

AN ETHNOGRAPHIC STUDY OF CAREGIVING AT A DAYCARE CENTRE
FOR DEVELOPMENTALLY CHALLENGED CHILDREN

by

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I declare that “An Ethnographic Study of Caregiving at a Daycare Centre for Developmentally Challenged Children” is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE

(Mrs R. du Preez)

DATE

30 November 2010

SUMMARY

In this qualitative study the researcher explores the experiences of various caregivers at a day care centre for developmentally challenged children. This study also attempts to draw a distinction between the experiences of formal and informal caregivers' experiences. The study is underpinned by two assumptions: 1) that in order to obtain a rich understanding of a phenomenon, the views and voices of a variety of individuals need to be considered and 2) that cultural values and practices play a significant role in the way individuals experience a certain phenomenon. The experiences of both formal and informal caregivers are documented using thematic analysis. An analysis of the participants' global themes revealed that "education/learning/skills development" and "communication barriers" were common themes among both participant groups. Each participant group also expressed unique experiences such as "being a parent", "becoming a foster parent" and "being useless as a professional-in-training". Focal areas for further research are highlighted.

Key Terms

Caregiving, Caregiver, Developmental challenges in children, Ethnography, Qualitative research, African perspective, Critical psychology, Coping, Caregiver stress, Bradburn's two-factor model of psychological well-being.

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CHAPTER 1

INTRODUCTION

1.1 Refeng Sebaka

Refeng Sebaka (“Give us a chance”) is situated in the township of Soshanguve, north-west of Pretoria. It is a small day care centre which caters for the needs of children with a variety of intellectual and developmental disabilities, who would otherwise most likely be left at home alone.



Figure 1.1

Refeng Sebaka Day Care Centre

Established in 1996, the centre is housed in a small three-bedroom house in a residential area (see Figure 1.1). The centre runs under the auspices of North Gauteng Mental Health and operates on funding from government, as well as donations and sponsorships from the business sector. Up to 30 children (aged between three and 17 years old) call this centre home from eight to three, five days a week. Most of the children are in the care of their family who drop them off at Refeng Sebaka on a daily basis while on their way to work and collect them in the afternoon.

The children are fully reliant on the care of the three caregivers, a cook and one supervisor, all of whom have received limited, informal to no training in the care of disabled children. Their duties include feeding, toileting, medicating and stimulating each of the children. Due to the nature of impairment of the children, these tasks require a tremendous amount of physical and mental energy, yet with limited resources and space, these brave and motivated ladies serve and cherish the children as if they were their own.

Besides the full-time caregivers, Refeng Sebaka is also frequented by Occupational Therapy students from a nearby University. The students visit the centre approximately once a week, providing stimulation to the children and assisting the caregivers with activities, while transferring valuable skills. The centre is also frequented by Clinical Psychology students from the University of South Africa as part of their practical training in their first year of the Masters degree. On a weekly basis, these Psychology students interact with both the children and caregivers, providing to the formal caregivers' needs in terms of basic training on the types of disabilities, counselling and emotional support.

1.2 Statement of the Problem

It is commonly believed that the families and caregivers of children with disabilities have high levels of stress associated with the care of the children. Caregivers often experience increased levels of stress, anxiety and depression (Britner, Morog, Pianta & Marvin, 2003; Gallagher, Phillips, Oliver & Carroll, 2008). But do caregivers only have negative experiences and can we make generalisations regarding the experiences of caregivers across all contexts?

According to Grant, Ramcharan, McGrath, Nolan and Keady (1998), the question of positive caregiving experiences has often been overlooked by the research community as there has been a tendency to view caring in pathological terms. Some researchers (e.g. Byrne & Cunningham, 1985) argue that studies have assumed, and focused on finding, stress but have failed to look at families and caregivers who do not experience heightened levels of stress. Glenn, Cunningham, Poole, Reeves and Weindlings (2008) suggest that there is a need for studies focussing on how caregivers adapt to children with disabilities, and the factors associated with the satisfaction and

pleasure of caring for and parenting a child with a disability. Grant and Ramcharan (1999) also state that research has failed to pay equal attention to both the strain and gain of caregiving.

According to Bradburn's two-factor model of psychological well-being (1969), happiness is composed of two separable components, namely: positive and negative affect. Bradburn hypothesises that happiness is really a global judgment made when people compare their negative affect with their positive affect. Within the caregiving context, this theory implies that caregivers may have both positive and negative experiences of their caregiving role (Lawton, Moss, Klaban, Glicksman, & Rovine, 1991). Some caregivers may report their overall experience of caring as stressful, while others may find it enriching and rewarding. This has major implications for research and interventions within the field as it broadens the scope of exploration into the experiences of caregivers. The Health Evidence Bulletin of Wales (HEBW) (2000) states that the main message from many research publications is that there is a need for flexibility. Due to the diversity in experiences of caregivers, there is a need for researchers and practitioners to be "carer sensitive" and to be open to a diversity of possible experiences of caregivers.

This study will use Bradburn's model of psychological well-being as a point of departure in exploring the experiences of caregivers of children with intellectual and developmental disabilities. Other theoretical models relating to the effects of stress and caregiving are further explored in Chapter 2 and will add to the theoretical foundation of this study.

Due to the country's political history, and over 300 years of oppression, African communities are amongst the poorest in South Africa. This affects access to health services as well as the quality of care available to disabled individuals in African communities. Apart from the impact of socio-economical factors, there are other factors which impact indirectly on the care that is provided to disabled individuals. According to B.H. Baloyi (1997), black communities, like any other community have certain attitudes toward different phenomena in the community, including disability. The individuals who provide care to the disabled also have specific attitudes toward disability. The attitudes of community members and that of carers alike are influenced by, amongst others; culture, tradition and religion (B.H. Baloyi, 1997).

L.J. Baloyi (2008) states that, today, much of our understanding in psychology is based on Western experiences and our conceptions of reality. Research in the area of African Epistemology implies that, in order to fully understand the experiences of Africans, there has to be recognition of indigenous experience and understanding. Kuokkanen (2006) states that this recognition will contribute towards our understanding of different ways of knowing and theorising. Within the arena of caregiving and disability, recognition of indigenous knowledge and understanding can contribute to the development of “carer sensitive” research, which represents a move away from the “one size fits all” approach so often adhered to.

1.3 Statement of the Purpose

In recognition of the possibly varied experiences of caregivers, and the importance of gaining a comprehensive understanding of caregiving within a specific context, this study will explore the experiences of various caregivers at a day care centre for developmentally challenged children. The experiences of the following role-players will be explored:

- Formal caregivers at Refeng Sebaka; and
- Informal caregivers who comprise a group of MA Clinical Psychology students who are currently completing their clinical training at Refeng Sebaka.

1.4 Research Question

The overarching question in this study is: What are the experiences, understandings and meanings that role-players at a day care centre attach to caring for children with disabilities?

This question will explore the following aspects:

1. What experiences do the formal caregivers have of their caregiving role at Refeng Sebaka?
2. What experiences do informal caregivers have of their role at Refeng Sebaka?

3. How do the experiences of the different groups of caregivers at Refeng Sebaka compare with each other?

A qualitative ethnographic approach will be adopted in this study. Qualitative research entails the collection, analysis, and interpretation of comprehensive narrative and visual data in order to gain insight into a particular phenomenon of interest. The phenomenon is studied as it occurs within its natural context (Gay, Mills & Airasian, 2006). Various data gathering methods will be employed, including: visual representations, individual interviews, a focus group and reflective writing. The visual representation activity will be used as a basis for discussion during the individual interviews. The individual interviews and focus group will take on a semi-structured form, framed by a sequence of open-ended questions. The reflective writing exercise will deliver samples of documentary data. Each meeting with the participants will be audio taped and transcribed to produce a sample of written data. Where necessary, the interviews will be translated by an external translator to English. The textual data will then undergo a process of thematic content analysis, as adapted from the work of Anderson (2007), Kelly (2006a), TerreBlance, Durrheim and Kelly (2006) and Kelly (2006b). This will entail identifying, reporting and analysing patterns or themes within the data.

1.5 Rationale for the Study

Psychology as a field of study in South Africa has mainly been rooted within a Western epistemology. Western-derived theories, which are presumed to be universal, have for many years been applied to, and imposed on, non-Western populations. This has resulted in the marginalisation of indigenous theoretical frameworks (Mkhize, 2004). For many years, psychologists have tried to understand people in non-Western societies with reference to Western theories and concepts. Research within non-Western societies has also not been free of this universalistic view of human experiences. Hence, much of the research conducted in this way has been largely irrelevant to the needs of local populations (Mkhize, 2004). L.J. Baloyi (2008) states that Western “science” has become problematic for Africans whose experiences and understanding of the world tend to be seen as inferior and insignificant.

The arguments stated above are, according to Mkhize (2004), consistent with the notion of critical psychology. Parker, as cited in Mkhize (2004), explains that critical psychology has the following aim: “to reflect upon the diverse ways in which men and women of various cultures and classes create meaning in their lives, including the manner in which they reflect upon their lived experience” (p. 28).

Furthermore, critical psychology maintains that all forms of psychological knowledge are grounded in cultural, historical and social contexts (Maiers, Parker & Tolman, cited in Mkhize, 2004). Thus, critical psychology as a paradigm allows the researcher to investigate a phenomenon or lived experiences of individuals or groups while acknowledging the impact that society, history and culture may have on their understanding, interpretation and experiences.

In this study it will be argued that the experiences and understandings of caregivers of children with disabilities cannot be viewed solely from a pathological point of view. We would like to explore the unique experiences and understandings of the formal caregivers within their community context and incorporate these with the experiences of the informal caregivers. The case to be made is that, in order to obtain a comprehensive understanding of the experiences of caregivers within a specific context, a comprehensive understanding of the attitudes and meanings attached to caring for disabled children needs to be attained from different points of view. This understanding cannot be based solely on Western assumptions and epistemology, but needs to be rooted in the social circumstances, lived experiences and cultural definitions which form part of who the caregivers are and, subsequently, how they experience the caregiving role.

1.6 Dissertation Outline

Chapter 1 provides an outline of the study by analysing the problem which lead to the investigation and orientates the reader in terms of the research approach employed in this study.

Chapter 2 gives a background and literary investigation of the key theoretical elements which relate to caregiving and the experiences of caregiving in general. Various models of caregiving are discussed.

Chapter 3 outlines the methodology employed in the present study. An argument is made for the appropriateness of a qualitative research design for this particular study and the various methodologies employed are discussed in detail.

Chapter 4 presents the findings of this study and provides a discussion on each of the themes that have been identified.

Chapter 5 provides a discussion of, and conclusions about the study. The main themes and implications for clinical practice are highlighted and recommendations for future research are made. Finally limitations and strengths of the study are discussed and the researcher's reflections given.

CHAPTER 2

CAREGIVING: BACKGROUND AND THEORY

2.1 Caregiving Defined

According to Payne and Ellis-Hill (2001), people define themselves in terms of their social relationships, or lack thereof, with others. Within these relationships we learn to be both cared for and to provide care for others.

Pearlin, Mullen and Skaff (1990) distinguished between two components of caregiving, namely: “the affective component of one’s commitment to the welfare of another” and “the behavioural expression of this commitment” (p. 583). The two components of caregiving highlight the sense of commitment towards others which is inherent in the caregiving role. According to the National Centre on Elder Abuse (NCEA, 2010), caregivers are “people who routinely help others who are limited by chronic conditions” (p.1). For the purpose of this study, caregiving is defined (according to Pearlin *et al.*, 1990) as the affective and practical components of an individual’s commitment to the welfare of others, which will influence the way he/she expresses and experiences this commitment.

There are two forms of caregiving, namely, formal and informal. Formal caregiving refers to caregivers who are paid, whereas informal caregiving takes place on an unpaid basis. Formal caregivers may include nursing staff, medical professionals or untrained caregivers who provide care to others as part of their job/career. Informal caregivers include family members, friends or acquaintances who provide care. This form of caregiving often involves specific kinds of behaviours that occur within the context of established roles, such as parent-child and wife-husband (Pearlin *et al.*, 1990). The roles and functions of caregivers vary according to the type and stage of disability or illness and may include direct (personal care) and/or indirect (care management) activities (Brubaker & Brubaker, 2010). The work load of formal caregivers in the public and private sector can become overwhelming, sometimes leading to burn-out. However,

informal caregiving reduces the demand on the health system by delaying the need for institutionalization or more formal modes of care (Brubaker & Brubaker, 2010).

The full-time caregivers at the centre where this study is done fulfill a formal caregiving role. Although mostly untrained, these caregivers are all paid for the job they do. On the other hand, the students involved at the centre are considered to be informal caregivers. They are unpaid, although their work at the centre forms part of their practical training as professionals-to-be. For both the formal and informal caregivers, their roles include both the affective and practical components of caregiving as described above, which will be explored during this study.

2.2 Caregiving: A Short History

Caregiving has a long and complicated history in human society. The history of caregiving and the connotations attributed to the term richly inform the way caregiving is viewed in the current day and age. In the book “A History of Caregiving”, Cavanaugh (2005) highlights the following key themes that arise in the study of the history of caregiving.

The bosom of the family or “hearth” has long been considered as sacred or set aside for safe-keeping from the hostile world. Taking care of one’s own family is expected from every human being and lies behind the impulse of all forms of hospitality. Caregiving, according to the author, was therefore rooted in the impulse to protect one’s immediate family. This impulse to protect one’s immediate family was then extended to strangers or guests who entered the home. At the time, this was considered a natural social value and a matter of honour and self-respect.

The act of extending caregiving beyond the family to a stranger was the revolutionary social concept of Jesus Christ introduced first to the Middle East, then to Western humanity and from there, to the whole world through the Catholic Church. Extending care beyond the family was not considered a natural impulse, but a moral value introduced by a moral teacher, and accepted under the title of Christian charity.

In history, the choice of caring for others has been identified to stem from two sources, namely, nature and a supernatural source. Firstly, a person’s nature or personality encompasses the

intellectual, emotional and physical inclination to take care of another person. From a supernatural point of view — within the Catholic tradition — the choice to provide caregiving was accepted, recognized, justified and promoted on the social basis of Catholic theological values. Individuals who chose this life path were often formally religious, that is, they belonged to a Catholic religious group.

According to Martin Luther, salvation is not attained through good deeds. His reformative ideas undermined the original Catholic motivation for caregiving as a good deed which contributes to salvation. This contributed to the decline of the practice of Christian caregiving and the subsequent deterioration of the hospital system as an entity run solely by the church. In 1546, King Henry VIII signed an agreement granting the power and responsibility of the hospital system to the state. So began the contemporary development of the pattern of secular hospitals, staffed and run for profit by the medical community — no longer just for the sake of caring.

In light of all of these developments, caregiving exists again, to a certain degree, in its original position as a means of extending care to people beyond one's own family. Individuals care for one another as a free extension of their care for another human being. Some are motivated to care by natural impulse while others are motivated by theological or other moral values. Today, caregiving is largely practiced outside of the formal service of the church and medical practitioners. According to Cavanaugh (2005, p.7), "The exercise of caregiving is, perhaps, most evident in individuals who choose to provide caregiving to the sick and dying under the protection of various community service programs".

2.3 Theoretical Models

When studying existing research and literature on caregiving, it becomes clear that much of the field of psychology has in the past focussed on the patient or care-receiver. According to Payne and Ellis-Hill (2001), it is only recently that researchers have started to recognise that caring for others with chronic and fatal illnesses has an impact on the caregivers, and considered caregivers worthy of investigation in their own right.

Several research studies (e.g. Greenberg, Seltzer, Krauss & Kim, 1997; McDermot, Valentine, Anderson, Gallup & Thompson, 1997; McGrother, Hauck, Bhaumik, Thorp & Taub, 1996; Murphy, Christian, Caplin, & Young, 2006) indicate that the effects of caregiving on caregivers may be far reaching and vary greatly depending on the nature and extent of the caregiving role and context. Caregiving may be associated with negative physical, emotional and functional health consequences, worry, an increased sense of responsibility, depression, fear and pessimism. In contrast to this, caregivers may also experience satisfaction, rewards, meaningfulness, unconditional acceptance, a positive sense of coherence and increased psychological well-being (Steenkamp & Potgieter, 2008; Grant *et al.*, 1998; Wahl & Newmark, 2009.).

Various models exist that either directly or indirectly explain the effect of caregiving on caregivers.

2.3.1 Bradburn's Two-factor Model of Psychological Wellbeing

The fundamental question underlying Bradburn's study of mental health in normal populations is understanding the psychological reactions of normal individuals to the stresses and strains of everyday life (Bradburn, 1969). Bradburn explains that people are found on a dimension of psychological well-being or happiness. A person's position on this dimension is further dependent on his/her position on two other dimensions, namely, positive and negative affect. A person will be high in psychological well-being if positive affect exceeds negative affect. On the other hand, a person will be low in psychological well-being if negative affect exceeds positive affect.

In many respects, this model is similar to the traditional pleasure-pain models that view an individual's happiness as the degree to which pleasure predominates pain in life experiences. Bradburn's research, however, indicates that positive and negative affect are independent of one another and that the respective factors contributing to positive and negative affect differed. This means that the absence of factors contributing to positive affect has no relation to negative affect and *vice versa*.

This finding suggested that, in order to fully understand an individual's level of psychological well-being, one would need to explore both positive and negative affect dimensions independently. Bradburn (1969) states the following in this regard:

The main point here is that the cycle of positive affect goes on independently of the cycle of negative affect.... Sometimes they go on together, sometimes not, and one cannot predict the level of one from knowing the level of the other. (p.12)

Within the context of caregiving, Bradburn's model has been applied by Lawton *et al.* (1991). These authors hypothesised that the objective stressors of caregiving (symptom severity of the care receiver and level of help provided by the caregiver) would strongly influence how caregivers appraised their circumstances within the caregiving role. Lawton *et al.* (1991) supports the notion that a person's psychological wellbeing is affected by his/her appraisal of the stressors he/she experiences in a situation as follows:

The central feature of [this] caregiving model is that two parallel processes occur in which the two types of appraisal differentially affect the two types of psychological well-being in ways that are congruent with the valance: satisfactions lead to positive affect and burdens to negative affect.(p.182)

As a practical application of the views of both Bradburn and Lawton *et al.*, this study will explore both the positive and negative affective experiences of caregivers at Refeng Sebaka.

2.3.2 The Lazarus and Folkman Process Model of Coping

It is well established that caregivers experience stress (Murphy *et al.*, 2006). Richard Lazarus, a pioneer in the study of emotion and stress, devoted much of his work to devising a few models for understanding the dynamics of coping and stress. One model he called the Theory of Coping

and, together with Folkman, he also developed the Process Model of Coping. These models both describe the effects of events and how people cope with the stress that may result.

At the heart of Lazarus' theory are two key concepts namely; *appraisal* – an individual's evaluation of the significance of what is happening for their well-being, and *coping* – an individual's efforts in thought and action to manage specific demands (Lazarus, 1993).

Lazarus (1991) describes stress as a relational concept. From this point of view, stress is not seen as an environmental stimulus or a specific pattern of psychological, behavioural or subjective reactions but rather as a relationship between individuals and their environment. Lazarus and Folkman (1986) define psychological stress as follows: "Psychological stress refers to the relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceeds available coping resources" (p. 63).

The outcome of a stressful event is therefore dependent on the individual's expectations or their appraisal with regard to the significance and outcome of the event (Khrono, 2002). Appraisals in turn are dependent on particular personal (e.g. motivational disposition, goals, values and generalised expectancies) and situational (e.g. predictability, controllability and imminence of a stressful event) factors.

Lazarus (1993) identified two forms of appraisal, namely; primary and secondary appraisal. Primary appraisal is concerned with the occurrence of something that is significant to the individual's well-being whereas secondary appraisal concerns coping options. Table 2.1 provides a brief summary of the components that make up primary and secondary appraisal according to Lazarus (1993).

Table 2.1.

Components of Primary and Secondary Appraisal (Lazarus, 1993)

Primary Appraisal	Secondary Appraisal
<p>Goal Relevance</p> <p>The extent to which an event relates to issues about which the person cares.</p>	<p>Blame or Credit</p> <p>The result of an individual's judgment of who is responsible for a particular event.</p>
<p>Goal Congruence</p> <p>The extent to which an episode proceeds in accordance with personal goals.</p>	<p>Coping Potential</p> <p>An individual's evaluation of the prospects for generating certain behavioural or cognitive actions that will lead to effective coping.</p>
<p>Type of Ego-Involvement</p> <p>Aspects of personal commitment, such as; self-esteem, moral values, ego-ideal or ego-identity.</p>	<p>Future Expectations</p> <p>The judgment of the further course of an event with respect to goal congruence and incongruence.</p>

Lazarus and Folkman (1984) go on to describe three types of stress that are a result of specific patterns of primary and secondary appraisal. These types of stress are:

- *Harm*: Psychological loss or damage that has already taken place
- *Threat*: Anticipation of harm that may be imminent
- *Challenge*: The result of demands that a person feels confident in mastering

Their Process Model of Coping suggests that coping mediates the effects of stress on an individual's wellbeing. Folkman, Schaefer and Lazarus (1979) identified five categories of coping resources, namely, problem-solving skills, social networks, general and specific beliefs, health/energy/morale and utilitarian resources. Their model also maintains that the psychological meaning (appraisal) of the event is the most influential element to the coping process. Therefore, the key feature of this model is that individuals differ in their appraisals of similar events or circumstances, leading to different stress outcomes.

Kelso, French and Fernandez (2005) applied this model to the area of caregiving. Figure 2.1 provides a visual illustration of Lazarus and Folkman's model by Bresbord cited in Kelso *et al* (2005). From this model, Kelso *et al.* (2005) argue that not all caregivers will necessarily experience the impairment of a child as a source of stress. The authors acknowledge that this view presumes that caregivers of children with disability are more vulnerable to the effects of stress than caregivers of normally developing children. However, they argue that this view is not a return to what they call the "return to the former practice of pathologising" (p. 4), but state that vulnerability does not imply pathology. Their hypothesis is that caregivers of children with disabilities are more vulnerable to poor adjustment due to the effects of stress but that there are factors which mediate the effect of stresses associated with caregiving.

Kelso *et al.* (2005) identified both stressful events and problem solving skills associated with caregiving of which some include:

Stressful events:

- Isolation
- Community responses – including a lack of understanding regarding the nature of a child's problems

Problem-solving skills (mediators):

- Previous coping experiences
- Intelligence
- Coping resources accessed – including social networks
- General and specific beliefs – including personality aspects, such as a need to be in control, maintaining a positive outlook and the need to maintain a sense of humour
- Health, energy and morale

Lazarus and Folkman's model is criticised for not examining the gratification associated with caregiving, although there is scope for looking beyond adjustment towards positives. In relation

to the relevance of this model to caregiving, Kelso *et al.* (2005) state that: “the Lazarus and Folkman model allows researchers to examine perceived satisfaction with life and impact on social activities, as well as perceptions and acceptance of the child” (p.4).

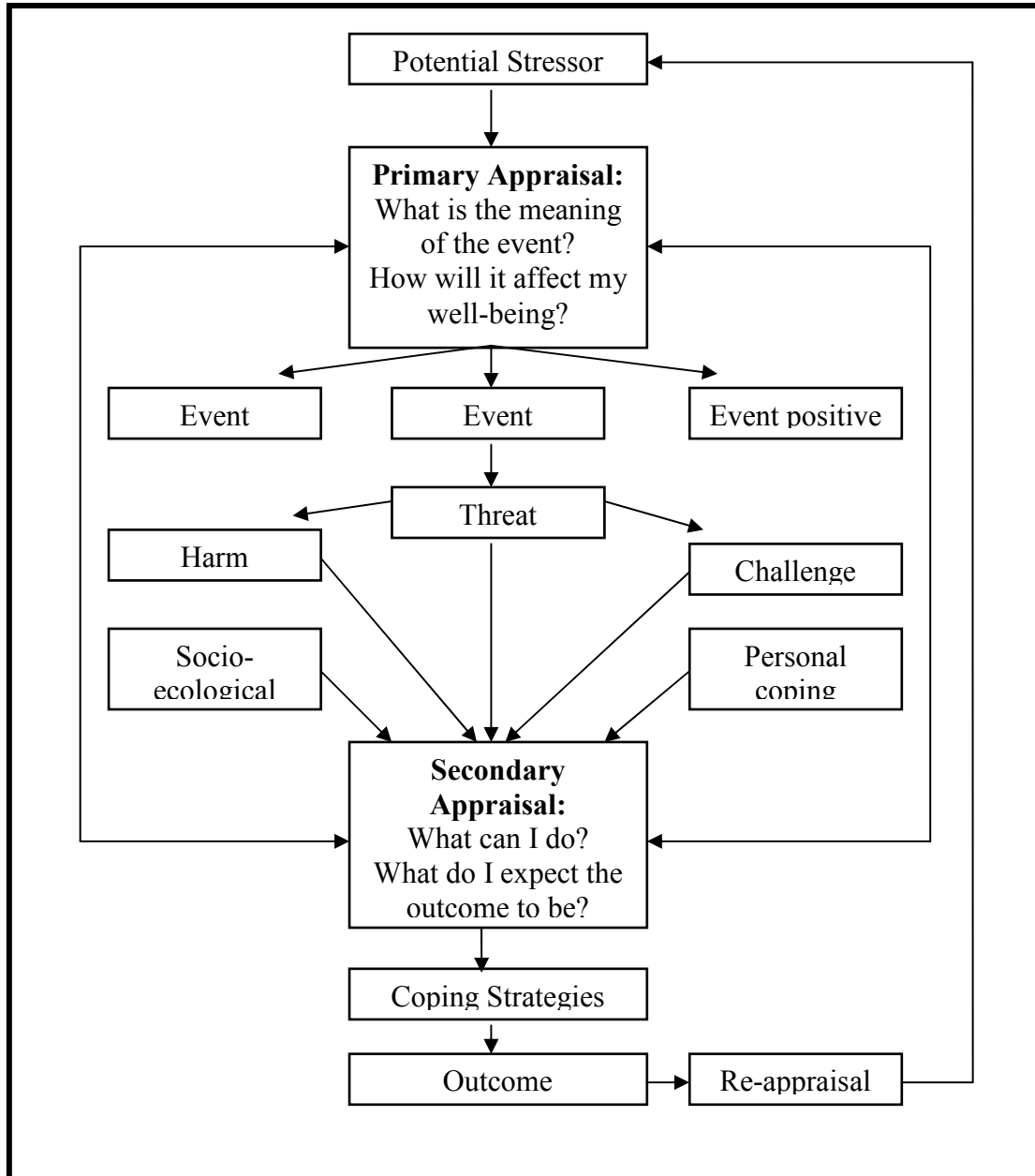


Figure 2.1.

The Lazarus and Folkman Process Model of Coping (Bresbord cited in Kelso *et al.*, 2005 p. xx)

This study will investigate the psychological meaning that caregivers at the day-care centre attribute to the act of caregiving. The stressful events, as well as mediating factors, will be explored in an attempt to determine the outcome of caregiving in the lives of the participants.

2.3.3 The Caregiving Stress Process Model

Pearlin *et al.* (1990), designed this model to assess the informal caregiving process affecting caregiver psychological health. According to this model, the caregiving experience and associated stress reflects a process that changes over time (Raina *et al.*, 2004).

Stressors were defined by Pearlin and his colleagues as the “problematic conditions and circumstances experienced by caregivers” that strain or supersede the individual’s capacity to adapt (Raina *et al.*, 2004 p.8). Stressors can be primary or secondary in nature. Primary stressors are directly linked to the individual receiving the care and the disability, while secondary stressors arise from the demands of the caregiving role itself.

The stress involved in the caregiving role potentially has abundant effects, indicating a complex process. This conceptualisation allows for numerous instances where moderators can impact the situation. These moderators may include social supports, self-mastery and self-efficacy that help to sustain the caregiver and lessen the effect of the stressors.

With this study, the primary and secondary stressors as well as mediators will be explored.

2.3.4 A Proposed Multidimensional Model

Drawing from the work of other theorists in this field (e.g. King, King, Rosenbaum & Goffin, 1999; Pearlin *et al.* 1990; Wallander *et al.*, 1989) Raina *et al.* (2004) proposed a multidimensional model that would incorporate the advantages from existing frameworks in this area. This combined model allows for application in all spheres of caregiving, in an attempt to guide future research in the area of caregiver psychological and physical health.

The main constructs included in the model are the characteristics of the care-receiver, and the following aspects with regard to the caregiver: background and context, strain, intrapsychic factors, coping/supportive factors and psychological and physical health outcomes. Another important construct addresses the setting in which caregiving takes place, including socioeconomic circumstances of the caregiving context (Raina *et al.*, 2004).

The characteristics of the care-receiver include factors that are objective conditions affecting caregiving, being manifestations of the patient's impairment. This construct constitutes the actual care demands. Raina *et al.* (2004) hypothesise that fewer care demands will be associated with more positive caregiver psychological and physical health outcomes.

With regard to the caregiver, the background and context refers to the experiential and social past. The construct of caregiver strain includes caregiving demands and the perception of formal care provided by formal services. Caregiving demands measure the daily demands on the caregiver in general, as well as conflict between the caregiving role and occupational roles of the caregiver in cases where parents are the primary caregivers (Raina *et al.*, 2004). The authors hypothesise that fewer demands will be associated with positive caregiver outcomes. The perception of formal care refers to the extent to which parental caregivers report formal services as being family-centred. Once again, it is hypothesised that lower scores on the construct of caregiver strain will be associated with increased physical and psychological health.

Caregiver intra-psychic factors pertain to the caregiver's internal state, with self-perception considered to be the most important factor. A caregiver's self-perception can include their self-esteem and sense of mastery over the caregiving situation. Raina *et al.* (2004) hypothesise that positive self-perception will be associated with higher perceived levels of social support, better family functioning and higher use of stress management strategies.

The coping/supportive factors construct include social support (relationships with extended family, friends and neighbours), family function (the extent to which a family works as a unit) and stress management (the number of strategies and practices of the caregiver in response to problematic situations). Factors such as these may constrain sources of stress and this can have a

positive influence on caregivers' psychological and physical health. Raina *et al.* (2004) hypothesise that higher levels of this construct will be associated with greater caregiver psychological and physical health.

In the present study, the various factors that may have implications for the caregivers' experiences of caregiving will be explored as a means of providing context for the description of their experiences.

2.3.5 An African Perspective on Caregiving

In African epistemology, a person is defined by his/her interconnectedness with others. This is illustrated by the well-known quote by Mbiti (1970), "I am because we are; and since we are, therefore I am" (p. 171). Menkiti (1984) reiterates that personhood from an African perspective is procedural, one becomes a person through social and ritual incorporation. To further illustrate this point, Menkiti (1984) argues that the pronoun "it" is used to refer to those who have passed since they have lost contact with their community.

According to Mkhize (2004), a worldview is "a set of basic assumptions that a group of people develops in order to explain their reality and their place and purpose in the world" (p. 35). A person's worldview influences the manner in which he/she will face problems in their lives and shapes his/her attitudes, beliefs and behaviour.

Mkhize (2004) is of the opinion that, in order for health care practitioners to be effective in dealing with people from different cultures, they need to consider alternative world views. The researcher believes that this notion should be extended to the practice of research. In order to gain an accurate understanding of the experiences of people, consideration of the various factors that may impact on people's worldview, and hence their lived experiences, is of vital importance.

Although there is some degree of universality in the challenges that human beings face, Heelas (cited in Mkhize, 2004), argues that there are cultural differences in the way people deal with these challenges. One would therefore expect that the experiences and meanings attributed to the

task of caregiving would also be influenced by cultural beliefs, norms and worldviews. Various African concepts that may influence the practice of caregiving and the meanings attributed to it will now be discussed. This study may reveal these cultural differences because the participants are from diverse cultural and educational backgrounds.

Community and *Ubuntu*

The concept of *ubuntu* forms a central part of African philosophy and defines what it means to be human (Ramose, 2007). The word *ubuntu* is an Nguni term and translates to “personhood” or “humanness”. Sociolinguistically, the term is considered by Kamwangamalu (1999) to be a multidimensional concept representing the core values of African ontologies. Some of these values include: respect for any human being, respect for human dignity and human life, collectiveness, sharing, obedience, solidarity, caring, hospitality and interdependence, amongst others. Through this concept the self is defined as interdependent of others (Laden, cited in Kamwangamalu, 1999).

Kamwangamalu (1999) further describes communalism as a core value of *ubuntu*. In African epistemology, the concepts of community and *ubuntu* go hand-in-hand. The interests of the individual is seen as subordinate to the interests of the group and hence the group constitutes the focus of individual activities. An extract from the *Zulu Declaration of Personhood* (Asante & Abarry, cited in Martin, 2008) clearly illustrates how the concept of *ubuntu* has entrenched the view of personhood in African epistemology:

“My neighbour and I have the same origins;

We have the same life-experience and a common destiny;

My neighbour’s sorrow is my sorrow;

His joy is my joy;

His survival is a precondition of my survival” (p. 213).

Where disability is concerned, Teffo (cited in Siyabulela & Duncan, 2006) highlights having compassion and sensitivity to the handicapped and those less privileged as an inherent feature of *ubuntu*. Teffo further qualifies compassion by linking it with the reciprocity and cohesiveness promised by *ubuntu*:

I am attracted to an existence in which people treat each other as human beings and not simply instruments or tools, where people become committed to one another without necessarily having to declare such commitment. When the chips are down it is compassion which makes it possible for others to rise to the occasion. Compassion integrates and binds people together. (p. 307).

With respect to children in African societies, *ubuntu* implies that children belong not only to their parents but are also under the authority and control of any adult within the community. Children are therefore taught to call all adults in the community, of a similar age to their parents, mother or father (Kamwangamalu, 1999).

Children

According to Mkhize (2004), African societies have many universal views and one can therefore generalise the views of one society to that of others. In this discussion on the African view of children, I will discuss the Batswana society with the understanding that it represents the wider view of many Africans.

Alverson (cited in Tshitswana, 2003) explains that cattle are considered the major maker of wealth, and the chief form of wealth, in Batswana society. Although a high value has always been placed on cattle in the Batswana culture, the value of children exceed that of cattle in the consideration of wealth. Children are therefore highly valued in African culture. Caring for a child is seen as the primary responsibility of the mother, and often her older female siblings share this responsibility. Other family members, such as the paternal uncles, also play a role in

disciplining and teaching children. The paternal uncle is usually considered the child's guardian should the child's father die (Tshitswana, 2003).

A common practice among the Batswana people is that of fosterage. Children are often sent to live with relatives for extended periods of time. The value of this, according to Schapera (cited in Tshitswana, 2003), is that it is considered a means of building kinship and establishing an allegiance to the larger community. In modern society, poverty and political circumstances have placed many families under severe financial pressure. The practice of fosterage has, according to Tshitswana (2003), "outgrown the boundaries of family circles" (p. 74). This has led to the practice of fosterage no longer being a free choice, but an option to be negotiated by the family and potential providers. It is therefore not uncommon that parents make use of care centres, pre-schools and after-school facilities to assist with the burden of taking care of their children while earning a living. Therefore, parents in Soshanguve, who make use of the day care centre of this study, use a form of "fosterage" for their children, which is in accordance with the African perspective.

African Worldview of Disability

As explained earlier, a person's worldview influences his/her attitudes and behaviour. It is through this worldview that a person attributes meaning to their experiences and consequently, this influences the way they act or behave in a given situation.

It is hypothesised that a particular society's worldview of disability may play a significant role in the meaning they attribute to the role of caregiving within this context. It is from this point of departure that an African perspective with regard to disability will now be discussed.

B.H. Baloyi (1997) identifies eight examples of common and prominent beliefs regarding the causes of disabilities within African communities. They are the following:

- Uncooked liver: The marriage between cousins is purified by eating the liver of a slaughtered cow or goat. It should be eaten raw to prevent disabilities occurring in the children conceived as the result of such a marriage.
- If a pregnant woman were to look at the disabled, she may have a disabled child. Pregnant women are therefore not permitted to look at the disabled.
- Laughing at the disabled will cause one to be the next victim of disability, whether through accident or illness, or through one's offspring.
- Witchcraft is often associated with disabilities. Individuals with disabilities are often thought to have been bewitched or cursed.
- If a person fails to respect taboos, a child in that person's family may become disabled, or there may be the birth of a disabled child in the family.
- A girl who has many boyfriends before she is married will, when she eventually marries, have a disabled child.
- When a man who is divorced remarries and his new wife uses the property of the first wife, the couple will have a disabled child.
- Father-daughter incest (due to molestation) is said to produce disabilities in children born from the incestuous relationship.

According to various individuals, such as Ntombela, Kisanji and Trent (cited in B.H. Baloyi, 1997), in the past, disabled individuals were viewed as taboo, an embarrassment, the result of sin, a burden, a curse and incompetent. As a result of these beliefs, people with any form of disability were killed. It is therefore obvious that disabilities are commonly associated with negative perceptions and, according to B.H. Baloyi (1997), positive perceptions of the disabled among the black community are rare.

Devlieger (1995), however, uses the Songye people of Zaire as an example to demonstrate one African perspective on disability. The Songye people believe that physical disability can induce a higher, lower or undetermined status in comparison to able-bodied individuals. This implies that not all disabled people are stigmatised or marginalised. "Abnormal" children are divided into three categories namely; "ceremonial" (*mishinga*), "bad" (*malwa*) and "faulty" (*bilema*) children.

“Ceremonial” children are believed to have special powers and healing capacities. They possess a high status. Examples include children who were born with the umbilical cord around their necks, or with their feet first.

“Bad” children, on the other hand, have a lower status and are not considered human by society. They are considered supernatural because it is believed that they have had contact with the anti-world of sorcerers. It is believed that they did not enter this world to live, but rather to die. Therefore, they are truly marginal and their interaction with the world is limited. Examples of “bad” children include albino, dwarf and hydrocephalic children.

“Faulty” children are considered those with an imperfection to the body which is believed to result in distorted relationships with others. Their status is considered in-between since they neither have the high status of “ceremonial” children nor the low status of bad children. “Faulty” children are those born with imperfections to the upper and lower limbs due to diseases, birth complications or congenital deformities.

In addition to B.H. Baloyi’s (1997) observations, Devlieger (1995) explains how the Songye society has an indifferent stance on the possibility of improvement in these children. The reason for this lies in the belief that the fault is merely a symptom of something more important – the underlying cause of the fault. The family would therefore focus their attention on searching for the cause and solving it, removing the focus from the individual with the disability or fault in this instance. This means that, within the Songye society, individuals with disabilities are not viewed as abnormal, deviant figures but rather as liminal ones. The person is therefore seen as one with “potential” and having a right to development. The following proverbs illustrate further how disabled individuals are considered in this society (Devlieger, 1995, p. 97):

- Do not mock the faulty; God keeps creating you (*“Tosepange lemene; Efile kiakupanga”*).

- When a person with a fault enters, the door is completely shut (*“Ha mulemane utwela, kibi e kubuwa kingo”*) – meaning the person with a fault has wisdom to be used and one should discuss problems with a “faulty” person that should not be heard by the indiscreet.

Other proverbs suggest that “faulty” individuals should not attempt to outdo themselves by engaging in activities that go beyond their capabilities:

- When the drum goes fast, the dance should go fast too (*“Ngoma lubilo, masha lubilo”*).

As shown above, the Songye people provide a rich illustration of the worldviews and perspectives on disability in an African society. This worldview can, however, not be freely generalised to all African societies, but serves as an example of ways of thinking about disability that a researcher may come across when doing research in African communities (for example, Soshanguve).

Certain beliefs (that share similarities with Songye beliefs) seem to be common in most African communities; the marginalization of certain disabled people in black communities and in contrast to this, the attribution of spiritual or higher status to the disabled. It is expected by the researcher in this study that caregiving of children viewed as “ceremonial” or “faulty” will be positively influenced due to the high status placed on “ceremonial” children and the idea that “faulty” children can improve respectively. On the other hand, the expectation is that the responsibility of caregiving for children who are viewed as “bad” will be negatively influenced since these children are regarded as “passers-by” who did not come to live in this world for a long period of time. When collecting the data, cognisance will be paid to the cultural perspectives of the participants in a way to allow for richer description and interpretation of the experiences of caregivers.

2.4 Conclusion

The different models of caregiving, and its effects on the caregivers, discussed so far suggest the need to explore caregiver experiences from various angles and denotes the important contribution of the caregiving context in relation to caregiver experiences. It is clear that both Western and African perceptions of caregiving can contribute to a more comprehensive understanding of caregiving within a specific context. In an attempt to explore the experiences of caregivers of children with disability within the context of a day care centre, this study will draw from these models in order to optimize the richness of describing and connecting the experiences of these specific caregivers.

CHAPTER 3

METHODOLOGY

“Peace is not unity in similarity but unity in diversity,
in the comparison and conciliation of differences.”

(Mikhail Gorbachev)

3.1 Introduction

In South Africa today, we are bombarded by images, relationships and experiences coloured by the diversity of our nation. In many ways, attempting to conduct social research in this context can be like navigating a mine field if one attempts to find a shoe that will fit all. On the other hand, the diversity of individuals creates a context where differences can be incorporated into a rich and meaningful whole, allowing qualitative research to provide a multi-faceted description of social phenomena.

The following chapter will describe the research methodology employed in the present study. A breakdown of the qualitative paradigm used in this study will be provided, including a description of the sample, data collection and data analysis. The chapter will start off with an overview into the qualitative and quantitative paradigms as background, and the appropriateness of a qualitative paradigm for this study will be argued.

3.2 Qualitative versus Quantitative Research

Bryman, as cited in Henn, Weinstein and Foard (2009) defines a paradigm to be “a cluster of beliefs and dictates which for scientists in a particular discipline influence what should be studied, how research should be done, how results should be interpreted” (p.11). Qualitative and quantitative research paradigms are illustrative of two different philosophical or world views

held, and represent two different assumptions about the nature of reality. On a basic level, qualitative and quantitative research paradigms base their findings on different types of data. In qualitative research, data is collected from written or spoken language, or in the form of observations that are recorded in language. The data collected is then analysed and various themes are identified. On the other hand, quantitative data is gathered from numbers and statistical types of data analysis are employed (Durrheim, 2006).

3.2.1 Qualitative Research

Qualitative research has its foundations in inductive theory construction. This implies that scientists who conduct qualitative research begin to construct a theory by first observing aspects of social life and then by seeking to discover patterns which may point to more universal beliefs or ideologies (Babbie, 2007). Qualitative researchers use themselves as the data collection tool in an attempt to explore human experiences and the meanings attributed to these experiences. Furthermore, data collection takes place in a naturalistic setting implicating the study of phenomena as they naturally occur. Researchers attempt to gain an understanding of a social event from the perspective of the participants. Qualitative researchers tend to immerse themselves in the research setting and spend an extended period of time with the participants. The findings from such studies are said to be context-bound and qualitative researchers do not attempt to generalise their findings to larger groups of people (Gay *et al.*, 2006).

Throughout the study, researchers remain open to exploring alternatives and finding different explanations, hence they avoid making premature assumptions and decisions about the study. A qualitative study includes the voices of the participants as well as that of the researcher and his/her biases or preferences concerning the research topic (Gay *et al.*, 2006). For this reason, qualitative research has often been criticised as being subjective. According to Breuer, Mruck and Roth (2002), qualitative research highlights the impact of the researcher on the study to a larger degree than quantitative research, and qualitative researchers engage with this “problem” in a reflexive way. Reflexivity requires the researcher to be aware of his/her own contribution to the construction of meaning throughout the research process. It acknowledges that there is no

such thing as objectivity in research and encourages researchers to explore the ways in which their involvement in the research impacts, informs and acts upon their research (Parker, 1999).

3.2.1.1 Reliability and Validity in Qualitative Research

Reliability in qualitative research is seen as the degree of dependability and applicability of the data gathered (Lincoln & Guba, cited in Golafshani, 2003). Validity in qualitative research is defined by Gay *et al.* (2006) as “the degree to which the qualitative data we collect accurately gauges what we are trying to measure” (p.403). The terms trustworthiness and understanding are also commonly used to describe the validity and reliability of qualitative data. According to Gay *et al.* (2006), trustworthiness of data can be established by addressing the following criteria: credibility, transferability, dependability and confirmability of the study and findings. Table 3.1 provides a brief summary of each of these criteria as described by Guba (cited in Gay *et al.*, 2006, p.405).

Table 3.1

Guba’s criteria for validity in qualitative research (Gay *et al.*, 2006, p.405).

Criteria	Definition
Credibility	The ability of the researcher to take all the complexities that present themselves in the study into account and to deal with patterns that are not easily explained.
Transferability	The researcher’s belief that everything is context-bound.
Dependability	The stability of the data.
Confirmability	The neutrality or objectivity of the data collected.

Gay *et al.* (2006) goes on to explain that, in order to contribute to the trustworthiness of a study, researchers should take into account descriptive, interpretive, theoretical and evaluative validity in their studies. Descriptive validity is the degree to which the data accurately reflects the information obtained from participants. Interpretive validity refers to the meaning that the researcher attributes to the behaviours or words of the participants. Researchers should ensure that they accurately interpret such data. Theoretical validity represents the ability of the

researcher to report and explain the studied phenomenon in relation to a theory. Lastly, evaluative validity refers to the researcher's ability to remain as objective as possible when reporting the data.

Stiles (1993) provides some guidelines to improving the trustworthiness of a qualitative study. This includes: disclosure of orientation, explication of social and cultural context, description of internal processes of investigation, engagement with the material, iteration and grounding interpretations. These guidelines will now be discussed briefly.

1. Disclosure of orientation

It is important for the researcher to disclose his/her theoretical orientation, expectations of the study and his/her preconceptions and values prior to interpretation of the data. Through doing this, the researcher enables readers to infer the observations' meanings to the researcher. Disclosure of the researcher's orientation also allows for the context of observation and interpretation to be defined and assists readers to place these into perspective.

2. Explication of social and cultural context

The social and cultural context within which the research is conducted plays an important role in "channelling" the interpretations that are made in the study. By describing the social and cultural context within which the research took place, the researcher allows readers to fully understand the perspectives from which the phenomenon was viewed. Although Stiles (1993) agrees that the full explication of social and cultural context is not possible, he notes that "a systematic attempt can at least alert readers to the ways in which results may be culturally bound" (p. 603).

3. Description of internal processes of investigation

Stiles (1993) views the internal processes of the researcher, which contribute to his/her "progressive subjectivity" (p. 603), as a significant part of the research context. The researcher's experience of the research process and outcomes, and their reactions towards their initial

expectations, are considered to be significant in themselves. Furthermore, qualitative researchers often investigate subjects which are personally significant to them. This should be shared with the readers since it constitutes a part of the study's meanings and interpretations. Stiles (1993) further states that, even though every attempt may be made by the researcher to describe his/her internal processes, it is inevitable that this description may not fully capture the truth.

4. Engagement with the material

Guba and Lincoln (cited in Stiles, 1993) describe engaging with the material as possibly including some of the following activities: personal contact with participants, intimate familiarity with the text, prolonged engagement, persistent observation, discussion of preliminary interpretations with other researchers, actively seeking disconfirming data and constantly checking the participants' reactions to the interpretation of the data. Through engagement with the material, the researcher's understanding of the participants and text is significantly deepened.

5. Iteration: cycling between interpretation and observation

It is considered good practice in qualitative research for the researcher to go through a process of "recycling" their interpretations of the data. This process requires the researcher to check and re-check the meanings he/she has attributed to the data systematically. This involves giving the interpretations back to the participants and obtaining their input/comments on it. This process may also involve the researcher reading and re-reading the text in order to re-conceptualise former conceptualisations as their observation of the context is extended.

6. Grounding interpretations

Stiles (1993) notes that it is essential that the researcher links his/her interpretations, summaries and/or narratives to the actual observations or interviews carried out. This often entails presenting excerpts from the interviews so as to highlight the connections between the identified themes and the actual interviews. Therefore, the interpretations are said to be concretely grounded in the actual data collected.

The trustworthiness of a qualitative study can be threatened in several ways. Henn *et al.* (2009) explains that reactivity, subjectivity and “going native” may threaten the trustworthiness of one’s study. These factors will now be elaborated on.

Reactivity

The manner in which research participants respond or behave may be unconsciously altered when they are placed in a research context. This effect is often observed when a sensitive area is studied. The researcher can attempt to reduce this effect by developing rapport with the participants and setting them at ease about the research process.

In the present study, the researcher had built rapport with the participants over the period of a year. The effect of reactivity was minimised by engaging the participants in a trusting relationship wherein they could feel free to explore their experiences without fear of judgment.

Subjectivity

The researcher’s own experiences, ideologies and worldviews influence the manner in which he/she observes and experiences the research context. The researcher’s own subjectivity influences what he/she sees as significant and worthy of study.

In the present study, my personal experiences with disability in my family, my love for children and initial curiosity and sense of unfamiliarity of the research context all contributed to the setting selected, the participants chosen and eventually the interpretations given to the data collected. In acknowledging my own subjectivity and including my own voice in the research project, an attempt is made at highlighting the context within which the research results are achieved and the lenses through which this study was viewed.

Going Native

By spending a prolonged period of time with the participants, there is a tendency in qualitative research for the researcher to develop empathy and become close to the participants' views and ways of doing things, which may cloud his/her observations and interpretations given to the data. The biases which the researcher has may lead to a distorted picture of the situation that is being researched.

In the present study, a period of approximately one year had been spent at the centre. The researcher had definitely gained a sense of empathy for the caregivers, since she could strongly identify with their struggles through the experiences she had as an informal caregiver at the centre. Through supervision and participation in a reflective group, she was able to gain an awareness of the possible biases that she had developed regarding the research participants. With this in mind, the data was analysed so as to allow for the possible influence of the researcher's own experiences when interpreting the experiences of the caregivers and other students.

3.2.2 Quantitative Research

Quantitative research is founded in deductive theory construction. Scientists who conduct quantitative research will use their data to test a given theory by confirming or denying precise hypotheses. Henn *et al.* (2009) therefore refers to it as the "theory-then-research" approach (p. 134). Quantitative researchers know in advance what they are looking for and all aspects and phases of the study are clearly planned out (Neill, 2007). These researchers use tools such as questionnaires, surveys and instruments to gather their data and they tend to remain objectively separated from their subject matter.

In contrast to qualitative research, the specific sample size and sample selection procedures employed in quantitative research tend to allow for generalisability to wider populations. Another strength of quantitative research is that it is commonly accepted as being objective.

However, the generalisability and objectivity of quantitative research has been criticised as not being strictly true and have been said to represent an ideal to which quantitative researchers strive (Durrheim & Painter, 2007).

Validity in quantitative research is determined by the tool used to collect the data. Durrheim and Painter (2007) define validity as “the degree to which a measure does what it is intended to do”. The idea of reliability in quantitative research refers to the dependability of an instrument. A reliable measure will therefore produce the same results on repeated trials.

3.4 The Appropriateness of a Qualitative Research Paradigm

Much debate has been entered into regarding the superiority and inferiority of quantitative and qualitative research paradigms. According to Silverman (2006), the decision between using a qualitative or quantitative approach lies in the research question that one wants to answer and, in essence, what it is that one wants to find out. In this study, the research question revolves around the experiences of caregivers within a very specific context. The researcher’s extended involvement with the participants, as well as her own experiences at the centre, has shaped the lens through which she will explore and interrogate the research question. A qualitative paradigm was chosen for this study in order to explore the experiences of the caregivers in such a way as to gather rich data which would allow for a unique and meaningful interpretation and description of their experiences of the caregiving role in the context of a day care centre. This would not have been possible within a quantitative paradigm.

3.4.1 The Compatibility of Qualitative Methods and the Assumptions Underlying Critical Psychology

Qualitative methods allow the researcher to explore phenomena as they occur naturally. It also allows the sequences (how) and participant meanings (what) that colour the phenomena to emerge (Silverman, 2006). As stated previously (see 1.5), Critical Psychology allows for the diverse voices of people to contribute to the understanding of a phenomenon. Qualitative

methods create a platform which allows the diversity of voices to emerge by creating an exploratory atmosphere where what “needs to be heard” is not predetermined in the study. Qualitative research methods also allow for the voice of the researcher to be heard which, according to the assumptions of Critical Psychology, contributes further to the understanding of the phenomenon. Therefore, in this study, participants’ (caregivers and students) voices are “heard” through the expression of their unique cultural perspectives and the way these perceptions weave into their experiences (keeping in mind that the researcher’s voice is also “heard” by the way the data is interpreted).

3.4.2 The Suitability of Qualitative Research Methods for the Research Context

As stated in Chapter 2, traditional Western Psychology has often been wrongfully applied to explain the experiences of Africans. It was argued that, in order to fully understand Africans, one would need to gain an understanding of their unique worldview and ideologies which will not be achieved through quantitative methods. The research context for this study includes a variety of voices stemming from a variety of worldviews and ideologies. Qualitative methods allow for the application of non-standardised methods, which do not particularly favour a specific cultural group. Furthermore, reflexivity — which allows the researcher to make known her own voice and biases — will highlight the impact of this on the findings. While aiming to explain, as accurately as possible, the experiences of caregivers in a caring context, the researcher also acknowledges the limitations of this representation. In such a way, the tendency to explain things from a traditionally Western point of view and silencing other voices is avoided as far as possible.

3.5 Ethnographic Approach

The approach employed in this study is based on an ethnographic stance. Ethnography, according to Gay *et al.* (2006), is a qualitative research approach which looks at the cultural patterns and perspectives of a group within its natural setting. Harris and Johnson (as cited in Genzok, 1999) describe ethnography as literally meaning “a portrait of people”. It comprises of

a description of the beliefs, behaviour and customs of a particular group of people. This description is based on information collected through fieldwork and the researcher “lives with and lives like” those who are studied (Van Maanen, as cited in Genzuk, 1999). This implies that the researcher is not only an observer, but also a participant in the context that is being studied.

Various methods can be applied in ethnographic studies and these include historical, observational and interview methods. These methods are employed as a means of obtaining and identifying significant categories of human experience at a very close and intimate level (Genzuk, 1999). Hammersley (as cited in Genzuk, 1999) identified several features which define ethnographic methodology. This includes that the studied behaviour of the participants is viewed in the everyday contexts and not under experimental conditions. Although data can be gathered from a range of sources, it is the relatively informal conversations and observations that are of utmost importance. The collected data, and the analysis thereof, is considered to be unsystematic in the sense that the data in its raw form is considered to be sufficient for analysis as it is. Lastly, the focus of research usually falls within a small group or single setting.

In the present study, the researcher set out to explore the experiences of a particular group of participants with the aim of describing the cultural patterns and perspectives related to caregiving. The researcher herself was intimately involved in the research context and shared in the experience of caregiving on an informal level. The researcher became part of the context through her role as an informal caregiver, and it was from this vantage point that the researcher interacted with, participated with and observed the participants in their natural context for the purpose of data collection and interpretation.

Several researchers have highlighted the importance of the researcher’s voice, experience and prejudice within the research (e.g. Neuman, as cited in Wall, 2006) and according to Ellis (as cited in Wall, 2006), the starting point for research lies with the researcher’s own experience.

Although the researcher is not considered a formal participant in the present study, her voice forms part of the voices of the other participants through the application of some autoethnographical principles. Due to the researcher’s extensive involvement at Refeng Sebaka as an informal caregiver, the possibility of her influence on the data collection and analysis

processes may not be ignored. The researcher's unique experiences of caregiving at Refeng Sebaka may have played a role in shaping the outcomes of this study and it is this way that her voice is unavoidably heard. Acknowledging how the researcher's voice is heard together with those of other participants, and recognising the researcher's influence in the process of data collection and analysis allows for a richer, more realistic description of the experiences of caregiving in this particular context.

3.6 Sampling and Participants

A sample is defined by Henn *et al.* (2009, p.153) as "a subsection of the population, chosen in such a way that their characteristics reflect those of the group from which they were chosen". In sampling, the study's objectives and characteristics of the population to be studied determines the sample size and selection method used (Mack, Woodson, MacQueen, Guest & Namey, 2005).

There are various methods of sampling available with regard to qualitative research. Mack *et al.* (2005) explains that the three most commonly used methods include purposive, quota and snowball sampling. Purposive, otherwise known as convenience sampling, was used in this study. This sampling method involves the researcher selecting whichever cases are conveniently available (Henn *et al.*, 2006). Cases were selected based on the availability of the participants to participate, their ability to provide descriptions of their experiences and their particular exposure to caring for children with developmental challenges.

The sample size was not predetermined but cases were rather added as needed in order to attain data saturation. According to Siegle (2002), data saturation is reached when the researcher is "no longer hearing or seeing new information" (p.1).

For the purposes of this study, nine participants were included, of which four were formal caregivers and five were informal caregivers. The formal caregivers were all female, aged approximately between 30-50 years. All of the formal caregivers are employed on a full-time

basis at Refeng Sebaka. The informal caregivers comprised of Masters Students in Clinical Psychology from UNISA who had been placed at the centre for practical training. The informal caregivers included one male and four females, aged approximately between 20-45 years. The languages of the participants varied between Tswana, Afrikaans and Zulu. Most participants had English as a second, third or fourth language.

3.7 Ethical Considerations

To ensure the ethical credibility of this study, a proposal was submitted for approval by the Department of Psychology at UNISA. The interests of the participants were protected in line with the Ethical Code of the Health Professions Council of South Africa, in the treatment of human subjects.

Permission to conduct the study at the day care centre was obtained from North Gauteng Mental Health via a written requisition outlining the aim of the study, as well as the methodology to be followed. All potential participants were informed of the nature and aim of the study via an informed consent letter, as well as a discussion, which was translated into a language that the participants could understand. Participants were given the opportunity to volunteer their participation in the study. Space was provided for questions to be asked throughout the process of the study and answers were translated into a language understandable to all participants.

The identity of the participants, as well as the information they provided, was kept confidential at all times. The anonymity of the children at the centre was respected and at no time were they directly involved in the study.

3.8 Data Collection

As previously discussed, the validity of the data collected is of utmost importance so as to accurately represent or capture the meanings ascribed to a specific phenomenon by the participants and the researcher.

To adhere to the principles of qualitative data collection and methodological triangulation, the researcher made use of visual data, unstructured individual interviews, a focus group and written sources of data obtained from a reflective writing activity.

3.8.1 Formal Caregivers

The following data collection methods were used to collect data from the formal caregivers:

3.8.1.1 The Collection of Visual Data

Franklin (cited in Roos & Ferreira, 2008), is of the opinion that the creation of expressive art necessitates the recreation of emotional and traditional processes. This, in turn, gives meaning to the participant's context and world of experience in the form of a visual narrative. According to Harper, Ravey and Johnson (cited in Roos, 2008), a "visual narrative assists both researcher and researched to engage with additional forms of communication in order to understand the social, cultural and psychological phenomenon under investigation" (p. 581).

In applying the above premises, the formal caregivers were provided with a variety of materials including potter's clay, coloured modelling clay, cardboard, pens, wooden and glass beads, buttons, sticks and strips of paper (see Figure 3.1). This technique of visual representation was based on the premise that a culturally sensitive data collection method was needed in order to explore the meanings attributed to the experience of caregiving among African women optimally. Most of the materials chosen are considered culturally familiar to the participants (e.g. clay, beads and sticks) but several other materials were also added to allow for choice. The researcher participated in this activity by creating her own visual representation of her experiences in order to provide an example for the participants and to "break the ice" in order for the participants to get going on their own representations.



Figure 3.1

Materials used in the collection of visual data

A series of questions were provided as a guideline for reflection, and brief guidelines were provided to assist the formal caregivers with telling their stories and sharing their experiences. The participants were then instructed to use any of the materials they wished to visually represent their stories/experiences. Each visual representation was then photographed and an individual discussion in the form of an unstructured interview followed.

3.8.1.2 Unstructured Interviews

According to Kelly (2006c), interviewing represents a more natural approach to data collection than, for example, filling out a questionnaire. Interviewing allows the researcher to interact with his/her participants on a more personal level and gives them the opportunity to get to know each other more intimately.

Qualitative interviews are generally less structured than quantitative interview methods (Babbie, 2007). Herbert and Rubin (cited in Babbie, 2007) distinguish between qualitative and quantitative interviewing by noting that qualitative interviewing is regarded as more flexible, continuous and iterative in comparison to quantitative interviewing, which is more rigidly

prepared in advance. Qualitative interviewing is seen as a process of interaction between the researcher and participant (Babbie, 2007) and is based on a rapport between the two parties. The researcher generally has an idea of which topics to be discussed in the interview but there are no pre-set questions set in a specific order or containing a specific set of words (Babbie, 2007).

In the present study each participant was asked to discuss their visual representations in an unstructured interview with the researcher. The goal of each interview was to allow the caregivers to express what they had presented visually, in a verbal manner. When participants were having difficulty verbalising their experiences, the researcher utilised the visual representations by asking the participants to explain the meanings they attributed to different parts of their representations. The interviews allowed the researcher to gain a richer understanding of the participants' visual representations of their experiences as caregivers. One of the caregivers was asked to translate the instructions and questions of the researcher to the other caregivers where they indicated necessary. An external translator was used to translate the recorded individual interviews and to assist with the transcription of these interviews.

3.8.1.3 Focus Group

Individual interviews allow the researcher to gain an understanding of the individual's subjective experience. Interviewing a group of participants (focus group) however, allows the researcher to gain insight into the inter-subjective experiences of the group of participants (Kelly, 2006c). Focus groups also assist the researcher in understanding the differences and commonalities between his/her participants' experiences.

In the present study, the formal caregivers at the centre were engaged in a group discussion (lead by the researcher) regarding their experiences of the visual representation exercise and their experiences of caregiving in general. Although focus groups generally consist of individuals who are not from a "naturally" existing social group (Kelly, 2006c), this focus group consisted of individuals who knew each other well. The constitution of this focus group is supported by the overall aims of ethnography to explore the experiences of a specific small group of people. The

fact that the participants were comfortable with each other and worked together enabled the group discussion to flow comfortably and freely. The participants were able to relate their stories in the group through informal conversations about their experiences at the centre. One of the participants was asked to assist the researcher in translating her comments to the other participants during the focus group session.

3.8.2 Informal Caregivers

The following data collection method was used to gather data from the informal caregivers:

3.8.2.1 Reflective Writing Exercise

A series of reflective questions was constructed and given to the Clinical Psychology students. The instruction was given to use the questions as a guideline to compose a written piece pertaining to their experiences and stories about being informal caregivers at the centre.

The following questions were provided as a guideline for the informal caregivers:

- How did you come to be at Refeng Sebaka?
- What does it mean to you to work at Refeng Sebaka?
- What do you enjoy the most about working at Refeng Sebaka?
- What do you enjoy the least about working at Refeng Sebaka?
- What do you find rewarding?
- What are the challenges?
- What support do you receive?

The informal caregivers were given freedom to write as much as they wanted to and were also encouraged to share whatever they wanted to. The written documents were collected and comprised another set of textual data presented for analysis.

3.8.5 Reflective Journaling

Ortlipp (2008) describes the use of a reflective journal for purposes broader than mere reflexivity. He describes the use of journaling by the researcher as a manner of revealing the researcher's history, values and assumptions, and opening this up to the reader's scrutiny.

Ellis (2004) describes some ways in which researchers can go about recording their own experiences in an autoethnographic study. This includes writing about personal experiences, using dialogue and scenes to draw the reader into what happened to the researcher, writing concretely and expressively, using writing as a tool for the researcher to find out what he/she knows, using different forms of expression such as artwork, and trying to listen to and portray the multiple perspectives of other people involved in the story.

Although the present study was not an autoethnographic study as such, the researcher made use of a reflective journal to record not only her assumptions, biases and experiences of the research process, but to keep record of the experiences, dialogues and stories she encountered at the centre. The researcher cannot deny that this may have influenced the interpretation/analysis of the data.

3.9 Data Analysis

According to Henn *et al.* (2006), the analysis of qualitative data may often be characterised by its lack of rules, although general approaches do exist which guide the researcher. The method of data analysis should be carefully considered as it aims to transform the information gathered so as to answer the research question (Durrheim, 2006). The method of data analysis should therefore be coherent to the purpose of the research and the overall research paradigm.

Qualitative data analysis is often characterised by its lack of distinct rules. Henn *et al.* (2006) describes this lack of rules or rigidity as liberating, as there are no right or wrong approaches. However, general processes do exist which are valuable in guiding the researcher in the process of analysis. Data analysis within an ethnographic approach entails the description of the culture sharing group, as well as the themes that are present in the group (Maritz & Visagie, 2010).

Thematic analysis is a descriptive presentation of data which involves the identification of themes from the text which are not imposed by the researcher. This means that the researcher employs an exploratory stance and is not deductive in his/her approach to the data analysis. Anderson (2007) describes themes as expressions of the communality of voices across different research participants. These themes are then discussed in detail to provide a reflection of the overall body of data gathered.

In the present study, all the individual interviews, and the group interview with the formal caregivers were recorded and transcribed in preparation for data analysis. The written reflections of the informal caregivers also formed part of the data. The process of data analysis employed in this study has been adapted from the work of Anderson (2007), Kelly (2006a), TerreBlance, Durrheim and Kelly (2006) and Kelly (2006b), and involves the following steps:

Step 1: Familiarisation and Immersion

The process of familiarisation and immersion involves the researcher reading and re-reading the textual data gathered in order to get a feel for the overall meaning, and the different types of meaning, in the text. In order for familiarisation and immersion to be effective, the researcher should develop a sense of the characteristic language and metaphors used by the respondents.

Step 2: Thematising

The process of thematising involves identifying the communalities that underlie the textual data. This is a meticulous process of going through the data and while doing so, highlighting and unpacking the different themes that immerse. Throughout this process, the researcher makes

notes and diagrams to unpack the themes and creates sub-categories and clusters of information that immerse. All information that adds to or describes these clusters of meaning is noted.

Step 3: Coding

The coding process requires the researcher to group together similar instances under the same theme. In this process the researcher marks different sections of the data as belonging to a specific theme identified in step 2. The processes of thematising and coding tend to blend together in practice and therefore do not necessarily comprise two different activities. Steps 2 and 3 are repeated until the researcher is confident that the themes or categories reflect the interview transcript as a whole.

Step 4: Elaboration

During the elaboration phase of data analysis, the identified themes are explored more closely in an attempt to capture the finer meanings that were missed in the original coding process. Through elaboration, it will be determined whether the coding system needs to be reviewed and the researcher may find him/herself moving between coding and elaboration until he/she feels that they can give a good account of what the data results are.

Step 5: Interpretation and Checking

This phase of the data analysis process involves the researcher reporting on, or putting together an account of the phenomenon that was explored. The report usually comprises of a presentation of the themes and sub-themes discovered. The research study is considered “complete” once a point of saturation has been achieved. Saturation is described as the point where the researcher is confident that he/she has fully described, and has a satisfactory sense of, the phenomenon or experience that he/she has set out to explore.

3.10 Conclusion

The use of a qualitative approach in this study is justified by the aim of the present study to explore the experiences of a variety of caregivers within their natural setting. A qualitative paradigm is consistent with the assumptions underlying Critical Psychology and allows for an in-depth look at the participants' experiences, as well as the inclusion of the researcher's voice in order to obtain a rich and full description of the cultural, historical and social contexts and experiences. Furthermore, this approach allowed for flexibility in data collection and analysis, which allows a variety of culturally-sensitive methods to be employed. An ethnographic approach was applied to highlight the customs, beliefs and practices of the participants in their caregiving context. The voice of the researcher in this study is acknowledged because of her experiences during her prolonged involvement and participation in the research context.

Convenience sampling was utilised to select participants who were available and willing to share their experiences. This fit with the qualitative, exploratory research design. The data collection methods were culturally appropriate. Methodological triangulation was employed by the application of a variety of data collection methods. This was done to enhance the validity of the data gathered, thus enhancing the accuracy with which the data represents the phenomenon studied. Thematic analysis was utilised for data analysis.

CHAPTER 4

PRESENTATION OF RESULTS

4.1 Introduction

This chapter will provide an outline of the basic themes that were identified when analysing the data that was gathered from for each participant group, namely formal and informal caregivers. A discussion of each theme will also attempt to link the findings of this study to current literature. The formal caregivers are employed on a full-time basis at Refeng Sebaka while the informal caregivers comprised the MA Clinical Psychology students placed at the centre for clinical training.

4.2 Experiential Themes of the Formal Caregivers at Refeng Sebaka

4.2.1 Being a Parent

A few of the formal caregivers described their personal experience as a parent as one of the reasons why they find their job easy and enjoyable. Being a parent inspired many of the caregivers to get involved in caregiving and in one of the cases, the caregiver has a developmentally challenged child of her own. This caregiver explained it as follows:

“I came here to cook for the children; I also have a disabled child. I cook for them, when I finish, I serve them.”

In the above caregiver’s visual representation she presented her role as cook by building a kitchen with different utensils, crockery and pots. This is shown in Figure 4.1. She decorated her table with flowers and a cloth. This demonstrated the care she takes as mother and caregiver.



Figure 4.1

Participant D: Visual Representation of Caregiving Experience

Some caregivers explained that the duties that they were assigned at Refeng Sebaka were a direct result of their personal experience as a parent; this caregiver explains:

“My job is not that difficult because I have children too. I usually change their nappies when they are wet because I have my own children.”

This theme highlighted the fact that the caregivers do not view their role of caregiving as different to that of being a parent. Their devotion to the children reaches beyond their basic duties as employees at Refeng Sebaka. They show a deep seated emotional commitment to the children. This theme extends into the next theme of becoming a foster parent. It is through being a parent themselves that these caregivers seem to be able to become a parent to the children at Refeng Sebaka. We also see in the next theme that becoming a parent is an expression of the cultural values of the formal caregivers.

4.2.2 Becoming a Foster Parent

An interesting theme that emerged from the data was that of becoming a “foster parent” to the children. This theme was implicit in the way the caregivers spoke of and described the children at Refeng Sebaka. In most cases, the caregivers would use the term “my” when referring to the children. It became evident that they considered the children to be like their own as is seen in the following extracts from the data:

*“This is **my** children you see.”*

*“Because you know **my** children they know me **my** children, **my** children love me.”*

This theme was also seen in the group discussion when the caregivers spoke about holiday times or times when they are not able to see the children. They described how they longed to see the children and how they miss them when they are apart:

“When we close this centre in December, when we come back in January we miss them very much (laughs).” (The researcher interprets the laughing in this context as an agreement with this statement, as could be seen in the manner in which the caregivers laughed, showing non-verbally that they all experience this).

“When I’m not here they can feel that I am not here and when I arrive they are happy. When they see me they smile. Even when I leave them in the classroom when I come back they smile. When I am not there they cry.”

The above caregiver’s visual representation is presented in Figure 4.2. One can clearly see how she represented *her* children at Refeng Sebaka, by labelling them and placing them prominently in her representation.

the value of caring and respect for human dignity and life as described by Kamwangamalu (1999) in section 2.3.5. Through caring for the children on such a deep level, these caregivers demonstrate a commitment to the emotional, physical and social well-being of the children. It is through this that they express the value they place on the lives of these children, despite it not being their own children.

The idea of fostering has been explained by Tshitswana (2003): non-biological parents can become “foster parents” to children. As we see at Refeng Sebaka, the formal caregivers strongly express their experience of caregiving as that of becoming a parent to the children. This phenomenon is not uncommon in modern day Africa and as explained in section 2.3.5, there are various advantages to fosterage for both the parents and children.

From Devlieger’s (1995) explanation in section 2.3.5, we see that it is possible that the caregivers view the children as “faulty” children who have the potential and right to development. It is this view that allows them to invest time and energy into their role as caregivers. The belief that the children can improve remains a motivation to them.

4.2.3 Connectedness

In fulfilling their roles as formal caregivers the ladies describe various activities which highlight their informal engagement with the children and which seem to contribute to a sense of connectedness with the children. This connection is often demonstrated through play activities. It is through engagement with the children that the caregivers experience fulfilment and happiness in their roles. The general idea of this theme seems to be the caregivers’ enjoyment of their jobs, as demonstrated in the following extracts from the data:

“I like playing with the kids and we play football and I show them what a donkey is and what the job is.”

The elements of another participant’s visual representation, indicated in Figure 4.3 below, include two black semi-circles along the perimeter of the model which she describes as follows:

“This is a circle that sometimes I like to play with them in, running around the centre.”



Figure 4.3

Participant A: Visual Representation of Caregiving Experience

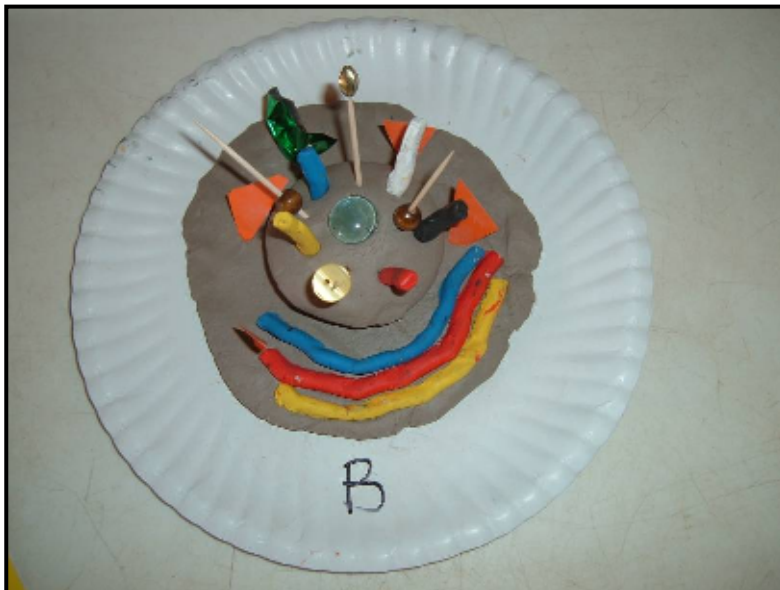


Figure 4.4

Participant B: Visual Representation of Caregiving Experience

In Figure 4.4 above, we see how another participant presented her caregiving experience visually. In describing her interaction with the children, she explains the following:

“Here I’m in the class with my children dancing, we open the radio so we play making dance in the class. Here I showed you when we finish to pray and to eat I helped the children with many different colours. I show you here yellow, red, green white and black. Different colours. I teach them how to use the colours.”

In their application of the Lazarus and Folkman Process Model of Coping (see section 2.3.2), Kelso et al. (2005) explain that not all caregivers will experience the impairment of a child as a source of stress. They identified, among others, energy and morale as a mediating factor to stress. In the current study, the ability of the caregivers to engage in positive and energetic play with the children may have a buffering effect in terms of the stress they experience in their roles as caregivers.

According to Lawton *et al.’s* (1991) application of Bradburn’s Two-factor Model of Psychological Wellbeing to the caregiving context (see section 2.3.1), satisfaction lead to positive affect. In this study we can see that the satisfaction experienced by the caregivers in engaging and playing with the children, contribute to a positive experience of caregiving in general. They describe their enjoyment of the children and how being with the children makes them happy.

It is common to find discrepancies in the manner in which the term “family” is defined in general. For the majority of experts in the field, the conclusion is that "there is no single correct definition of what a family is" (Fine 1993, p. 235). Crosbie-Burnett and Lewis (cited in Fine, 1993) adopt a pedi-focal definition of family which includes in the family all members who are involved in the nurturance and care of the children. This definition includes non-relatives in the family and allows for flexible boundaries of the family. From this point of view, we can conclude that the caregivers and children at Refeng Sebaka constitute a family.

Social connectedness has been described in Hill’s Theory of Family Stress and Buffer Factors (cited in McDonald, 2010) as a factor that can buffer the impact of stress in families. According

to Hill's theory, social connectedness can act as a protective factor which may allow families cope more effectively with various stressors. McDonald (2010) suggests play as an activity to increase social connectedness between parents and children. The formal caregivers play and dance with the children, increasing the sense of connectedness between them and the children.

From the discussion on cultural views of parenting (section 4.2.2) it is clear that the caregivers view their relation to the children as that of a family. In the current study, we clearly see the social engagement between the caregivers and children in their play activities. From Hill's theory described above we can say that it is through social connectedness between the children and caregivers that the impact of stressors of the caregiving role may be buffered. This may contribute to the positive experience of caregiving described by the caregivers.

4.2.4 Skills Development

The idea of being equipped with new skills was a prominent theme among the formal caregivers. These caregivers described how their experience at Refeng Sebaka with the Psychology and Occupational Therapy students from different universities had allowed them to develop new skills which seemed to add value to their job performance and to their self-esteem as individuals. Two of the participants describe the personal value of skills development as follows:

"I enjoy working in here, it's nice to meet so many people, different students, they are teaching me new things. I enjoy learning more things. In life I know I know many things — different things, I'm lucky too."

"This is my picture. This is my real work at Refeng Sebaka. I enjoy this work. I have many skills and certificates for what I've done."

Another participant described the impact of skills development on her ability to do her job as follows:

“I know how to train my children I'm doing different things with different children, I enjoy it.”

And yet another one described her experience with skills development as follows:

“I learned that from the Occupational Therapy students from Medunsa. They teach me how to feed the CP children. And also the students from Unisa, they teach you the difference between mentally retarded children and CP children and how the children react.”

Greene and Monahan (1989) found that education for caregivers had a significant impact in reducing anxiety, depression and the burden of caregivers. Moen, Robison and Dempster-McClain (1995) hypothesise that a caregiver's personal resources, such as education and prior-wellbeing, will allow for greater resilience against the negative impacts of caregiving by moderating the effect of caregiving on current well-being. The learning that takes place in the lives of the caregivers and the exposure that they get at the centre seems to act as mediating factors against the negative impact of caregiving. This may contribute to their positive experience of caregiving and may act as a buffer against the impact of the stressors that they experience in their jobs.

4.2.5 Communication Barriers

The formal caregivers reported communication barriers between them and the children as a significant difficulty in their job. Most of the children at Refeng Sebaka have difficulty communicating verbally and many cannot communicate verbally at all. At times, the caregivers find it difficult to understand what the children need and it becomes a frustration for them trying to act on the child's behaviour (e.g. crying continuously) in an attempt to meet the child's needs. One of the caregivers describes this difficulty as follows:

“...when the children are sick and she can't talk to tell me at all. I must think okay the stomach is not okay today or she's got a headache. They are difficult things.”

Another difficulty linked to the communication barrier between the caregivers and children is that of noise levels in the centre. The caregivers explain that many of the children cry and scream a lot while others make noises in an attempt to communicate with them. Because of the limited space available at the centre (there is an average of 10 children in a room) a cacophony prevails when all of them are attempting to communicate their needs at the same time. Despite this, the caregivers explain that as time goes by, one seems to get accustomed to the noise and that this is only a difficulty in the beginning. The newest caregiver at the centre explains her difficulty:

“I don't like the noise because sometimes my head hurts. Sometimes I drink a lot of grandpas and I always become happy. I really like my job because I'm a new member. I've been with Refeng Sebaka for one month.”

However, another caregiver (being at the centre for a longer time) says the following about the noise in the centre:

“When you work here everyday, you will get used to it.”

When considering the communication barriers and levels of noise present at Refeng Sebaka, it is clear that this may be a stressor which impacts negatively on the caregivers' experiences of caregiving. These caregivers demonstrate an intense need to be useful and to impact the lives of the children which can make the barriers in communication all the more frustrating to them. However, when one looks at how the caregivers explain their knowledge of each individual child, it is clear that they have found a way to overcome some of these communication barriers and have adjusted to an extent to the high levels of noise. It is through their experience with each child that the initial communication barrier becomes less significant and they seem to “understand” the needs of the child more accurately. This “understanding” is demonstrated through how the caregivers acknowledge that each child is different and how they need different things. This is explained by one caregiver as follows:

“I enjoy it because some of my children I know how to stimulate them, to train my children because I know they are different. I know that this one I have to train him this way like sitting. That is why I enjoy it because I am used to doing this job. I know how to train my children. I'm doing different things with different children, I enjoy it.”

4.3 Experiential Themes of the Informal Caregivers at Refeng Sebaka

4.3.1 Connection versus Disconnection

A strong theme of connection versus disconnection emerged in the data gathered from the informal caregivers. In their time at the Refeng Sebaka, these caregivers expressed a longing to connect with the children and to find a way to do so effectively. Engaging the children in activities and interacting with them in a meaningful way while enjoying the interaction with the children and seeing them enjoy it too, became a positive experience for these caregivers. A few of them described it as follows:

“Something about her was special to me, her eyes spoke to me and the way in which she responded when I walked in drew me closer. I had a special bond with her, even though we could not talk. I copied the sounds she made and she would smile.”

“I enjoyed interacting with the children at Refeng Sebaka, stimulating them...”

“I enjoy having meaningful encounters with the kids; seeing the children join in and respond to my presence and the activities is what stands out.”

On the other hand, some caregivers also experienced a sense of disconnection or being disengaged from the children. The reasons for the sense of disconnection experienced varied but were mostly due to personal feelings of incompetence on the part of the caregivers. Some of the caregivers explained that they initially did not know how to interact with developmentally

challenged children and felt uncomfortable around them. These participants explained it as follows:

“There were times when I did not know how to get the children’s attention or how to get them to respond to me. Some of them felt so distant and I felt stupid for not being able to engage them.”

“In the beginning I distanced myself from the children there as it was difficult for me to engage with them because of the different disabilities and challenges they face. My own feelings of sadness and discomfort prevented me from interacting optimally with the children.”

“The greatest challenge I faced entailed trusting my intuition when working with the kids, making sure that I strive to enter their world and connect with them beyond their physical and mental disabilities.”

Thoits (cited in Hagedoorn, Sanderman, Buunk & Wobbes, 2002) found that it is specifically stressors relating to one’s identity that cause distress in the caregiving role. It is when caring for someone who is significant to you, that problems in one’s identity or feelings of failing in the caregiving role can become significant stressors. An individual’s perception of how they fare in the caregiving role may therefore influence the level of distress that they experience. In the present study, we see that the feelings of incompetence or inability to connect in a meaningful way with the children as an initial stressor in the informal caregivers’ experience of caregiving at Refeng Sebaka. It is evident that the feelings of incompetence they experienced with regard to their ability to engage the children in what they felt was a meaningful way, created the perception of failure which may have lead to some distress. On the other hand, it is also evident that although this was a stressor to some caregivers, the ability to engage with the children and the experience of being successful in their role at the centre became a positive experience as time passed.

4.3.2 The Lack of Resources

The informal caregivers described the lack of resources at Refeng Sebaka as a barrier in their ability to perform their caregiving role to the best of their ability. The amount of space at the centre, the limited access to professional services and the lack of physical resources in the building were seen as impacting negatively on their experiences as informal caregivers. At times the informal caregivers found it difficult to do the things they wanted to do for the children and formal caregivers. They expressed some frustration with regard to the vision they had for the children and formal caregivers at Refeng Sebaka and the way in which the lack of resources limited them in realising this vision. Figures 1.1 and 4.5 show that Refeng Sebaka is a rather needy facility — a place of limited space and resources. The following extracts from the informal caregivers’ reflections show their frustration with the lack of resources:

“The lack of resources is quite a challenge and I find it very frustrating at times as it impedes on the plans I had.”

“Lack of resources — specifically the small building and small yard is a challenge to me because at times I was limited to what I could do with the kids.”



Figure 4.5:

The outside yard at Refeng Sebaka

“The financial support is also a challenge; more equipment might be needed for stimulation of the children. Rails on the sides of the walls could assist them when they walk or when they struggles with their balance. Due to the financial resources that were available many of these ideas cannot be implemented.”

“Seeing the need for interventions from other professions such as remedial therapists, educational psychologists, occupational therapists and physio- as well as speech therapists frustrated me.”

In the Lazarus and Folkman Process Model of Coping presented in Figure 2.1 we see that Socio-ecological factors impact on an individual’s secondary appraisal of a stressor. In this study, the lack of resources at Refeng Sebaka will therefore impact on the informal caregivers’ perception of what they are able to do and what the outcome of their caregiving role will be.

In this theme we see that the informal caregivers perceive the lack of resources at Refeng Sebaka as a negative factor which impedes on their ability to contribute what they would like to contribute. However, this does not imply that the lack of resources will lead only to negative experiences of caregiving. As we see in the model presented in Figure 2.1, the coping strategies employed by these caregivers to deal with the lack of resources will determine the outcome of their experience. Therefore, if they employ effective coping strategies in dealing with the lack of resources, it may not become a significant stressor in their caregiving experience.

4.3.3 Learning/education

In this theme, the informal caregivers expressed the value of the learning that took place at Refeng Sebaka. The informal caregivers indicated that they had found the practical training at the centre useful as it taught them various skills that they found would be valuable to their professional development. The experience of learning and acquiring new skills was seen in a positive light and enriched their experience of caregiving.

Three of these participants explained their experience of learning at Refeng Sebaka as follows:

“I have learned a great deal about how a community functions, especially how the environment and the rest of the community affects the children and the caregivers. I have learned much more about the developmental stages of children, and specifically about Cerebral Palsy.”

“Above all I have learnt how to communicate without using words and how to connect with people who cannot speak my language. This has helped me become a better therapist since I am more tuned-in to non-verbal behaviour and what it communicates to me.”

“From a personal perspective it is for me the process of learning about their disorders and applying innovative psychological techniques.”

In this theme we again see how education has made a positive impact on the caregiving experience. As with the formal caregivers, the informal caregivers have benefited from their role as caregivers at Refeng Sebaka by developing skills that would be useful to them in their professional development. The work of Greene and Monahan (1989) as well as that of Moen *et al.* (1995) described in section 4.2.4 is therefore applicable to this theme also. The education or learning that the informal caregivers received in their caregiving role may contribute to reducing anxiety, depression and the caregiving burden, mediating the impact of stressors in the caregiving role.

4.3.4 Personal Growth

This theme describes the way in which the caregiving experience touched the informal caregivers on a deeper level, allowing for personal growth. Caring for the children at Refeng Sebaka was a new experience for most of the informal caregivers. Given the context of their placement at the centre, quite a few of them were expecting to learn and be educated on a professional level of becoming psychologists only. These extracts from the data are

demonstrative of the personal impact that caring for the children at Refeng Sebaka has had on the informal caregivers:

“I went there to learn how to do therapy. Although that is not what I got to practise there all the time, I came back each week having learnt something about life from the children and caregivers at the centre. Before, I had never been exposed to life in a township. Being placed at Refeng Sebaka allowed me to experience African people for who they are and I feel I am a better person for it.”

“I learnt that my time, my effort and compassion was worth far more than just ‘helping’ others from a distance.”

“...despite my feelings of not having been at Refeng long enough to really get into things, I experienced working with the children there as meaningful and rewarding.”

“Refeng Sebaka meant a great deal for my personal growth.”

From this theme we see how the caregiving experience contributed to the learning of the informal caregivers in ways that they did not expect. Many of the informal caregivers had expectations to be enriched only on a professional level but their experiences at Refeng Sebaka allowed for not only professional but also personal growth. In this sense, what they received out of their role as caregivers was beyond what they had expected. This impacted positively on them and allowed them to view their role as caregivers in a positive light and could therefore also have a positive affect on them as future professional psychologists.

4.3.5 Making a Difference

In working with the children over a period of a year, the informal caregivers expressed the positive impact that the physical and emotional progress shown by the children over this period of time was tremendously rewarding to them.

“I could not believe how much she had changed. I was so proud for being part of the team that had impacted her life so tremendously! I am looking forward to seeing more progress.”

“One of the most profound things for me was to see how the children’s development improved over a couple of months. Some of the children who arrived in the beginning of the year would not stop crying, later their emotions stabilised and they laughed and interacted with other children.”

“It is really rewarding to see progress after working with a child for some time. The sense of achievement is overwhelming and knowing I made a small difference in the life of that child is wonderful. In one child’s case it was teaching her to count to 20.”

The mere act of being present in the lives of these children and the knowledge that it makes a difference was also a positive experience for one of the informal caregivers:

“Working in Refeng means that I am making a difference in adding value to the lives of the children who are mostly misunderstood because their world is different from what we call ‘normal’.”

In their study on the impact of a future outlook on caregiving, Rakowski and Clark (1985) found that an impaired outlook on the health care situation led to greater stress. In this study we see that the informal caregivers experienced the progress they saw in the children as a positive sign which impacted positively on their future outlook. From Rakowski and Clark’s work, we can therefore say that the positive future outlook held by the caregivers, impact positively on their experience of caregiving by reducing the stress that they experience in their roles.

4.3.6 Being “Useless” as a Professional-in-training.

At times the informal caregivers experienced a sense of uselessness as caregivers within the field of Psychology. This theme was specifically portrayed in the participants' initial entry into the centre – the feeling of not knowing what to do with the children and how to help them; feeling

overwhelmed by the new context within which they found themselves. Because their involvement at Refeng Sebaka forms part of their practical training as Clinical Psychologists, it was evident that the informal caregivers had a sense of urgency with regard to how they performed on a professional level and they evaluated themselves as to whether they had a positive impact on the children and formal caregivers at Refeng Sebaka.

“I felt that all I was doing was sitting there with the children and talking to the caregivers. I did not always think that I was being useful to them. It did not feel at the time that I was doing therapy and I became disillusioned.”

“I didn’t like seeing the need and then feel helpless that I can’t offer these services to the children.”

“I often wondered how a way could be found to stimulate them all adequately. What I could offer during my weekly visits was only a small drop in the ocean of their huge need.”

“...working in Refeng Sebaka, which can be quite-overwhelming.”

“The first couple of times that we went to Refeng Sebaka we only played with the children and we got to know them and the caregivers better. I still felt like as psychology students in training we needed to be doing more for them.”

Again we see how one’s identity may have an impact on the experience of caregiving. As described by Hagedoorn et al. (2002) in section 4.3.1, a person’s perception of their ability to perform their caregiving role successfully has an impact on the level of distress they may experience. In this study, we see that the informal caregivers’ experience of not being as useful as they would have liked to be as caregivers may have contributed to the distress they experienced in their role as caregivers at Refeng Sebaka.

4.3.7 Communication Barriers

As with the formal caregivers, the informal caregivers experienced communication barriers between them and the children as a stressor in their role as caregivers at Refeng Sebaka. However, the communication barriers they explained included not only the inability to communicate verbally with all the children but also the language differences between them, the children and the formal caregivers as explained in the following extracts from the data:

“I often felt limited by my inability to speak Tswana. Sometimes I was not able to assess a child accurately because I could only ask questions in English. I had to ask the caregivers to explain but not all the caregivers were fluent in English. It was difficult at times as I could not do all that I wanted to do”

It was clear from the data that some of the informal caregivers overcame these communication barriers after a period of time by using other skills that they already possessed, or by developing skills that could help them communicate:

“Not being able to speak the language of the children and caregivers was also challenging. I found that my experience in communicating with my own babies and other children before the age of speech development provided me with some skills to assist in overcoming these language barriers.”

“When I could not understand a child or one of the caregivers, I started using my observation skills to allow me to enter into their world and to try and understand some of the context of what was being discussed. I also started to mimic the behaviour and sounds of the children in an attempt to communicate with them. Sometimes this worked, sometimes it didn’t”

Communication barriers can be seen as a major stressor when it impedes on the ability of the caregiver to perform their role sufficiently. As we see in this study, the perception of what it means to be effective as a caregiver varies from individual to individual. Some caregivers had

the perception that being able to communicate verbally meant that they could be more effective as caregivers. Others perceived their inability to communicate verbally as a minor problem that could be easily overcome by applying other skills that they had. The impact that communication barriers have on a caregiver's experience of caregiving in this study, can therefore be said to depend on their perception of whether or not they have the necessary skills to overcome such barriers and to make the best of the situation that they find themselves in.

4.4 Comparison of Participant Groups

The results of this study demonstrate how the experiences the formal and informal caregivers at Refeng Sebaka differ in some aspects while in others there are striking similarities. Both participant groups expressed that they learnt something from their experiences as caregivers (the theme "education/learning/ skills development") and both groups had difficulties in communicating with these children (the theme "communication barriers"). Themes that were not shared by the two groups are the following: while the formal caregivers experienced that they were like parents to these children (the themes "being a parent" and "becoming a foster parent"), the informal caregivers sometimes felt overwhelmed by the new experience (the theme "being useless as a professional-in-training").

The findings also indicate that caregiver experiences may vary from positive to negative. Bradburn's two-factor model of psychological well-being (1969) describes that an individual's sense of psychological well-being or happiness is found on a continuum and that their position on this continuum is dependent of their position on the dimensions of positive and negative affect. Bradburn's model implies that in order to explore an individual's psychological well-being, one would need to look at both positive and negative affect. In this study, the experiences of the formal and informal caregivers at Refeng Sebaka were explored. Lawton *et al.*'s (1991) application of Bradburn's model indicates that the objective stressors of caregiving would strongly influence how caregivers appraised their role as caregivers. Table 4.1 and 4.2 provide an overview of the positive and negative experiences of caregiving found in this study and show that more positive themes were identified in the formal caregivers which could imply that they are mostly happy about their work with the developmentally challenged children. They also

seemed mostly happy when the researcher observed them. The positive and negative themes identified with the informal caregivers are an even number, which could point to positive and negative affect that “goes on independently” according to Bradburn (1969, p. 12), and can be interpreted that they experience “two parallel process ... of psychological well-being” (Lawton et al., 1991, p. 182 — see section 2.3.1) which could be part of their development as students in training, who are still searching for their own identities as future Clinical Psychologists.

Table 4.1

Overview of the Positive and Negative Experiences of the Formal Caregivers at Refeng Sebaka

Positive Experiences	Negative Experiences
Being a parent	Communication barriers
Becoming a foster parent	
Connectedness	
Skills Development	

Table 4.2

Overview of the Positive and Negative Experiences of the Informal Caregivers at Refeng Sebaka

Positive Experiences	Negative Experiences
Connection	Disconnection
Learning/education	Lack of resources
Personal growth	Being “useless” as a professional-in-training
Making a difference	Communication barriers

It is clear that the commitment of the caregivers to Refeng Sebaka, whether they are formal or informal, plays a significant role in the way they experience their caregiving role. In this sense, the experiences of the formal caregivers, who are involved at Refeng Sebaka on a more permanent basis, are seen to be slightly more personal than those of the informal caregivers, who are involved at the centre as part of their professional training. We do however see a tendency

for the experience to become increasingly personal to the informal caregivers as they reflect back on their involvement at the centre towards the end of their placement. Where initially they may have come to the centre for professional experience, their experience seems to become more personalised as time passes.

4.5 Conclusion

It is clear that the context of caregiving does not seem to simplify the experiences of all caregivers to a universal voice. In this study, the findings have been presented in two groups namely, formal and informal caregivers. Despite the similarities in issues faced by these groups of caregivers at the centre, the uniqueness of each participant's individual experience should not be negated.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In this qualitative study the researcher aimed to explore the experiences of various caregivers at a day care centre for developmentally challenged children in Soshanguve. Attempts were made to draw distinctions between the experiences of formal and informal caregivers. The study was grounded in two basic assumptions. Firstly in the assumption that in order to obtain a rich understanding of a phenomenon, the views and voices of a variety of individuals need to be heard and secondly that cultural values and practices play a significant role in the way individuals experience a certain phenomenon. The experiences of both formal and informal caregivers were documented using thematic analysis. Throughout this study, the various voices of participants were considered in order to obtain a full picture of how different types of caregivers at Refeng Sebaka experience their roles as caregivers.

An analysis of the participants' global themes revealed that both the formal and informal caregivers experienced that they learnt skills and developed/grew (the themes "education/learning/skills development" and "personal growth") by being involved in this centre for developmentally challenged children and that both groups had difficulties in communicating with these children ("communication barriers"). Each participant group also expressed unique experiences such as "being a parent", "becoming a parent" (the formal caregivers) and "being useless as a professional-in-training" (the informal caregivers). In the light of the findings of this study, it is clear that there are differences and commonalities within the voices of the two participant groups, and when looking at individual participants' expressions, it is further clear that the experiences of various caregivers within a similar context may vary.

In Lawton *et al.*'s (1991) application of Bradburn's two-factor model of psychological well-being (section 2.3.1), we see how two parallel processes occur in the appraisal of an event and

how this impacts on the individual's psychological well-being. Accordingly, caregivers may experience both positive and negative affect independently of each other. Bradburn (1969) also pays cognisance to the fact that positive and negative affect may be dependent on each other at times. The findings of this study clearly demonstrated the application of Bradburn's model to the caregiving context. Both the formal and informal caregivers reported positive and negative experiences about their role as caregivers. It is however not possible to make conclusions regarding the overall experience of caregiving — Bradburn (1969) clearly states with regard to positive and negative affect: "...one cannot predict the level of one from knowing the level of the other." (p.12) In this study we do however see how despite the dire circumstances and challenges faced by the caregivers, they did report having learnt something from the caregiving context and the role that they played in the context.

5.2 Main Themes of the Two Participant Groups

The following is an overview of the most prominent findings pertaining to the formal caregivers at Refeng Sebaka:

- The formal caregivers expressed that being a parent themselves assisted them tremendously in their caregiving roles at Refeng Sebaka.
- The cultural values of community, ubuntu and the cultural views around the value of children and disabled children allowed the formal caregivers to view the children as their own. The idea of fosterage became prominent.
- Being connected and engaging with the children on a deep level, added to the positive experience that these caregivers described with regard to their role at the centre.
- Communication barriers between the formal caregivers and the children were viewed as challenges in the caregiving role. The caregivers experienced some frustration in meeting the needs of the children due to these communication barriers.

The following is an overview of the most prominent findings pertaining to the informal caregivers at Refeng Sebaka:

- The idea of connection versus disconnection between the informal caregivers and the children was evident. The informal caregivers expressed difficulty in connecting or engaging with the children on a meaningful level. At other times, they expressed that a deeper connection was possible which contributed to a positive experience of their caregiving role.
- The lack of resources at Refeng Sebaka was a significant stressor for the informal caregiver. They experienced this lack of resources as a limiting factor in their role as caregivers.
- Being able to see the impact of their participation at Refeng Sebaka on the children was a positive experience for the informal caregivers.
- Feeling “useless” as a professional-in-training was a frustrating factor to the informal caregivers. They initially expressed feeling limited as a psychologist in how they could assist the children of Refeng Sebaka because of their own uncertainties.
- Communication barriers between the informal caregivers and the children as well as between the informal caregivers and the formal caregivers were expressed as a difficulty which could be overcome if the right skills were applied.

5.3 Implications for Clinical Practice and Suggestions for Future Research

Implications for clinical practice:

The findings of this study have several implications for clinical practice. It highlights the importance of considering the cultural context and the role it plays in the way people perceive, experience and cope with events around them. Clinicians should acknowledge this context in the way they explore and attempt to co-create meaning with their clients. An understanding and genuine respect for a client’s cultural values and practices provides a powerful lever for change in therapy. It is only when clinicians consider and respect the cultural values and practices of their clients, that interventions will have a meaningful impact.

On a broader level, this study has implications for the manner in which clinicians enter the therapeutic context. The exploratory approach followed in this study highlights the importance of taking on a not-knowing stance in therapy. This means that clinicians can be more effective when they enter therapy with a sense of exploration, with as little as possible predetermined ideas about what the client is putting on the table. Instead, by taking on a not-knowing stance, the therapist creates a context where the client's full story can be heard.

This study also highlights that in therapy, reality is co-constructed by the clinician and the client. In this study we see how the stories of the various role-players (the formal and informal caregivers), merged to create a bigger picture of the experiences of caregiving within a specific context. In the same way, clinicians should remain sensitive to the way that they contribute to and shape the stories told by their clients within the context of therapy. The co-construction of stories in therapy should be viewed in a positive light and clinicians should acknowledge their role in therapy without attempting to minimise the effect they have on the client. It is through the lack of awareness of the impact one has on a client in therapy, that clinicians jeopardise their efficiency in therapy.

Suggestions for research and training:

From the findings of the research study, the researcher suggests that:

- variables impacting on the differences in experiences by formal and informal caregivers need to be explored in a future study.
- cultural variables impacting on the experiences of African non-family caregivers need to be elaborated on in a future study.
- the experiences of individual caregivers within a particular context be further explored.
- future studies focus on a broader sample of non-family caregivers' experiences within a South African context.
- the impact of socio-economic circumstances on the caregiving experience need to be further explored in a South African context.

- the effect of the caregiving role on caregivers be researched, focussing on both positive and negative outcomes.
- the factors which contribute to the resilience we see in formal caregivers be further explored.
- clinical psychology training programmes in South Africa be adapted to take place within a variety of contexts, including rural contexts, which expose the learner to a larger diversity of cultures.

5.4 Limitations of the study

The researcher acknowledges that her own involvement and history with Refeng Sebaka may have impacted on the way in which the interviews were constructed, data was collected and interpretations were made. She acknowledges that this study does not represent the absolute truth but rather a co-constructed version of the truth within a particular context.

The study's qualitative stance limits the generalisations that can be made regarding the experiences of caregivers beyond those who form part of the context of this study. For this reason, the study strictly presents a version of the experiences of caregivers at Refeng Sebaka who were involved in the study.

Although all attempts were made to be culturally sensitive to the needs of the various caregivers involved in this study, some of the data collection methods used may have been less effective in obtaining data in a manner that is fully congruent with the cultural practices of certain individuals. The use of visual representation and the use of semi-structured interviews was an attempt to be sensitive to the predominantly oral tradition of Africans. This oral tradition was respected in allowing the formal caregivers to talk about and build models which reflect their experiences rather than limiting them to writing about their experiences. Despite this, the possibility that these methods were not fully appropriate for each individual remains.

For logistical reasons beyond the control of the researcher, an external translator was not available during the data collection session with the formal caregivers in Refeng Sebaka. One of

the caregivers was asked to translate the instructions and questions of the researcher to the other caregivers where they indicated necessary. The use of one of the participants as a translator may have been a less effective way in ensuring that the message was translated without any added meaning – there could have been some subjectivity of the participant who was translating and therefore some meaning may have been lost or added in this manner. To counter this effect, the participants were asked to respond in Tswana so as to prevent additional translation during the course of the interview. An external translator was then used to transcribe and translate the interviews conducted with the caregivers.

5.5 Strengths of the study

Considering the variety of available literature on caregiving experiences and outcomes, the researcher is of the opinion that the design of the current study was well suited for an exploratory approach. A qualitative approach allowed the researcher to work inductively by exploring meanings as the study progressed and allowing for a rich description of the particular research context. In this way, preconceptions about the findings and the ability of these preconceptions to guide the research approach were minimised as far as possible.

Another strength of this study was the use of methodological triangulation as a means to enhance the reliability of the data collected. A variety of methods were employed to collect data from the various participants and attempts were made to cater for the cultural differences of the participants through the use of different methods. Thematic content analysis was performed by the researcher and verified by her supervisor to further ensure the reliability of the identified themes.

The study was strongly grounded in a respect for differences and a sensitivity to the needs of the participants from various cultural backgrounds. This allowed the researcher to maximise on the quality and accuracy of the data collected, despite the limitations incurred by language and cultural barriers.

This study has enhanced the current literature available on caregiver experiences within a South African context, particularly non-family caregivers. It has contributed to a better understanding of how cultural factors may impact on the way in which caregiving is experienced by various individuals. The study has also highlighted that experiences may vary within particular groups and that future studies may need to be more sensitive to the individual caregiver's experience.

5.6 Reflections of the researcher

This research study can be best described as having perturbed the researcher in exploring how cultural values shape the experiences, behaviours and ideologies of individuals and groups over a variety of contexts. The study allowed the researcher to enter into a world which she had previously not even dreamt of accessing. Through conducting this study, the researcher's practical training at Refeng Sebaka and her experiences as an informal caregiver were given a voice. Accessing the voices of many different caregivers allowed the researcher to place into context not only her own ideas of caregiving but also those of others. This enriched her understanding of what it means to be a caregiver and that caregiving has positive as well as negative implications for the stress levels of the caregiver.

With the diversity of our South African nation, a unique variety of problems can be experienced when diverse groups interact with one another. These interactions are often characterised by racism, disrespect and conflict. The researcher came to the understanding that the common areas of conflict in a South African society are often based in "cultural misunderstandings". Clinical psychologists often unconsciously make themselves guilty of these types of misunderstandings, wreaking havoc in the lives of others. The researcher is of the opinion that "cultural misunderstandings" can be overcome when individuals are stimulated to show a genuine interest in understanding the various perspectives and cultures of those around them. She also believes that adopting this approach as a clinician will greatly increase one's efficiency in therapy and the positive, sustainable impact one can have on the lives of others. The following quotation summarises the researcher's learning journey:

“Mutual respect is the foundation of genuine harmony. We should strive for a spirit of harmony, not for political or economic reasons, but rather simply because we realize the value of other traditions.”

(Dalai Lama, 1989 Nobel Peace Prize, b.1935)

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