of care, family and community support and quality of life.

5.3.1 Caregivers’ experiences of the intensive five-day course of therapy with the Malamulele Onward therapists and volunteers

All the participants in the Malamulele Onward study found it worthwhile to attend the intensive five-day sessions over the three-year period, despite difficulties in getting their children to bus stops and taxi ranks to catch public transport to the venues. They expressed positive sentiments about the

sessions, most saying how “nice” it was to come to the hospitals and adding that they hoped the therapists would continue helping them and their children.

When devising suitable home programmes and providing relevant specialised equipment, the Malamulele Onward Intervention Approach incorporates close collaboration with caregivers so as to understand each participant’s unique challenges pertaining to the care and rehabilitation of the child with cerebral palsy. This approach is in keeping with the proposals made by King et al. (2004) that rehabilitation should take into account, “*that parents know their children best and want the best for their children; that families are unique and different; and that the optimal child functioning occurs within a supportive family and community context*” (p.79). Ones et al. (2005) also encouraged caregiver participation in management and rehabilitation of their children.

When consulting with the Malamulele Onward therapists for the purposes of obtaining information to use when formulating the home programmes, participants in this study felt that they were treated with respect, despite working through interpreters due to language differences. This made them feel welcome and special in keeping with the theme of ‘validation’. Other researchers had also highlighted the importance of good relationships between therapists and caregivers. For example, Wiart et al. (2010) emphasised that cooperative relationships are vital when it comes to goal-setting and drawing up rehabilitation programmes for children with cerebral palsy. Similar sentiments were echoed in a study done in the USA by

Schreiber et al. (2011) who reported that participants enjoyed the personalised and sustained relationships with the therapists. Respectful service from therapists was also highly rated by caregivers in a Scandinavian study (Jeglinsky et al., 2012b).

In their Kenyan studies, Gona et al. (2010 and 2013) recommended that caregivers acquired new skills for coping with the disabilities. Each participant in the Malamulele Onward study had something to say about what they had learned during the intensive five-day sessions. In most cases, this had to do with changes in approaches to activities of daily living, such as feeding, drinking, washing, dressing, sitting, standing and sleeping. Acquisition of these skills and those pertaining to the home rehabilitation programme were included in a category that contributed to the theme, 'empowerment'. What the participants found particularly useful was the opportunity to practice these skills until they could perform them correctly. This coincided with the view expressed by Novak and Cusick (2006) about the importance of support and guidance from therapists to ensure caregivers' competence when implementing the rehabilitation programme at home.

Nigerian researchers, Olawale et al. (2013), reported that caregivers requested adequate information about cerebral palsy which they believed would help them cope with the responsibility of caring for a child with cerebral palsy. Participants in the Malamulele Onward study also appreciated learning more about cerebral palsy as it promoted better understanding of their

children's condition and dispelled previously held misconceptions and superstitions about the causes and nature thereof. Analysis of the focus group data showed that they experienced this as being 'empowering'. Armed with this new information some participants were able to revise their expectations of their children's improvement with therapy and their prognosis for future development. This was in keeping with findings of a study in the USA by Cohn who observed that the caregivers "reframed their expectations" (2001, p. 291) after involvement in their children's occupational therapy sessions. In some participants in the Malamulele Onward study, the revision of expectations enabled further 'validation' and acceptance of the children's disabilities. Some participants even admitted that they were no longer ashamed of their children and were able to accept them and their disabilities and speak about them with pride, thereby enhancing the bond between them.

5.3.2 Caregivers' experiences of coping with their children at home after implementing therapy ideas and suggestions and since using the specialised equipment

Using new techniques for handling and rehabilitating their children as well as specialised equipment made everyday care of the children with cerebral palsy easier and more effective. This reduced their burden of care as well as psychological distress when using incorrect techniques for feeding, etc. Consistent with findings in well-resourced settings (Ahl et al., 2005; Cullen & Barlow, 2003) there was improved sense of caregiver 'empowerment' and 'wellbeing' with training and experience. These findings concurred with those

reported by Jansen et al. (2003) whereby training in physical therapy techniques improved parents' self-confidence and competence. Through involvement in the rehabilitation programmes participants gained better understanding of their children's disabilities and gained confidence. Their knowledge and competence improved with time and they seemed to enjoy "teaching" their children. Accordingly, the concept of "caregiver self-efficacy" reported by Cullen and Barlow (2003) was incorporated as a subtheme to the main theme, 'empowerment' as identified in this study.

Special equipment and assistive devices made important contributions towards a sense of 'wellbeing' in caregivers, particularly in households where there was little or no assistance. The use of wheelchairs and buggies meant that caregivers no longer needed to carry their children, thereby reducing the physical burden, pain and injury prevalent in caregivers of children with cerebral palsy in both well-resources and resourced constrained settings (Brehaut et al., 2009; Dambi, et al., 2015a). Most children enjoyed using the equipment and caregivers could leave them in wheelchairs, buggies and standing boxes for some time, thereby acquiring valuable respite for their caregivers during which time they could attend to other activities. Special feeding utensils made mealtimes easier for caregiver and child, and special splints, shoes and benches helped correct contractures and other postural abnormalities.

The special equipment had another advantage in the form of social

acceptance and support from family, neighbours, community members and children, which added to the sense of 'validation' of the caregiver. Others were more willing to look after the children with cerebral palsy if they were in their wheelchairs and buggies. This sort of social support was a moderating factor in reducing burden of care according to Marrón et al. (2013) and Manual et al. (2003) and the demands on caregivers' time (Sawyer et al. 2011). In turn, this allowed the caregivers more free time to attend social gatherings, etc., and decreased caregiver strain and psychological distress, thereby contributing to their physical and psychological 'wellbeing'.

5.3.3 Caregivers' perceptions of changes in their burden of care, family and community support and quality of life

Enhanced handling techniques facilitated activities of daily living, such as washing, dressing and feeding, that were previously difficult for the caregiver and distressing for the child, also contributed to 'wellbeing' in both the caregiver and the child. In some cases, children became more self-sufficient, which was consistent with what Ahl, Johansson, Granat, et al (2005) reported in a collaborative rehabilitation study between therapists and caregivers in Sweden. Special equipment afforded the children greater mobility and freedom as well as acceptance from other children who wanted to play with them. This meant that the children were happier which, in turn, made their caregivers happier. Relationships with other family members, neighbours and the community improved in most cases, offering much needed support to the caregivers in looking after their children. Again, this reduced the caregivers'

perception of burden of care and improved their psychological status and that of their children and this concurred with the results of studies in well-resourced settings (Britner et al., 2003; Button et al., 2001; Hirose & Ueda, 1990).

Improvement in their children's condition, however small, evoked gratitude on the part of caregivers and gave them 'faith and hope' for further improvement. There were times that this hope was wishful thinking and out of keeping with realistic goals for the child's level of disability. Nevertheless, a study by Piggot, Patterson and Hocking (2008) also showed that, as caregivers became more accepting of their children with cerebral palsy, so they became more enthusiastic about participation in the rehabilitation programme. With regard to faith and in concert with studies done in Kenya and Nigeria (Gona et al., 2010; Olawale et al., 2013), participants in the Malamulele study demonstrated strong religious beliefs that formed an important part of their coping strategies. Believing in assistance from a higher power made it easier for participants in this study to deal with their burden of care. Their faith that God would help their child as well as their hope for continued improvement increased caregiver optimism. Lerdal et al. (2012) linked optimism to reduced caregiver stress, which coincided with psychological aspects of 'wellbeing' identified in this study.

Opinions and attitudes towards the children with cerebral palsy from caregivers, neighbours and community members also changed for the better.

Once participants joined the Malamulele Onward Intervention Approach programme, their confidence in caring for their children improved the bond between them and their children. In the community, their children were viewed with curiosity and respect in line with 'validation', particularly when they came home with specialised equipment. Neighbours and community members noticed when there was improvement in the children's condition and encouraged caregivers to persist with the sessions and home programmes. When the children were accepted as members of the community, this had positive psychosocial consequences for their caregivers in the form of satisfaction and happiness. According to studies done in well-resourced settings (Rentinck et al. 2006; Wanamaker & Glenwick, 2011), satisfaction with one's social support system is a moderating factor that counteracts stress and depression.

In keeping with the findings of a study in the USA by Schreiber et al. (2011), caregivers in the Malamulele Onward study found moral support in associating with other caregivers of children with cerebral palsy who were involved in the programme. This ameliorated their feelings of isolation and exclusion and contributed to their 'wellbeing'. They were able to talk about their children with other parents who were dealing with similar issues and difficulties. From a psychologist's personal perspective I noticed considerable cohesion and mutual support amongst members of the focus group members. It seems likely that the comradery that developed amongst the caregivers also had a positive psychosocial outcome.

Despite the optimistic outcomes mentioned above, there were some participants who continued to experience financial, physical, social and psychological difficulties in coping with the children with cerebral palsy. In this study persistent poverty, physical and mental demands, and social isolation was identified 'stress and strain'.

Even in well-resourced countries raising children with cerebral palsy is expensive (Bourke-Taylor et al. 2014) and financial resources are diverted to cover treatment and equipment required by the disabled child. In the Malamulele Onward study financial constraints due to loss of income resulted in some caregivers living in poverty, which Pugin (2007) reported is all too common in female caregivers and is a significant contributor to stress. Single female caregivers are more vulnerable to poverty (Schor, 2003) are more likely to be socially ostracised, which is not uncommon in African communities (Gona et al., 2010; Hamzat & Mordi, 2007). This meant a lack of support and assistance in caring for their children as well as excessive demands on caregivers' time, with the risk of impairing mental as well as physical health as noted by Sawyer et al. (2011).

Despite improvement in their children's condition since becoming involved with the Malamulele Onward Intervention Approach, ongoing psychological and physical strain reported by some participants could be related to differences in life cycles. A European study done by Schuengel et al. (2009) showed that parents who had very young children with cerebral palsy were

more affected than parents of older children. This was largely due to residual trauma to learning that their children were disabled (Huang, Kellett & St John, 2010). Schuengel et al. (ibid) recommended that these parents be given specific, additional support to adjust to their children's disabilities, especially when the children have more severe forms of cerebral palsy. Lin (2000) also cautioned that daily caregiving becomes more demanding and burdensome as the child grows bigger and heavier with age whilst the caregiver becomes weaker and frailer. Older caregivers would be more prone to physical symptoms of strain, such as backache (Hamzat & Mordi, 2007) and possible injury, resulting in pain thereby lowering their health-related quality of life (Dambi et al., 2015b) with increased risk of burnout (Tothill, 2010). Consequently, as noted by Kruijsen-Terpstra et al. (2014), both caregivers and their children with cerebral palsy have different needs at different times of their lives. Some participants expressed the need for special schools, day care centres and weekly boarding facilities as a means of lightening their burden of care. In this study, life cycle changes were most noticeable in the five caregiver grandmothers. Kresak, Gallagher and Kelley (2014) showed that caregiver grandmothers experienced greater personal needs than younger caregivers, but were less likely to receive support and assistance. Grandmother participants in this study hoped they would live long enough to raise their children with cerebral palsy and were anxious about their grandchildren's care in the event of their deaths.

5.4 Comments on findings

In order to interpret the findings within the context of this study I chose to use Bronfenbrenner's Bioecological Model of Human Development (2006). This model describes an individual's state of being as constant and reciprocal interaction and interrelationships with ever-expanding environmental systems.

Despite their financial hardships and lack of resources, input from the Malamulele Onward Intervention Approach in the form of education and training, as well as provision of specialised equipment, changed the way in which participant caregivers viewed themselves. They felt validated and empowered and discovered they had the inner resources and self-confidence to cope. These positive cognitive and emotional changes within their "*microsystem*" (i.e., pertaining to the individual) affected their attitude and behaviour towards their children with cerebral palsy. This, in turn, influenced the attitudes and behaviour of other family members within what Bronfenbrenner (ibid) called the "*mesosystem*". Family members became more accepting of the children with cerebral palsy and more willing to help with their care. This reduced the burden of care for the caregivers and enhanced their sense of wellbeing. Like ripples in a pond these favourable effects spread to the community. Changes in community attitudes and behaviour lead to increased involvement and allowed the caregivers and their children with cerebral palsy to feel a sense of belonging within their "*macrosystem*".

5.5 Summary of discussion

Participants in this study reacted positively to the three-year period of assessment, intervention and implementation of home-based rehabilitation programmes from Malamulele Onward Intervention Approach. All of them reported that the improved handling techniques, the rehabilitation programmes and the specialised equipment and assistive devices had changed their lives for the better and that they noticed varying degrees of improvement in their children with cerebral palsy. In most cases, this was associated with reduced physical burden of care, enhanced social interaction and support, and happiness, all of which contributed to an overall improvement in their overall quality of life.

Young mothers who are the sole breadwinners and who gave up their jobs to look after their children with cerebral palsy and caregiver grandmothers reported ongoing financial, physical and psychological hardships. Some of the longer-term participants expressed the need for special schools, day care centres and weekly boarding facilities to lighten their load.

CHAPTER 6

6. CONCLUSIONS

6.1 General

Vargus-Adams (2011) demonstrated that caregiver stress adversely affected the status of their children with cerebral palsy in the USA and suggested an integrated family-centred approach designed to support the caregiver and reduce their burden of care with a view to maximising the child's improvement. This study explored the effect of the intensive family-based Malamulele Onwards Intervention Approach involving caregiver education and training in home-based rehabilitation programmes for children with cerebral palsy on the daily lives of caregivers in the remote, under-resourced Mnquma district in the Eastern Cape. Furthermore, it examined the effect of special equipment and assistive devices in easing caregiver burden. Notwithstanding reservations, it was hoped that, in implementing their additional knowledge and skills and in using the specialised equipment and assistive devices, caregivers would find it easier to manage their children at home, which should reduce their stress and improve their physical and psychological wellbeing whilst enhancing their children progress with rehabilitation.

Rather than place additional stress on the caregivers (Saloojee, 2005), the techniques learned and equipment and devices provided as part of the Malamulele Onward Intervention Approach reduced the physical demands and psychological distress associated with looking after their children with

cerebral palsy. Analysis of data collected during focus groups revealed five main themes, four of which, namely ‘validation’, ‘empowerment, ‘wellbeing’, ‘faith and hope’, suggested considerable personal growth in the caregivers themselves as well as in their ability to care for their children. These themes were consistent with positive findings of reduced burden of care, improved physical and mental status and enhanced quality of life reported by researchers in well-resourced settings, such as Cullen & Barlow (2003) and Jansen et al., (2003).

Contributing categories and subthemes indicated favourable reactions to the education in cerebral palsy as well as training in improved handling techniques, rehabilitation home programmes, and in the use of specialised equipment and assistive devices. All participants reported that they enjoyed the sessions and that there was some degree of improvement in their children with cerebral palsy with the home rehabilitation programmes. Cultural, socio-economic and language differences between the volunteer therapists and the caregivers did not appear to interfere with their ability to benefit from the Approach.

Overall, the Malamulele Onward Intervention Approach the Approach, with its emphasis on addressing queries and uncertainties and engaging caregivers in their children’s care and rehabilitation, provided caregivers with additional information and skills to what they had received in the past, thereby increasing their expertise in looking after their children. Their responses

during the focus groups suggested that this Approach could well be a practical alternative means of service delivery in under-resourced areas in Southern Africa. This finding concurred that reported by Dambi and Jelsma (2014) when they investigated an out-reach programme in community settings in Zimbabwe.

Financial, physical and psychological strain and stress were reported by certain caregivers, namely mothers who were forced to leave their jobs and grandmothers who were concerned about their ability to continue caring for their children with cerebral palsy. Caregivers whose children had grown and were becoming more difficult to look after highlighted the need for special schools, day care centres and weekly boarding facilities in remote areas to provide alternative placement and allow caregivers some respite to attend to other responsibilities and to resume earning a living.

6.2 Limitations of the study

I was not involved in the planning of the original study entitled "*Provision of annual intensive five day blocks of Bobath-based therapy on children with cerebral palsy living in a poor rural area: a longitudinal study to evaluate sustainability and impact*" (Saloojee, 2007). Consequently, I had no control over the design of the study, the choice of participants, the procedure for collecting the data and choice of facilitators. Furthermore, my study involved secondary analysis of the data that was collected.

As I was not conversant in IsiXhosa, which was the home language of the caregivers, I had to rely on translation of the focus group audiotape recordings into English. Professional translators were used to minimise the loss of certain information that occurs with translation and transcription. To check the transcripts and to capture additional tonal and emotional information I listened to all the original tapes in the presence of an interpreter (also see 3.5, Data Analysis).

Although trained in running focus groups the facilitators were still relatively inexperienced. However, as they are both mothers of children with cerebral palsy and are fluent in IsiXhosa it was felt that they would engender a climate of openness amongst participants more readily than a professional researcher who had no personal experience in raising a child with cerebral palsy and who was not conversant in the participants' mother tongue. However, the possibility of transference could not be excluded.

I was not present during the focus group discussions in 2008 and 2009. To compensate for this I listened to these tapes as mentioned above so that I could experience the audio-interaction that occurred between the participants.

6.3 Recommendations

There should be ongoing research into refining the Malamulele Onwards Intervention Approach as it seems well suited to provide effective alternative

rehabilitation opportunities to caregivers and their children with cerebral palsy who live in remote, resource-constrained rural areas of Southern Africa.

Local self-help groups of caregivers associated with the Malamulele Onward project may prove useful in addressing a variety of issues that could arise between visits when the caregivers are left to their own devices. The addition of a psychologist or social worker to the Malamulele Onward team could be considered as a means of addressing the residual trauma reported by some participants.

While the ideal situation would be to include other health professionals in this Intervention Approach, the lack of resources and the willingness of professionals to work in such rural and under-resourced areas may not make this recommendation feasible in the long-term. More important is the initiative that caregivers themselves have implemented to educate and train other caregivers of children with cerebral palsy. Some have already conducted therapy sessions and workshops. Thus, with their new-found hands-on expertise and confidence caregivers are ensuring sustainability and ongoing success of the Malamulele Onward Intervention Approach in resource-constrained areas of Southern Africa. These initiatives need to be supported and encouraged through ongoing education of the caregivers and the sourcing of equipment through benefactors.

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