

Experiences of nurses who care for patients with severe/profound intellectual disabilities at a level 3 Psychiatric hospital in the Western Cape.

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A mini-thesis submitted in partial fulfilment of the requirements for the Degree of Magister Curationis in the School of Nursing, Faculty of Community and Health Sciences, University of the Western Cape.

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Declaration

I declare that *Experiences of nurses who care for patients with severe /profound intellectual disabilities at a level 3 Psychiatric hospital in the Western Cape* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged.

Sibongile Princess Mgandela

Date: 10/05/2013

Signed:.....



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Key words

- ✦ Severe Intellectual disability,
- ✦ Caring,
- ✦ Lived experiences,
- ✦ Phenomenological research,
- ✦ Developing country,
- ✦ Disability,
- ✦ Level 3 psychiatric hospital,
- ✦ Cape Town.



Dedications

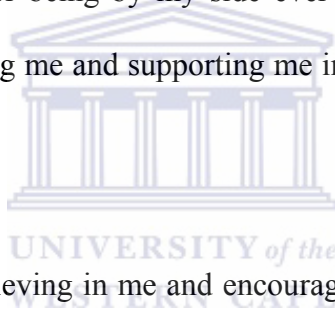
- ✦ To my late father Justice Mgandela,
- ✦ My mom Ntombokuqala Mgandela,
- ✦ My siblings and their children, and
- ✦ My boys Songezo and Mivuyo.



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Lord Almighty, You open doors that no one can close. You listen to our prayers and you say “when time is right go”. You knew when it was the right time to accomplish this qualification. I thank you Lord for being allocated to Doctor Jeggels as my supervisor. Without her I would not have managed to submit this mini-thesis. Being supervised by her is God’s blessing indeed. She is really dedicated to her work. I thank you Doctor Jeggels for your immeasurable support and guidance throughout this journey. The journey was long and patchy, but you persevered with me.

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I am grateful to my family for believing in me and encouraging me all the way. This is for you *ndlukatatomkulu uMkrazuli*.

My gratitude also goes to Lentegour hospital ethics committee for allowing me to conduct the interviews. To my participants, I say thank you very much for participating in this study; your input is highly appreciated.

To the Dlova family, thank you for looking after my little boy when I was not at home.

My mother Ntombokuqala Mgandela, thank you for your support and prayers, you are the best mom any child would wish for.

Abstract

The study explores the experiences of nurses who care for severe/profound intellectual disabled patients at Level 3 Psychiatric Hospital in Cape Town.

People with severe intellectual disabilities require constant care and supervision which can only be provided in specialised units. In the Western Cape, one such facility is a special section for the intellectually disabled at a level three hospital. Intellectual disability is a serious lifelong disability that places a heavy burden on affected individuals. Caring for these patients may affect the individuals who work within the intellectual disability services. This study explores the experiences of nurses who care for these patients.

A Phenomenological research design was chosen as the researcher identified it as the most appropriate method to describe the lived experiences of the nurses. Purposive sampling was used to select 10 participants. However, data saturation was reached after interviewing eight participants. Data was collected through in-depth unstructured interviews. The audio-taped responses were transcribed verbatim and phenomenological data analysis done.

Ethical clearance was obtained from the Higher Degrees Committee of the University of the Western Cape. Permission to do the research at the level three hospitals was sought from the Associated Psychiatric Hospital Committee. Consent to participate in the study was obtained from the participants, and ethical principles were adhered to. Participants were informed of the right to withdraw at any stage of the study and intervention offered when required. Trustworthiness of the research process was ensured.

Findings: from this study the nurses who care for severe/profound intellectual disabled patients reported that they were not adequately prepared to care for these patients. It has also been reported that caring for the severely/profound disabled comes with some consequences, where emotional (negative and positive), physical and professional consequences were mentioned. The shortage of resources was found to be one of the challenges the nurses experienced. The nurses felt unappreciated for the work they did and less supported by their employer.



Table of contents

CONTENT	PAGE
Declaration.....	ii
Keywords.....	iii
Dedications.....	iv
Acknowledgements.....	v
Abstract.....	vi
Chapter1.....	1
1. Orientation to the study.....	1
1.1 Introduction.....	1
1.2 Back ground of the study/Rationale.....	3
1.3 Problem Statement.....	4
1.4 Significance of the study.....	5
1.5 Limitations.....	5
1.6 Research question.....	6
1.7 Research Aims and Objectives.....	6
1.7.1 Aim.....	6
1.7.2 Objectives.....	6



1.8 Concept definitions.....	7
1.9 Research design and process.....	7
1.10 Chapter outline of the study.....	8
1.11 Summary.....	10
Chapter 2.....	11
2. Literature review.....	11
2.1 Introduction.....	11
2.2 Intellectual disability.....	11
2.3 The causes of intellectual disabilities.....	12
2.4 Prevalence of intellectual disability.....	13
2.5 Clinical features of severe/profound disabled.....	14
2.5.1 Epilepsy.....	14
2.5.2 Sleep difficulties.....	15
2.5.3 Dysphasia.....	15
2.5.4 Osteomalacia or immobility- related osteoporosis.....	15
2.5.5 Self- Injurious Behaviors.....	15
2.6 The care giving concept.....	16
2.7 Preparation for caring.....	17



2.8 Consequences of caring.....	18
2.9 Shortage of nurses.....	18
2.10 Need for staff support.....	19
2.11 Second cycle of Literature review.....	20
2.11.1 Burden of care.....	20
2.11.2 Burnout and Coping.....	20
2.12 Conclusion.....	21
Chapter 3.....	21
3. Research Methodology.....	21
3.1 Introduction.....	21
3.2 Research design.....	21
3.3 Origins of phenomenology	22
3.4 Phenomenology study design.....	23
3.4.1 Essences.....	24
3.4.2 Intuiting.....	24
3.4.3 Reduction.....	25
3.4.4 Bracketing.....	25
3.5 Research setting.....	25



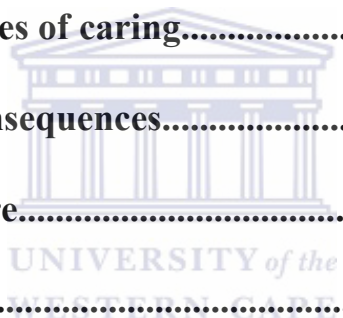
3.6 Population and sampling.....	26
3.7 Sampling process.....	26
3.7.1 Sampling procedure.....	27
3.8 Data Collection.....	28
3.8.1 Data collection instrument.....	29
3.9 Data analysis.....	30
3.10 Trustworthiness.....	31
3.10.1 Credibility.....	31
3.10.2 Transferability.....	31
3.10.3 Conformability.....	31
3.10.4 Dependability.....	32
3.10.5 Reflexivity.....	32
3.11 Conclusion.....	32
Chapter 4.....	34
Research Findings.....	34
4.1 Introduction.....	34
4.2 Demographic data.....	36
4.3 Description and summary of main themes.....	37



4.3.1 Preparedness to care.....	38
4.3.1.1 Prepared to care.....	38
4.3.1.2 Unprepared to care.....	40
4.3.2 Caring experience.....	41
4.3.2.1 Describing patients.....	41
4.3.2.2 Providing care.....	43
4.3.2.2.1 Physical care.....	43
4.3.2.2.2 Specialized care.....	44
4.3.3 Consequences of caring.....	45
4.3.3.1 Physical consequences.....	45
4.3.3.2 Emotional consequences.....	46
4.3.4 Coping with caring.....	48
4.3.4.1 Burnout.....	48
4.3.4.2 Team work.....	49
4.3.5 Support.....	50
4.3.5.1 Family support.....	50
4.3.5.2 Professional support.....	51
4.3.5.3 Peer support.....	51
4.4 Conclusion.....	52



Chapter 5.....	53
Discussion, recommendations and conclusion.....	53
5.1 Introduction.....	53
5.2 Discussion of demographic data.....	53
5.3 Discussion of research findings.....	53
5.3.1 Preparedness to care.....	53
5.3.2 Caring experiences.....	55
5.3.3 The consequences of caring.....	56
5.3.4 Professional consequences.....	58
5.3.5 Coping with care.....	59
5.3.6 Support.....	61
5.4 Recommendations.....	62
5.5 Conclusion.....	63
References.....	64
Appendices.....	77

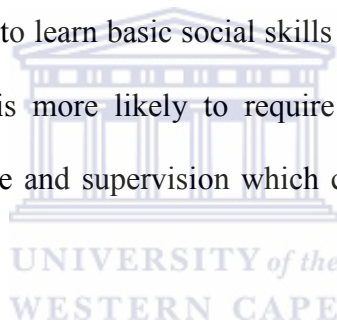


Chapter 1

1. Orientation to the study

1.1 Introduction

People with intellectual disability (ID) have significant lower than average intellectual ability and deficits in social and adaptive functioning namely: limitations in such areas as communication, social interaction, activities of daily living and/or movement skills (Law reform commission, 2011). They often access a range of health and social care services and for some of them, these services are an integral part of daily life (Mcpherson, 2010). A person with severe or profound disability may be unable to learn basic social skills such as coherent speech, unassisted walking and personal care, and is more likely to require supported accommodation. These individuals may need constant care and supervision which can only be provided in specialised units.



In the Western Cape Province, one such facility is a special section for the intellectually disabled (ID) at a level three hospital. People with severe or profound intellectual disability will need more intensive support and supervision during their entire life (Daily, Andinger & Homes, 2000). Due to the level of specialized and labour intensive care, the time the nurse needs to spend with one patient may not be enough as it takes much time and energy to care for one patient.

People with severe or profound and multiple disabilities present significant challenges to those who care for them, and those who commission and manage the services they receive. Hasting

(2002) revealed that from the staff survey that was conducted, around one third of staff working in adult services experience stress. Staff under relatively high levels of stress has been found to engage differently with clients; interact less frequently with clients and engage in fewer positive interactions with clients (Hasting, *et al.* 1999).

In the context of ID services, staff is often short of resources which may result in burnout, which is characterised by a syndrome experienced by those working in human services and is hypothesised to occur as work demands on staff exceed the resources available to deal with the workload (Hobfoll & Freedy, 1993). Burnout can cost the national health services millions of Rands each year (Hartley& Kennard, 2009).

The aim of the study is to give a voice to the nurses who care for severe/ profound intellectually disabled patients. In this study, the experiences of assistant nurses, enrolled nurses and registered nurses that provide direct care to ID patients will be described. The study will be conducted at a level three Psychiatric hospital in Cape Town, Western Cape Province. This hospital operates in the Cape Town Metropolitan region. The hospital forms part of the Associated Psychiatric Hospital in the Western Cape. It is divided into two sections, namely, Psychiatric section and Intellectual disability (IDS) section. IDS section has a twenty-four hour in-patient service area with a bed capacity of 330. The section has 15 units and 6 of the units are reserved for the severe and profound intellectually disabled. The staff complement at the IDS section is 194 (including nurse managers). The staff allocation to the units comprises five nurses during the day shift and three nurses during the night shift.

1.2 Back ground of study/ Rationale

According to the United Nations (2002), more than half a billion people worldwide are disabled as a result of mental, physical or sensory impairment. Approximately 80% of these disabled persons live in developing countries. The President Committee for People with Intellectual Disabilities (2007) estimates that seven to eight million Americans of all ages experience intellectual disability.

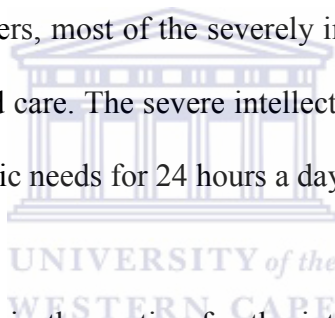
The data collected in the Census (2001) indicates that there were 2,255,982 people living with various disabilities in South Africa. This number constituted 5% of the total population at the time. Approximately 3% of South African population is intellectually disabled, however, only 4 out of 1000 have an IQ lower than 50 and 1 per 1000 has an IQ lower than 30 (Bauman, 2007).



In terms of the United Nations Convention on the rights of the persons with disabilities: persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which may hinder their full and effective participation in society on equal basis with others (City of Cape Town, 2010). Intellectual disability is a term used when people have certain limitations in mental functioning and social skills such as communicating or taking care of themselves (NICHY, 2009). The term 'intellectual disability' is synonymous with the term 'mental retardation', but is replacing it as the preferred terminology. According to the Mental Health Act 17 of 2002, severe or profound intellectual disability means a range of intellectual functioning extending from partial self-maintenance under close supervision in controlled

environments, through limited self-care and constant supervision to severely restricted sensory and motor functioning and requiring nursing care.

It is difficult for a person with no formal training to care of severely intellectual/ profound disabled patients. In the Western Cape Province, there are about 30 group homes and 34 specialised care centres (non-profit organisations) that accommodate these patients (WFID, 2011). The decentralisation of mental healthcare (South African Health Plan, 2010) has resulted in the relocation of 200 institutionalised patients to group homes or to reside with their families (University of Cape Town, 2011). However, as a result of the selection criteria used for the relocation of mental health care users, most of the severely intellectual disabled patients are still hospitalised and require specialised care. The severe intellectually disabled are totally dependent on nurses to provide in all their basic needs for 24 hours a day.



Being a novice professional nurse in the section for the intellectually disabled, I realised how challenging it is to care for the severe intellectually disabled. I have also experienced job stress related to poor working conditions and a heavy work load due to understaffing. This stimulated my interest to explore the experiences of other nurses in similar situations.

1.3 Problem Statement

Nurses have been involved in the care of people with intellectual disabilities for many years (Uys & Middleton, 2004). Despite the implementation of 2010 health plan to decentralise mental health care in South Africa, there are a number of patients that are cared for in long term wards (South African Health Plan, 2010). Hospitalised patients generally require more intensive care

than out-patients. Intellectual disability (ID) is a serious lifelong disability that places a heavy burden on affected individuals, their families, society and the healthcare system (McPherson, 2010). Patient health outcomes have become a driving force within the health-care delivery system with little emphasis placed on the potential consequences on the nurses who provide care within such a health-care system (Sabo, 2006). It is not known how the nurses who care for these clients experience the situation, that is, how they will describe their experiences or the impact that the caring for severe intellectual disabled has on them. This study may provide some insight into these nurses' experiences.

1.4 Significance of the study

The major purpose of conducting any study is to provide knowledge and insight as well as to provide relevance for practitioners (Neutens & Rubinson, 1997). The research allowed the practitioners to share their experiences and by doing so may provide an insight to the meaning that the experiences hold for them. It will give a voice to the carers who are often silent while providing a 24 hour service to the intellectually disabled. There is a possibility that the managers of the institution will become aware of the experiences and may provide the relevant support for the practitioners. Such support could enhance the quality of life of the nurses and that of the disabled patients.

1.5 Limitations of the study

Qualitative methodology uses smaller samples than quantitative methods, seeing that each individual as a unique being. A qualitative study is more interested in the depth of the data rather than breadth and requires the researcher to play an active role in the data collection (Wimmer

&Dominick 1997:84). Drawing definitive conclusions from the findings of the study can be difficult. Holloway & Wheeler (2002) state that research findings cannot be generalised to other similar conditions and situations. This means the qualitative data that was collected at a level 3 psychiatric hospital about the experiences of nurses who care for severe/ profound intellectual disabled patients, may be limited to the institution but could be compared to the data collected at a contextually similar research setting.

1.6 Research question

What are the experiences of nurses who care for patients with severe/profound intellectual disabilities in a level 3 psychiatric hospital?

1.7 Research Aims and Objectives



1.7.1 Aim

To explore the lived experiences of nurses who care for patients with severe/profound intellectual disabilities in a level 3 psychiatric hospital in Cape Town.

1.7.2 Objectives

1. To describe the lived experiences of nurses caring for patients with severe/profound intellectual disabilities at a level three psychiatric hospital in Cape Town.
2. To describe the meaning attached to those experiences.

1.8 Definitions of concepts

Severe intellectual disability: defined as having an IQ score of 20-40, their communication skills and self- help skills are very basic and many individuals in this category require safety supervision and supportive assistance (DSMIV TR-2000)

Profound intellectual disability is defined as having an IQ score under 25. They need a high level of structure and supervision (DSM TR-2000).

Nurse: a person formally trained to care for the sick or disabled and is registered or enrolled with South African nursing council (APA, 2002).

Care: service rendered by members of the health profession for the benefit of a patient (The free dictionary, 2013).



Experiences: In this study, experiences refer to the positive or negative events or circumstances experienced by nurses who care for severe/profound intellectual disabled patients.

A Level Three Psychiatric Hospital: it is a health establishment that renders specialist and sub-specialist psychiatric care (Cullinan, 2006).

1.9 Research design and process

A qualitative approach and a phenomenological design were used to reveal the experiences of nurses who care for severe profound intellectual disabled patients. Phenomenological research is

a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants (Creswell, 2009).

Data was collected through in-depth interviews, each participant was given an information sheet and it was read by the researcher to make sure that the participants understand every detail of the study. Consent forms were completed by the participants. Each interview schedule had demographic portion where the subjects were asked to complete their demographic information. The interviews were audio taped and transcribed verbatim thereafter. Collaizzi's seven steps were used to analyse the data (Diekelman *et al.* (1989). Ethical consideration was adhered to, that is, permission was obtained from UWC ethics committee, where the ethical clearance was forwarded to Level 3 psychiatric hospital's ethics committee. Permission was then granted by Ethics committee to the researcher to collect data from the nurses. No names were included in the participants' transcripts, but codes that are known by the researcher were used. Participants were given chance to ask questions about the study before the interview.

1.10 Chapter outline of the study

Chapter 1

This chapter defines the study and gives a contextual overview of the study to the reader. It briefly explains the background and the rationale of conducting the study at a level 3 Psychiatric hospital. The problem statement as well as the aim and objectives of the research are described.

Chapter 2

Relevant literature is reviewed in this chapter. A limited literature review is done prior to data collection and a second cycle of literature is reviewed during the data analysis phase.

Chapter 3

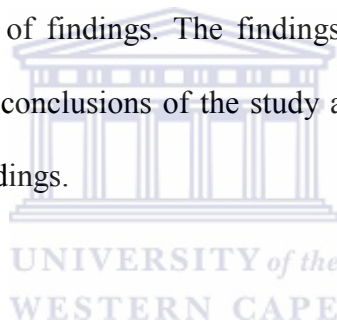
In this chapter, the research methodology is presented. The study design, study sample and characteristic of sample are described. Data collection, data analysis and procedures to scrutinise trustworthiness are elaborated on in this chapter.

Chapter 4

This chapter presents an analysis and in-depth discussion of the research findings. A phenomenological data analysis process is used to uncover the meaning of the participants' experiences.

Chapter 5

This chapter presents a summary of findings. The findings are discussed in relation to other studies and relevant theories. The conclusions of the study are presented and recommendations are made based on the research findings.



1.11 Summary

The chapter covered the introduction of the study, the background, problem statement and purpose of the study. The researcher outlined the aim and objectives and gave a brief overview of the research design and methodology. Caring for severe/profound Intellectual disabled patients may be challenging. These patients need one-hundred percent nursing care most of the time. The researcher had an intention of exploring the experiences of nurses who care for severe/profound intellectual disabled patients in a psychiatric hospital. The literature review is presented in the next chapter.

Chapter 2

2. Literature review

2.1 Introduction

This chapter provides an overview of the initial literature reviewed. A literature review gives the overview of the subject, issue or theory under consideration and is obtained from a number of different sources, for example: books, journals and internet databases. The aim of the literature review was to familiarise myself with the topic of study, in order to integrate this study with related previous research. The literature review will be presented as follows: prevalence of ID, clinical features of ID and nursing care of the ID,

2.2 Intellectual disability

The Diagnostic and Statistical Manual of mental disorders, fourth edition (DSMIV-TR) states that intellectual disability is a significantly sub-average intellectual functioning. The DSMIV-TR (2000) defines intellectual disability as follows:

- Significantly sub-average intellectual functioning - An intelligence quotient (IQ) of approximately 70 or below.
- Concurrent deficits or impairments in adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- Onset before 18 years of age.

The South African Mental Health Act no 17 of 2002 states that severe or profound intellectual disability represents a range of intellectual functioning including severely restricted sensory and

motor functioning. For the purpose of this study, focus is on the care of ID patients with severely restricted sensory and motor impairments who require 24 hour care.

The cause of a person's intellectual disability is not known in most cases. Some identifiable causes include: hereditary factors; chromosome abnormalities such as in Down Syndrome; brain damage before or at birth; brain damage after birth due to illness or accident; malnutrition or other deprivation in early childhood (NICHY, 2009).

The severity and consequences of an intellectual disability will vary from person to person and generalisations about the needs of people with an intellectual disability must be treated with caution. A person's intellectual disability can be classified as "mild", "moderate", "severe" or "profound", based upon certain IQ (intelligence quotient) ranges. A person with a "severe" or "profound" disability may be unable to learn basic social skills such as speech, walking and personal care and is likely to require supported accommodation (WHO, 2010).

2.3 The causes of intellectual disabilities

Intellectual disability has various causes including: genetic (Down syndrome), inherited (fragile x syndrome), maternal infections (rubella and HIV/AIDS), toxic substances (ethanol), and delivery complications (asphyxia). The two-way link between poverty and disability creates a vicious circle. Poor people are more at risk of acquiring a disability because of lack of access to good nutrition, health care, sanitation, as well as safe living and working conditions (NICHY, 2009).

Environmental causes include a wide variety of factors that can affect brain development before, during, or after birth. During pregnancy, a woman's general health and nutrition greatly affect the unborn baby. The use of prescription, non-prescription, or illegal drugs can affect the baby's brain development process. The consumption of alcohol can lead to a condition in the baby called foetal alcohol syndrome. Uys and Middleton (2004) and Baumann (2007) concur that foetal alcohol syndrome is the serious problem causing ID in South Africa.

2.4 Prevalence of Intellectual disability

The estimates of the prevalence of intellectual disability vary and depend on the definition being used by the population in question. The incidence of severe intellectual disability (IQ <50) is estimated at around 0.4%. The prevalence of intellectual disability is expected to rise by 1% per year during the next 10 years, as better prenatal, neonatal and general health care improves the survival rate and life expectancy of children and adults with more complex needs (WHO, 2010).

Intellectual disability affects about one in ten families in the United States (AAIDD, 2007). Estimates of the disorder's prevalence vary, depending on diagnostic criteria, study design, and methods of ascertainment. For example, when diagnosis is based on IQ alone, prevalence is estimated at approximately 3% but, when the AAIDD's tri-dimensional definition is used (AAIDD), the national prevalence rate is estimated at 1% (AACAP, 1999). Intellectual disability is more common in males than in females, with a male-to-female ratio of approximately 1.5 to 1 (APA, 2000). There are more than one million individuals with intellectual disabilities in South Africa, many of whom live in social isolation, with little support or opportunities to participate in society. The availability of recent, accurate statistical information on disability issues, particularly intellectual disability, is scarce (Umsobomvu Youth Fund, 2009: 9).

2.5 Clinical features of severe/profound Intellectual disabled

Severe Intellectual Disabled patients are classified under grade one category. The clients in this category are low severely or profoundly intellectually disabled, that is, clients with the Intellectual capacity of approximately a 6 month – 2 years old baby or child. These clients usually have a physical disability or are very frail. They are usually bound to chair, buggy or bed ridden. They are usually non-verbal or have a very limited vocabulary. This group may require total, full time physical care (feeding, toileting and dressing) and will continue to need this into adulthood (Donald, Lazarus & Lolwana, 2002). Intellectually disabled patients present with a number of clinical features. The following were selected for the purpose of this study.

2.5.1 Epilepsy

People with intellectual disability are often said to have epilepsy. They experience different forms of seizures ranging from absences, where individuals appear to ‘go blank’ to tonic-clonic seizures during which an individual may lose consciousness and their limbs and body may shake. Severe intellectual disabled patients are more likely to have epilepsy. Epileptic patients need to be monitored at all times to prevent injuries and aspirations in the case of an attack (Bisson, Craddock, Holman *et. al.*, 2013).

2.5.2 Sleep difficulties

The prevalence of sleep difficulties among people with profound intellectual and multiple disabilities is high. Parents reported 86% of their daughters and sons had “occasional” or

“frequent” sleep problems, of which 32% were prescribed drugs with a sedative effect (Hogg, 1999).

2.5.3 Dysphasia

Difficulties with feeding are prevalent among people with severe/ profound intellectual and multiple disabilities and arise from a variety of causes (Geskey, 2007).

2.5.4 Osteomalacia or immobility-related osteoporosis

In belated response to this situation, a strategy involving bone-strengthening medication, increased staff supervision, wheelchair safety and careful housekeeping to maintain a safe environment have all been introduced (Hogg, 1999).

2.5.5 Self-Injurious Behaviours

Some of these behaviours include: head-banging, poking inside the mouth or rectum, screaming, crying, shouting, irritability, isolation, hitting out, self-injury, scratching and attention seeking behaviour (Brown & Benson 1994 in Davies, 2008).

Geskey (2007) further states that adults with ID who are non-verbal may demonstrate self-injurious behaviour (SIB) as a manifestation of pain from fracture, constipation, or other medical illnesses. The prevalence of SIB in this population ranges from 2% to 50%.

2.6 The care giving concept

Watson (1978) believed that caring is an endorsement of professional nurses identity. It is the surgeon who saves a person's life and it is the nurse who helps the person live. According to Watson, the nurse's role is to establish a caring relationship with patients and treat patients' holistically, that is, body, mind and spirit. Watson believed that through the nurse's attitude and competence, a patient's world can become larger or smaller, brighter and drab, rich or dull, threatening or secure. This means that patients' quality care depends mainly on two aspects, namely, attitude and competence, meaning that a nurse with positive attitude and who is competent can provide first class patient care.

According to WHO (2004), placing children and adults with severe or profound intellectual disabilities in institutions has been a traditional practice. In South Africa, however, it is still practiced as poverty and the intensity of caring can be challenging to families. Nursing care for individuals with developmental disabilities is focused on assisting them to attain and maintain an optimal state of wellness across their natural life span (CME Resource, 2010).

2.7 Preparation for caring

Professional nurses in South Africa complete a four-year programme in order to be registered with the professional body, the South African Nursing Council (SANC). However, South African citizens have to complete a compulsory one year community service prior to registration as professional nurse (SANC, 2011). During the four year training and the community service period, there is no special training to care for patients with severe intellectual disabilities. At the University of Western Cape, students spend 120 hours in a placement to care for patients with

intellectual disabilities. The other categories are prepared for the period of two years to become an Enrolled nursing (EN); Enrolled nursing assistant undergoes one year in-house training to become an auxiliary nurse (Nursing Act 2005:34-35)

The report by Krahn & Drum on Mental retardation and developmental disabilities review (2007) done in United States, highlighted that the treatment of individuals with an intellectual disability is seldom addressed in the basic training of nurses and other healthcare providers and other health care providers. Fisher (2004) indicated that exposure to working with individuals with developmental disabilities early in a training programme will increase the likelihood that practitioners will accept this population group into their practice. A majority of nurses that responded to a survey on education and training in developmental disabilities done in USA reported that little or no training in this area as well as no further continuing education on the topic had been done (Walsh, Hammermann, Josephson & Krupka, 2000). Integration of curriculum improves the education of nurses and their healthcare providers and directly benefits the affected (Hahn, 2003).

2.8 Consequences of caring

It has been stated that the nurses who care for ID patients experience stress and that has serious implications for nurse's well-being, for people with ID and for services. In terms of the implications for staff, recent surveys have suggested that around one-third of staff working in adult services experience stress at levels indicative of the presence of a mental health problem. From the perspective of people with ID, staff under relatively high levels of stress has been

found to engage differently with clients (Hastings, Horne & Mitchell, 2004). Violence seems to be accepted as a natural part of the daily care for adult persons with intellectual disabilities. Most of the aggression occurs in helping situations when persons with intellectual disabilities do not co-operate.

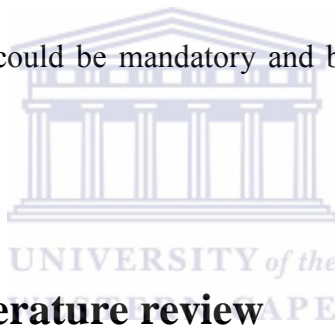
2.9 Shortage of nurses

A worldwide shortage of nurses has been acknowledged by the multidisciplinary Global Advisory Group of the World Health Organisation. Mental health services depend primarily on trained human resources rather than the sophisticated equipment or supplies (WHO, 2011). It is however noteworthy that mental health receives a low funding priority from governments. An analysis of the human resources for mental health settings in 58 Low and Middle Income Countries reveals substantial shortages in the mental health work force and that the situation will worsen by 2015 if the additional workers are not trained (WHO, 2011).

Buchan and Diken (2010) described the main causes of nursing shortage as the inadequate work force planning and allocation mechanisms, resource constraints, undersupply of new staff, poor recruitments, retention and return policies and ineffective use of available nursing resources. The shortage of personnel leads to work overload, which places a heavy load on the individuals who are on duty at the time. Hospitals with low nurse staffing levels tend to have higher rates of poor patient outcomes such as pneumonia, shock, cardiac arrest and urinary tract infections (Stanton, 2002).

2.10 Need for Staff support

In the field of caring for people with developmental disabilities, the professional habilitative process includes both the individual in need of support and the environment in which this person lives. It is of crucial importance to identify the staffs' difficulties in establishing mutually beneficial relationships with their clients (Dychawy- Rosner, Eklund & Isacson, 2001). It is also essential to detect in which phase of the process of practice the staff needs help. Providing support to staff in the institution is vital, both to improve current practice, education and training. Similar organisational measures are often an efficient tool for preventing burnout. Staff should therefore receive intensive training in implementing best practice in work with individuals with disabilities. This type of training could be mandatory and be presented as workshops or short courses (Dyschawy *et.al*, 2001).



2.11 Second cycle of Literature review

2.11.1 Burden of care

Caregiver burden is defined as alterations in caregivers' emotional and physical health; this can occur when the demands outweigh available resources (Given *et.al.*, 1992). Salama and Abou El-Soud (2012) in their study identified caregiver burden as a state resulting from providing the necessary care to an impaired older adult but that threatens either the physical or psychological wellbeing of the caregiver.

In Salama and Abou El-Soud (2012), 35 % of respondents reported a varied degree of burden where 63,9% reported to have experienced severe burden. Caring for a chronically ill or

physically disabled person has been referred to as physically or emotionally stressful, placing the caregiver at a heightened risk of burden. Kropt, Lee and Yoon, 2007; Salama and Abou El-Soud, 2012 concur that some factors such as resources and social support may trigger burden of care.

2.11.2 Burnout and coping

The burnout syndrome involve three distinct states in which employees feel emotionally ‘‘spent’’ (emotional exhaustion) where they display a detached attitude towards others and experience a low sense of efficacy at work (Maslach & Jackson, 1986 in Brotheridge & Grandey, 2002). Emotional exhaustion refers to feelings of being worn-out of emotional resources which results in loss of energy and fatigue (Pines & Aronson, 1988 in Sears, Urizar & Evans, 2000).

Coping responses play a major role in an individual’s physical and psychological well-being when he or she is confronted with stressful life events (Kammerer & Dixon, 2001). They suggest that coping responses play a major role in an individual’s physical and psychological wellbeing when he or she is confronted with stressful life events.

Coping is defined as the manner in which an individual responds to stress. Coping in itself is a defense mechanism that protects the emotional and psychological well-being of the person exposed to stress (Ospina, Kammerer, Dixon, Tallahassee & Valdosta, 2008). Frisch and Frisch states that when an individual is undergoing a crisis that person is in a state of disequilibrium and any intervention may serve to re-establish balance. Ericken et al, 1993 in Frisch & Frisch (2002) developed a model called Adaptive Potential Assessment (APAM). This model describes three

states of coping potential i.e. arousal, equilibrium and impoverishment, where arousal and impoverishment are stress states. In arousal the person has coping resources, whereas in impoverishment the resources are depleted. Equilibrium is when the person is able to cope and maintain balance in his functioning (Frisch & Frisch, 2002).

2.12 Conclusion

The chapter highlighted that caring for intellectually disabled patients can be challenging to the carers more especially if the carers have inadequate knowledge and understanding on the concept. It is evident from the literature that Intellectual disability is a worldwide problem and it is more prevalent in the developing countries. The review of literature was limited by the paucity of local studies on the study topic. Umsobomvu Youth Fund (2009) highlighted that in South Africa there is scarce or little statistical information on disability, particularly Intellectual disability. The literature also stresses that caring for severe intellectually disabled patient is complex and caregivers need an on-going support to cope with the challenges that may come with the caring.

The following chapter focuses on the research methodology and design that the researcher has used to conduct the study.

Chapter 3

3. Research Methodology

3.1 Introduction

The research methodology used for the study is described in this chapter. The study employed a qualitative approach and phenomenological research design. A qualitative paradigm was chosen as the most appropriate because the researcher was interested in understanding the phenomenon, which is the experience of caring for a severely/profound/Intellectual disabled patient. The lived experience being the focus of this research, a phenomenological design was chosen. A detailed description of the selection of participants, data collection and data analysis is given. The trustworthiness of the research study as well as the ethical consideration is discussed.



According to Welman, Kruger and Mitchell (2005: 2) research methodology considers and explains the logic behind research methods and techniques. Through the use of methods and techniques, the researcher may come to conclusions that are valid and reliable.

3.2 Research design

Research design refers to the overall structure or plan of the research (Bowling, 2002). This study adopted the qualitative paradigm and phenomenological design to explore the experiences of nurses caring for severe/profound Intellectual disabled patients. Qualitative research can, theoretically speaking, be described as an approach rather than a particular design (Welman *et*

al., 2005: 188). It is a systematic, subjective approach used to describe life experiences and gives them significance. It is the way to gain insights through discovering meanings (Burns & Grove, 2009). In addition, the approach aims to study people in their natural social setting and collect naturally occurring data. The researcher has the advantage of getting close to the research material, and can obtain a great deal of in-depth information (Brink, 2002).

According to Van Maanen (1979) cited in Welman *et al.* (2005), design is an umbrella phrase covering an array of interpretive techniques which seek to describe decode, translate and otherwise come to terms with the meaning of naturally occurring phenomena in the social world. In qualitative research, the researchers rely on their ability to describe and write down how events occurred in a manner that brings to mind the events as they happened and in a manner that conveys the context and the process involved in arriving at the conclusions (Dickie, 2003).

Richards (2003: 9) explains that in a qualitative inquiry, the researcher is actively involved in the whole process and becomes part of the research. Creswell (1998) states that qualitative researchers bracket their own preconceptions of the phenomenon being investigated to avoid influencing the experiences of the participants. Holloway (2005) further describes qualitative research as using methods of inquiry that produce text rather than numbers, where textual data include transcripts of interviews or conversations.

3.3 Origins of phenomenology

Edmund Husserl (1859-1938) was a philosopher and a mathematician is considered the founding father of phenomenology (Holloway, 2005). Phenomenology stemmed from the rejection of the

scientific method of inquiry. The aim of phenomenology is to gain an understanding of the phenomena through recognition of its meaning (Van der Zalm & Bergum, 2000).

Four constants through Husserl's philosophy have been identified (Spielberg, 1982 in Cohen). The first constant was the *ideal of vigorous science*. Husserl hoped that philosophy, after its re-organisation, would be able to help even objective scientists clarify and critique their un-clarified fundamental concepts and assumptions. The second constant was *his philosophic radicalism*. The starting point for Husserl was his idea that human experience contains a meaningful structure. The third constant was the *ethos of radical autonomy*: He believed that people were responsible for themselves and for their culture. The final constant in Husserl's philosophy was the *respect for wonders*. The central focus was the being that is aware of its own beings and of other beings. Since Husserl, there have been a number of philosophers who have modified his philosophical views in different ways, some disagreeing with his core ideas. Husserl's student, Heidegger adopted what he believed was a phenomenological attitude in his famous work, *Being and time*, and often used term 'essence' in his writings (Holloway, 2005).

3.4 Phenomenology study design

According to Schram (2006), as cited in Vos, Strydom, Fouche and Delpont (2008) phenomenology aims to describe what the world consists of, or more specifically, what concepts and structures of experience give form and meaning to it. This method of research seeks to uncover the meaning of humanly lived experience through the analysis of the participants' descriptions to disclose the internal meaning of the lived experience. With its focus on human

experience as it is expressed phenomenology is a method consistent with the values and beliefs of the humanistic discipline of nursing.

Some important concepts used in phenomenological research include: *essences, intuiting, reduction and bracketing*. These concepts relate to the true meaning of something, arriving at a common understanding about the phenomenon under investigation, identifying any preconceived notions or ideas about the phenomenon under investigation and separating out of consciousness what the researcher/s know or believe about the topic under investigation (Strubert-Speziale & Carpenter, 2003).

3.4.1 Essences

Essences are the elements that are related to the ideal or true meaning of something, the concepts that give common understanding to the phenomenon under investigation (Streubert & Carpenter, 1999). In this study the purpose is to establish the experiences of nurses who care for severe/profound intellectual disabled patients. The researcher will try to provide an in-depth discussion of such interpretations and identifying essences of caring for intellectual disabled.

3.4.2. Intuiting

It is an accurate interpretation of what is meant in the description of the phenomenon under investigation (Streubert & Carpenter, 1999). The researcher will seek the common understanding of the phenomenon under investigation. This was done by varying the investigative process until a common thread appeared.

3.4.3 Reduction

The phenomenological reduction is the meditative practice described by Edmund Husserl, the founder of phenomenology. The researcher has tried to put aside scientific theory and knowledge to the phenomenon being investigated and focused on the meanings as described by those who experienced it (Streubert & Carpenter, 1999).

3.4.4 Bracketing

Bracketing is a qualitative term primarily used in phenomenology. Polit and Hungler (1999) define bracketing as a process of identifying and holding within any preconceived beliefs and opinions one might have about the phenomenon under investigation. Knowledge about the phenomenon under study is acknowledged by the researcher. As the researcher has worked in these units of intellectually disabled she is aware of personal feelings, but did not allow her experiences to influence the participants' narratives.

3.5 Research setting

The level three Psychiatric hospital operates in one of the districts of the Cape Town Metropolitan region. The hospital forms part of the Associated Psychiatric Hospital in the Western Cape. It is divided into two sections, namely, Psychiatric section and Intellectual disability (IDS) section. The intellectual disabled patients are further divided into categories, that is, *grade I* is for low severely or profound Intellectual disabled, *grade II* is for moderate intellectual disabled and *grade III* clients who are mild Intellectual disabled.


3.6 Population and sampling

A population is a complete set of persons or objects that possess some common characteristics that is of interest to the researcher (Brink, 2006). The study population comprised all the nurses working permanently in the intellectual disability section.

3.6.1 Inclusion criteria: Nurses who care for severely /profound intellectually disabled patients who have been employed in the institution for at least two years.

3.6.2 Exclusion criteria: Nurses who do not care for severe/profound intellectual disabled patients, newly appointed employees and the agency nurses were not included.

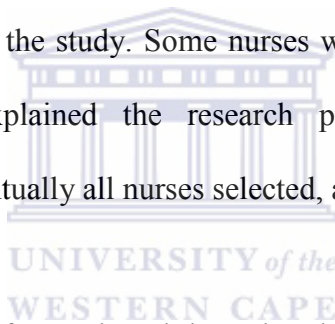
3.7 Sampling process



Purposive sampling was used to select participants. According Bowling (2002), purposive sampling is a deliberate non-random method of sampling which aims to sample a group of people with a particular characteristic. Sample sizes of qualitative studies are necessarily small because of the complexity of the data which are expensive and time consuming to analyse (Bowling, 2002). Initially 10 participants were planned to be recruited, however, at participant 7 the researcher realised that there was no more new information from the participant. The researcher decided to continue in case new information would come up. However, data saturation was reached at participant 8. According to Lobiondo-Wood and Haber (2006), data saturation occurs when the information being shared with the researcher becomes repetitive.

3.7.1 Sampling procedure

After obtaining permission from the hospital ethics committee, the researcher contacted staff in the wards that were identified as wards that accommodate severe/profound intellectually disabled patients. I then arranged to visit the ward and during the visit the researcher made contact with the sister in charge of the ward and secured the appointment to visit the ward. Most of the wards have one sister (professional nurse), one staff nurse (enrolled nurse) and two to three nursing assistants. The aim of this study was to describe the experiences of nurses from all three categories. However, of the registered nurses in the five wards that were identified, two did not fit the inclusive criteria. On the day of the appointment, the nurses were approached and asked if they were willing to participate in the study. Some nurses were sceptical about participating in research and the researcher explained the research process and more especially the confidentiality of the process. Eventually all nurses selected, agreed to participate in the study.



The consultant and area manager of IDS alerted them that the interviews would be starting soon (Appendix D). After the participants were selected, the researcher scheduled appointments with them to start the interview process and all dates and times were chosen by participants. During the scheduled date, the participant was given an information sheet which was read to the participant to make sure that the purpose of the study was clearly understood by the participant. After the participant agreed to participate in the study, the consent form was signed and the interview process commenced (Appendix C).

3.8 Data Collection

Data collection started after the researcher introduced herself and shared the information from the information sheet with the participant (Appendix B). Participants were given the chance to ask questions about the study before the interview commenced. The interview started after consent was given by the participant. Interviews were conducted in the sister's office and did not exceed more than one hour. A broad question was used to elicit a narrative response from the participants on caring for the severe intellectually disabled patients (Appendix A). When participants went off the point, the researcher tried to bring them back on track by using probe questions. The aim of collecting information, regardless of how it is conducted, is to obtain data that are both relevant and sufficient to answer a research question (Depoy & Giltin, 2005).

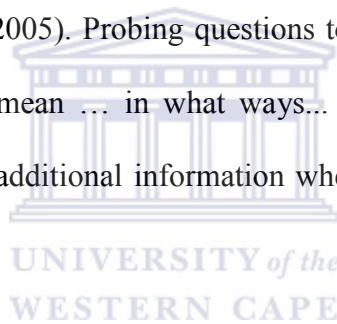
An audio tape was used to record the interviews and the recordings were transcribed verbatim. All the information that was obtained from the participants was stored on a compact disc and a code was allocated to each of the respondents to ensure anonymity. The compact disc was locked away and only accessible to the researcher. The first two interviews were not very successfully done. When the research supervisor read the transcripts it was noted that the researcher used too many leading questions. The researcher used them as practice so as to refine her interviewing skills. The researcher did not include the explorative interviews in the data analyses.

3.8.1 Data collection instrument

In phenomenological research, interviews are the primary data collection methods (Holloway, 2005). In-depth, unstructured interviews were used to collect the data. Un-structured interviews are more like a normal conversation, but with a purpose. They produce more in-depth

information on the subjects' beliefs and attitudes that cannot be obtained through any other data gathering procedure (Brink, 2006). Holloway (2005: 39) states that researchers need special listening skills and should create atmosphere of trust and respect so that the interview is conducive to exploring the experience of participants without giving them a sense of lack of control or intimidation.

The researcher used a broad question to elicit a narrative account of the nurse's experiences, that is, would you please tell me about your experience of caring for the severe intellectually disabled patients? This style of questioning allows the respondent to present their experience in their own words and their style (Holloway, 2005). Probing questions to explore deeper feelings were also used, for example, what do you mean ... in what ways... anything else? Probing is done to stimulate interviewees to provide additional information when the responses are vague (deVos, 1998: 310).



The demographic data was collected to obtain the characteristics of participants recruited to participate in the study (Appendix E). The data collected included the age of the participant, number of years working as nurse, number of years working with ID patients and whether they received in-service training on caring. All this information was used to get the contextual background of the participants and to possibly link it to their experiences related to caring for these ID patients.

3.9 Data analysis

According to Creswell (2003: 191) data analysis for a phenomenological study entails the analysis of important statements made by participants concerning their experiences. The statements are classified into meaningful units, which are then described to uncover the experience related to the phenomenon. Merriam (2002:14) suggests that data analysis is done concurrently with data collection. This helps to guide the researcher to make adjustments accordingly as the process of data collection continues. Colaizzi encourages researchers to be flexible with these stages, and we have found this to be useful. Diekelman, *et. al.* (1989) who are nurse researchers described the following process:

The seven stage processes of Colaizzi were employed to analyse data, namely:

- Reading interviews to gain a holistic impression;
- Writing interpretive summaries and searching for potential themes;
- Analyzing transcripts;
- Returning to the text or participant to clarify certain issues;
- Comparing cases to identify common meanings and shared practices;
- Identify patterns linking the themes; and
- Asking the interpretive peers for suggestions on the final drafts.

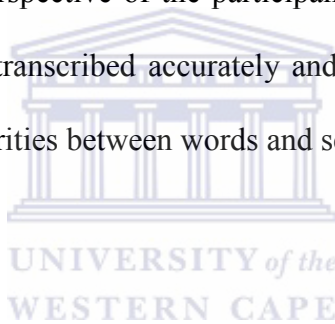
The detailed process of data analysis will be discussed in chapter 4.

3.10 Trustworthiness

Guba proposed four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study. By addressing similar issues, Guba's constructs correspond to the criteria employed by the positivist investigator (Guba, 1981).

3.10.1 Credibility

Guba and Lincoln (1989) as cited in Koch (1993) believed that a study will be credible if it presents truthful descriptions. Trochim (2006) believed that the results of the research must be credible or believable from the perspective of the participants in the research. In an attempt to establish credibility the data was transcribed accurately and the data analysis included line by line analysis in order to find similarities between words and sentences.



3.10.2 Transferability

Transferability refers to the probability that the study findings have meaning to others in similar situations (Streubet-Speziale & Carpenter, 2003). A purposive sample was used. Furthermore, a complete description of the methodology was done and verbatim quotes from individual interviews were included.

3.10.3 Conformability

Refers to the degree to which the results could be confirmed or corroborated by others. To enhance conformability, the researcher documented the procedures for checking and rechecking the data throughout (Streubet-Speziale & Carpenter, 2003).

3.10.4 Dependability

Emphasizes the need for the researcher to account for the ever-changing context within which research occurs and how these changes affected the way the researcher approaches the study. Colaizzi steps of data analysis was followed and the context and described in detail (Streubet–Speziale & Carpenter, 2003).

3.10.5 Reflexivity

Reflexivity can be described as the researcher's awareness and engagement with aspects of their role or possible influence in the process (Eagle, Hayes & Sibanda, 1999). The research topic was of interest to me after being allocated in the Intellectual disabled section on a permanent basis and witnessing the working conditions of the nurses in the service units. The researcher noticed that there were some challenges in caring for intellectually disabled more especially the severe and profound ones. As the researcher has worked in these units it could assist in the understanding of their experiences and may have contributed to sensitivity to their experiences. However, I needed to be aware of the specific role of a researcher and that of a registered nurse. My role as a researcher was made clear at the start of the interviews.

3.11 Conclusion

Chapter 3 dealt with the research methodology which was aimed at uncovering the experiences of nurses caring for severe/ profound intellectual disabled patients. A qualitative, phenomenological approach was employed for this study. The study was conducted at a level three Psychiatric Hospital in the Cape Town Metropolitan area. The researcher had complied

with all the principles related to research ethics and ensured that the data was collected and analysed in a trustworthy manner. The research findings will be presented in the next chapter.

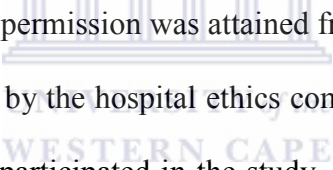


Chapter 4

Research Findings

4.1. Introduction

According to Creswell (2003: 191), data analysis for a phenomenological study entails the analysis of important statements made by participants concerning their experiences. The statements are classified into meaningful units, which are then described to uncover the experience related to the phenomenon. Merriam (2002:14) suggests that data analysis is done concurrently with data collection. This helps to guide the researcher to make adjustments accordingly as the process of data collection continues.



The research was initiated after the permission was attained from the relevant hospital authorities and the final permission was given by the hospital ethics committee. Consent to be interviewed was given by all respondents who participated in the study. The interviews were recorded on a digital voice recorder. The taped interviews were then saved to the researcher's personal computer, where a file was opened for each interview. The researcher's computer is password protected and no one else had access to the computer. After all the interviews were saved in voice and text format the interview recordings on the voice recorder were deleted.

The audio taped interviews were transcribed verbatim. Each interview was read over and over until the researcher understood each line of the interview. Codes were assigned to each unit giving a description of what the line/s meant. All similar codes were grouped together into

categories. The categories were conceptually analysed into five themes to provide information about the experiences of nurses who care for severe intellectually disabled patients.

4.2 Demographic data

Demographic data was captured prior to the commencement of the interviews. The researcher used face-to-face interviews to collect the primary research data. The demographic data is presented in Table 1.

Participant	Age	Designation	Number of years as a nurse	Number of years caring for ID patients	In-service training
JM9601	50-60	NA	20-30	20-30	YES
NC10302	50-60	NA	20-30	20-30	YES
CW9903	40-50	NA	20-30	20-30	NO
MM1004	30-40	RN	10-20	10-20	YES
NC9905	30-40	RN	5-10	2-5	NO
KCM9906	50-60	EN	5-10	5-10	NO
LA10507	50-60	NA	20-30	20-30	YES
NK9608	30-40	EN	5-10	5-10	NO

Table 1: Demographic data

The researcher initially planned to collect data from 10 participants. However, after the eighth interview, saturation of data was reached because no new information was forthcoming. The sample consisted of eight (N= 8) nurses who care for severe intellectual disabled patient at a level 3 hospital in the Western Cape. Two (N=2) of the carers who participated in the study were

registered nurses, three (N=3) were enrolled nurses (staff nurses), and four (N=4) were enrolled assistant nurses.

The ages of the participants who participated in the study ranged between 36 and 60 years. The mean age group of the participants ranged between 50-60 years (N=4). This was followed by 30-40 years (N=3) and 40-50 years (N=1). The participants have cared for severely intellectually disabled patients for (N= 4) 20-30 years, (N=1) 10-20 years, (N=1) 5-10 years and (N=2), 2-5 years. This means that all the participants in this study, except for one (NC9905) have more than five years of experience caring for ID patients.

The findings about in-service training revealed that not all nurses received in-service training and most of the newly employed participants did not receive in-service training on caring for ID patients; they only learned through the observation of experienced nurses and from on the spot teachings by peers. Four nurses (N=4) received in-service training and four (N=4) did not receive in-service training.

All the nursing categories were included although many participants were assistant nurses, who are the majority category allocated to these units on both shifts, that is, day and night shifts.

4.3. Description and summary of the main themes

The responses of the caregivers were thematically analysed and the following themes emerged which describe the experiences of caregivers of severely intellectually disabled patients at a level three Psychiatric hospital in Cape Town. The themes and categories are listed below.

Themes	Categories
1.Preparedness to care	Prepared to care Unprepared to care
2.Caring experiences	Describing patients Providing care Providing special care
3. Consequences of caring	Physical consequences Emotional consequences Professional consequences
4.Coping with care	Burnout Team work
5.Support	Family support Peer support

Table 2: Themes and Categories

4.3.1. Preparedness to care

During the interviews, some of the participants indicated that they were exposed to the intellectually disabled clients during their formal training. Some stated that they were never exposed to the intellectually disabled clients and others did not receive any formal training regarding the care of ID patients. Some participated in in-service training sessions about caring for intellectually disabled patients and others learnt by observing experienced nurses in their units.

4.3.1.1 Prepared to care

Prepared to care has different dimensions: some of the participants indicated that they have been prepared to care for these clients during their training; others indicated that their training did not embrace intellectual disability, but they were mentored by fellow carers; some indicated that they received on the job training. Here are their responses:

MM1004...I first started working as a student while I was doing my fourth year, I was first placed at the Psychiatric side and then later I was allocated in IDS.

LA10507... yes... that time the senior nurses taught us all the basic skills that we need to teach the patients, teaching us how to do all these things and we did everything they taught us, and that is what we are still doing...nowadays you can even make use of internet; you can learn these things...

LA10507...we were trained on how to care for aggressive patients, how to bath; feed the patients.

It was noted that many of the carers gained their experience through on the job training, where they observe the experienced carers while performing the daily caring duties; others attended in-service training.

KCM9906... There were other nurses who have been long to the ward... they shared with their first experience when they started here and they were always there with me, they taught me how to care for these patients

MM1004... when I started here we had an in-service training on how to feed the spastic patient child ... you need to have a way of handling them, how to roll them, how to change them because of their disabilities, a person really need an idea on how to care for them.

NC10302... when we first came to the ward there were nurses who worked there for a while, so we used to watch them what they were doing, like who is eating soft diet or full ward diet, also the nurses used to orientate us ... like they tell us when they are going to bathe the patients ...what time are they feeding, etc. So if you are fast learner you end up grasping everything they do and end up knowing the routine of the ward.

Some participants stated that they prepared themselves to care; they dedicated themselves to caring for these patients even though they were not trained.

CW9903...I was told verbally that I am just here three months because there was a shortage of staff, there was a need of male nurse and I thought to myself well its fine I will stay that three months and then I will go back, but I am still here it is now 15 years and I am quite happy content do not have any intentions to go back.

NC10302: It was kind of scary at first, but I just reminded myself that I am a nurse and these patients need me and I just need to learn caring for them you know these patients they really miss love, so we here for them, we give them love; because most of them were never given love by their parents... we take ourselves as their parents even though we are nurses... we take them as our own children.

From the responses, it appeared that those carers that are not professional nurses did not get any formal training on intellectual disability. However, many of them used different strategies to gain skills to care for the ID patients and despite being unprepared initially remained in the units for an extended period of time. They dedicated themselves to the caring and conformed to a profession that expects caring to be part of the job description.

4.3.1.2 Unprepared to care

The carers, whose training did not include psychiatry where the concept of intellectual disability is taught, were unprepared to care. They indicated that after they completed their training they

were placed in these units of the intellectually disabled and they were the novice carers. Others who received formal training were not placed in the ID units. They too were unprepared.

NC9905...I was so surprised when I came to these wards, seeing the setting, the type of patients it was very shocking to me, even though during my training I was placed to a psychiatric hospital, there was no intellectual disabled patients there.

NK9608...It was my first institution to employ me after I have completed my training. I started in 2005 in ward 95 with severe intellectual disabled patients. When I first started here it was very difficult for me to adapt to that kind of patients because I was very young...and I never saw people like these in my life.

4.3.2 Caring experience

Many of the participants started describing their caring experiences by giving details about the patients and the type of caring because that provided the background to their caring experiences.

4.3.2.1. Describing patients

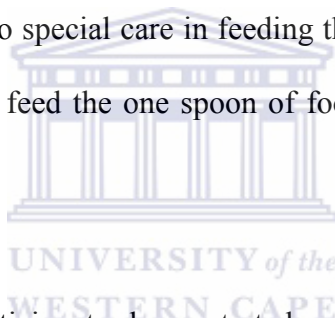
The participants used different words to describe these patients amongst others: they appear scary, needy and dependent; they display behavioural problems and limited cognition. Some participants would describe the physical characteristic like the way they eat and their deformities, others concentrate on their behaviour, how they tend to act out. Some described their need for physical care, skin care and special care. These were some of their responses:

NC9905..... some of them have deformities of the mouth... they have swallowing difficulties... they can choke easily.

MM1004...They are low functioning they do not understand you and it is difficult to communicate with them...

KCM9906...the way they are built, it was a scary experience...the way they eat was so disgusting

NC10302...so we need to do special care in feeding them and we need to be patient with them, for instance you can feed the one spoon of food five times, because she keep on spitting the food out.



It appeared as if some of the participants demonstrated a reluctance to care for the severely intellectually disabled patients; it appeared as if they were just obeying the orders of their seniors and they were just doing their jobs.

KCM9906... If I was given a chance to choose the ward I would not have chosen to work here, because of their condition, the way they are, the way they eat it is disgusting, it really makes me sick.

MM1004... mh... it is hard work working here and for myself I was put here... I just enjoyed myself while I was placed in Psychiatric, but not here.

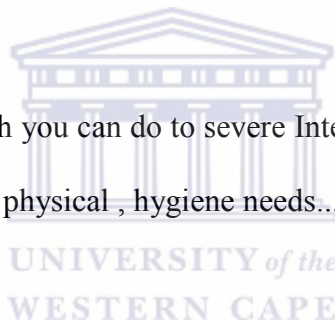
4.3.2.2. Providing care

Participants described different types of caring, amongst others: physical care, emotional care, and special care.

4.3.2.2.1 Physical care

From most of the participants' responses it became clear that the physical care formed the basis of their caring tasks. They further stated that the ID patients are totally dependent on nursing care as a result of their physical deformities and some were very low functioning and unable to care for their personal hygiene.

JM9601...: there is not much you can do to severe Intellectual disabled patients... you just take care for their personal, physical , hygiene needs... there is not much you can do... just care for them.



NCB10302...You know at night we bathe these patients, we feed them, later midnight we do rounds, that is, a nappy change round, and also in the morning we do the same.

KCM9906... I happen not to have anything do in my scope of practice as the registered nurse does most of the duties, so I ended up changing nappies, bathing and feeding the whole day.

4.3.2.2.2 Specialised care

Caring for the severe intellectual disabled patients has been described by the participants as providing cautious care and intellectual stimulation as part of the therapeutic nursing care. These patients were also identified as patients with deformities of the mouth, being physically disabled and having fragile bodies.

LA10507...we learn them how to eat...,that is,. taking the spoon and showing them how to hold it and take it to the mouth...even how to dress themselves and undress themselves... for example: We teach them that when dressing like... the females must first put the bra ... following by a panty then clothes last.

NC9905...when you feeding you have to be careful... give small portions and breaks in between to allow swallowing... it takes time to feed one patient... otherwise if you rush they will ended up choking and we don't want that.

JM9601...Participant: you need to be very careful how you feed them, how you bath... how do you do everything for them... a person needs to be careful when moving them or sitting them in their buggies... because you do not want to cause further deformity to them...

It appears that the even the basic nursing care provided to ID patients required that nurses develop specific specialised skills to attend to the basic needs of the patients.

4.3.3 Consequences of caring

The consequences of caring are manifold, some respondents shared positive consequences while many focused on the negative consequences of caring for the ID patients. Despite facing caring challenges, the nurses deliberately try and deal with these challenges. The participants articulated their physical, emotional and professional consequences.

4.3.3.1. Physical consequences

The physical consequences related to physical endurance, amongst others that caring is tiring and occasionally strenuous. Many refer to the physical effort of caring for the ID patients as draining.

NCB10302...When you finish working we come out sweating and the body is aching.

NC9905...you know working here it's very challenging ... you do all these basic duties even though you are a sister and remember they are spastic, you bend you strain really...you feel it...

JM9601...these patients could be small built but they are so heavy... they drain you physically and emotionally ... because the whole day you are lifting them from bed to their buggies

MM1004... Caring for them is physically draining because some of them are not mobile... you have to lift them to the bath; also dressing them is tiring...

4.3.3.2 Emotional consequences

Emotionally, the participants expressed positive and negative emotional outcomes. The positive emotional outcomes expressed were amongst others: happy about patient recovery and caring was regarded as rewarding. These were some responses:

NCB10302... at the end when you finish bathing them or changing their nappies to make them dry ...you find that they give you smile, they are so relaxed and they end up sleeping peacefully like our small children...

MM1004... For me that is positive if you...It is a tiring job caring for these patients... whatever, but ... uhm... seeing that you can enlighten them ... you see a smile in their face... also when you are away for like a week or two weeks... when you come back that smile they will give you almost like they understand where you coming from... where were you this whole time. Also, when you feed them ... they smile showing that they are satisfied, even thou they cannot communicate with you, but you can see they are satisfied ... for that it is positive enough.

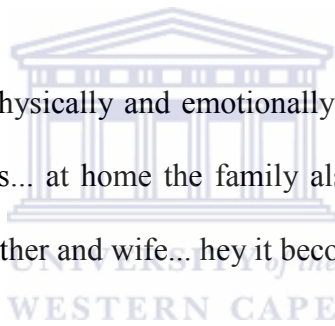
KCM9906...I find it rewarding to me when I see that the patient's condition has improved and patient is now free from discomfort and no distress, going home seeing an improvement to the patient makes me happy.

Participants express some of the following negative emotional outcomes about caring for ID patients; feelings of powerlessness, stress and frustration.

NC9905...Yes...you know caring for these patients can be very emotional... you know during festive season you just think about them... where are their parents... you just put yourself in their shoes ...The other thing when I was pregnant I used to pray to God that: Oh God do not let my child to be like these patients... you worry really when you look at them... it affects us psychologically and emotionally.

MM1004: It is also mentally tiring because if you give them a command they will look at you, do not respond to what you are saying.

JM9601: They drain you physically and emotionally ... you also think for them as they cannot think for themselves... at home the family also expect you to do everything for them, because you are a mother and wife... hey it becomes so stressful...



Professionally, nurses appear to feel unappreciated by the management structures; they fear that they may become deskilled and have no incentives, for example, performance bonuses.

CW9903...The thing that makes me unhappy is the fact that the management do not recognise the hard work we doing here; we are rendering services here and with no appreciation of. It will be appreciated if they can communicate with us on day to day basis.

KCM9069... The other thing if you work here you do not gain any new knowledge and experience in other duties as per job description of an enrolled nurse, for example we only do basic nursing care, its seldom than we do dressing or administer medication... the way things are I can even end up forgetting some of skills of my scope of practice. She further said: ...We work hard with these patients but we do not even get staff performance appraisal bonuses, although you will find out some few nurses do get bonuses, but what amuses me we do the same job.

4.3.4. Coping with caring

Many of the participants described caring of severe intellectually disabled patients as unusually difficult especially when you are confronted with them for the very first time. They stated that there are some of the experienced nurses that always have a way of making their life seem easy so as to manage to finish the day with less stress. It appeared as if some nurses coped better than others.

4.3.4.1 Burnout

Most of the participants appeared to be employing different strategies for preventing burnout.

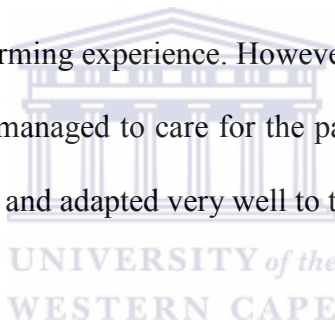
LA10507... what I do I do not think, talk about work when I am with my family... I think this the reason why nurses burnout ... they talk about work or think about it even when they are off duty... when I go out of that gate ...I leave everything here ... and will see work again when I am back ... Well... you have to change your mood, the look in your

face... no long faces... you need to leave all your worries at home... they like to be kissed and hugged.

CW9903...There are times a person feels burned out, but I try to overcome that when I am off by relaxing, reading, go to the beach and just forget about work when I am off to prevent physical burnout

4.3.4.2 Team work

All participants interviewed expressed that when they were first confronted with the severely intellectually disabled it was an alarming experience. However, as a result of the support they got from their experienced peers they managed to care for the patients the next day and next month until they found themselves coping and adapted very well to the caring.



NC9905...It is because of team work... I'll never forget those nurses ...if it were not for them I do not think I should have been still working here at this hospital.

NK9608... there were other nurses who have been long to the ward... they shared with their first experience when they started here and they were always there with me...

KCM9906... When we understaffed we only bath fully those who are on nappy and later in the afternoon we bath the non-nappy patients who are toilet trained, this works for us because we have prioritised, sometimes we take our teas and lunches late so as to make sure the work is done.

4.3.5. Support

Most participants acknowledged that they were supported by family members and their colleagues.

4.3.5.1 Family support

Many of the participants interviewed acknowledged support from their families. Two participants indicated that although the family give them support, they still have to do their house chores. One felt that her family did not have insight about the concept of intellectual disability and that it was the reason they did not provide any support.

LA10075...my family gives me a lot of support ... they know I am working long hours and every time I come home I am always tired... they help me with house chores... and sometimes they just let me rest and do everything themselves.

NK9608...Yes my husband does rub my feet when I come from work, although he is also tired him... as a wife I am still expected to prepare supper ... there is nothing much they can do for me

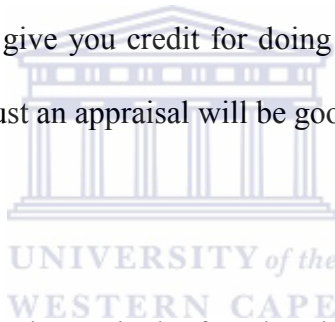
NC10302...my family is very supportive; they understand that I am working hard here. When I get home I always find food ready, they don't expect me to come prepare food, even my husband knows that when I come from work I am tired and I need to rest.

4.3.5.2 Professional support

Among the respondents who participated in the study, only one acknowledged that she received some support from the institution. The remaining participants felt that they were unappreciated; they stated that most of the support was from the peers.

NK9608... I went for a stress management course... it helped me a lot, but I still need more courses on that.

JM9601...shortage of staff is a problem in the whole IDS... you had to do two or three people's work and nobody give you credit for doing that... you not being... uhm... yes I know it is my work ... but just an appraisal will be good for your spirit... it makes you feel better about yourself ...



CW9903: What makes me unhappy is the fact that the management do not recognise the hard work we doing here. We are rendering services here and with no appreciation. It will be appreciated if they can communicate with us on day to day basis.

4.3.5.3 Peer support

Most of the participants acknowledged the support they received from their peers. They mentioned that when they were placed in the units the core workers shared their knowledge, skills and experiences related to the care of ID patients.

KCM9906 ...there were other nurses who have been long to the ward... they shared with their first experience when they started here and they were always there with me...

NK9608... and they used to comfort me saying me that I am going to be fine as time goes ... and they were also like me when they started working here.

NC9905...I will never forget those nurses ...if it were not for them I do not think I should have been still working here at this hospital.

4.4 Conclusion

Despite the challenges the participants claimed to have encountered, they displayed love and compassion for the ID patients. Some stated that they are just caring because they do not have a choice but to obey their superiors who placed them in those units. Most of the participants seem to understand that in spite of challenges they faced, the patients had nothing to do with the fact that they are in need of someone to take care of them and that they do not have insight of what is happening around them.

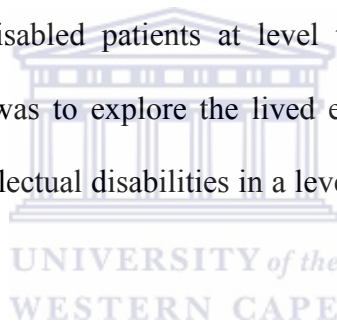
The shortage of resources, which was acknowledged by participants and inadequate support services seem to have caused a bad feeling towards the caring for intellectually disabled patients at this institution. However, it is a reality that the care provided to the ID patients is labour intensive and takes an emotional toll on the carers. It is also important to draw on support structures to cope with the demands of the care. In the next chapter, the findings will be discussed and will be compared with the findings of other research studies.

Chapter 5

Discussion, recommendations and conclusion

5.1 Introduction

In this chapter, the findings of the study are presented and discussed. The researcher relates the research findings to other literature on the topic and relevant theories. The discussion of findings will be based on the four themes that emerged from the data analysis in the previous chapter. The summary of study findings and the recommendations relating to the experiences of nurses who care for severely intellectually disabled patients at level three psychiatric hospitals will be presented. The aim of the study was to explore the lived experiences of nurses who care for patients with severe/profound intellectual disabilities in a level three Psychiatric hospital in Cape Town.



5.2. Discussion of Demographic data

From the demographic data it was found that all except one of the participants in this study (NC9905) have more than five years of experience in caring for ID patients. This means that what they share could be considered valuable information.

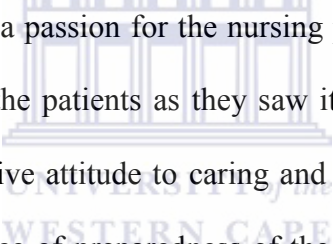
5.3 Discussion of research finding

5.3.1 Preparedness to care

The study revealed that some nurses were prepared during their training and others were not. All the registered nurses except for one were prepared to care for the intellectually disabled during

their pre-registration period. This one registered nurse claimed that although the subject content of intellectual disability was presented in the classroom, as a student, she was not placed in a clinical facility to ensure exposure to intellectually disabled patients.

The nurses (assistant nurses) and enrolled nurse reported that their studies did not prepare them for caring for this type of patients, nor did their training embrace the care of intellectually disabled patients. I identified the need for an induction program related to the concept of intellectual disability and on-going debriefing of this level of nurses until they become skilled to care for ID patients.



Some of the carers, who exhibited a passion for the nursing profession, prepared themselves by dedicating themselves to care for the patients as they saw it as part of their nursing duty. The researcher concludes that the positive attitude to caring and the quality of care given to the ID patients are dependent on the degree of preparedness of the nurses. Arantzumendi, Addington-Hall, Suracabar and Richardson (2012) indicated that nurses who are prepared to care and are given appropriate support are able to fulfil their role and provide a high quality of care.

This finding is similar to that of Sundstrom and Dahlberg (2012) who suggest that preparedness and support are essential elements of quality care. Preparedness to care is deemed to be important by Arantzumendi *e.tal.* (2012) which may indicate that there is real need for preparing carers, in particular those who have to care for ID patients.

5.3.2 Caring experiences

The participants described their caring experience by describing the patients, how they were providing care with a focus on providing special care.

When the participants started to describe their patients, it appeared that they are painting a picture to someone who has not been exposed to these kinds of patients. From the descriptions, one could note how burdensome it is to care for the severely intellectually disabled patients. One could also become aware of how dedicated they were even though they are faced with many challenges.

Many of the nurses worked in these units for many years. They choose to be carers for these ID patients even though they had a choice to resign and look for a job elsewhere. The care they provided was special and needed a kind, caring person that was passionate about nursing. Watson (1997) identified ten factors as the essential aspects of caring in nursing. Some of these factors are: altruism, installation of faith, cultivation of sensitivity to one's self and to others..... Watson states that without these factors, nurses could not be seen as practicing professionals, but were functioning as technicians or skilled workers within the dominant framework of medical techno-cure science. The nurses in this study displayed most of these factors. Watson says that Altruistic system of values begins developmentally at an early age with the values shared with our parents. This system is perceived as necessary to the nurses own maturation which then promotes altruistic behaviour towards others.

The following finding represents what Watson said: NC10306...”I really love them and when I am caring for them I make sure I take time and do my work properly. I am here for fifteen years and I never requested to be placed in any other ward and I am intending to work here till I pension because I love these patients”.

5.3.3 The consequences of caring

Caring includes physical consequences as well as emotional consequences, which have two dimensions: negative and positive emotions.

This study revealed that caring had some negative consequences on the carers’ physical well-being which could have resulted in the reported absenteeism and shortage of staff. Caring for an ID patient has been reported as complex and resulted in fatigue and body aches. One of the participants (LA10507) claimed to have a chronic back problem which she said may have been aggravated by the physical demands of caring for ID patients. She stated “Yes I was told it was caused by patient lifting... these patients are so heavy... sometime during the night ...you work alone and all the work is waiting for you ...”Simon *et. al.* (2008) concur by stating that back and neck pain is a common problem in hospitals and is aggravated by the physical and psychological risk factors related to caring for the disabled. The working environment determines the type of physical and psychosocial factors that nurses are exposed to and back pain is a major cause of health related absenteeism which contributes to staff shortages.

With the emotional consequences, the findings of the study revealed that participants experienced positive and negative emotional consequences. The positive emotional

consequences related to the participants feeling rewarded for caring for the ID patients as they knew that most of the families could not care for these patients adequately at home. They mentioned that some of patients were abandoned by their families so they perceived them to be in need of care. Providing in these needy patients' basic needs to the best of their ability was considered as a worthwhile endeavour. One of the participants (NC9905 ...) said, "You know most people do not like to work here... the fact that I am caring for them is very rewarding because I know God is happy for what we are doing we as nurses... spiritually there is something with it ... you feel great for caring for them."

Findings by the Social Care Research 54 of 1994 about caring for severely disabled child, reported that just at the beginning of caring, parents thought themselves as parents not just carers, they say the pleasure and satisfaction gained through the relationship with the child was the vital reason why parents felt able to continue. This tallies with findings of this study where most participants took themselves as parents to those disabled patients. I remember when I started working there I could hear them calling these patients as children. This is what LA105 had to say, "... most of them do not come and visit ...so we are here as mothers to them ... as friends and you need to build a relationship with the patient".

I also found that the participants reported quite a number of negative emotional consequences. They got frustrated when dealing with low functioning patients. Occasionally, they were unable to provide in the basic needs of the ID patients, for example, there were inadequate linen and other resources. Morrow (2008) states that caring for someone who is ill or disabled can be very

taxing emotionally as well. Sometimes the person you are caring for cannot remember you, or has a hard time following directions or communicating their needs.

5.3.4 Professional consequences

Findings of the study revealed that some participants felt that caring for these patients is basically physical care and they felt that there is some kind of hindrance in their professional growth. KCM9906 suggested that instead of the registered nurses caring for the ID patients, home-based caregivers were best suited to care for those patients. As a registered nurse in the unit, I do not agree with her suggestion because I am aware of the need for a professional health practitioner to give guidance and supervision to the proposed home-based caregivers.

The participants also felt unappreciated and even mentioned that they felt that managers were not consistent with incentives like performance bonuses. According to The Rehabilitation Research & Training Institute (RRTI) in New York, nurses who are unfamiliar with the field of Developmental Disability nursing are concerned that they may not be using their skills and will become out-of-touch. They mentioned that nursing skills required in Developmental Disability nursing are broad and intense. DD nursing is a prime opportunity to develop skills in areas that most nurses do not get the chance to learn about. They further mentioned that nurses discovered that past experience might not be important rather learning new skill in caring for these patients might be of interest and can be professional rewarding.

5.3.5 Coping with care

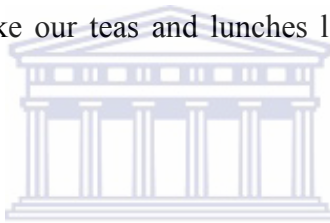
As participants responded on how they are coping with caring; burnout prevention and team work was mentioned by many of them; they acknowledged some challenges they were facing in the process of caring which included shortage of resources. Hobfall and Freedy, 1993; Leiter, (1993) describes burnout as a syndrome experienced by people working in human services and is hypothesized to occur as work demands on staff exceeds the resources available to deal with load. Even though the lack of resources was mentioned by many in this study, participants remained caring and they indicated that team work facilitated the prevention of burnout.

The findings of this study suggested that although caring for the severely intellectually disabled patients is complex and come with many challenges, these carers had a way of dealing with their frustrations. Distraction was used by most participants, that is, they tried to think less about the work situation when they are away from work, one participant said: LA10507 “what I do I do not think, talk about work when I am with my family... I think this the reason why nurses burnout ... they talk about work or think about it even when they are off duty... when I go out of that gate ...I leave everything here ... and will see work again when I am back”.

According to Epiphanion, *et al.* (2012), coping refers to the participants’ means of managing care giving related challenges and stresses. They mentioned that some participants chose to internalise the physical or psychological burden of care giving to protect the patients. In their study, the caregivers reported adopting several approaches to coping, for example, using distractive activities. Some participants chose to explore the positive aspects of care giving to boost their motivation while caring.

This study also revealed that participants did not only dwell on negative aspects of caring, but chose to look at caring as rewarding to them as they focussed on how the clients respond to them after being adequately cared for, that seemed to distract them from the challenges they were facing.

They also used many ways of distraction to minimise stress at work. One way was to talk to the peers on how to make the work easy and enjoyable, the following statement is evidence to that, (CW9903) “When we understaffed we only bath fully those who are on nappy and later in the afternoon we bath the non-nappy patients who are toilet trained, this works for us because we have prioritised, sometimes we take our teas and lunches late so as to make sure the work is done”.



Crawford, Adedeji, Price and Rutter (2009) also suggested that team-work, that is, joint responsibility for service users and mutual support between staff, was said to be important to maintaining healthy working practices. Workers stated that it was too easy to lose perspective within therapeutic relationships with clients, sharing the difficulties of working with particular service users and getting advice was said to be very important.

In this study participants stated that they work together in all daily activities even though there were difficulties experienced with caring. One participant said (LA10507), “We sit and discuss how we are going to work... and who’s doing what... for instance we divide ourselves, some will be bathing patients on the other side of the ward ... some will be starting to feed those finished to

bath... also if there is a new patient who still need to be potty trained we discuss how are going to train this patient”.

Steenkamp and van der Merve (1998) from their study of psycho-social functions of nurses in a burns unit suggested that good relations amongst the nurses and support enable them to cope with stressors.

5.3.6 Support

Most of the participants mentioned that when they were first confronted to care for these patients they were shocked and did not want to come back the following day. For some of them, it was the first time to see to such deformities. From the experience that I have had working with ID clients, I know how a person feels when they come to these units for the first time. One feels that they cannot do this on their own. It becomes clear that support is needed from staff, employers and/or family.

In this study, employer support was hardly mentioned. Lack of support from the institution made the participants feel unappreciated. Campbell (2011) found that the main support was from individuals within their immediate work environment, which had a buffering effect on their levels of stress. Campbell further stated that the need for staff to have access to support that appropriately meets their needs is essential. The support should ideally be individualized, as their support needs may vary between individuals. He said it is important for the participants to receive recognition for the work they do.

5.4 Recommendations

The recommendations include: Providing support to nurses, improving resources allocation and providing incentives to staff.

Providing support services to nurses. The main recommendation would be to provide initial and on-going support services to nurses within the ID service units. This can be done by using some of the following strategies:

Induction of new appointees: as the cares come for the very first time in this section of intellectual disability they need fully be inducted as some of would not have ever been exposed to the kind of patients and some of them not prepared to care for the patients. Inducting them might eliminate anxieties they might be having and preparing those with negative attitude on the care of severe intellectual disability. Orientation to patient's activities of daily living is important. This orientation would clearly indicate what is expected from them and they would know their roles in the caring process.

Appointment of preceptors: Preceptors would continually support the novice carers during their first encounter in the care of severely intellectually disabled until they have fully adapted to the caring.

In-service training programmes: In service training programmes related on caring for the severe/profound patient on continuous bases would be of help and upgrade carers knowledge to this specialised caring.

Improving resource allocation:

Shortage of nurse's has been reported in this study and it is a worldwide problem. Since this has been an outstanding problem, it does not seem to be ending in the near future, hence the training

of lay health workers or home-care givers would give the nurses in the institution an extra hand in the caring process.

Providing incentives to staff: The most common way of motivating employees is giving them an incentive. Incentives with monetary value have been reported to be causing conflict among staff since the performance bonuses could not be given to everyone. However, one of the cheapest forms of incentive is recognition. This is a cheaper way of motivating employees but is just as effective as incentives. Recognition as the word implies involves recognising and appreciating an employee's performance. These can be the sincere words of gratitude to the carers.

5.5 Conclusion

The study revealed that not all carers were prepared to care for severe intellectually disabled patients. Participants in this study described their patients and highlighted that caring for them is special care and comes with complexity. Despite the challenges they encountered, they continued to dedicate themselves to caring. They mentioned some of the strategies that they used to cope with work stress and prevent burnout. They acknowledged that caring for these patients does not only have negative consequences, but also positive consequences. Many of the participants acknowledged the support that they received from their peers and their own families. Most of them felt that their hard work was not recognized by the management and they felt unappreciated.

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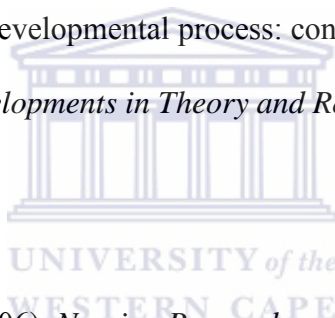
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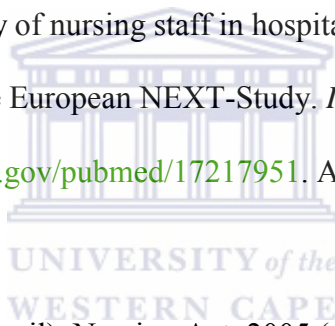
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University of California Los Angeles School of Nursing, Factor Building Room 5-145, 700 Tiverton, Box 956919, Los Angeles, CA 90095-6919, USA. jhahn@sonnet.ucla.edu

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Appendix A: Interview schedule

THE INTERVIEW SCHEDULE

The researcher will pose the following broad question to the participants:

Would you please tell me about your experience of caring for the severe/profound intellectual disabled patients?

The researcher will use the following probe questions:

What do you mean by?

In what ways?

Anything else?



Appendix B: Participants Information Sheet



**UNIVERSITY of the
WESTERN CAPE**

University of the Western Cape

Sibongile Princess Mgandela
48 Inez Avenue
Brentwood Park
Bluedowns
7100
0840964298
2558798@uwc.ac.za

Study Title: Experiences of nurses who care for patients with severe intellectual disabilities at a level 3 Psychiatric hospital in the Western Cape.

What is this study about?

This is a research project being conducted by Sibongile Mgandela at the University of the Western Cape. We are inviting you to participate in this research project where you will have an opportunity to voice out your experiences on caring for severely intellectual disabled patients. The purpose of this research project is to explore on experiences of caring for disabled patients.

What will I be asked to do if I agree to participate?

You will be asked to come to a private room close to the nurses' station, where an interview will be done by the researcher and will not take longer than an hour.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, personal information will be kept in locked cabinet, and password – protected computers will be utilised to store the information. Your name will not be included on the collected data instead identification codes will be used and the researcher will use an identification key and will be able to link the collected data to your identity. If we write a report about this research project, your identity will be protected to the maximum extent possible

What are the risks of this research?

There are no known risks associated with participating in this research project.

What are the benefits of this research?

The research is not designed to help you personally, but the results may help the investigator to learn more about the nurse's experiences on caring for disabled patient. We hope that, in the future, other people might benefit from this study through improved understanding of the experiences of nurses who care for disabled patients.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in this study?

If a participant feels the need for counselling, it will be the researchers' responsibility to make an appointment with a relevant counsellor for the participant.

What if I have questions?

This research is being conducted by Sibongile Princess Mgandela of the Department of Nursing at the University of the Western Cape. If you have any questions about the research study itself, please the researcher her contact details are on the top of the previous page.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Dean of the Faculty of Community and Health Sciences:

Professor R. Mpofu

University of the Western Cape

Private Bag X17

Bellville 7535

021 959 2631

rmpofu@uwc.ac.za

Head of Department:

Professor T. Khanyile

University of the Western Cape

Private Bag X17

Bellville 7535

021 959 2271

tkhanyile@uwc.ac.za

Supervisor:

Dr Jeggels

University of the Western Cape

Private Bag X17 Bellville 7535

021 959 2278

jjeggels@uwc.ac.za



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Appendix C: Informed Consent



**UNIVERSITY of the
WESTERN CAPE**

University of the Western Cape

Sibongile Princess Mgandela

48 Inez Avenue

Brentwood park

Bluedowns 7100

0840964298

2558798@uwc.ac.za

CONSENT FORM

Title of Research Project:

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name

Participant's signature

Witness name

Witness signature

Date

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name:

Dr Jeggels

University of the Western Cape

Private Bag X17 Bellville 7535 (021 959 2278) / jjeggels@uwc.ac.za

Appendix D: Application Letter to Lentegeur Hospital for Data collection

Sibongile Mgandela
48 Inez Avenue
Brent Wood Park
Bluedowns
7100
Cell: 0840964298
28/11/11

**Through: Mrs B. L. Swartz (Director of Nursing)
To The Chairperson
Research Ethics Committee
Lentegeur Psychiatric Hospital**

Dear sir/ Madam

Re: Application for Permission to Conduct Research at Lentegeur Psychiatric Hospital

I am a postgraduate student at the University of Western Cape, pursuing master of nursing degree (M Nurs). As a requirement of the degree, I am required to conduct a research. The title of my research, **“Experiences of nurses who care for the patients with severe/profound Intellectual disabilities at a level 3 Psychiatric hospital in Cape Town.**

The aim of the study is to explore the experiences of nurses who care for severe/ profound intellectual disabled patients. This will uncover the meanings attached to their experiences. I humbly request for permission to conduct my research in the Hospital. A report of the findings will be presented to your office after completion of the study.

Attached please find letter of ethical clearance from the Research Ethics Committee and School of Nursing of the University of Western Cape.

Yours Sincerely

S.P. Mgandela

Appendix E

Title: the experiences of nurses who care for severe/profound Intellectual disabled patients.

Date of interview

Name of facility:

Section A

Please answer the following questions by ticking in the appropriate box.

1. Age

18-30	
30-40	
40-50	
50-60	



What is your designation?

OPM	
RN	
EN	
NA	

How long have you been working as a nurse

2-5	
5-10	
10-20	
20-30	
30-40	

How long have been allocated to care for severe/profound patients

2-5	
5-10	
10-20	
20-30	

Did you receive any in-service training on caring for severe/profound patients?

Yes	
No	

Thank you for your time.





07 March 2012

Lentegeur Hospital Research Ethics Committee

Lentegeur Hospital
Highlands Drive
Mitchells Plain
7785

To whom it may concern

Re: Research Project - **Experiences of nurses who care for patients with severe intellectual disabilities at a level 3 Psychiatric hospital in the Western Cape.**
Principal Investigator - Sibongile Princess Mgandela

This serves to confirm that the above research project has been granted ethical approval by the hospital Research Ethics Committee.

Yours Faithfully

Dr P Smith
Chair – Research Ethics Committee
Lentegeur Hospital





UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

25 November 2011

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Ms SP Mgandela (School of Nursing)

Research Project: The experiences of nurses who care for patients with severe/profound intellectual disabled at a level 3 psychiatric hospital in Cape Town.

Registration no: 11/10/36

UNIVERSITY of the
WESTERN CAPE

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*



13/05/2013

Dear Sibongile,

Your mini-thesis really makes a very interesting reading. The content is adequate. However, there are some changes that I have made that concern:

- the consistent use of British English
- grammatical errors (here and there)
- spelling errors (here and there)
- use of shortened forms instead of complete ones
- repetitions (in some instances)
- referencing

Please go through this carefully and you are free to either accept or reject my changes which are mere suggestions anyway. After that please check your page numbers on the contents page as they are likely to change after my editing.

The full amount that you paid for the editing services that I rendered to you is R1125.00

Good luck with the examination process.

Yours sincerely,

Gift Mheta (PhD)

Durban University of Technology

Alan Pittendrigh Library

Steve Biko Campus

P O Box 953, Durban, 4000

Telephone: (031) 3733006

Cell: 0739548913

