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EXPLORING THE SOCIO-EMOTIONAL EXPERIENCES OF ADULTS WITH CEREBRAL PALSY IN A RESIDENTIAL CARE FACILITY IN JOHANNESBURG, SOUTH AFRICA

A report on a project presented to

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School of Human and Community Development

Faculty of Humanities

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In partial fulfilment of the requirements

For the Degree Bachelor of Social Work

By

Dimpho Tsiane

January, 2017

DECLARATION

I hereby declare that this report is my own unaided work and that the assistance obtained has been only in the form of professional guidance and supervision, that neither it nor any part of this report has been previously submitted to any other university for any degree save the one for which I am presently registered as a student; that the information used in this report has been obtained by me while working under the aegis of the Department of Social Work, University of the Witwatersrand; and that all references used have been acknowledged and appropriately cited.



Signature

15 January 2017

Date

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And lastly to the Almighty for keeping me strong throughout my darkest hours and providing the friends, family and staff who helped me complete this research paper.

ABSTRACT

There has been much written on the biomedical concerns of cerebral palsy, yet there has been very little researched or reported on the socio-emotional aspects of cerebral palsy in a residential care facility. This study aimed to explore the socio-emotional experiences of adults with cerebral palsy in a residential care facility. The study made use of an exploratory qualitative design and employed semi-structured interviews with a purposive sample of 10 cerebral palsied adults. Some important findings that emerged from a thematic qualitative analysis of the data included being overwhelmed by the new environment; feelings of freedom, happiness and independence; support from various role players; age and communication challenges; and residents accepting circumstances and remaining positive. The main conclusion drawn from the study was that despite the challenges the residents faced, they were resilient enough to employ coping methods that assisted them through the process.

Key words: cerebral palsy, socio-emotional, transitioning, residential care facility

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

There are 7.5% of people living with disabilities in South Africa (Statistics South Africa, 2011). Despite disability not being an inherent reason not to participate in socio-economic and recreational activities, the World Health Organisation (2011), hereafter referred to as WHO, acknowledges that people living with disabilities are often marginalised and their lives are often characterised by prejudice, social isolation, poverty and discrimination in all societies. It is this South African demographic that inspired the study.

Cerebral Palsy is a common neurological problem in children and is reported as occurring in approximately 2-2.5 of 1000 live births globally (Donald et al., 2014). It was originally reported by Little in 1861 and initially called *"cerebral paresis"* (Rosenbaum et al., 2006). For the past one hundred years, cerebral palsy has been the subject of books and papers by some of the most distinguished medical minds (Rosenbaum et al., 2006). Although not extensively so, the scope of the study of cerebral palsy, both in South Africa and globally, has been of a medical focus. This condition begins very early in childhood and persists right through to adulthood.

Adults with cerebral palsy have been documented to participate less in in areas such as social interactions, employment, marriage, and independent living (Liptak, 2008). As a result of their disability, some people with cerebral palsy end up living in residential care facilities where they receive round the clock 24-hour care.

This chapter will highlight, very briefly, the research problem, the rationale for the study as well as the aims, objectives and definitions of key terms. A basic description of the methodology, research design, as well as an overview of the research report will be discussed.

1.2 Statement of the Problem

Moving to a new environment can be distressing and bring with it a plethora of social and emotional challenges. Relocation is a transition that can disrupt existing social networks and it can be challenging for the individual affected to reconstruct the social networks (Dupuis-Blanchard, Neufeld & Strang, 2009). According to Jungers (2010) loneliness is a risk of anticipated transitioning from one environment to another and for some people the feeling

of loneliness is strongest during the beginning of the adjustment phase and for others the loneliness never goes away.

There seems to be limited research on the socio-emotional experiences of adults with cerebral palsy in residential care. According to Hubbard, Tester and Downs (2003) residents living with disabilities tend to be excluded in research and they are more likely to experience social and emotional isolation in institutional care. Their study on the meaningful social interactions between older people in institutional care settings found that the most common activity amongst residents is talking and most conversations are centred on feelings about living in the facility (Hubbard et al., 2003).

Furthermore, South African research around cerebral palsy is medically focused. Cerebral palsy in South African research is seen mainly as a condition that requires treatment, as with the biomedical model. According to a review by Donald et al. (2014) that aimed to establish what has been reported about cerebral palsy on the African continent, the results showed sixteen publications on the prevalence and aetiology of cerebral palsy, four of which were from South Africa. This shows how limited research into cerebral palsy is, not only in South Africa, but on the continent as well. A look at these studies showed that they were medically oriented and were concerned with the condition itself and not how people live with it beyond the hospital, especially within residential care settings.

1.3 Rationale

The rationale for this study was that the study could have the potential to fill a portion of the knowledge gap on cerebral palsy and the socio-emotional experiences of residents living with this disability in a residential care facility. This study further hoped to provide an understanding of the social and emotional experiences of adults with cerebral palsy that have transitioned from their homes into a long term residential care facility. It was anticipated that this study would help social workers tailor interventions that will help residents adjust and transition into residential settings appropriately, as well as to give social workers working in such settings an understanding of the socio-emotional experiences that residents may have with regards to moving in. It is also expected that the study will yield recommendations that may contribute to helping service professionals in the relevant settings and field to tailor appropriate, future programs that will help residents adjust to and experience being in a residential care facility positively.

1.4 Aim of the Study

To explore residents' socioemotional experiences with regards to transitioning and adjusting to a residential care facility

1.5 Research Objectives

- To understand the socio-emotional experiences of residents about transitioning and adjusting to a residential care facility.
- To explore the challenges that residents experience whilst in a residential care facility.
- To identify the participants' recommendations on how transitioning and adjusting to a residential care facility can be made easier for them
- To identify the participants' recommendations on what they can do to improve their socio-emotional experiences of adjusting and transitioning into a residential care facility.

1.6 Definition of Key Terms

Cerebral palsy - "Cerebral palsy is primarily a disorder of movement and posture. It is defined as an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development" (Sankar & Mundkur, 2005, p. 865)

Socio-emotional - Santrock (2007) defines socioemotional experiences as a process that occurs in a person's emotions, personality and relationships with others during one's lifetime.

Transitioning - is defined as "a psychological process where people gradually accept the details of the new situation and the change that comes with it" (Bridges, 2013, p. 4).

Residential Care Facility - is defined as a licensed facility that provides 24-hour care to residents who are semi-dependent and supervises residents' diets, prepares meals, organises social activities, assists with personal care, provides housekeeping, stores and distributes the residents' medication and supervises healthcare under the direction of a licensed health professional (Alzheimer's Association, 2005; Older Persons Act, 13/2006).

1.7 Research Design and Methodology

The methodology for the study was exploratory qualitative research. Qualitative research "is a means for exploring and understanding the meaning individuals ascribe to a social human problem" (Creswell, 2014, p. 4). The research design was exploratory research design which is used to gain insight into a phenomenon, situation or individual due to either a lack of information on a new area of interest or to get acquainted with a situation (Fouché & de Vos, 2011). The participant sample was recruited through the application of a non-probability, purposive sampling method. 10 semi-structured interviews were conducted with 10 participants who were between the ages of 22 and 69. The data that was collected from the study was analysed using thematic analysis.

1.8 Limitations of the Study

Due to the small, non-probability, purposive sample size of 10 participants, the knowledge that may be produced from this study might not be able to be generalised to other populations with cerebral palsy in residential care and may only be unique to the population included in the study. The results of the study relied heavily on the answers of the participants, it is possible that the researcher may have gotten socially desirable answers; it may also be difficult to independently verify the data collected.

1.9 Overview of the Research Report

This research report is comprised of a total of five chapters. Chapter One gives a summary of all the main elements of the study comprised of the problem statement, the rationale of the study, the aims and objectives of the study, definition of key terms as well as the methodology employed for the study. Chapter Two discusses the literature that underpins this study. Chapter Three details the research design and methodology used for the study. The findings of the research will be presented and discussed in Chapter Four and Chapter Five is based on the discussion of the main findings and will also present and discuss the conclusion as well as recommendations that emanated from the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

There has been much written on the biomedical concerns of adults with cerebral palsy, however there has been very little written on the psychosocial, let alone socio-emotional, aspects of cerebral palsy (Horsman et al., 2010). A review by Donald et al. (2010) found that the estimated prevalence for cerebral palsy in South Africa is 10 per 1000 children born. This is much higher than the global prevalence rate, yet there is very little, beyond the biomedical, that we know about this particular population. Much of cerebral palsy research is centred around children, mainly because cerebral palsy is diagnosed after a child turns one and for many people, it is seen as a paediatric condition (Sankar & Mundkur, 2005). However, according to Haak et al. (2009) children with cerebral palsy almost always grow up to be adults yet little is known about how the experience of aging and quality of life in people with cerebral palsy differs from the experience of adults without known disabilities.

Hubbard, Tester and Downs (2003) say that existing work on people's social interaction in institutions has tended to exclude those with severe disabilities and with whom communication is difficult due to sensory or cognitive impairments. Furthermore, Hubbard et al. (2003) go on to say that it is the very same residents with disabilities that tend to be excluded that are the ones whom are likely to experience social and emotional isolation in institutional care facilities.

2.2 The challenges of caring for a cerebral palsied individual

Although children are blessings from God, caregivers with cerebral palsied children appear to face more challenges than caregivers of children who are not cerebral palsied (Dambi et al., 2015). According to the study conducted on caring for a child with cerebral palsy, caregivers reported experiencing inconvenience, physical strain, confinement, family adjustment, disrupted personal plans, work adjustments, financial strain and simply being overwhelmed (Dambi et al.,2015, p. 4). Dambi et al. (2015) further go on to list the factors that cause caregiver strain to be the age of the child, the age of the caregiver, the caregiver's relationship with the child, and the severity of the cerebral palsy.

The older the child, the more strain caused on the caregiver due to the increased needs of the child (Dambi et al., 2015). The age of the child also correlates with that of the caregiver

as well as the severity of the cerebral palsy. The severity of the cerebral palsy plays a role in the limitations that the children face, which may lead to the children requiring assistance completing their daily activities of living (ADLS) (Dambi et al., 2015). Severity of disability is considered as one of the main factors affecting functional status and thus independence in cerebral palsy (Brooks et al., 2014). This would then require lifting and carrying of the children by the caregiver which may subsequently result in pain for the caregiver (Dambi et al., 2015). The heavy lifting of the children will also affect the caregiver adversely due to reduced physical strength that comes with age.

Although this study has been done with children, it would not be unreasonable to presume that the challenges can become more difficult to cope with as time goes on, considering that two of the factors that contribute to caregiver strain are related to both the age of the caregiver and that of the child. As the child grows older, so does the caregiver and as they become more frail with age, they may no longer be able to provide adequate care for the individual with cerebral palsy. Some caregivers may die because of old age and this will leave the individual with cerebral palsy without a caregiver.

More often than not in South Africa, the responsibility may be passed on to someone else who is capable of taking care of the cerebral palsied individual and this may be family, siblings or friends. However, caring for a cerebral palsied individual has the potential to result in changes in the caregiver's personal plans and this may further influence their social life and social networks (Dambi et al., 2015). However, those fortunate enough to have the means, are able to find alternative institutional care for their loved ones so that they too can continue with their lives.

2.3 Relocating

According to Brandburg (2007), the preadmission process is important in defining the severity of some of the post admission issues that a potential resident may face. The preadmission process consists of analysing the number of basic conditions which are being met for the potential resident (Brandburg, 2007). The basic conditions which are being referred to may be the desire to move, legitimate reasons for moving and voluntary control (Brandburg, 2007). This speaks to the potential resident being consulted about the move to the care facility as well as their active involvement in choosing the facility. This can only be achieved through communication in which the desire to move can be explored or legitimate reasons for the move discussed. This continues to make the potential resident feel like they

are in control of their life and they have not lost their sense of autonomy (Grenade & Boldy, 2008).

According to Chenitz (as cited in Brandburg, 2007) there is a relationship between the pre-admission process and how well a resident will adjust. The more basic conditions met, the higher the likelihood of the potential resident accepting the move into the residential care facility (Brandburg, 2007). The less basic conditions met, the more likely the resident will feel dumped and this increases the likelihood of the resident resisting the move into the home or resigning themselves helplessly to their situation.

2.4 Transitioning

Transitions occur throughout the lifespan and they mark the stages of an individual's life and are often associated with uncertainty (Brandburg, 2007). According to Grenade and Boldy (2008) this may be due to the impact of moving from a familiar environment to an unfamiliar one. As such, a move to a residential care facility may bring with it significant changes to a person's social networks (Grenade & Boldy, 2008).

Brandburg (2007) speaks of transitioning in three phases: being overwhelmed, adjustment and initial acceptance. Being overwhelmed involves being emotional, crying, feeling lonely and focusing of self – this is the initial phase when the resident arrives at the facility; The second stage is after some time where the resident begins to establish new social networks and begins to realise that there is a future; the last stage of acceptance arrives when the individual decides to focus on more than just the self (Brandburg, 2007).

2.5 Residential care

Given the nature of the residential care environment, it is presumed that the likelihood of loneliness would be reduced because residential care offers communal living, onsite care and support (Grenade & Boldy, 2008). However, Cacioppo and Hawkley (2009) say that adults who are institutionalised are lonelier than their community-dwelling counterparts. Dupuis-Blanchard, Neufeld and Strang (2009) also point out that institutional care settings are not barren domains of solitude and emptiness.

Cacioppo and Hawkley (2009) acknowledge that it is also loneliness that influences the likelihood of institutionalisation, considering that loneliness has been found to be higher in adults with cerebral palsy than in people without cerebral palsy (Haak et al., 2009). Individuals who are living alone can be protected from loneliness by participating in

institutional care centre activities (Cacioppo & Hawkley, 2009). Despite moving to a new environment being distressing, some people felt that being in institutional care provided a form of support (Jungers, 2010). Given the literature, one can conclude that the residential care setting can be both a welcomed or stressful transition for different people.

2.6 Social experiences

2.6.1 Social support

According to Horsman et al. (2010), a study by King and colleagues showed that social support plays a significant role in how individuals with disabilities adapt to events and experiences that are challenging. This study revealed three types of support: emotional, instrumental and cognitive support (Horsman et al., 2015). Emotional support involves making people feel better about themselves whereas instrumental support refers to the tools and strategies used to address issues and cognitive support speaks to how being understood helps an individual to not feel alone in facing situations and processes (Horsman et al., 2015).

2.6.2 Social isolation

Relocating to a residential facility, not knowing anyone, carries the risk of exposing residents to social isolation. Although social isolation is often confused and sometimes erroneously used interchangeably with loneliness, they are two different concepts all together. “Social isolation is usually regarded as an objective state where an individual has minimal contact with others and/or a generally low level of involvement in community life” (Grenade & Boldy, 2008, p. 469). Factors that contribute to social isolation are a person's social networks, for example, the number and frequency of contacts (Grenade & Boldy, 2008). This poses questions about whether friends and family from the community come to visit the resident and if so, how often? The living arrangements at the institution can also contribute to social isolation in residential care because before the residents moved into residential care, they were living at home in their communities, surrounded by the people they loved and have long known (Grenade & Boldy, 2008). Being in their own room, not knowing anyone around them and lacking a confidant can lead to social isolation (Grenade & Boldy, 2008).

2.6.3 Family and friends

Although research has shown that family and significant others continue to play an important role in a resident’s life after they have been admitted, the frequency and/or nature of contact between residents and family members may change significantly (Grenade & Boldy, 2008).

According to Grenade and Boldy (2008) a study by Port and colleagues found that the degree of contact with family and friends was reduced by half after admission compared to reported pre-admission contact. The frequency of contact and relationships is also negatively affected more especially if the resident had children or was married as studies have shown that the kind of support the spouse provided for the resident changes as does the level of intimacy (Grenade & Boldy, 2008).

Given the research, this may have negative implications on the resident because their contact with their loved ones reduces more than what they are used to and this may contribute to feelings of increased loneliness for the resident because according to Ballin and Balandin (2007) having a family reduces feelings of loneliness in residents. However, a study that was conducted in the US showed that social relationships of residents formed with other residents appeared to be more protective against loneliness than their existing relationships with their friends and family outside the residential care facility (Grenade & Boldy, 2008). This shows that although family is important, the relationships which residents can make in the residential care facility may be more significant in protecting them from loneliness

2.7 Emotional experiences

2.7.1 Loneliness

Loneliness is generally a more subjective experience that is usually negative and unwelcome (Grenade & Boldy, 2008). It is related to how a person perceives their social relationships or level of social engagement as being deficient in some way (Grenade & Boldy, 2008). The subjective aspect of loneliness speaks to the fact that a person with many social networks can still feel lonely and conversely, one with limited social networks may not experience loneliness at all (Grenade & Boldy, 2008). This explains why people can still feel lonely despite the fact that they are surrounded by many people. It is for this reason that the frequency of contact of contact with friends will not determine a person's feelings of loneliness (Ballin & Balandin, 2007).

Given this knowledge, it is understandable why loneliness is an experience that residents may go through during transitioning into a residential care facility and it may continue to go on beyond the transition phase. The residents have been removed from an environment where they felt accepted and they were comfortable in, a safe space. It is usually the absence of a confidant that contributes to feelings of loneliness in residents in a residential care facility (Grenade & Boldy, 2008). This further supports the cognitive support aspect by

Horsman et al. (2015), which was discussed earlier, which stated that being understood helps a person not feel alone in facing situations and processes. It is expected that a confidant is someone who aims to understand the person confiding in them, thus assisting the person not to feel alone.

2.7.2 Loss

(Many residents may experience some form of loss following moving into a residential care facility as a result of having to leave their home, family and friends (sometimes pets), local communities and previous lifestyles (Grenade & Boldy, 2008). The sense of loss comes from 'losing' everything that they knew, loved and felt comfortable with to going to an environment they know nothing about. Residential facilities also have rules and routines that the residents are not accustomed to (Grenade & Boldy, 2008). At home, life was a little different for the residents, there may have been very little structure as opposed to what there was at home, and now being in a residential care facility, the rules have changed. This may have a major negative impact on a person's sense of autonomy, control over their lives and individuality (Grenade & Boldy, 2008).

Being dependent on others for care and support may also have a negative impact of the residents in the sense that it may lead to reduced self-esteem, loss of identity and depression (Grenade & Boldy, 2008). This may be due to the fact that at home, they may have had a role to play in assisting with their care as opposed to the fact that it is offered and wholly catered for in a residential care facility. They may begin to feel that they are no longer able to do things and could possibly cause the residents to feel useless.

2.8 The role of staff

Being in a residential care facility puts one in a position of increased dependency (Grenade & Boldy, 2008). Being in this position implies that residents will have frequent contact with staff, with some residents having more contact than others, and these interactions may have the potential to reduce the risk of isolation and or loneliness (Grenade & Boldy, 2008). Murphy (as cited in Ballin & Balandin, 2007) found that 72% of cerebral palsied adults with little or no functional speech were with staff. This may be due to the fact that the residents find confidants within the staff that they interact with on a daily basis as they are the people that the residents see more often.

However, one relates to staffing based on factors such as staff retention, turnover and the increasing reliance on casually employed agency staff (Grenade & Boldy, 2008). This means that a resident could find a confidant in one of their care workers, only to discover a few months later that the staff member is no longer available because they were a casual worker. This may negatively affect the resident because they would have to start afresh in finding a confidant and perhaps this time they may be more reserved for the fear of being 'abandoned' once again.

In South Africa, we have 11 official languages and often, staff is made up of a multitude of different cultural representations. The diversity of language and or cultural backgrounds of the care staff may limit the extent to which meaningful relationships can develop (Grenade & Boldy, 2008). This can make communication between the care staff and the residents very difficult because they do not understand each other fully or because meanings have been lost in translation. Despite the possibility of staff becoming residents' confidants, a study conducted in Australia showed that most staff-resident interactions are mainly of a task-orientated nature (Grenade & Boldy, 2008). This means that despite the frequent contact, it is more likely that the contact the staff have with the residents is focused on providing the service that they have been hired to do.

2.9 Protective methods and/or interventions

The following are two protective methods which are currently being used in residential care facilities to help ensure that residents are not socially excluded or do not feel lonely. They are organised activities and the introduction of pets and animals.

2.9.1 Organised activities

According to Grenade and Boldy (2008), evidence suggests that participation in organised social activities can help reduce social isolation, as well as increase the self-esteem of residents and build a sense of empowerment. Residential care facilities usually offer organised activities which support social interactions between residents, 'family-friendly' policies and practices and strategies which will help residents maintain their links with the wider community such as outings and organising visits from outside groups (Grenade & Boldy, 2008). This gives the residents an opportunity to interact with other people outside of the people that they live with at the residential care facility. This could also help the residents not feel disconnected from the outside world.

2.9.2 Pets and animals

Some residential care facilities have implemented policies or strategies that allow residents to have contact with animals- such as owning a pet or introducing a 'communal' pet or providing animal assisted therapy (Grenade & Boldy, 2008). Kruger, Trachtenberg and Serpell (as cited in Jackson, 2012, p. 2) define animal assisted therapy as "a goal-directed intervention in which an animal that meets specific criteria is an integral part of the treatment process". The aim of animal assisted therapy is to improve the human physical, mental, emotional and social functioning (Jackson, 2012). Animal assisted therapy come in many forms, but the most popular is canine-assisted therapy which is used across a variety of populations (Jackson, 2012). Feline-assisted therapy however, is found typically in long term care facilities as the presence of an animal may give the facility a more comfortable and home-like feeling (Jackson, 2012). This is important because Brandburg (2007) days that residents may initially experience feelings of homelessness and a home-like feeling provided by the presence of a cat may assist in adjusting.

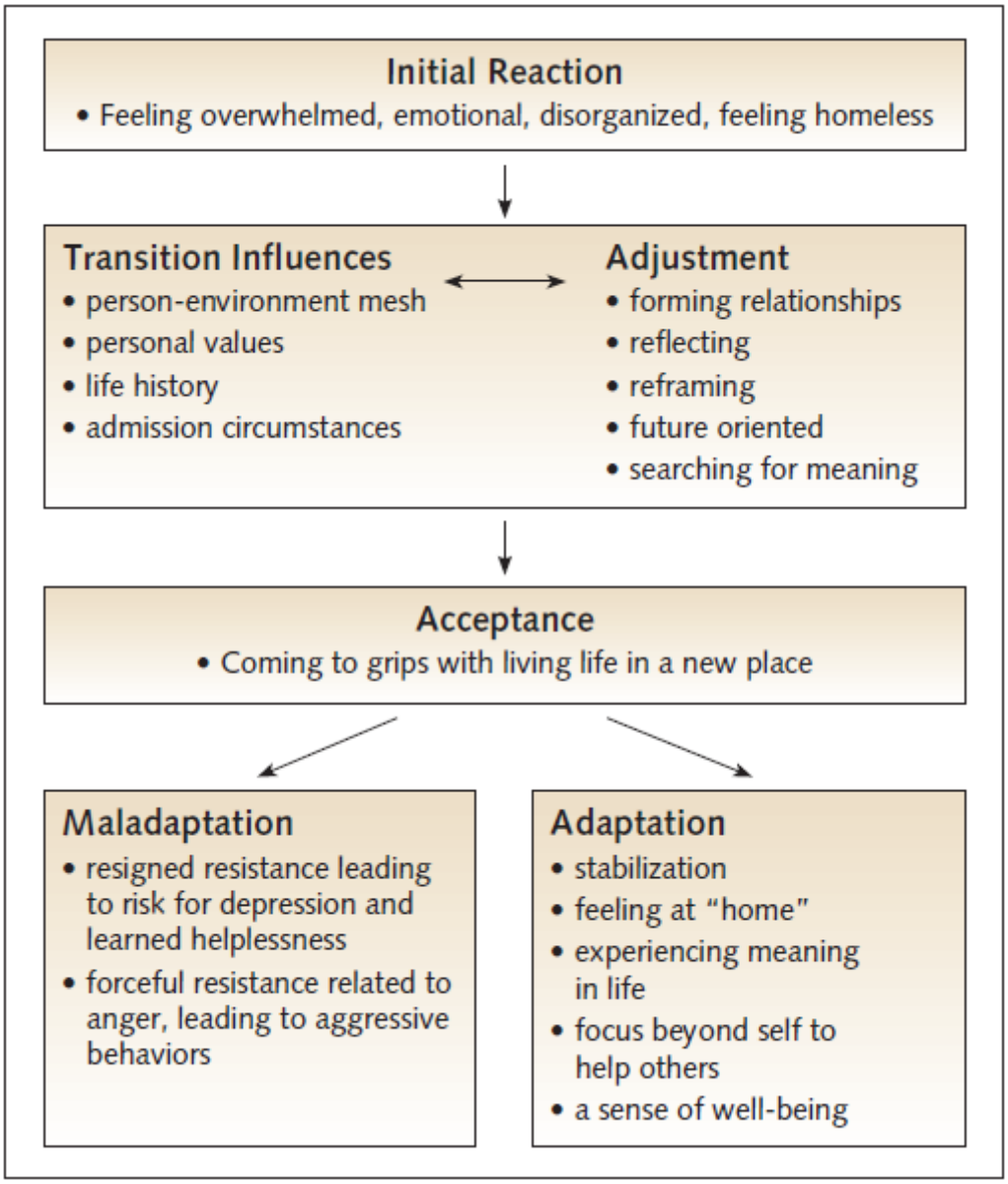
2.10 Theoretical framework

This study is guided by two theoretical frameworks, namely: the transition process framework and the biopsychosocial theory.

2.10.1 Transition process framework

Brandburg (2007) developed a transition process framework that would act as a guide to assist residential staff develop interventions that will support residents during transition. According to Brandburg (2007) the transition process framework consists of four components, namely: initial reaction, transitional influences, adjustment and acceptance which can be viewed as either adaptive or maladaptive. Figure 2.10.1 on the following page depicts the transition process framework.

Figure 2.10.1: Transition Process Framework



Extracted from (Brandburg, 2007, p. 54)

The initial phase of the transition framework is marked by the initial reaction to being in the residential care facility. Whether the transition was planned or not, most residents will exhibit an emotional reaction of some sort (Brandburg, 2007). The second and third stages of transition go together and work in a back and forth pattern whilst residents adjust and readjust to being in the residential care facility (Brandburg, 2007). A person's life history may influence how easily they make friends and whether the resident will have a future oriented attitude will depend on the admission circumstances (Brandburg, 2007).The acceptance stage comes at the end of the transitional process and it may be adaptive or maladaptive (Brandburg, 2007) When the acceptance is adaptive, the residents begin finding

new meaning in life at the residential care facility, however, when it is maladaptive it can lead to depression, withdrawal and helplessness (Brandburg, 2007).

This framework was considered appropriate because it had the potential to assist in understanding the transitional experiences that the residents had when they first arrived at the residential care facility. It also had the potential to help in understanding where the residents currently stand post the transitional process.

2.10.2 Biopsychosocial theory

To supplement Brandburg's transition framework and further understand the experiences of the residents, biopsychosocial theory will also be used as the study looked largely into the social and emotional experiences the residents had that could have played a role in the residents' transitioning. According to Rassool (2011) biopsychosocial theory takes into consideration factors such as genetic inheritance, psychological differences, family, community, peer, or social pressure.

There are three elements that must be taken into consideration in order to understand the person in perspective using biopsychosocial theory. The first element speaks to how one must have knowledge of a person, meaning that things such as individual characteristics, biological conditions, development, behaviour, patterns of adaptations and beliefs need be taken into cognisance (Compton, Galaway & Cournoyer, 2005). The second element speaks to the knowledge that one has acquired about a situation, which is made up of groups, organisations, communities, cultures, formal and informal social systems assets and resources (Compton, Galaway & Cournoyer, 2005). The last element speaks to possessing knowledge about interpersonal relationships (Compton, Galaway & Cournoyer, 2005).

Biopsychosocial theory aims to assist in understanding the nature of human beings as individuals and as members of families, groups, communities and societies (Compton, Galaway & Cournoyer, 2005). This framework was considered appropriate for this study because it had the potential to assist in understanding the participants' background and it may or may not have played a role in the participants' transition. It was also considered appropriate because it helped with understanding the experiences the participants' had with regards to transitioning.

2.11 Summary of chapter

This chapter discussed the challenges of caring for individuals with cerebral palsy, relocation and transitioning, as well as the various emotional and social experiences cerebral palsied adults experience in residential care. The chapter went on to further discuss the protective factors that are currently being employed to assist residents in residential care. The chapter concluded with the theoretical frameworks relevant for the study. Against this backdrop, the methodology underpinning this study is discussed in Chapter Three.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter gives a detailed discussion of the methodology used in this study. The research approach and design, sampling methods and data collection instruments used in the data collection process of this study will also be discussed in detail. This chapter will further go on to discuss and describe the manner in which the trustworthiness of this study was strengthened during the analysis of data. The ethical issues concerning this study as well as how they were addressed will also be discussed in this chapter.

3.2 Aim

The research aim was to explore residents' socioemotional experiences with regards to transitioning and adjusting to a residential care facility.

3.3 Objectives

- To understand the socio-emotional experiences of residents about transitioning and adjusting to a residential care facility.
- To explore the challenges that residents experience whilst in a residential care facility.
- To identify the participants' recommendations on how transitioning and adjusting to a residential care facility can be made easier for them
- To identify the participants' recommendations on what they can do to improve their socio-emotional experiences of adjusting and transitioning into a residential care facility.

3.4 Research Questions

- What are the socio-emotional experiences of residents about transitioning and adjusting to a residential care facility?
- What are participants' recommendations on how transitioning and adjusting to a residential care facility can be made easier for them?
- What can the participants' do to improve their socio-emotional experiences of adjusting and transitioning into a residential care facility?

3.5 Research Approach and Design

"Research designs are plans and procedures for research that span decisions from broad assumptions to detailed methods of data collection and analysis" (Creswell, 2009, p. 3). The research method used for this study was qualitative. Qualitative research "is a means for exploring and understanding the meaning individuals ascribe to a social human problem" (Creswell, 2009, p. 4). The research design that was employed for this study was exploratory research design which was used to gain insight into a phenomenon, situation or individual due to either a lack of information on a new area of interest or to get acquainted with a situation (Fouché & de Vos, 2011).

The exploratory may be the first of a series of studies and it attempts to answer the 'what' questions of a study (Fouché & de Vos, 2011). The reason for this choice of design in a qualitative approach is because this study is interested in asking 'what' questions. It is also because there is very little research on the phenomenon of interest, thus the choice of design. However, sadly qualitative research is not objectively verifiable, is labour intensive and relies heavily on the participants' responses (Choy, 2014).

On the contrary though, qualitative designs offer a broad and open-ended inquiry approach which allows participants to issues which are important to them (Choy, 2014). This is why approach was considered appropriate to explore the socio-emotional experiences of the participants about being in a residential care facility.

3.6 Population and Sampling

The study used non-probability purposive sampling which entails selecting a sample "on the basis of your [researcher] own knowledge of the population, its elements and the nature of your research aims" (Babbie, 1990, p. 97). Payls (2008) goes on to further break down purposive sampling to criterion sampling which was used in this study. Criterion sampling involves looking for cases or individuals who meet a certain criterion (Payls, 2008). As such, the participants were not selected by random chance as they were selected based on particular characteristics (MacNealy, 1999).

Ten participants were selected for the study based on the following criteria:

- Residents who have been residing in the residential care facility for a minimum of two years. This criterion was chosen because the focus of the study was the transitional experiences of cerebral palsied residents in a residential care facility over a long period of time.
- Residents who have intelligible speech as according to agency classifications. This criterion was chosen because the research tool and data collection method chosen for the study requires verbal communication. The criteria of intelligible speech, would assist in capturing data as effectively as possible.
- Residents who are cognitively higher functioning and have minimal memory problems as according to agency classifications. The reason for this criterion was to ensure that the participants that take part in the study will understand the questions that are being asked, as well as being able to answer them. As the study focused on the long term experiences of the residents, minimal memory problems would be important for the study.
- The participants could be male or female between the ages of 22 and 69. The reason for the huge age gap was because the facility catered for residents of various age groups with no obvious modal age. The pre-requisite was that they are adults with cerebral palsy.

3.7 Research Instrument

The research instrument used to collect data from participants in this study was a semi-structured interview schedule. A semi-structured interview schedule is comprised of a set of questions that guide the researcher (Harrell & Bradley, 2009). The order in which the questions are asked is to the researcher's discretion, however the questions are standardised and probes may be used to ensure that the researcher covers the correct material (Harrell & Bradley, 2009). The standardised nature of the semi-structured interview schedule ensure that every participant will get asked the same question, which may have a positive effect on the study's reliability (Monette, Sullivan & DeJong, 2011). The reason this research instrument was chosen is because it allows the researcher to gather detailed information in a some-what conversational manner and because interviews are used to gather information on past and present experiences (Harrell & Bradley, 2009) which was the focus of this study.

3.8 Pretesting of the research instrument

A pretest was conducted with two participants to see whether the interview questions were clear and appropriate for the envisioned sample population. Although conducting a pretest does not guarantee the success of a study, it is still important to conduct one as doing so may give the researcher an advance warning about where the research study could fail, where research protocols may not be followed, or if the research instrument and proposed methods may be complicated or inappropriate (van Teijlingen & Hundley, 2001). The two pretest participants were given the opportunity to express their opinions on the appropriateness and clarity of the interview questions. No questions were amended because according to the participants, the questions were found to be clear and appropriate. The duration of each pretest interview was approximately half an hour.

3.9 Data collection

Data was collected through individual, one on one interviews with the duration of each interview ranging from 45 minutes to an hour, which was significantly longer than the time it took to conduct the pretest interviews. This method gave the researcher the opportunity to ask the participants a series of open-ended questions. This method of data collection was considered appropriate because it allowed the interviewer a degree of flexibility which other methods did not. According to Monette et al. (2011) semi-structured interviews allow for probing, rephrasing of questions as well as asking them in any order fitting the particular interview.

The study had the risk potential of inducing emotional distress. The researcher used the following strategies identified by Draucker, Martsolf and Poole (2009) to minimise distress:

- Consistent monitoring of participants' emotional reactions
- Providing frequent breaks during stressful data collection procedures where it was necessary
- Providing the participants with information on available psychological or social services.

All interviews were arranged by prior appointment and were conducted at a time and venue that was convenient for the respondents. Although permission was sought to audio record the interviews, due to the participants' disability and various agency structures, the interviews were not recorded. The researcher instead, took verbatim handwritten notes to the best of their ability. Although this method was not preferable and the study's accuracy and

credibility could have benefitted more from audio recording the interviews, often all that researchers need to record are the key points that a respondent makes (Monette et al., 2011).

3.10 Data analysis

The qualitative data gathered from the interviews was analysed using thematic analysis. Braun and Clarke (2006) define thematic analysis as a method of identifying, analysing and reporting patterns or themes within data. Thematic analysis requires that the researcher familiarise themselves with the data (Braun & Clarke, 2006). This is achieved through first transcribing the data, then reading and re-reading it, noting down initial ideas (Braun & Clarke, 2006). By doing this, one will begin generating a code that will eventually bring the themes that are contained within the data to the fore.

The raw data was analysed according to the six-phase guide to thematic analysis as outlined in Braun and Clarke (2006).

- **Phase 1: familiarising yourself with the data** – the researcher familiarised themselves with the data by reading and re-reading the transcriptions.
- **Phase 2: generating initial codes** – once the initial data was read and re-read, the researcher worked systematically through the entire data set, giving complete and equal attention to each data item and identifying and noting interesting aspects in the data which may have formed repeated patterns/themes. The researcher then used coloured pens to indicate potential patterns in order to assist with coding the data.
- **Phase 3: searching for themes** – once all the data was coded, the different codes were sorted into potential themes. Some codes went on to form main themes and others were discarded completely or temporarily stored under a theme named miscellaneous.
- **Phase 4: reviewing themes** – once a set of candidate themes was devised, the researcher went back to refine them. This phase assisted the researcher in noticing that some candidate themes were not really themes and that others needed to be further subdivided into themes and sub-themes. This phase focused on reviewing and refining the themes.
- **Phase 5: defining and naming themes** – once the researcher was satisfied with the thematic map of the data, they began to ‘define and refine’ the data by identifying the essence of each theme as well as determining which aspect of the data each theme addressed.

- **Phase 6: producing the report** – the final phase involved the final analysis and the write-up of the research report.

3.11 Trustworthiness

Trustworthiness is related to establishing the truth value, applicability, consistency and neutrality of a study (Anney, 2014). There are four constructs of trustworthiness which are transferability, confirmability, dependability and credibility (Shenton, 2004).

Credibility speaks to how a researcher has done their research and how they tell others about the way they have done their research (Morrow, 2005). It speaks to the truth of the research findings (Anney, 2014). To enhance the credibility of the study, the researcher had prolonged engagement with the research site. Data collection requires that one immerse themselves in the participants' world (Anney, 2014). This assisted the researcher in gaining an insight into the context of the study which, in turn, minimised the distortion of the information gathered because of the researcher's presence in the field (Anney, 2014).

An attempt to provide a thick description of the phenomenon under study was also made, this allows readers to have a proper understanding of the phenomenon and may enable them to compare the instances of this phenomenon to those that they have seen emerge in their own situations (Shenton, 2004). This contributed positively to the *transferability* of the study. Although the study comprised of a small non-probability sample size, the generalisability of the study to similar contexts was reduced, however it does not completely exclude it.

An attempt to report the processes of the study in detail has been made, not only does this allow the study to be repeated should the need arise but this may allow the reader to assess if proper research practices were followed. This enhanced the *dependability* of the study. *Confirmability* speaks to ensuring that the findings are, as far as possible, the participants' ideas and experiences and not the researcher's (Shenton, 2004). To ensure all this, the researcher kept a self-reflective journal from the onset of the data collection process until the end, which contained an ongoing record of the researcher's experiences, reactions, assumptions or biases that the researcher noticed. This helped in maintaining subjectivity as it made the researcher aware of any biases they may have held.

3.12 Ethical considerations

Ethics are the responsibilities that the researcher holds towards the participants, sponsors and potential beneficiaries of a study (Monette et al., 2011). They are considered very important because they are meant to protect the participants of the study (Monette et al., 2011). Efforts were made to comply with the following ethical principles:

Review by Ethics Committee

Ethical clearance from the University of the Witwatersrand's Non-Medical Human Ethics Committee was applied for by the researcher and the Research Ethics Certificate which is set out in Appendix E was granted.

Confidentiality

Confidentiality means that the information or data gathered from those that choose to participate in the study will not be shared with the public in a way in which it can be linked to the participant (Monette et al., 2011). This was explained to the participants in the participant information sheet and was further explained and elaborated by the researcher face. The participants were informed that their names will not be used and they were made aware of a pseudonym that the researcher used in the transcriptions and the research report. The participants were informed that the data gathered would be kept in a safe and that the information gathered would only be seen by the supervisor.

Informed Consent

This involves telling the participants about all aspects of the research which may affect their decision to participate in the study (Monette et al., 2011). Due to the different cognitive abilities of the potential participants, information about all aspects of the research was given in simple English, avoiding research jargon that the participants may not understand. The participants were told about the study i.e. that they were taking part in research, the purpose as well as the procedure of the research was explained to the participants before they were requested to consent forms to participate in the study. A copy of the consent form for participation in the study is set out in Appendix B and a copy of the consent form for audio recording is set out in Appendix C.

Voluntary Participation

Voluntary participation requires that people are not coerced into taking part in the research study (Trochim, 2006). None of the participants were coerced to participate in the study. The

participants were informed that they were taking part in a study and that they are allowed to withdraw from the study at their own discretion and at any time they wished to do so without recourse. They were given a participant information sheet, set out in Appendix A, containing information about the study.

Doing no harm

According to Monette et al. (2011) a researcher should avoid exposing participants to physical or mental distress and if the potential for such distress exists in the research study, then the participants should be informed of this. Due to the nature of the research, there was a potential for emotional distress that could have come from participating in the study. Debriefing and counselling services were arranged with the organisation's resident social worker for the participants to use should they need to. This was communicated to the participants and they were informed of this potential so that they were able to choose if they were interested in participating in the research study or not and they were made aware of the availability of debriefing afterwards, should they need it.

3.13 Summary of chapter

This chapter outlined and discussed the research design and methodology employed in the study. Considering this, the results are presented and discussed in the following chapter.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF FINDINGS

4.1 Introduction

This chapter presents and discusses the research findings according to the research objectives. In order to analyse and present the demographic information, descriptive statistics were used. The participant's responses to the open-ended questions, which formed the qualitative data, were analysed using thematic analysis. The emerging themes from analysing the data are shown by the use of participants' verbatim responses.

4.2 Participant demographics

Table 4.2.1 gives a visual summary of the demographic profile of cerebral palsied adults in the residential care facility who participated in the study.

Table 4.2.1: Demographic Profile of Participants (N=10)

Demographic Factor	Sub Category	No of Participants
Age (years)	20 – 29	1
	30 - 39	2
	40 - 49	3
	50 - 59	1
	60 - 69	3
Gender	Male	4
	Female	6

Participant number	Number of years at the facility
1	6
2	13
3	40
4	6
5	3
6	6
7	43
8	7
9	26
10	9

Table 4.2.1 illustrates that 10 participants were interviewed. One participant fell within the 20-29 age category, two in the 30-39, 3 within the 40-49, one in the 50-59 and three participants fell within the 60-69 age category. Four of the participants were male whilst the remaining six were female. Each participant has been identified with the corresponding number of years that they have spent at the facility.

4.3 Overview of objectives and themes

The analysis of the data assisted in identifying many significant themes which are illustrated in table 4.3.1

Table 4.3.1: Objectives and Themes

Objectives	Themes
The socio-emotional experiences of residents about transitioning and adjusting to the facility.	Feeling overwhelmed by new environment and levels of disability Feelings of freedom, happiness and independence The role of staff in social support Friends and family Support Development of residential relationships and friendships
Post-admission challenges experienced in the residential care facility.	Age dynamics Different levels of cognitive and communication abilities Teasing, residential gossip and social exclusion
Recommendations on residential improvements to make residents' transitions easier.	General satisfaction with the facility Installation of more assistive devices More room for personal space
Recommendations for self to improve the socio-emotional experiences of adjusting and transitioning.	Coping Accepting circumstances and remaining positive

4.4 The socio-emotional experiences of residents about transitioning and adjusting to the facility

The first objective was to understand the socio-emotional experiences of residents about transitioning and adjusting to a residential care facility.

The participants' responses to the questions aimed at exploring this objective, the following themes emerged:

Theme one: Feeling overwhelmed by new environment and levels of disability

When asked about their initial feelings about moving into the facility, 5 of the participants expressed that they felt overwhelmed by being in a new and strange environment and by the levels of disability that they were seeing at the facility. The participants had mild cases of cerebral palsy and when they arrived at the facility, they were faced with residents that had varying levels of disability and they reported this as part of the reasons they felt overwhelmed. The following responses illustrate this theme:

"At first to be honest, it was all freaky because I didn't know anybody and I have never seen people the way that they are. Some of it was overwhelming" (Participant 2, aged 31).

"How do you explain freaked out? I got a bit scared. Some people here, I have never seen that kind of disability in my life, so I got a bit scared and uncomfortable" (Participant 5, aged 22).

This theme is strongly supported by Brandburg's (2007) 'initial reaction' phase of her transition framework. The initial reactions when moving into residential care are marked by emotional responses (Brandburg, 2007). Thus reports of residents feeling overwhelmed, disorganised and emotional have been identified as initial responses to the facility (Brandburg, 2007). According to Grenade and Boldy (2008) these feelings could be brought on by the impact of moving from a familiar territory to an unfamiliar one. This is illustrated by how the participants' responses clearly state that they have never had experiences like they were having at the facility before.

Theme two: Feelings of freedom, happiness and independence

Not all residents felt negatively about being in the facility. The 5 participants of the sample group expressed happiness about being in the residential facility. The participants further went on to say that moving into the facility has given them independence and the freedom

of movement that they did not have at home. The satisfaction came from doing things the way that they wanted to, however and whenever they wanted to. The following responses encapsulate this theme:

"... coming here makes me happy because there is more ground for me to cover and I was never able to do that at home you know what I mean? I don't have to be picked up and I like that" (Participant 6, aged 43).

"... I can be independent and show them that even though I am cerebral palsied, I can interact with the outside world" (Participant 2, aged 31).

"I'm now knitting and I'm my own boss and work at my own pace and time." (Participant 9, aged 63).

Disability has been defined as "…the expression of limitations in individual functioning within a social context that represent a substantial disadvantage to the individual" (Buntinx & Schalock, 2010, p. 284). The social context that the participants came from was disabling them so much that they could not be independent. The facility made many significant changes to the context to improve the residents' independence and this has worked positively as the participants felt more independent in the facility than they did at home or in the community.

Theme three: The role of care staff in transitioning and adjusting

When participants were asked about how they felt about the care staff and what they thought the care staff could have done differently for them to make their move into the facility more comfortable, nine participants said: nothing. The participants expressed general satisfaction with the way the care staff was treating them and most expressed gratitude. This theme is highlighted in the following responses:

"They listen if you got a problem, if you sad they're always there. They never push you away and say they're busy. Of course they are busy, but they make time" (Participant 1, aged 43).

"When I was getting weak, they allowed me to move to another cottage where I could get more help. They were treating me nicely" (Participant 4, aged 40).

Contrary to all the positive responses about the staff, one participant felt that the staff contributed to the gossip that was going on at the facility. As opposed to minimising the

gossip, she felt that they were involved and escalated the matter and as a result, she lost her trust for the staff. This is encapsulated in the following response:

"I just don't trust the care workers because they contribute to the gossip around here" (Participant 5, aged 22).

According to Ballin and Balandin (2007) adults with cerebral palsy live and interact mostly with staff who are paid to support them. It could be for this reason that some residents develop fulfilling relationships with staff (Perkins et al., 2013). This is why most facilities have introduced and implemented policies that ensure that relationships between staff are professional and support oriented (Ballin & Balandin, 2007). Research has shown that positive, supportive social relationships between staff and residents can be more effective in reducing loneliness and social isolation more than relationships with friends and family in the community (Ballin & Balandin, 2007). However, like those living outside the facility, staff have competing demands (Perkins et al., 2013). This can explain why although supportive relationships with staff reduce social isolation, they don't eliminate it due to the fact that the staff are not always readily available.

Theme four: Friends and family support in relation to transitioning and adjusting

In their responses, four participants reported changes in their relationship with their friends and family. Friends and family did not contact or visit them as often as they did pre-admission. Relations are strained and they no longer know what is happening at home. For some, their relationships improved and they spoke more often with their family post-admission as opposed to pre-admission. Five participants reported no changes in their relationships with friends and family. They kept constant contact and would see one another often. One participant reported no changes with family, yet changes with their friends in the community. The responses were a combination of both positive and negative aspect for those whose relationships changed and those whose relationships did not.

"I always had issues, I wasn't a good person but I try my best to be a better person now and I am a good person… and now I am an inspiration for my friends and family" (Participant 1, aged 43).

"They say to me: 'John what will happen to you when we go?' and my sister called this place and I come here end of 2009 to take part in the holiday sports. And then I come here in 2010 when the world cup come here, is when I first came" (Participant 4, aged 40).

"It's always been kind of messed up [relationship with family] so I wouldn't say that it's changed. They've always been caught up in their own lives and I would be the last to know. It's still my brother who comes and picks me up occasionally … I would say more my friends because they wrote me off. We drifted apart because we didn't get the opportunity to see each other often" (Participant 5, aged 22).

Family ties remain very important for residents in care facilities, however not all residents have family support (Perkins et al., 2013). Even when the support the residents are receiving from family is significant, the frequency and nature of contact between family and the resident may get cut by up to 50%, with family members typically available on a weekly basis at most (Perkins et al., 2015; Grenade & Boldy, 2008). According to Grenade and Boldy (2007) the levels of intimacy change and they just don't visit as often as they used to. This explains why some residents who used to see their family and go home often are usually reduced to seeing one or a few regular members of their family and going home every now and then.

Theme five: Development of residential relationships and friendships in relation to adjusting

One of the themes that emerged was the development of residential relationships and friendships. The facility allows the residents to have romantic relationships amongst themselves and some participants expressed their happiness about this whilst one participant was heartbroken by the departure of his girlfriend. Others were able to make friends with whom they can form social networks. This theme is captured in the following responses:

"I have about three people as friends here" (Participant 2, aged 31).

"… sometimes I do sit with my girlfriends and that makes me happy. Even when I see her it makes me happy" (Participant 8, aged 36).

"… when my girlfriend left here my heart was very sore." (Participant 3, aged 63).

According to Grenade and Boldy (2008) relationships among residents appeared to be more protective against loneliness than any existing relationships with friends and family outside the facility. This may explain why one participant felt very happy when they saw their girlfriend and the other felt heartbroken when their girlfriend left the facility. The relationships appear to be significant enough for the presence and/or absence of the other party to cause emotional reactions.

4.5 Post-admission challenges experienced in the residential care facility

The second objective was to explore the challenges that the residents experienced whilst in a residential care facility.

Nine participants reported having faced challenges. Most of the challenges highlighted were very general and from analysing the participant's responses to the questions aimed at addressing this objective, these were the themes that emerged:

Theme one: Age dynamics

Age appeared to play a significant role in how the participants felt about how they could relate to others as well as their general feeling about being at the facility. The participants felt that the different age groups made it difficult for them to find people that they could relate to and interact with. The following responses illustrate this theme:

"It's just I wish there were more people who were grown up like me, who can talk a bit of sense, you know what I mean" (Participant 1, aged 43).

"I hate it. I feel I am too young for this place. The workshop bores me, I feel I am capable of so much more than screws and plastics. You know, people my age don't stay in on Saturday nights and I feel that I am missing out on so much. You don't get to meet people who are your age and brain set" (Participant 5, aged 22).

According to Perkins et al. (2013) residents often form bonds along lines of commonality based on race, class, gender, health, functional ability, culture, religion and even age. This explains why one participant wished that there were residents who were in their age bracket so that they can talk about things that they have in common. It further explains why the other participant feels that they are too young for the facility and that there is no one they can relate to let alone have conversations with. This shows that age plays a very important role in how people relate to one another, especially in residential settings.

Theme two: Different levels of cognitive and communicative abilities

participants expressed different levels of cognitive and communicative levels as a challenge. Due to the difficulty involved in communicating with residents who have communication impairments and are cognitively challenged, the participants are challenged in attempting to build social relationships with them. The following responses encapsulate this theme:

"I think the biggest one was to find someone I could get along with, you know, to make friends, especially since there are many people who are not on the same level as I am on. Finding some I could actually relate to" (Participant 5, aged 22).

"And to this day I still distance myself because unfortunately they are at a lower communication level than me. Look I'm not trying to bad mouth them, it's just that if the communication was the same, all would be fine" (Participant 2, aged 31).

In the social context of residential care facilities, stigma associated with disability and decline, especially if it relates to cognitive impairments, is among the key relationship barriers (Perkins et al., 2013). Any differences, especially amongst residents with significant impairments, limited those residents' opportunities for social interaction (Perkins et al., 2013). This means that residents who have more difficulties than others tend to be excluded and for some participants having the vast majority of people you are expected to form social relationship with have significant impairments was challenging for them.

Other participants did not express any difficulty communicating with or relating to other residents based on their cognitive abilities. This was not important for them and was not considered a challenge, others were indifferent about the varying cognitive and communicative abilities.

Theme three: Teasing, residential gossip and social exclusion

Three participants expressed that there was a lot of gossiping going on at the facility and sometimes they were victims of this gossip. They pointed out that being victims of the gossip was the challenging part as lies were spread about them and people ended up having incorrect impressions about them. The following responses capture part of this theme:

"For a while I was fine but Jennifer started gossiping about me and spreading lies" (Participant 5, aged 22).*

"Sometimes people put me down but I got back up and sometimes people gossip behind your back. Whoo, they can gossip these people" (Participant 1, aged 43).

The participants in the sample group were victims of the gossip, they expressed never retaliating, however the gossiping affected them in a negative way, especially because one participant was so desperate for the gossiping to stop, she contemplated suicide.

"I almost committed suicide but I gave my heart to the Lord and got support from my family" (Participant 1, aged 43).

A further three participants stated that their challenge was experiencing teasing and being socially excluded. One participant felt that the others left him out and when they had general information to share with everyone else, the other residents did not share this information with them. This theme is apparent in the following responses:

"... people used to tease me but I decided to rise above from that" (Participant 10, aged 57)

"The other residents I was angry with them before because some residents won't share news of any meetings" (Participant 8, aged 36).

Social exclusion is a hugely contested term which not only refers to phenomena and processes that are related to poverty, deprivation and hardships, but categories of excluded people as well as places of exclusion (Peace, 2001). In this context, social exclusion is "the inability to participate in the normal relationships and activities available to the majority of people in a society" (Levitas et al., 2007, p. 9). Exclusion affects an individual's quality of life as well as the cohesion of society (Peace, 2001). Although the facility is not a society per se, it is a community in which the participants spend a lot of their time and should be involved in the decision making processes and be made aware of any information that affects them. By not receiving the news about meetings, he was denied the opportunity to take part in resident affairs/politics.

The teasing and social exclusion affected the residents negatively. According to one participant, it elicited feelings of anger in him towards the other residents. The other two participants reported being upset. In order to cope they either turned the other cheek because they felt that management did very little to address their problems or they prayed about things.

4.6 Recommendations on residential improvements to make residents' transitions easier

The third objective was to identify the participants' recommendations on how transitioning and adjusting to a residential care facility can be made easier for them.

Theme one: General satisfaction with the facility

Six participants expressed general satisfaction with how the facility was run and the way that the staff treated them. They did not expect any changes because they felt that the staff had done the best that they could have done to make their transition into the facility as easy as possible. The following response captures this theme:

"It's fine as it is. I haven't got anything to say because they are great in my life. I just wish that we can get more people like these staff members that are so good for us" (Participant 1, aged 43).

Contrary to the feelings of general satisfaction, the other four participants thought the facility could benefit from some improvements. One participant felt that the facility could install more assistive devices so that shower time could be easier for them. They found that bath time could be very challenging for them because he needs to get help getting in and out the bath. It appears that the participant wants more independence than what he was already getting and the facility enables that.

The following responses encapsulate the contrary thoughts:

"I'm asking… they help me here but they can make it more easier for me by getting one of those machines that they can pick you up and put you in the bathtub" (Participant 8, aged 36).

One participant also felt that the facility could benefit from changing the management structure and staff of the facility. This resident has been at the facility for 63 years and has seen different management teams come and go but, in his opinion, this management team is the worst he has seen. He feels they (management) treat residents like children and they restrain the residents' freedom too much. This is evident in his response:

"A lot of us old people, I tell you the facility got worse… they must change the top" (Participant 3, aged 63).

Theme two: More room for personal space

Three participants wished that there were more rooms at the facility so that they could have their own rooms and privacy. Most of the residents may be at the facility indefinitely and they would like it if they did not have to share a room for the remainder of their lives. The following response encapsulates this theme:

"I initially had to share and it would have been nice to have my own room" (Participant 9, aged 63).

4.7 Recommendations for self to improve the socio-emotional experiences of adjusting and transitioning

The fourth and final objective was to identify the participants' recommendations on what they can do to improve their socio-emotional experiences of adjusting and transitioning into a residential care facility.

Theme one: Coping

Three of the participants, who were Christian, expressed using religion to cope with the adjustment process and the emotional responses to transitioning. This for them, was an effective way to cope and it is still a method for coping with the stresses of residential life. One participant even expressed that he prayed for other residents to cope. The following responses encapsulate this theme:

"I almost committed suicide but I gave my heart to the Lord and I got support from my family. I made it through" (Participant 1, aged 43).

"I feel I can pray for people" (Participant 4, aged 40).

One participant expressed that she would remain sceptical not believe everything that she heard. Usually rumours made their rounds at the facility and more often than not they were not true. These rumours caused her panic and eventually got her into trouble. In order to not be an easy target for rumours and gossip, she felt that it was best to take everything she heard with a pinch of salt. This may be effective because according to Perkins et al. (2013) setting boundaries is important in ensuring that one is not the target of residential gossip. The following response highlights this coping method:

"Don't listen to everything I hear… or don't believe everything I hear" (Participant 5, aged 22).

The other four participants cope with being in the residential facility by either engaging in social activities with others, working on improving themselves and becoming better people or doing their favourite things/hobbies. They do things that they find joy in. This is evident in the following response:

"…sometimes I do sit with my girlfriend and that makes me happy." (Participant 8, aged 36).

Theme two: Accepting circumstances and remaining positive

Although some participants did not like being at the facility, nine participants expressed acceptance of their current circumstances and one participant even expressed attempting to remain positive by looking at life at the facility from a different perspective and being grateful for what they have. This theme is evident in the following responses:

"It couldn't have been better. This was the best option for me" (Participant 9, aged 63).

"Well at the moment there is nothing I want to change. I have accepted. So there is nothing I can change or want to change" (Participant 10, aged 57).

"Maybe also not be so negative about things and see things positively, even though it's the hardest thing to do in this place, but it's worth a shot" (Participant 5, aged 22).

According to Brandburg (2007) acceptance is the outcome of the transitional process and it may be adaptive or maladaptive. With adaptive acceptance, residents tend to find meaning in life at the facility, whilst maladaptive acceptance may lead to depression, withdrawal and helplessness (Brandburg, 2007). Although not all the participants have reached adaptive acceptance, they all seem to be working towards it. This is especially noticeable through their willingness to be positive throughout their residential experience.

4.8 Chapter Summary

The socio-emotional experiences of being in a residential care facility saw residents being overwhelmed by being in a new environment as well as by the level of disability they were faced with. Feelings of freedom and independence and the roles of staff, family and friends in support were also significant themes. Participants were challenged by age dynamics, varying levels of communication and cognitive abilities as well as residential gossip and teasing. A majority of the participants expressed general satisfaction with the facility, however, a few suggested the need for more space and the installation of more assistive devices. Participants suggested remaining sceptical, religion and prayer and acceptance of circumstances as effective ways of coping with the process of transitioning and adjustment.

CHAPTER FIVE

MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter gives a summary and conclusion of the main findings which emerged from the study's objectives. It will also give recommendations based on the main findings.

5.2 Summary of key findings

5.2.1 The socio-emotional experiences of residents about transitioning and adjusting to the facility

Brandburg (2007) states that most residents will have some form of emotional reaction to relocation and Grenade and Boldy (2008) say that relocating can disrupt a person's existing social networks. Participants who were interviewed about their socio-emotional experiences of transitioning and adjusting spoke about feeling overwhelmed by the levels of disability they encountered, experiencing feelings of freedom, happiness and independence and the role of care staff in helping the transition and adjust to the facility. They further went on to discuss the changes or lack thereof of their relationships with the families during the transitioning and adjusting process, as well as the importance of developing residential relationships and their role in assisting with adjusting.

These findings drew heavily on the biopsychosocial theory in that they spoke of family and friends, as well as the community and the changes that the residents experienced in these factors. The findings give a better understanding of the socio-emotional experiences of adults, post-admission. Some residents had positive experiences, some had negative experiences and other had mixed experiences.

5.2.2 Post-admission challenges experienced in the residential care facility

The literature review highlights that social isolation and loneliness are risks of transitioning and adjusting to residential care facilities. The findings of this study do not highlight loneliness as a challenge, however they do speak of social exclusion, gossiping and teasing as presenting challenges. Teasing and social exclusion have the potential to result in an individual feeling socially isolated as social isolation may be regarded as a subjective state where one has a generally low level of community involvement (Grenade & Boldy, 2008).

Being in a facility with a variety of ages posed as a challenge for some residents with regards to their ability to relate to one another. The differences in cognitive and communicative abilities among different residents posed as a challenge for some residents as this limited the amount of people they could create social relationships with. These findings assist in understanding the potential challenges linked to interpersonal relationships, which are a part of biopsychosocial theory.

5.2.3 Recommendations on residential improvements to make residents' transitions easier

When asked about what the facility can change to make transitions easier, most of the participants expressed general satisfaction with the services that the facility offered. They were grateful for the staff and the opportunity to be at the facility. One participant felt like the participant could benefit from adding more assistive devices to help improve his independence, whilst another felt that the management structures had to be changed so that he could have the possibility of enjoying his autonomy again.

Other participants felt that they could benefit from being in their own rooms without having to share. Although the literature review suggests that being alone in a room without anyone to talk to could contribute to feelings of loneliness, this study's participants were more concerned with having privacy. This is understandable because Brandburg (2007) recommends alone time for reflecting in the early phases of the transition process as well as throughout the transitional influences and adjustments phase so that residents can come to grips with living life in the residential care facility.

5.2.4 Recommendations for self to improve the socio-emotional experiences of adjusting and transitioning

The participants had various ways of coping, form using prayer to being sceptical of residential gossip and maintaining healthy social and romantic relationships or doing things that simply made them happy. This supports the notion that using organised activities could act as a protective method against the challenges of transitioning and adapting.

The participants agreed that working on positively accepting one's circumstances at the facility by looking to the future positively and beginning to take the facility as one's home goes a long way in positively assisting with the transitioning and adapting process. After all, according to Brandburg (2007) acceptance marks the end of the transition period. Working

on acceptance in a positive way has the possibility to lead to adaptive acceptance and possibly many joyous years at the facility.

5.3 Conclusions

Through data analysis, many significant findings which were in line with the objective were identified. The residents' social-emotional experiences with regards to the transitioning and adapting to the residential care facility were comprised of initial feelings of freedom and independence as well as being overwhelmed. The residents experienced a variety of challenges and all had different expectations of the facility. However, to cope they each did what made them happy and they all agreed that working towards positive acceptance is the best thing any new resident can do to improve their experience of transitioning and adapting to the facility. The findings highlighted that although some findings are in line with the current literature, others contradict the literature proving that context is very important.

5.4 Recommendations

Taking into consideration the findings of the study, the following recommendations have been developed.

5.4.1 Recommendations for social work practitioners

Cerebral palsied adults transitioning and adapting into residential care facilities experience a variety of socio-emotional experiences and challenges. It is recommended that social workers working in these settings endeavour to explore new residents' experiences and tailor interventions that will assist them in transitioning smoothly into the facility. The findings suggest that residents should find their own way around solving problems, it is thus recommended that social workers assist residents with problem solving, perhaps even equipping them with the skills to be able to do it themselves.

5.4.2 Recommendations for residential care facilities

Residential care facilities need to be aware of their position of authority and how the power imbalances between themselves and the residents affect the residents' transition and adapting process. It is recommended that they implement obvious and simple communication channels so that residents can give them feedback on what they think the residential care facilities can do to improve their experiences. It is recommended that the feedback be

acknowledged and a response delivered to the residents. This illustrates mutual respect between both parties.

5.4.3 Recommendations for future research

Given that some family relationships with residents change post-admission and relatives and friends don't visit often, a worthwhile area of research would be exploring the challenges friends and family face with regards to maintaining relationships with loved ones in care post-admission. Another area of research would be exploring how residents' various methods of coping assist in the adaptation process.

A limitation of this study was that it did not explore the residents' social activities at the facility. It wold be beneficial to conduct research on how these social activities impact and shape the residents' social experiences. It would also be beneficial to replicate this study in different residential care facilities for cerebral palsied adults in South Africa.

5.5 Concluding comment

The findings show that cerebral palsied adults encounter a variety of socio-emotional experiences and challenges throughout the transition and adaption process. Despite their difficulties, they are resilient enough to employ positive coping methods that will assist them through the process and they know they need to be working towards achieving adaptive acceptance.

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APPENDIX A

University of the Witwatersrand

School of Human and Community Development

Participant Information Sheet

Good day,

My name is Dimpho Tsiane and I am a final year student registered for the degree Bachelor of Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research on the socio-emotional experiences of adults with cerebral palsy in a residential care facility. This study hopes to give social workers a better understanding of the experiences of adults with cerebral palsy living in residential care facilities and help to improve the experiences of future residents.

I would like to invite you to take part in my study. Your participation is completely voluntary and your refusal to take part in the study will not be held against you in any way. Should you agree to take part in this interview, I will arrange to interview you at a time and place that is suitable for you. The interview will be approximately one hour. You may withdraw from the study at any time and you may also refuse to answer any questions that you feel uncomfortable answering.

With your permission, the interview will be tape-recorded. No one other than my supervisor will have access to the tapes. The tapes and interview schedules will be kept for two years following any publications or six years if the study does not get published. Please be assured that your name and personal details will be kept confidential and no information that can connect you to the study will be included in the final research report.

As the interview will include sensitive issues, there is a possibility that you may experience some feelings of emotional distress. Should you feel the need for supportive counselling following the interview, I have arranged for this service to be provided free of charge by the social worker at the organisation.

Please feel free to ask any questions about the study. I will answer them to the best of my ability. I may be contacted on **079 728 7269**, or my supervisor Ms. Laetitia Petersen on **011 717 4474**. Should you wish to get a summary of the results of the study, an abstract will be made available upon request.

Thank you for taking the time to consider taking part in the study.

Yours Sincerely

Dimpho Tsiane

APPENDIX B



University of the Witwatersrand

School of Human and Community Development

Consent Form for Participation in the Study

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any questions that make me feel uncomfortable or withdraw from the study at any time without any negative consequences. I understand that my responses will be kept confidential.

Name of Participant: _____

Date: _____

Signature: _____

APPENDIX C

University of the Witwatersrand

School of Human and Community Development

Consent Form for Audio-Taping of the Interview

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and that the tapes will be destroyed two years after any publication coming from the study or six years after the study has been completed if there are no publications.

Name of Participant: _____

Date: _____

Signature: _____

APPENDIX D

University of the Witwatersrand

School of Human and Community Development

Interview Schedule

PARTICIPANT DEMOGRAPHICS

Age

20-29 ☐ **30-39** ☐ **40-49** ☐ **50-59** ☐ **60-69** ☐

Gender

Male ☐ **Female** ☐

Number of years at the facility: _____

QUESTIONS

Interview date: _____

Participant Pseudonym: _____

1. When you first moved into the facility, how did you feel about being here?
2. Has moving into the facility changed your relationship with your friends in the community as well as your family?

   YES ☐ **NO** ☐

   2a) If yes, how has it changed?

   2b) If no, how have you managed to keep the relationships the same?
3. When you first arrived, how did you feel about the other residents and the staff members?
4. Currently, have those feelings changed and why?

5. What do you think the staff could have done to make your move into the facility more comfortable?
6. What are the challenges that you faced when you first moved in?

   6a) Are you still facing those challenges?

   YES ☐ **NO** ☐ **SOME** ☐

   6b) What are you doing and/or have done about them?
7. How do you feel about being in the facility now?
8. What do you think you could have done to make your experience here better for yourself?

APPENDIX E

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

DEPARTMENTAL HUMAN RESEARCH ETHICS COMMITTEE (SOCIAL WORK) CLEARANCE CERTIFICATE

PROTOCOL NUMBER: SW/2/16/7/12

ROJECT TITLE: Exploring the socio-emotional experiences of adults with cerebral palsy in a residential care facility in Johannesburg South Africa

RESEARCHER/S: Ms Dimpho Tsiane (712851)

SCHOOL/DEPARTMENT: SHCD Social Work

DATE CONSIDERED: 07 July 2016

DECISION OF THE COMMITTEE: Approved

EXPIRY DATE: 30 November 2017

DATE: 14/11/16 **CHAIRPERSON:** K Perkins

Cc: Supervisor: Dr Ajwang' Warria

DECLARATION OF RESEARCHER(S)

To be completed in **DUPLICATE** and **ONE COPY** returned to the Administrative Assistant, Room 8, Department of Social Work, Umthombo Building Basement.

I/We fully understand the conditions under which I am/we are authorised to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the committee. **For Masters and PhD an annual progress report is required.**

Dimpho
SIGNATURE

12/01/2017
DATE

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES