# THE EXPERIENCES OF STUDENT NURSES CARING FOR MENTAL HEALTH CARE USERS WITH PROFOUND INTELLECTUAL DISABILITIES

by

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# **DECLARATION**

I Rakgadi Grace Malapela declare that the dissertation THE EXPERIENCES OF STUDENT NURSES CARING FOR MENTAL HEALTH CARE USERS WITH PROFOUND INTELLECTUAL DISABILITIES is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institutions.

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8 January 2015

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#### **ABSTRACT**

The purpose of the study was to describe and explore the experiences of student nurses in caring for mental health users with profound intellectual disabilities in one of the care and rehabilitation centre at Gauteng province incorporating the Common Sense Model. Qualitative descriptive and explorative research was conducted to explore the experiences of student caring for mental health care users with profound intellectual disabilities and to recommend the best practices in caring for mental health care users with profound intellectual disabilities. Data collection was done using reflective diaries and in depth interviews. Twelve participants participated in the study. The study composed of student nurses (n=12) caring for mental health care users with profound intellectual disabilities. Five themes emerged from the study i.e. emotionally challenging, communication difficulties, lack of knowledge on the nature of intellectual disability, burden of care and mixed feelings. Findings of the study revealed that completing nurses find working with profound intellectual disabilities to be emotionally challenging and that negative experiences outweigh the positive experiences, resulting in their reluctance to want to work with profound intellectual disability users. It is therefore incumbent upon policy makers and hospital administrators to take cognisance of these negative feelings so that ways of minimising these frustrations and promoting the wellbeing of nurses caring for mental health care users with profound intellectual disabilities are promoted.

# **Key concepts:**

Care and Rehabilitation Centre, caring, mental health care users, nursing education institutions (NEIs), profound intellectual disabilities and student nurse.

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I dedicate this study to my family for their undying support and prayers in making my study a success:

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# LIST OF ABBREVIATIONS

AAIDD American Association of Intellectual and Developmental Disabilities

CLWP Community Living Well and Pelham

CSM Common Sense Model

CRC Convention on the Rights of the Child

CRC Care and rehabilitation centre

CRPD Convention on the Rights of Persons with Disabilities.

CWD Children with disabilities

DoH Department of Health

DSW Direct Support Workers

DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders

EMB Emotional well-being

GBD Global burden of disease

ICD International classification of disease

ID Intellectual disability

IPR Interpersonal relations

IQ Intellectual quotient

MWB Material well-being

MHCA Mental Health Care Act

MHCU Mental health care user

MSST Multi-sensory Storytelling

NDOH National Department of Health

NEIs Nursing Education Institutions

NGO Non-Governmental Organization

PD Personal development

PHWB Physical well-being

PID Profound intellectual disability

QOL Quality of life

R Rights

RDP Reconstruction and Development Programme

SANC South African Nursing Council

SD Self-determination

SI Social Inclusion

XLMR X-linked mental retardation

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# **CHAPTER 1**

# OVERVIEW OF THE STUDY

#### 1.1 INTRODUCTION

Caring for mental health care users (MHCUs) with profound intellectual disabilities (PIDs) is complex. Previous research (Read & Cartlidge 2012:23) has shown that the complexity is in terms of the care that is required and the knowledge that a range of different health care professionals need to care for this population, especially the nurses. Identifying and assessing the needs of patients with profound mental health illness is often neglected. This neglect results in this group having poorer health than the rest of the population (British Department of Health 2001). In South Africa, the National Department of Health (NDoH) has noted in the Reconstruction and Development Programme (RDP) that people with intellectual disabilities are classified as in difficult circumstances due to the complex nature of their intellectual disability. The constitution of South Africa (1996:section 28), is against any form of maltreatment, neglect and abuse or degradation. It ensures that all inhabitants of South Africa are protected against any harm and any form of maltreatment will be regarded as unlawful.

As children grow they gain skills on how to take care of themselves and the dependency diminishes as time goes by. Unfortunately this is not the case with mental health users with profound intellectual disabilities. Mental health care users rely totally on caregivers to assist them in meeting activities of daily living in order to achieve a sense of wellbeing (Read & Cartlidge 2012:23). This confirms the difficult circumstances under which they are exposed to.

The intellectually disabled is defined as someone whose intellectual function and adaptive behaviour (everyday social and practical skills) differs significantly from what is normative in his or her society (American Association of Intellectual and Developmental Disabilities (AAIDD) 2011, as cited in (Aldersey 2011:02). This implies the difficulty that they are exposed to, including difficulties in meeting activities of daily living and inability to work independently.

The intelligence quotient (IQ), which is a gradient standardized measurement of intelligence, ranges from 130 (being the highest) to 70 (being the lowest) (Lambrechts, Kuppens & Maes 2009:623). Profound intellectual disability is classified as an IQ score below 70 or a developmental age below two years. (Lambrechts et al 2009:623). This means mental health care users diagnosed with profound intellectual disabilities have characteristics of a two-year-old child irrespective of their chronological age. There is delay in achieving milestones in comparison with the chronological age (Lambrechts et al 2009:623).

According to Gecz, Shoubridge and Corbett (2009:308-309) an estimated one third of the general population suffer from intellectual disability which is also referred to as the X-linked mental retardation (XLMR). Furthermore, it states that intellectual disability is characterized by substantial limitations both in intellectual functioning and in adaptive behaviour. It commonly affects males than females and is usually diagnosed before the age of 18.

Thus, the objectives of this chapter are to describe the experiences of fourth year nursing students in caring for mental health care users with profound intellectual disabilities; to explore the meaning attached to caring for mental health care users with profound intellectual disabilities and to recommend best practices in caring for mental health care users with profound intellectual disabilities.

#### 1.2 BACKGROUND TO THE RESEARCH PROBLEM

According to Gecz et al (2009:309), the governments of many countries spend large amounts of money in the care of people with intellectual disabilities, and this ranks highly on the health care expenditure of many countries. The National Department of Health ([s.a.]:03) estimates that in developing countries mental health problems make up 8,1% of the Global Burden of Disease (GBD).

Student nurses, do a four year comprehensive course at a nursing college in Gauteng province. This training includes training for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery, commonly referred to as (R425). Student nurses are expected to render care and rehabilitation to the mental health care users with profound

intellectual disabilities as part of the learning outcomes to be achieved during the clinical psychiatric placement. South African Nursing Council (SANC) Regulation R425 stipulates that the curriculum for the four-year course shall consist of Psychiatric Nursing Science (PNS) – at least for two (02) years. Within the two years of PNS exposure, students are placed for two weeks at the care and rehabilitation to make provision for care, treatment and rehabilitation to MHCUs which is in line with the Mental Health Care Act No. 17 of 2002 (South Africa:chapter III, 81-82). Placement of students is summarised in table 1.1.

Table 1.1 Student placement at the care and rehabilitation centre: 2014

Student placement at the care and rehabilitation centre for 2014 is as follows:

Ward	Number of MHCUs	Number of students allocated	Type of ward
02	19	09	Adult males – self-destructive and destructive to property, hyperactive, partially dependant, need constant supervision
05	20	09	Adult males – moderate self-care with minimal supervision
06	28	09	Adult females – moderate self-care with minimal supervision. Some fully dependant, self-destructive, hyperactive, need constant supervision
07	21	10	Female and male children – fully dependant and bedridden
08	14	10	Frail female and male adults, fully dependant and bedridden
09	14	09	Male children-fully dependant, self- destructive, rehabilitation possible, need constant supervision
Total	N=116	N=56	

R425 Students undergoing training at one of the nursing colleges in Gauteng are guided by the Gauteng Nursing Colleges Curriculum (2002:68) as amended. It stipulates that the provision of care should be in line with the scientific approach of the nursing process, which entails assessment, diagnosing, planning of nursing interventions, implementation and recording/reporting. The provision of care should also be in

accordance with the SANC Regulation (R2598) Scope of Practice which stipulates that student nurses should work under the direct and indirect supervision of a registered nurse and that student nurses are held responsible for their acts, and omissions as stipulated in SANC Regulation (R387). The provision of care should contribute towards the care and rehabilitation centre's vision, namely, "To be a model of excellence for the care of the severely and profound intellectually disabled care users in the province of Gauteng and National Department of Health (National Department of Health 2013-2014:1) strategic plan vision "A long and Healthy Life for all".

The researcher has observed that even though, all students rotate through the rehabilitation centre where mental health care users with profound mental health disabilities are, very few students on completion choose to work in such centres. These observations are further supported in a study at the University of Venda, where mothers shared their burden and lifelong pain of caring for their children with intellectual disabilities at home (Mudhovozi, Maphula & Mashamba 2012:148). Students verbally reported that they are scared to nurse MHCUs with PIDs and given a choice they would not want to be allocated to those care and rehabilitation centres. R425 Student nurses, after completion of the four-year course, are given choices where they would like to be placed in order to do their community service for a period of one year, as illustrated in the Table.

Table 1.2 College statistic of the community service placement

Table 1.2 shows the College statistic of the community service placement.

Year	Total number of	Gender		Total number of students
i oui	students	Female	Male	placed
2011	85	04	01	05 students
2012	155	04	01	05 students
2013	181	01	01	02 students
2014	147	05	03	08 students
Total	568	14	06	20=3,5%

Therefore, it is vital that students' experiences are heard and listened to so that their challenges can be easily identified.

Previous literature review indicated that there is limited research examining care, burden, coping strategies and experiences of carers and parents of children disabilities (CWD) in low countries, with little research in the African context (Gona et al 2011 as cited in McNally & Mannan 2013:01).

# 1.3 STATEMENT OF THE RESEARCH PROBLEM

According to Botma, Greeff, Mulaudzi and Wright (2010:53), a research problem is a situation in need of a solution, or improvement. Whereas, Bruce, Klopper and Mellish (2011:381), define research problem as a broad area of interest. The research problem of this study emanates from different sources such as clinical practice, nursing education and training, observation and previous research.

There have been numerous reports on nurses' shortage in the rehabilitation centres especially professional nurses (personal communication with the centre deputy manager 2013). According to Centre's 2013 situational analysis, the report indicated that in 2013 the centre lost eleven (11) professional nurses due through resignation. The main problems identified and solutions suggested by the Centre were as shown in table 1.3.

Table 1.3 Situational analysis results for the centre

Problem	Solution
Absenteeism due to ill health	Employee Wellness Programme referrals
Low morale staff	Incentive package introduced by the Executive
	Committee. Motto (DDD) to Drive, Discipline
	and Develop staff introduced
High staff turn-over (professional nurses) and	Research on possible areas that can enhance
retention of staff	attraction and retention of professional nurses
	in order to improve staffing and service
	delivery was recommended.

Previous research has shown that nurses' shortage has always been a consistent problem in mental health settings (Hercenlinskyj 2010:87), whereas Buerhaus, Donelan, Ulrich, Norman and Dittus cited in Allen (2008:35) stated that in general nursing shortage emerged in 1998 and peaked consistently in 2002. It is evident from the background information and literature review that caring for mental health care

users with profound mental disability is shunned and nurses are less interested in this field. Therefore, nursing shortage is thus considered to be a global crisis not only at the study area. According to the information in the study area there has been consistent high turnover of professional nurses within the period of two years due to transfers and some due to resignation and or taking promotions in other departments. Since 2010-2014 the study area lost twenty (20) professional nurses due to resignation, four (04) due to retirements and five (05) due to deaths.

During the clinical accompaniment of student nurses placed at the care and rehabilitation centre for the past four years (2010-2014), the researcher observed acute shortage to confirm what is in the centre's report. The student nurses and the registered nurses verbalized that there is a severe shortage of nurses' personal observation made by the researcher is that at the care and rehabilitation centre, exhibits low morale and burnout due to severe workload. This feeling was deduced from the nurses' statement of being tired, wanting to resign and looking for opportunities elsewhere.

Student nurses, after completion of the four-year course of training, are given choices where they would like to be placed in order to do their community service for a period of one year. Very few students since 2010 had willingly chosen the rehabilitation centre. This was an area of interest and of concern. According to the college statistics, the report indicates that since 2010-2014 only 3,5% students trained from this specific nursing college have chosen to work at the care and rehabilitation centre. It is on this premise that the study seeks to explore the experiences of fourth year student nurses in caring for mental health care users with profound intellectual disabilities. Previous research has stated that individuals with intellectual disabilities, regardless of whether they have physical disabilities, are often stigmatized encountering attitudinal and physical barriers in daily life (Murphy & Carbone as cited in Gaede & Surujlal 2011:344).

This study would hopefully assist in identifying what could be the barriers in attracting nurses to the care and rehabilitation centre.

# 1.4 THEORETICAL/META-THEORETICAL GROUNDING

For the purpose of this study, Leventhal's theory of Common Sense Model (CSM) will be used. The CSM works on the premise that the individual is "an active problem solver "and it has various title such as Common Sense Model of Illness Representation, Leventhal's theory and Self-Regulation Theory but for ease of communication it will be referred as Common Sense Model (CSM) (Diefenbach & Leventhal 1996:450).

According to Ward, Clark and Heldrich (2009:04) the Common Sense Model (CSM) postulates that individuals use common sense beliefs to construct lay theories, called representation of health threats or illness. These representations are based on ideas, attitudes, and beliefs formed by experience, cultural traditions, formal education, and stories from family and friends (Diefenbach & Leventhal 1996; Ward 1993). The seven key dimensions of illness representations as identified by CSM will be incorporated in this study, and these are:

**Identity:** Focuses on the ideas, beliefs, attitudes formed by experiences of 4<sup>th</sup> year student nurses in an accredited nursing education institution whilst caring for mental health care users in a care and rehabilitation centre in Gauteng province.

**Cause:** Refers to beliefs about the barriers and challenges faced by the student nurses in caring for mental health care users with profound intellectual disabilities.

**Timeline:** Relates to beliefs about whether the duration of two weeks clinical exposure was beneficial or not.

**Consequences:** Refers to the beliefs about the positive and negative outcomes achieved with regard to caring for users with profound intellectual disability and the belief about whether they would like to work there after completion given the choice.

**Cure/Controllability:** Refers to the belief about coping mechanisms that will assist student nurses develop worthwhile experiences. The beliefs about best practices that will assist student nurses develop positive interest in rendering health care service delivery to users with profound intellectual disabilities during training and after completion.

**Illness coherence:** Involves the meaning attached in relation to caring for users with profound intellectual disabilities.

**Emotional representation:** Refers to the emotional impact in response to caring for users with profound intellectual disabilities. The experiences about what and how did it feel like caring for users with profound intellectual disabilities. Furthermore, depending on the age, gender, race, cultural background, experiences, ideas, attitudes, beliefs of the student nurses, information might or might not differ.

#### 1.5 DEFINITION OF CONCEPTS

Key concepts used in the study are: care and rehabilitation centre; caring; mental health care users; nursing education institutions (NEIs), profound intellectual disabilities and student nurse.

#### 1.5.1 Care and rehabilitation centre

It means health establishment for the care, treatment and rehabilitation of people with intellectual disabilities (Mental Health Care Act No. 17 of 2002). (South Africa 2002:chapter 1). Rehabilitation comes from the Latin word habilitas, which means "to make able" (Carter 2012:668).

# **1.5.2 Caring**

Watson explains caring as a complex concept involving developmental of a range of knowledge, skills and expertise encompassing holism, empathy, communication, clinical competence, technical proficiency and interpersonal skills. Nursing is not a series of tasks to be performed but service driven by specific value systems regarding human caring. Her theory is based on assumptions about science of caring (Alligood 2010:111-112).

### 1.5.3 Mental health care user

Refers to a person receiving care, treatment and rehabilitation services; or using a health service at a health establishment aimed at enhancing the mental health status of a user (Mental Health Care Act No. 17 of 2002) (South Africa 2002:chapter 1).

# 1.5.4 Nursing Education Institution (NEIs)

It means a post-secondary educational institution which offers professional nursing education at basic and post basic levels where nursing education has been approved in terms of the South African Nursing Act No. 50 of 1978 section 15(2) as amended by Nursing Act No. 33 of 2005 (South Africa 2005).

# 1.5.5 Profound intellectual disability

It means a range of intellectual functioning extending from partial self-maintenance under close supervision, together with limited self-protection skills in a controlled environment through limited self-care and requiring constant aid and supervision, to severely restrict sensory and motor functioning and requiring nursing care (Mental Health Care Act No. 17 of 2002:section 1 as cited in Calitz 2011:68).

Profound intellectual disability is defined as an IQ below 20 or a developmental age below 2 years (Lambrechts et al 2009:623; Mudhovozi et al 2012:149). An IQ <20 is proposed for profound intellectual disability, although in reality this is not measurable using standardised tests.

Alternatively, marked discrepancies between chronological age and level of development have been proposed with functioning typical of the sensory motor period (0-24) used to identify profound intellectual disability, as well as criteria based on individuals' functional abilities (Fryers 1984 cited in Hogg, Juhlberg & Lambe 2007:367).

#### 1.5.6 Student nurse

It refers to a person on training at a registered accredited nursing education institution for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery in accordance with SANC Regulation R425.

# 1.6 OPERATIONAL DEFINITIONS

According to Bruce et al (2011:383), operational definitions assign meaning to variables precisely according to the meaning they have in the study.

For the purpose of this study, the following definitions will be used:

#### **1.6.1 Centre**

Centre refers to the institution where mental health care users are institutionalised to receive care, treatment and rehabilitation situated in Gauteng province Metsweding district.

### 1.6.2 Student

Student refers to a person on training at a registered accredited nursing college in Gauteng Province for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery according to SANC Regulation R425.

# 1.6.3 User

User refers to a mental health care user admitted at the selected care and rehabilitation centre, receiving care, treatment and rehabilitation in Gauteng province.

#### 1.7 RESEARCH AIM/PURPOSE

The purpose of this study will be to explore the experiences of student nurses in caring for mental health care users with profound intellectual disabilities incorporating the Common Sense Model.

#### 1.8 RESEARCH OBJECTIVES

The objectives of this study will be to

- describe the experiences of fourth year nursing students in caring for mental health care users with profound intellectual disabilities
- explore the meaning attached to caring for mental health care users with profound intellectual disabilities
- recommend best practices in caring for mental health care users with profound intellectual disabilities

#### 1.9 RESEARCH QUESTIONS

The research questions that the study intends to answer incorporating the seven dimensional representations of the Common Sense Model (CSM) are:

- What are the experiences of 4<sup>th</sup> year student nurses in caring for mental health care users with profound intellectual disabilities?
- What barriers/challenges are encountered in relation to caring for MHCUs with profound intellectual disabilities?
- What meanings are attached to caring for mental health care users with profound intellectual disability?
- What are best practice recommendations for retaining and attracting nurses in the care and rehabilitation centre?

# 1.10 RESEARCH METHODOLOGY

In this study a qualitative, descriptive, interpretive, exploratory and contextual research will be used. The methodology will be explained in more details in chapter 3.

# 1.11 ETHICAL CONSIDERATIONS

The goal of taking into account research ethics is to ensure that participants' basic rights are upheld and to minimise the risk to participants (Bak 2004:28; Bless, Smith & Sithole 2013:29). The following ethical principles will be upheld (Bless et al 2013:29-33):

#### 1.11.1 Permissions

Research Ethics Committees were set up to assess the ethical implications of studies which can otherwise be unknowingly detrimental to the lives of research participants. The code of ethics and its guidelines are concerned with the protection of human rights violation in research involving human subjects. (Parahoo 2006:112). For this study the University of South Africa (UNISA), Higher Degrees Committee reviewed the study proposal and granted clearance for the research (Annexure A). Permission to conduct the study was also sought and approved from the Department of Health in South Africa (Annexure B). The researcher further sought permission and approval was granted by the Rehabilitation Centre where the study was conducted (Annexure C). The researcher also sought permission and was approved from SG Lourens Nursing College (Annexure D). Lastly permission to conduct the interviews was sought and granted by the participants (Annexure F)

#### 1.11.2 Non-maleficence

Non-maleficence is referred to as the obligation not to do harm. The most basic principle of research is that participants must not be harmed by participating in the research activities. Confidentiality and the protection from invasion of privacy will be prioritised. Confidentiality will be maintained from data collection where participants will be interviewed individually at a time and place agreed upon by the researcher and the participants. Reflective diaries will not have the participants' name but a code identifier.

#### 1.11.3 Beneficence

Beneficence is referred to obligation to maximise possible benefits and to minimise possible harm (De Vos, Strydom, Fouché & Delport 2011:116). The potential risks to the participants from this study include stress from perceived victimisation from the

researcher, who is also their lecturer on sharing their experiences. The risks will be minimised through assurance and strict observance of confidentiality. During interviewing; should participants experience emotional harm and discomfort, the participants will be referred to counselling for debriefing and support.

#### 1.11.4 Informed consent

The researcher, in her capacity as a student of University of South Africa will first ensure that the Ethics committee grants permission to conduct the study. The purpose of the study, study duration and method of data collection will be explained to the participants in an understandable manner without deception. A well-detailed information leaflet was distributed to all the fourth year nursing students who are placed at the care and the rehabilitation centre so that they could make informed choices of participating or not participating.

Participants' right to make informed, voluntary decisions about study participation requires full disclosure. According to Polit and Beck (2008:172), full disclosure means that the researcher has fully described the nature of the study, the person's right to refuse participation, the researcher's responsibilities, and likely risks and benefits. Informed consent should be based on the right to self-determination and the right to full disclosure. Participants will be informed about the rights to withdraw if they wish so. Nobody should ever be coerced into participating in a research project, because participation must always be voluntary (Neuman 2003:124 cited in De Vos et al 2011:117). Participants who agreed to take part in the study sign the informed consent (Annexure F).

# 1.11.5 The right to self determination

This refers to prospective participants having the right to decide voluntarily whether to participate in a study, without risking any penalty or prejudicial treatment. Humans should be treated as autonomous agents, capable of controlling their own activities. It also means that people have the right to ask questions, to refuse to give information, or to withdraw from the study (Polit & Beck 2008:171-172)

# **1.11.6** Justice

According to Belmont Report, justice includes participants' right to fair treatment and their right to privacy (Belmont Report 1979:6). The selection of study participants should be based on research requirements and not on the vulnerability or compromised position of certain people. The principle of justice also guards against individuals who are unable to protect their own interest to ensure that they are not exploited for the advancement of knowledge. The right to fair treatment means that researchers must treat people who decline to participate in a study (or who withdraw from the study after agreeing to participate) in a non-prejudicial manner; that they must honour all agreements made with participants (including the payment of any promised stipends); that they demonstrate sensitivity to and respect for the beliefs, habits, and lifestyles of people from different backgrounds or cultures; that they give participants access to research personnel for any desired clarification; and that they afford participants tactful treatment at all times.

Participants' right to privacy should be maintained throughout the study. Participants have the right to expect that any data they provide should be kept in strictest confidence (Polit & Beck 2008:173-174).

#### 1.12 SIGNIFICANCE

The significance of this study is discussed under the short term benefits and the long term benefits.

# 1.12.1 Short-term benefits of this study

An in depth understanding of the experiences of student nurses on caring for mental health care users with profound intellectual disabilities will add value to the profession, nursing education and training and the practical application of Common Sense Model.

By exploring the experiences with participants, more information will emerge that will assist student nurses to develop worthwhile experiences essential for improving quality patient care during and after training. Findings of the study will be shared in research workshops and conferences.

In relation to the participants, this study will equip student nurses with knowledge that will enable them to better understand the needs of persons with profound intellectual disabilities.

# 1.12.2 Long-term benefits

The result of the study may form basis for further research which may ultimately improve quality of patients in the care and rehabilitation settings.

Nursing profession, education and training and the public will benefit at large, caring is the essence of nursing and it is of practical significance.

#### 1.13 SCOPE AND LIMITATIONS

The study is only limited to fourth year student nurses who are registered for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery R425. The participants are also drawn from one specific nursing education institution in Gauteng province who have been exposed to caring for mental health care users with profound intellectual disabilities in one of the care and rehabilitation centres in Gauteng province. Therefore, its generalisability will be limited even though conditions of rigour will be upheld.

# 1.14 CONCLUSION

Chapter 1 gave an overview of the study. The background of the study, statement of the problem the main purpose of the study with objectives and questions to be answered by this study was discussed. The significance of the study and the ethical principles adhered to in this study is given.

# **CHAPTER 2**

# LITERATURE REVIEW

#### 2.1 INTRODUCTION

The purpose of the literature review is to enable the researcher to gain in depth understanding of the topic studied in order to determine what is known and not known about the proposed topic. The focus of this study is on student nurses' experiences; caring, mental health care users (MHCUs); profound intellectual disabilities; care and rehabilitation centre; recruitment of nurses to the care and rehabilitation centre after completion; nursing colleges; and legal framework related to intellectual disabilities. The proposed study will be illuminated by application of the Common Sense Model. Previous study conducted in Tanzania recommends the need for further qualitative research in order to provide rich insights into the realities of care (McNally & Mannan 2013:01).

# 2.2 RECOLLECTED EXPERIENCES OF STUDENT NURSES INCLUDING OTHER CARERS

Negativity towards mental health nursing was mentioned by a group of nursing students and social workers who are both in direct entry mental health nursing programmes and tertiary based comprehensive programmes (Wells, Ryan & Mc Elwee 2000 cited in Hercelinskyj 2010:88). Furthermore, the authors also reported that students' negative experiences of their mental health nursing role was influenced by the negative publicity on mental health services and the mentally ill by nurses in other areas of practice, and also by media reports. Student attrition was influenced by the treatment and experiences students had during clinical placements and respondents became aware of the stress associated with nursing as they confront the reality of clinical practice. Students also became aware of wider systemic issues such as the lack of funding and resources as they progressed through their course. According to the study conducted in South Africa, the South African public health sector serves 75-80% of the population sustained by the very limited government funding (Zubi & Connolly 2013:81). Personal

observation made by the researcher upon reading students' reflective essays post clinical exposure to care and rehabilitation centre, reveals that students seem to be scared and become traumatic to care of mental health care users with profound intellectual disabilities. Care and rehabilitation centre falls within the mental health nursing or psychiatric nursing.

Given the options of clinical placement choices, the centre dealing with profound intellectual disabilities was going to be avoided. A recent investigation, which explored student nurses' attitude towards psychiatric/mental health nursing as a career, found that students were negative about the prospect of working in this area. The authors concluded that this was a direct result of negative attitudes towards mental health service users (Vijayalakshmin, Reddy, Math & Thimmah 2013:72; Johnston & Dixon 2006:01). Moreover, mental health institutions are faced with contemporary challenges of shortage of mental health practitioners, increased workload of existing staff members, raised levels of stress, fatigue, emotional exhaustion, all of which compromise the quality and safety of care (Zubi & Connolly 2013:81).

A finding of previous research has recommended the incorporation of Common Sense Model to reduce disparities in mental health and mental health care (Ward et al 2009:13). Not much is known about the experiences of student nurses when caring for mental health care users with profound intellectual disabilities integrating Leventhal's Common Sense Model.

Van Staden (2013:58) and Vijayalakshmi et al (2013:66) found that furtherance of better and positive attitude towards mental illness is a prerequisite for the provision of holistic care. However, Weber (2010:494) concludes that to change attitudes of staff in working with people with profound intellectual and multiple disabilities, support and vocational training courses to deal with challenging behaviour of staff's daily work is necessary. Student nurses also form part of the staff who works with profound intellectual disability and are therefore to be included in such training.

# 2.2.1 Experiences of mothers, parents and families

More negative experiences about caring for children with disabilities have been identified than the positive experiences (McNally & Mannaan 2013:01). Individuals with

disabilities, regardless of whether such disabilities are physical or intellectual, are often stigmatised, encountering attitudinal and physical barriers in daily life (Murphy & Carbone 2008 cited in Gaede & Surujlal 2011:344). Often, carers find it difficult to deal with their complex nature of their needs; they lack social skills and social competence. Resch, Mireles, Benz, Grenwelge, Peterson and Zhang (2010:140) state that the responsibilities of carers are physically demanding, affect social and family relationships, and adversely affect employment and indeed, the 'person-environment interaction' affect employment. This means that parents devote all their attention to assist their children meet activities of daily living. Few that reported on the positive experiences stated that it is fulfilling and worthwhile exposure to care for children with profound intellectual disability. Family support remains an important aspect in the lives of the children with intellectual disabilities.

However, families find it difficult to deal with the challenges of caring for children with such disabilities and rely on nurses together with student nurses to ease the burden. Previous research done in Scotland has shown that 60% of parents with a child with profound intellectual and multiple disabilities devote 18 hours a day on essential caring tasks and therapeutic and educational activities (Tadema & Vlaskamp 2009:42). Furthermore, parents were woken three times per night on average (Mencap 2001); this poses high levels of parental stress.

Mothers and parents experience dealing with profound intellectual disability as a burden, traumatic, lifelong pain and very stressful for caregivers in the family (Mudhovozi et al 2012:148; Gona et al 2011 as cited in McNally & Mannan 2013:01). Tadema and Vlaskamp (2009:42) state that parenting a child with profound intellectual disability and multiple disabilities is thus far from easy due to the intensity of care parents have to provide resulting from the multitude of problems children with profound intellectual and multiple disabilities exhibit. However, in a study of hope as a psychological resilience factor in parents of children with disabilities, Lloyd and Hastings (2009) cited in Aldersey (2012:02), found that hope predicted increased positive wellbeing of families and decreased their psychological distress.

According to a study conducted in Tanzania, Ambikile and Outwater (2011:02), caregivers of mentally ill children which include learning disorders/intellectual disabilities experience various psychological, emotional, social and economic challenges. The

study concludes that professional assistance, public awareness of mental illnesses in children, social support by the government, private sector, and non-governmental organisations (NGOs) are important in addressing these challenges.

# 2.2.2 Experiences of teachers

According to the study conducted in Bosnia and Herzegovina (BiH) of Memisevic and Hodzic (2011:706), a positive trend in teachers' attitude towards inclusion of individuals with profound intellectual disabilities was revealed. Teachers were willing to teach students. Furthermore, the study noted a slow decline in the number of students with mild intellectual disability who are enrolling in special schools (Buturovic 2008 cited in Memisevic & Hodzic 2011:701), and a greater number of students with moderate, severe and combined disabilities such as psychiatric and neurological disorders enrolling in greater numbers in special schools. This calls for a thorough reform of special education schools and their transformation into multisystem rehabilitation centres. This multisystem rehabilitation centre should not only provide educational support but also occupational therapy, speech therapy, psychological and medical supports to their students. The study concluded that teachers stressed the need for inclusion of additional training and positive legislation in order to feel confident and competent about the inclusion.

However, Evans, Howlett, Kremser, Simpson, Kayess and Trollor (2012:1102) discussed that positive legislation is far from achieving a rights based approach to service provision and Martin (2010:500), stated that even though the revised National Curriculum in Wales was put in place, teachers are still faced with the challenge of improving outcomes for learners with profound and multiple disabilities. According to a study conducted in South Africa, Western Cape Province, Murungi (2011:11-12), the duty to provide basic education for children with severe and profound intellectual disabilities under section 29(1) (a) of the South African Constitution and international laws such as The United Nations Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) is compulsory. However, the study reported that the effect of the decision is still a milestone away towards realising the educational rights of children with severe and profound intellectual disabilities.

#### 2.2.3 Student nurses

A student nurse refers to a person on training at a registered accredited nursing education institution for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery in accordance with SANC Regulation R.425. In this study student nurses refer to students who are doing fourth year at a nursing college in Gauteng province Tshwane district. Those that had the opportunity and clinical psychiatric exposure to take care of mental health care users with profound intellectual in a care and rehabilitation centre in Metsweding district, Gauteng province.

# 2.3 CARING

Caring for mental health care users is challenging and not easy (Tadema & Vlaskamp 2009:42). According to Watson's theory of human caring, caring remains a complex concept; it involves developmental of a range of knowledge, skills and expertise encompassing holism, empathy, communication, clinical competence, technical proficiency and interpersonal skills. Bruce et al (2011:51) and Alligood (2010:111-112) state that caring is the most valuable attribute that nursing has to offer. In the field of intellectual disability a wide range of knowledge is necessary to enhance quality of care to mental health care users suffering from profound intellectual disability. Caring is associated with mothering and parenting.

How caring, parenting and mothering are provided depends on the individual cognitive representation of the illness. In integrating the Common Sense Model (CSM) or Leventhal's theory, personal differences play a role in caring and mothering mental care users. Mothering a profound intellectual disability involves attending to daily activities and special education needed to improve mental health. Rogers (2011:563) suggests that mothering and intellectual disability is partnership rhetoric within mental health practice. This means that in caring and mothering for mental health care users with profound intellectual disability partnership and teamwork are necessary within health, education and social work professions to deal with emotional roller-coaster that carers experience. Student nurses undergoing training in an accredited nursing education institution are expected for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery in accordance with SANC Regulation R425 form part of the

partnership team in caring for intellectually disabled mental health care users attain the Quality of Life. According to Plato and Aristotle, Quality of Life (QOL) means "Happiness and Well-being" (Claes, Van Hove, Van Loon, Vandevelde & Schalock 2009:62), whereas in the field of intellectual disability, QOL defined in terms of gains in adaptive behaviour skills or increases in scores on intelligence tests (Campo et al 1997 cited in Claes et al 2009:62).

Eight QOL domains used in the field of intellectual disability to enhance an individual's well-being and quality improvement that have been validated in a series of cross-cultural studies (Claes et al 2009:64) are as follows:

# 2.3.1 Personal development (PD)

Student nurses as team players and care givers need to assess the need of the users and offer stimulation programme to users and families that will assist individuals meet activities of daily living. Student nurses attend to the daily needs of users such as bathing, feeding, mobility, toilet training, communication and environmental hygiene of users to enhance a sense of general well-being and happiness.

Van der Putten and Vlaskamp (2010:496) state that people with profound intellectual disabilities are at risk of being physically inactive, and information about motor activation in daily life is lacking. Vlaskamp and Van der Putten (2010:496), further elaborate that in residential care, opportunities to offer motor activities to people with profound intellectual disabilities seem not to be fully utilised. Nurses should be aware of the motor abilities people with profound intellectual disabilities have, and facilitate the person with profound intellectual disabilities to use these abilities optimally during daily life.

It is therefore important that student nurses develop stimulation programme that will promote personal development and enhance a sense of personal independence as a way of applying Common Sense Model of self-regulation.

# 2.3.2 Self-determination (SD)

To promote self-determination, student nurses' need to consider users' choices, decisions and control in order to promote quality improvement strategies. Users need to be treated like any normal people who have the right to be treated as unique individuals with one's own needs. They need to be allowed to utilise opportunities to develop one's potential and to exercise their rights and freedom to choose without any victimisation. Student nurses need to inform users of their rights so that they are well informed. The choices and decisions taken will be based on the information received. Whatever choices and decisions they take need to be treated with respect and dignity in order to promote Common Sense Model of self-regulation. A Previous study concluded that the quality of the communication is an essential factor contributing to the well-being of people with profound intellectual disability and self-determination in life (Chen & Chen 2010:496) and that satisfactory bodily hygienic care ensures a person's well-being. Dezonia (2010:494) highlights the need for formalised training on person centred strategies that direct support workers (DSW) can use to guide their decision making when working with individuals with profound intellectual disabilities. Training will equip DSW with the necessary skill to stimulate the users' Common sense which is a challenge.

# 2.3.3 Interpersonal relations (IPR)

Mental health care users with profound intellectual are human beings who deserve to make friendship with anyone without any form of abuse or degradation. Uys and Middleton (2014:148) state that they have the right to relationships, holidays, a normal routine for every day or week and recognition of personal events such as birthdays. To promote the high interaction between staff and mental health care users, nurses need to make time to play and communicate with users. During specific activities, a staff interactive style like Multisensory Storytelling (MSST) might be of good benefit to achieve high-quality interaction.

According to Penne, Ten Brug, Van der Putten, Vlaskamp and Maes (2012:167), Multisensory Storytelling (MSST) is an individualised activity suitable for people with profound intellectual and multiple disabilities in which a story is being told with an emphasis on sensory experiences and social interaction. Stories contribute towards

learning and development and people grow up with stories and storytelling. Stories can be stimulating for language and communication.

The story should be adapted to the possibilities, age and interest of users with profound intellectual disabilities. Nurses should develop a personalised story which reflects personal experiences, life and individual's personality.

According to Penne et al (2012:168), the story should be kept short, and kept to a maximum of 15 sentences because of a shorter attention span of users with profound intellectual disabilities. Simple language should be adapted as far as possible to the person's age and cognitive abilities. Telling the story regularly, in the same form and the same wording, might contribute to the recognisability for the person and stimulate the comprehension. A paragraph in the story should be explained by an object of reference. The object should draw the person's attention, invite users to exploration and support meaning making.

It is illustrated by the study of Petry et al (2005) cited in Hostyn, Petry, Lambrechts and Maes (2011:407), that personal relationships was found to be the only domain crucial for the quality of life of persons with profound intellectual disabilities. Chen and Chen (2010:496) concluded that the priority of bodily care is hygienic care which allows for social interaction between caregiver and people with profound intellectual disability. This means that good personal hygiene has a positive influence on the promotion of good interpersonal relationship. Therefore, students as part of their daily work of caring for mental health care users should ensure that users are clean and tidy on a daily basis.

## 2.3.4 Social Inclusion (SI): Community integration/participation

People with profound intellectual disability often suffer the chronic restriction of freedom and dehumanisation due to institutionalisation in care and rehabilitation centres for life (Uys & Middleton 2014:148).

This means that they are kept in the institution for life excluded from social inclusion and community participation. According to Uys and Middleton (2014:548), people with intellectual disability are not readily accepted in the community at the best of times, and to be further handicapped by unacceptable behaviour is an almost certain recipe for

rejection. Due to the complex nature of intellectual functioning, they communicate usually in a pre- or proto-symbolic way, using subtle facial or bodily expressions and vocalisations that are difficult to interpret (Penne et al 2012:174-175). Therefore, Gross (2010:497) concludes that giving people with disabilities the opportunity to access literature in an inclusive community has positive changes in social interaction and overall comfort for being in the community.

It is important to listen to the individual stories of people with disabilities to allow them to tell us what it means to be empowered. Student nurses need to stimulate users in activities that will promote communication and social skills.

Much of the care and treatment of people with intellectual disability has to do with stimulation; teaching and helping to unlearn negative behaviours. Users with profound intellectual disability need to have fun and pleasure. Uys and Middelton (2014:581) mention that various modalities for promoting socialisation and preventing institutional neurosis can be used in institutions where people with intellectual disabilities live permanently.

Multisensory storytelling (MSST) can be used by the students whereby>when stories are told to users with profound intellectual disabilities, adapted to their possibilities, age and interests. It refers to the emphasis on sensory experiences of what is being told and contributes to the recognisability for the person and stimulate apprehension (Penne et al 2011:168). Storytelling positively engages people with profound intellectual disabilities and their carers and highlights the educational value of their use (Young, Lambe, Fenwick & Hogg 2010:497). The content of MSST-books focuses on the daily life experiences of the users and direct supporters can construct a book according to guidelines. However users find it difficult to follow the guidelines when reading. Ten Brug, Van der Putten and Vlaskamp 2010:498 and Wilder and Graniund (2010:499) conclude that there may be few links between child characteristics/dyadic interactions and family accommodations/social networks. The results of the study indicate that children with profound intellectual and multiple disabilities may not participate fully in family life.

## 2.3.5 Rights (R) Human and legal

In caring for users with intellectual disability, student nurses need to implement quality improvement strategies that take into consideration the right of the individuals with intellectual disabilities.

The Common Sense Model posits that an individual is "an active problem solver" and this implies that student nurses will make necessary adjustments and take actions that consider human rights based approach. The Common Sense behaviour and actions are self-regulated by personal types and personal differences as well as social, environmental and cultural influences.

Human rights are universal. A health system is meant to work and produce positive outcomes for everyone as outlined by the National Department of Health's (2013-2014) development vision. In South Africa there are a number of policies, acts and regulations that prohibit any form of abuse, exploitation, maltreatment and unfair discrimination (Constitution of South Africa No. 108 of 1996 Section 28, The child care Act No. 38 of 2005 as amended, Mental Health care Act No.17 of 2002, Nursing Act No.33 of 2005, National Health Act No. 61 of 2003, Patient Rights Charter (DOH 2002), Batho Pele Principles. A human rights-based approach is essential for the development and provision of mental health services with intellectual disabilities. These include improved policy with measurable outcomes, improved service access via clear referral pathways and the sharing of resources across disability and mental health services, and improved service delivery through training and education initiatives for both the mental health and disability workforce (Evans et al; Kayess & Trollor 2012:1098). The rights of the intellectually handicapped as outlined by Steenkamp and Steenkamp (1992:137) are as follows:

- Right to love and understanding.
- Right to adequate nutrition and medical care.
- Right to free education.
- Right educational, training and rehabilitation programmes to enable his/her to develop the highest potential no matter how severe his/her degree of disability.
- Right to be evaluated objectively by qualified expert.

- Right to live with his/her parents at home or to be accommodated in an institution.
- Right to name and nationality.
- Right to full opportunity for play and recreation.
- Right to protection from exploitation, abuse and degrading treatment.
- Right to be among the first to receive relief in times of disaster.

According to Uys and Middlleton (2014:148), dehumanisation denies people with intellectual disabilities of their basic rights.

## These rights are:

- The right to live as normal a life as possible, for example the right to relationships, holidays, a normal routine for every day or week and recognition of personal events such as birthdays.
- The right to privacy.
- The right to be treated as a unique individual with one's own needs.
- The right to be treated with dignity.
- The right to utilise opportunities to develop one's potential. The African Schools
  Act 84 of 1996 as amended which governs the education of intellectually
  disabled children, states that it is seldom possible to provide inclusive education
  for the more profoundly affected children.
- The right to a reasonable quality environment.

Therefore, student nurses need to be aware of the users' rights and make users aware of their rights. Users with profound intellectual disability are often unaware of their right and any form of violation of their rights. In an attempt to educate people with intellectual disability about their rights, Community Living Welland Pelham (CLWP), an Association for Community Living in alliance with researchers from Brock University, developed the 3R's; Rights, Respect and Responsibility Human Rights Project (Mullins 2009:12). Student nurses in an attempt to educate users with profound intellectual can follow and develop the 3R's approach. However, Siska (2010:501) has revealed that people with severe disabilities face typical and specific risks of discrimination in all areas of life, but to a different extent. Du Plessis (2007:413) and Nkuepo (2011:06) highlight that women with disability suffer multi-layered discrimination or injustice than disabled men. Women

are forced to undergo sterilisation for various reasons; including menstrual management and personal care (Wilson et al 1994 cited in Nkuepo 2011:07), prevention of pregnancy and pregnancy caused by sexual violence (Australian Family Law Council 1994) and this is a global and general issue in South Africa. This could be attributed to a dominant patriarchal system, as well as varying degrees of racism, conservative traditionalism, fundamentalist religious interpretations and class inequalities.

The South African Constitution recognises the right of everyone to have access to health care services and reproductive health care, and it calls on the state to take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of the right to health care (Constitution of the Republic of South Africa, Section 27). Research has shown that medical practitioners are often human rights violators, to the extent that they administer degrading and humiliating treatment to impaired women (Degenaar 2000 cited in Nkuepo 2011:09). The right to health is indispensable for the enjoyment of other rights (UN ECOSOC 2000 cited in Evans et al 2012:1099). This study further states that the inequitable health status with intellectual disability is more evident in the area of mental health and despite their high risk of mental illness, only a minority group of people with an intellectual disability receive appropriate care. This means that people with intellectual disability get poorer health compared to other people without disability.

# 2.3.6 Emotional well-being (EMB): Safety and security

People with profound intellectual disability are the most vulnerable due to long term institutionalisation in a care and rehabilitation centre. Uys and Middleton (2014:148) explain that the chronic restriction of freedom may lead to the dehumanisation of the mental health care users which in turn results in phenomena such as regression, aggression and masturbation.

To promote the emotional well-being of mental health care users, the student nurses need to address the mental health needs of users with profound ID to ensure that their human rights are upheld like those of all other citizens (Evans et al 2012:1098). Often mental health care users with profound intellectual disabilities find it difficult to communicate their feelings of displeasure and tensions due to poor communication skills. Penne et al (2012:174) state that persons with profound intellectual disabilities

usually communicate in a pre- or proto-symbolic way, using subtle facial or bodily expressions and vocalisations that are difficult to interpret.

Nurses need to understand and develop insight on how users with profound intellectual disability express their emotions in order to address their emotional needs properly. Petry et al (2005), Forster and Icano 2008 cited in Hostyn et al (2011:408) illustrated that meeting a person's need play a central aspect of basic security and to develop positive affective relationship.

A high intensive interaction approach is needed in order to establish a positive emotional climate. The establishment of rapport between nurses and users is vital for the development of an affective and reciprocal therapeutic relationship. People with PID rely on nurses for safe and consistent care giving relationships for support. Due to the complex nature of their motor and sensory needs, often they find it difficult to communicate their feelings and lack a sense of urgency. These result to deregulation of affect and helplessness. Gregorowski and Seedat (2013:2) explain dysregulation of affect include emotional lability, numbing, difficulty identifying and verbalising affective states and poor communication of needs (Van der Kolk 2005; Ford & Courtois 2009). The resulting helplessness can lead to excessive clinginess, excessive anxiety, internally or externally directed aggression and dissociation (Cook et al 2005; Van der Kolk 2005, Bailey, Moran & Pederson 2007 cited in Gregorowski & Seedat 2013:2) whereas with institutionalised users most common problems are hyperactivity, aggression, absconding and self-mutilation (Amam & Singh 1983 cited in Uys & Middleton 2014:585).

According to Uys and Middleton (2014:585-586), research has indicated that users with profound intellectual disability display negative behaviour to achieve social goals and express frustration. To decrease the problem behaviour, self-care and social skills training are therefore important. Uys and Middleton (2014:559) also state that contingency management is key in managing negative behaviour, which means that positive or desired behaviour followed by a reward and that negative or undesirable behaviour is not followed by a reward. A social reward such as smile and physical reward such as giving a user a cookie can be used to reinforce positive behaviour. If users throw temper tantrums modify the behaviour by not giving attention and reward.

These will enable users to achieve quality of life and to develop a sense of selfregulation of negative behaviour.

# 2.3.7 Physical well-being (PHWB): Health and nutritional status

It is illustrated by the study of Nakken and Vlaskamp (2002), Petry and Maes (2007) cited in Hostyn et al (2011:407) that people with profound intellectual disability are almost totally dependent on other people to attain an optimal life quality and wellbeing, because of their complex needs.

Student nurses are placed at care and rehabilitation centres to assist nurses in ensuring that physical needs of users are met. They assist in activities of daily living such as bathing, feeding and toilet training.

People with profound intellectual disability have the right to live as normal a life as possible. For example, a normal routine for every day or week without any deprivation. Students need to teach and stimulate users to promote independency on self-care practices even though it is a challenge with profound intellectual disabilities.

Observation and assessment are of great significance before teaching any skill. Uys and Middleton (2014:559-579) mention that the most important key aspects is the promotion of self-care. Reward and praise is vital in order to reinforce positive behaviour.

# 2.3.8 Material well-being (MWB): Financial status, employment

Goldberg (2000) cited in Uys and Middleton (2014:583) suggests that people with intellectual disability should be prepared for the world of work throughout their lives. Due to the complex nature of users with profound intellectual disabilities, preparing users for world of work is difficult and as a result social support system and financial assistance programme (disability grant) may be of benefit to the users.

Household chores can be taught to encourage self-care and independent living skills. Chores should be introduced one at a time until competence is reached and offer reward and compliments to improve the self-esteem. The use of ward routine programme is of benefit as users tend to adjust better with routine.

Often users with profound intellectual disability are physically inactive, therefore involving users in ward routine will promote physical activity. According to Uys and Middleton (2014:585-586), a review of studies indicates that only a third of intellectually disabled engages in adequate physical activity and this results in many health problems related to inactivity. It is therefore important that health promotion receives adequate attention, and such health promotion should include a strong focus on physical activity. Even though training profound intellectual disabilities is a challenge, students can teach simple social skills such as making positive physical contact such as holding hands, or returning an item, or greeting a person. A simple self-care skill such as being able to get something to drink or to eat can greatly reduce discomfort and frustration. However, learning is dependent on intellectual capacity and special skills and techniques. Uys and Middleton (2014:558) mention that the effective teaching behaviours when working with people with intellectual disability such as removing distractions from the teaching environment, for instance other people with noises, ensuring basic needs, such as toileting, are attended to first, before commencing teaching and ensuring eye-contact by positioning yourself at the level of the patient and within his/her direct view are key.

## 2.4 INTELLECTUAL DISABILITY

Different names are used interchangeably to explain intellectual disability which includes mental retardation, mentally handicapped, learning disabilities and mentally disabled.

Defining intellectual disability remains a complex issue and a variety of explanation exits. However, Nkuepo (2011:06) argues that disability has a negative connotation. The word 'impairment' should be used instead of 'disability'. This is still a challenge as many national laws even in South Africa still continue to use the word 'disability' instead of 'impairment'. According to the study conducted in Tanzania, the study defines intellectual disability as a cultural creation: disability status depends less on the nature or degree of a person's impairment and more on societal standards for normative bodies, minds, behaviours, and roles (Armstrong & Fitzgerald 1996; Ingstad & Whyte 1995 cited in Aldersey 2012:02).

Furthermore, the study defined intellectual disability as a condition for someone whose intellectual function and adaptive behaviour (everyday social and practical skills) differs significantly from what is normative in his or her society (American Association of Intellectual and Developmental Disabilities (AAIDD) 2011 cited in Aldersey 2012:02). This definition is closely linked with the American Association of Mental Retardations which reads as follows: "A disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. Adaptive behaviour is the collection of conceptual, social, and practical skills that people have learned so they can function in their everyday lives. Significant limitations in adaptive behaviour impact a person's daily life and affect the ability to respond to a particular situation or to the environment" (Calitz 2011:68).

According to the International Classification of Disease (ICD-10) cited in (Calitz 2011:68), mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the development period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.

Mental retardation, according to the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM-IV-TR), is defined as significantly sub-average general intellectual functioning (having an IQ of 70 or less) that is accompanied by significant limitations in adaptive functioning in at least two of the following skills areas: communication, self- care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. The onset must occur before age eighteen years.

According to Diagnostic and Statistical Manual for Mental Disorders, 5<sup>th</sup> edition, text-revision (DSM-V-TR), mental retardation is classified into four main categories including their IQ scores (Heward 2006 cited in Mudhovozi, Maphula & Mashamba 2012:149; Uys & Middleton 2014:538).

- Mild mental retardation, IQ score is 50-55 to approximately 70-75
- Moderate mental retardation, IQ score is 35-40 to 50-55
- Severe mental retardation, IQ scores: 20-25 to 35-40
- Profound mental retardation, IQ score is below 20-25 (Murungi 2011:10)

## 2.4.1 Profound intellectual disability

According to Mental Health Act No. 17 (South Africa 2002:chapter 1xxxvi), severe or profound intellectual disability means a range of intellectual functions extending from partial self-protection skills in a controlled environment through limited self-care and requiring constant aid and supervision, to severely restricted sensory and motor functioning and requiring nursing care. The Mental Health Care Act does not make mention of the Intelligence Quotient (IQ) scores to determine the severity of the intellectual disabilities. However, defining profound intellectual disabilities remain a complex issue. A variety of definitions exists and in conventional classification systems an IQ below 20 is proposed for profound intellectual disabilities (Hogg et al 2007:367; Murungi 2011:10; Uys & Middleton 2014:538) and in reality this is not measurable using standardised tests. The IQ means an expression of a person's mental age as a percentage of the chronological age and the mental age is usually equal to the chronological age (Calitz 2011:70). A mental health care user with profound intellectual disabilities has an IQ score below 20 and may have a mental age of 0-2 years (Lambrechts et al 2009:623). This means that there is no correlation between the chronological age and mental age, irrespective of their chronological age; even though they are old they will function similar like a two (02) year old child. The incorporation of the seven dimensions of Common Sense Model of self-regulation of health and illness to explain intellectual disability (Ward et al 2009:04).

# 2.4.1.1 Identity/symptoms

Intellectual disability is an illness and a health threat. It is classified into categories to differentiate the degree and severity of intellectual disability. Profound intellectual disability is proposed as an IQ < 20 using the standardised test. Alternatively it is explained as marked discrepancies between chronological age and level of development with a functioning typical of the sensorimotor period (0-24 months) based on individuals' functional abilities (Fryers 1984 cited in Hogg et al 2007:367; Lambrechts et al 2009:623).

Persons with intellectual disability have slow cognitive development which means that they have difficulties with reasoning, problem-solving, remembering, generalising,

learning and education, language and compliance with the demands and expectations of society (Gulliford & Upton 1992; Stakes & Hornby, 1997 cited in Olivier & Williams 2005:20-21). Greenspan and Shoultz (1981) cited in Tekinarslan, Pinar and Sucuoglu (2012:2783) state that cognitive limitations of individuals with mental retardation adversely affect their decision making about how to behave in some certain situations (Huang & Cuvo 1997). It is related to magnitude and multitude of disabilities. They need heavy or total dependence on personal assistance for physical care, education, stimulation and recreation. According to Tadema and Vlaskamp (2009:42), they have severe intellectual and physical disabilities combined with sensory impairments (Ferguson et al 1996; Logan et al 2001; Vlaskamp 2005).

Apart from their cognitive, motor and sensory impairments, they are at risk of developing several additional health problems. Almost all children with profound intellectual disabilities have physical difficulties such as food ingestion that prompts use of gastrointestinal feeding tubes (Zijlstra & Vlaskamp 2005 cited in Tadema & Vlaskamp 2009:42). Epilepsy is alsocommon (Hogg 1992 cited in Tadema & Vlaskamp 2009:42). Many suffer from gastro-oesophageal reflux (Bohmer et al 1999 cited in Tadema & Vlaskamp 2009:42), which leads to chronic respiratory disorders and recurrent pneumonia. Respiratory disease was found to be the principal cause of death according to a study done in Scottish region (Hogg et al 2007:366).

Dysphagia, constipation, osteoporosis, and contractures are frequently observed health problems (Veugelers 2006 cited in Tadema & Vlaskamp 2009:42).

Sleep disorders are common (Didden et al 2002 cited in Tadema & Vlaskamp 2009:42).

### 2.4.1.2 Cause

Gecz et al (2009:308) mention that the cause of ID is idiopathic with an assumed genetic basis linked to X chromosome genes. According to Kids Health Organisation (2002:120), some problems that can cause intellectual disabilities are:

Genes are inherited from both parents, so a baby might receive genes that are abnormal or the genes might change while the baby is developing.

There could be a problem during pregnancy. Sometimes, the mother gets an illness or infection that can harm the baby. Taking certain medicines while pregnant can cause problems for the baby. Drinking alcohol or taking illegal drugs can also damage a baby's developing brain.

During childbirth, the baby doesn't get enough oxygen. After being born, the baby gets a serious brain infection. Any time in life, a serious head injury can hurt the brain and cause intellectual disabilities. Some of these disabilities are temporary and others can be permanent. (That's why it is important to wear your bike helmet and always wear a seatbelt in the car.)

### 2.4.1.3 Timeline

The intensity of care needed for users with profound intellectual disability is more complex than the general nursing care. Caring for users is highly intensive and long lasting. It is estimated that parents averagely devote 18 hours a day on essential caring tasks and wake three times per night Tadema and Vlaskamp (2009:38).

# 2.4.1.4 Consequences

Users with profound intellectual disability have a heavy and a total dependence on personal assistance for physical care, education, stimulation and recreation as mentioned by (Tadema & Vlaskamp 2009:42) due to their complex nature of their needs.

## 2.4.1.5 Cure or controllability

Users with profound intellectual disability are put on treatment to deal with multiple disabilities and other challenging behaviours. Intensive interpersonal relationship plays a major role in controlling users with profound intellectual disabilities. Challenging behaviour has been considered to be functional and adaptive, shaped through interaction with the physical and social world, more precisely through the environmental consequences (Emerson 2001; Hall et al 2003 cited in Lambrechts et al 2009:621).

According to a study conducted in South Africa, Gaede and Surujlal (2011:353) conclude that structured recreation activities contribute significantly to their Quality of Life (QOL). Recreation activities provide opportunities to attain a healthy optimistic lifestyle and contribute towards emotional wellbeing. Recreation activities should be compatible with the needs and experiences of the users with profound intellectual disabilities to allow participation and co-operation.

### 2.4.1.6 Illness coherence

Challenging behaviour of profound intellectual disabilities has been defined as 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy. It could also mean behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Lambrechts et al 2009:621).

## 2.4.1.8 Emotional representation

The challenging behaviours of users with profound intellectual disabilities elicit negative emotions. The users display self-injurious behaviour, stereotyped behaviour and/or aggressive/destructive behaviour (Lambrechts et al 2009:620).

### 2.5 CARE AND REHABILITATION CENTRE

People with an intellectual disability are often admitted to care and rehabilitation centres for life (Uys & Middleton 2014:148). Presently there is one state care and rehabilitation centre to cater for people in Gauteng province and the rest being Non-Governmental Organisation (NGO) community centres and semi-private institutions. institutionalisation has taken place (Wiesel 2009:603), with the closure of the state run institution in the East Rand region and a move towards the community care model of service provision. Often parents find it difficult to provide care to children with intellectual disabilities at home. Previous research done in Scotland showed that 60% of parents who cared for their children at home devoted 18 hours a day on essential caring, therapeutic and educational tasks and activities. Furthermore, parents were woken up three (03) times per night on average (Mencap 2001 cited in Tadema & Vlaskamp 2009:42). This means that parents never have time for themselves and this might be a

lifelong burden and stressful to their daily lives. Therefore, institutionalisation in a care and rehabilitation centre assists to reduce the burden and heavy load.

According to Mental Health Care Act No. 17 of 2002 (South Africa 2002:chapter 1v) of South Africa, care and rehabilitation centres mean health establishments for the care, treatment and rehabilitation of people with intellectual disabilities. Health establishment means institutions, facilities, buildings or places where persons receive care, treatment, rehabilitative assistance, diagnostic or therapeutic interventions or other health services and include facilities such as community health and rehabilitation centres, clinics, hospitals and psychiatric hospitals (Mental Health Care Act No. 17 of 2002) (South Africa 2002:chapter 1xii).

Therefore, they get admitted to care and rehabilitation centre for care, treatment and rehabilitation centre. The Children's Act Section 150 defines a child in need of care and protection as those who display behaviour which cannot be controlled by the parent or caregiver; has been exploited or lives in circumstances that expose the child to exploitation; lives in or is exposed to circumstances which may seriously harm that child's physical, mental or social well-being; may be at risk if returned to the custody of the parent, guardian or caregiver of the child as there is reason to believe that he/she will live in or be exposed to circumstances which may seriously harm the physical, mental or social well-being of the child (South Africa 2007). However, Horan (2004:29) states that the environment with which intellectual disability nursing takes place is often quite different from generalist nurse settings and hinders application in the sense that the self-care model (Orem 2001 cited in Horan 2004:28) was too complex to be applied successfully to the needs of those with intellectual disability. The care is for the integration of users within the community with a goal of normalisation (Uys & Middleton 2014:580; Horan 2004:29). Normalisation principle is applicable to individuals where people live permanently in order to promote socialisation and prevent institutional neurosis.

### 2.6 MENTAL HEALTH CARE USER

Mental health care user refers to a person receiving care; treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user. Where the person concerned is below the age of 18

years or is incapable of taking decisions. In certain circumstances may include; prospective user and the person's next of kin. In this literature study mental health care users refer to users admitted in care and rehabilitation centre that deals with profound intellectual disability.

### 2.7 NURSING COLLEGE

A nursing college is a nursing education institution (Hercelinskyi 2010:87). It is a post-secondary educational institution which offers professional nursing education and training programmes at basic and post-basic levels where nursing education has been approved in terms of the Nursing Act No. 50 of 1978 section 15(2) as amended by Nursing Act No. 33 of 2005 (South Africa 2005). The nursing college is a founded establishment or organisation consisting of a building or complex of buildings and its associated resources. Students are exposed to integration of theory and practice with regard to mental health through the nursing college as a mechanism to assist nursing students in coming to view mental illness and the mentally ill more objectively (Hercelinskyi 2010:87). Furthermore, the study explains that the challenge for the higher education sector and the healthcare industry is to promote different discipline specific areas and encourage students to consider their career options.

# 2.8 RECRUITING OF STUDENT NURSES TO CARE AND REHABILITATION CENTRE AFTER COMPLETION OF TRAINING

Much research has been done about intellectual disability. However, the research concentrated more broadly on the intellectual without specifying the degree of the severity of the condition. In this study the researcher intends to concentrate more on profound intellectual disability. The researcher observed that after completion of the four year course, that is, Diploma in Nursing (General, Psychiatric and Community) and Midwife in accordance with SANC Regulation R425, students are reluctant to work in care and rehabilitation centres that deals with profound intellectual disability. According to institutional statistics where students undergo training, only 2,8% of all completing students since 2011-2012 have chosen to work at the care and rehabilitation centre that deals with profound disabilities. Previous research indicated that individuals with intellectual disabilities often are stigmatised encountering attitudinal and physical barriers in daily life (Murphy & Carbone cited in Gaede & Surujlal 20011:344).

Recruitment of nurses in mental health continues to be a consistent challenge (Hercelinskyj 2010:87) compromising nurses' shortage, care and quality of patient care. According to a study conducted in South Africa, regardless of the introduction of community service for health care professional which was intended to reduce challenges, mental health care still faces understaffing, staff attrition and reduced job satisfaction (Zubi & Connolly 2013:81). According to the 2013 situational analysis report of the centre, the centre is faced with the challenge of absenteeism, low morale of staff and high staff turnover. The centre recommended research on the current challenges faced. Van Staden (2013:58) encourages experts-by-training and experts-by-experiences to embark on new frontiers by which mental health and attitudes towards mental illnesses and difficulties may be improved. It is within the present study that the researcher aims to explore the experiences of student nurses on caring for mental health care users with profound intellectual disabilities.

Incorporating the Leventhal's Common Sense Model in order to identify the barriers to the ill preparedness of student nurses after completion to work in care and rehabilitation centres so as to better attitudes and improve difficulties towards caring for users with profound intellectual disabilities. Failing which it will compromise the centre's vision to be a model of excellence for the care of the severe and profound intellectual disabled mental health care users in Gauteng province and the National Department of Health vision "A Long and Healthy life for all".

# 2.9 CONCLUSION

Even though previous researches have been conducted and a body of literature exists about intellectual disability, challenges continue to emerge pertaining to caring for mental health care users. Despite growing body of literature most researchers have failed to address the experiences of student nurses caring for mental health care users with profound intellectual disability integrating the Leventhal's Common Sense Model of self-regulation of health and illness.

Caring for mental health care users with profound intellectual disability is never an easy task at all. More negativity has been reported than positivity regarding caring for these users. Normally, it is expected of a normal person as he continues to grow, to be able to attend to his basic needs such as feeding, dressing, bathing, and walking

independently. This is not the case forth is group. Apart from the cognitive, intellectual, motor and sensory impairments, multiple of disabilities still exist which poses a health threat as mentioned by the Leventhal's Common Sense Model of self-regulation. They have physical difficulties with food ingestion (dysphagia), gastro-intestinal reflux which may need gastro-intestinal feeding tubes, epilepsy, chronic respiratory disorders, recurrent pneumonia, constipation, osteoporosis, contractures. Therefore, nurses including student nurses need to constantly attend to the basic needs such as eating, drinking, bathing, dressing, and changing, lifting and positing care to assist users with profound intellectual disability develop sense of self-regulation and well-being. This group is totally dependent on the individuals to achieve optimal Quality of life (QOL) hence Tadema and Valskamp (2009:42) mention that caring for people with profound intellectual disability is regarded as both highly intensive and long lasting. These group of people need to be treated with respect and dignity. Often they are treated with little interest or sympathy, with uneasiness, fear, embarrassment and /or even disgust. Rights are universal to all. Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) cited in (Evans et al 2012:1099) specifies the right to health for people with intellectual disabilities and is indispensable for the enjoyment of other rights.

## **CHAPTER 3**

# **DESIGN AND METHODOLOGY**

## 3.1 INTRODUCTION

The purpose of this chapter was to provide the overview of the research methodology that the researcher took into consideration in order to obtain information about the experiences of student nurses caring for mental health care users with profound intellectual disabilities. The research design, research methodology, data collection, data analysis and conclusions were discussed in detail in order to ensure trustworthiness and to maintain rigour in the study.

### 3.2 RESEARCH DESIGN

Research design is the overall plan or blueprint that the researcher undertakes for carrying out the study (Bruce et al 2011:384). Furthermore, a research design is concerned with whether the research methods of data collection and analysis are of high quality. The purpose of a research design is to ensure that it relates directly to the answering of a research question (Bless et al 2013:130-131). For the purpose and objectives of this study, a qualitative design was used in order to explore the experiences of student nurses caring for mental health care users with profound intellectual disabilities and to recommend the best practices in caring for mental health care users with profound intellectual disabilities.

### 3.3 DEFINITION OF QUALITATIVE DESIGN

According to Botma et al (2010:211), a qualitative research provides in depth exploration and description of a phenomenon that differs from the broad explanation that quantitative research provides. Qualitative research is anti-positivistic, idiographic, holistic in nature with non-statistical methods and small samples, often purposively selected (De Vos et al 2011:65). According to Grove, Burns and Gray (2013:23), qualitative research is a systematic, interactive, subjective, holistic approach used to

describe life experiences and give them meaning. In this study, expressed views were used to qualify and record information about the experiences of student nurses caring for mental health care users with profound intellectual disabilities. The researcher's primary motivation was to use the applied research in order to assist solve a particular problem facing the care and rehabilitation centre in Metsweding district (Gauteng province). The problem was that after completion it seemed like students were less interested in working at the centre that cares for the mental health care users with profound intellectual disabilities. Applied research is referred to the study that is concerned with seeking solution of a practical problem (Botma et al 2010:53; De Vos et al 2011:65). Furthermore, applied research is often achieved by applying basic research findings to a particular community's challenge (Bless et al 2013:59).

# 3.3.1 Nature of qualitative research

A qualitative research that is exploratory, descriptive, interpretive and contextual in nature was used with the goal of applied research.

# 3.3.1.1 Descriptive research

Descriptive research produced data in the participant's own written or spoken words. It refers to a more intensive examination of phenomena and their deeper meanings, thus leading to thicker description (De Vos et al 2011:65, 96). In this study, the researcher was interested in finding the participants' opinion about caring for mental health care users with profound intellectual disabilities and the impact of the experiences after placement and completion of training. According to Bless et al (2013:61), descriptive research uses different ways of collecting data in order to obtain a variety of information. In this case participants described their experiences in caring for mental care users in written and spoken words and, stated whether they would like to be placed at the centre after completion or not.

Words and sentences from the recorded in depth interviews, reflective diaries, field notes and participant observation were used in order to obtain thick descriptive data and a comprehensive summaries of the student nurses' experiences in caring for mental health care users with profound intellectual disabilities in everyday language. Botma et

al (2010:194), state that qualitative descriptive design tends to be eclectic and is based on the general premises of naturalistic inquiry.

## 3.3.1.2 Explorative research

According to Botma et al (2010:196), explorative research is used when the researcher seeks to listen to participants and build understanding based on what is heard especially because not much has been written about the topic. The purpose of this research was to gain a broad understanding of a particular situation, phenomenon or community (Bless et al 2013: 60) that is student nurses' experiences registered at one of the nursing colleges in Gauteng province for the course leading to Diploma in Nursing (General, Psychiatric and Community) and Midwifery (R425) in caring for mental health care users with profound intellectual disabilities. In this case, little was known about the experiences of student nurses caring for mental health care users with profound intellectual disabilities incorporating the Leventhal's theory of Common Sense Model into the study.

Furthermore, not much was known about the use of Common Sense Model in mental health and mental health care (Ward et al 2009:13). In order to obtain information, a variety of data collection methods were used these include grand tour question, reflective diaries, tape recorded interviews, observation, and field notes.

# 3.3.1.3 Interpretive research

According to De Vos et al (2011:08) and Holzemer (2010:129), interpretive approach is also called the phenomenological approach. This approach maintains that all human beings are engaged in the process of making sense of their worlds and continuously interpret, create, give meaning, define, justify and rationalise daily actions. In this study, the researcher incorporated the Common Sense model (CSM) so that participants used common sense in order to interpret, create, give meaning, define, justify and rationalise daily actions and experiences in caring for mental health care users with profound intellectual disabilities.

## 3.3.1.4 Contextual research

Contextual research is valid in a specific real context and not meant for generalisation (Botma et al 2010:195, 289). In this case, field notes, reflective diaries, in-depth interviews, observation and questionnaire were used at the centre where the participants were clinically placed for psychiatric clinical exposure and also at one of the colleges where the participants undergo training for the course leading to registration for the Diploma in Nursing (General, Psychiatric an Community) and Midwifery R425. Therefore, findings of this study were only limited to the centre and the college where this study was conducted. The findings contributed towards the furtherance of research in that it forms a base for other researches.

### 3.4 THE PHILOSOPHICAL PERSPECTIVE

The philosophical perspective of this qualitative research will be guided by constructivism. Grove et al (2013:57) describe philosophy as the view of science that values the uniqueness of the individual and the holistic approach to understanding human experiences. In this instance, in order to understand the whole picture of student nurses' experiences in their workplace, participants were actively involved in the research process and had a say in everything that took place. Digitally recorded one-toone in-depth interviews, written reflective diaries, observation and field notes were used in order to obtain multiple realities. An open ended question /grand tour question was asked in order to encourage the participants to open up and share views. Every participant had his/her own reality; therefore multiple realities emerged. The grand tour question for this study was: What are your experiences as a 4th year student nurse in caring for mental health care users with profound intellectual disabilities? This broad question was asked in order to encourage participant to open up and give their insider perspectives. It was followed by other subsequent questions in order to obtain multiple realities and rich data. Pieces of information collected from different participants were joined together to make a whole.

# 3.4.1 Population

According to Botma et al (2010:123, 211), population is all the elements (individuals) that meet certain criteria for inclusion in a given universe and in which the researcher is

interested. The target population of this study was the 4th year student nurses undergoing training for the diploma in Nursing (General, Psychiatric and Community) and Midwife in accordance with the SANC Regulation (R425). The target population is the entire set or persons, behaviour or events that meet the sampling criteria (Botma et al 2010:124). In this case, a particular group of student nurses that were accessible and available during data collection were used in order to seek answers to the research questions.

## 3.4.1.1 Sample criteria

Sample is defined as the population that includes both the inclusion and exclusion criteria. In this study, the inclusion and exclusion criteria were outlined as follows:

## 3.4.1.1.1 Inclusion criteria

It is the criteria that define who should be included in the population (Botma et al 2010:124; Polit & Beck 2008:338). In this case, only 4<sup>th</sup> year student nurses (R425) who were undergoing training at one of the nursing college in Gauteng province and willing to be participants formed part of the study. Furthermore, only 4<sup>th</sup> year student nurses who had the opportunities to be exposed to caring for mental health care users with profound intellectual disabilities at one of the care and rehabilitation centre in Metsweding District were included. In this study the inclusion criteria were as follows:

- Participant's relevance to the research topic of study.
- Participants who were registered at one of the specified nursing college in Gauteng province.
- Participants who were doing fourth year and had the opportunity to care for mental health care users with profound intellectual disabilities at one of the care and rehabilitation centre.
- Participants who were able to give the best information irrespective of race, gender and age.
- Participant who had prior knowledge of caring for mental health care users with profound intellectual disabilities.
- Participants who were receptive to an interview.

- Participants who were able to reflect in their diaries their daily experiences of caring for mental health care users with profound intellectual disabilities.
- Participants who were more articulate.
- Participants who were fluent in written and spoken English.
- Participants above 21 years.
- Participants who had time to be interviewed.
- Participants who were willing to participate in the method required by the researcher.
- Participants who volunteered and showed interest irrespective of race and gender.

### 3.4.1.1.2 Exclusion criteria

Exclusion criteria are defined as criteria that stipulates who should be excluded in the population (Polit & Beck 2008:338). All 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> year student nurses were excluded as they have not yet been exposed to caring for mental health care users with profound intellectual disabilities. The excluding criteria were as follows:

- Participants who were not registered at one of the specified nursing college in Gauteng province.
- Participants who were doing 1<sup>st</sup>, 2nd and 3<sup>rd</sup> year of the R425 four year courses.
- Participants who did not have opportunities to care for mental health care users with profound intellectual disabilities at one of the care and rehabilitation centre in Metsweding district, Gauteng province.
- Participants who were not fluent in written and spoken English.
- Participants below 21 years.
- Participants who lacked interest.
- Participants who were unwilling to participate in the method required by the researcher.
- Participants who lacked time to be interviewed.

## 3.4.2 Sample size

The sample is the portion of the population that you will study in order to get information about the entire population (Bruce et al 2011:384). In qualitative research, the sample size is determined by the quality of information obtained from the participants, event, situation and documents sampled versus the size of the sample (Grove et al 2013:371). According to Botma et al (2010:200), in order to determine the sample size, the two criteria for 'enough' that is, sufficiency and saturation should be followed. Monette et al (2005:242) cited in (Botma et al 2010:200), state that sufficiency is achieved if there are sufficient numbers to reflect the range of participants and sites that make up the population so that others outside the sample might have a chance to connect to the experience of those in it. In this case, 4th year student nurses were sampled out of the particular group placed at that particular time during data collection. A group of fifty six (56) student nurses were placed at the care and rehabilitation centre at a time.

Saturation means that no new or relevant data are emerging; the researcher has pursued all avenues or leads, and the story or theory is complete and redundancy achieved (Mayan 2001:10; Polit & Beck 2008:357). According to Morse (1994:226) (cited in Botma et al 2010:10), saturation has occurred when the researcher is familiar with the setting, routine or data being collected - perhaps even bored, feeling as if he/she has "seen it all". In this case, the researcher considered reflective diaries and repeated digital recorded in depth interviews with participants until data saturation was achieved. Data saturation was reached with the twelve participants and in depth scope of the study was obtained. The researcher was very satisfied with the new information and multiple realities obtained from each participant. In this study, high quality data were obtained from the variety of data collection methods, that is reflective diaries, oneto-one in-depth interviews, open-ended questions; observations made by the researcher during students' accompaniment, field notes and prolong engagement made by researcher whilst accompanying students. Furthermore in this study, high quality of information was obtained from the 4<sup>th</sup> year senior student nurses who were about to complete their studies. This meant that by virtue of being senior nurses, they were more experienced and well informed compared to other levels. Participants in this study were able to share more rich data in a clear and concise manner.

The topic was clear as it was based on the participants' experiences, personal views, thoughts and feelings. The Common sense model (CSM) was integrated into the study in order to determine what makes sense of the topic intended to be studied.

# 3.4.3 Sampling frame

According to Bless et al (2013:165), a sampling frame is used in order to ensure a complete and correct representative sample. In this study, a placement list was used to determine which group was accessible and available during data collection. A total of fifty six (56) students were placed at a time. Out of the fifty six students placed at the care and rehabilitation centre, 20% students were chosen. A group list was utilised in order to determine which participants were available for the topic intended to be studied.

### 3.5 RECRUITMENT PROCEDURE AND RETAINING RESEARCH PARTICIPANTS

The efficient recruitment of participants played a major role for the success of this study. According to Grove et al (2013:374), recruitment involves identifying, accessing and communicating with potential study participants who are representative of the target population. In this study, the researcher communicated the process of the research topic to the potential participants so that they could make informed choices of whether to take part or not to take part. Failure to recruit enough samples would result in under representation, making generalisation more unfavourable. In this study, the researcher was able to recruit 20% of prospective participants and not a single participant withdrew from the study. The freedom to withdraw was more emphasized throughout the study. The adequacy of recruitment procedures relates to the size of the sampling pool, the effectiveness of recruitment approaches and the recruitment time (Sidani & Braden 2011:186).

# 3.5.1 Sampling pool

First and foremost, the research topic was initially introduced to the population at large that is, all 4<sup>th</sup> year student nurses who are undergoing training at one of the registered nursing college in Gauteng province during orientation programme at the beginning of the year. The initial communication was pleasant and positive. All students were told about the researcher's intention to conduct the study and students applauded to that

and the response was positive. According to the plan of this study, the anticipated date of data collection was June 2014. During the month, a group of 56 students was allocated at the clinical site where the researcher intended to conduct the research. The focus of the study was to explore the experiences of fourth-year student nurses in caring for mental health care users with profound intellectual disabilities at one of the care and rehabilitation centre in Metsweding district Gauteng province. The researcher aimed to recruit 20% out of fifty six students who met the eligible criteria in order to cover for no shows. The inclusion criteria of this study were participants who were willing to be interviewed and showed interest.

Participants who were fluent in written and spoken English were considered irrespective of race, gender, age and culture. All fifty six were given information regarding this qualitative type of data. All students were given information letter regarding the topic to be studied and the consent letter. The information letter highlighted the title, principal investigator, background, purpose of the study, procedure, benefits, confidentiality, contact details of the researcher and right to withdraw from the study. Students were told that the study was easy to follow; all that was requested of them was to give honest opinions and personal views regarding their personal experiences in caring for mental health care users with profound intellectual disabilities. Students, who agreed to take part in the study, were given reflective diaries to reflect on their daily experiences during clinical placement at the centre and thereafter digital recorded one to one in depth interviews were conducted in response to the grand question asked. The Grand tour question was: "What are your experiences as a fourth year student in caring for mental health care users with profound intellectual disabilities". This openended question allowed participants to respond by giving personal views without being constrained to specific responses.

The study also integrated the Leventhal's theory which is the Common Sense Model (CSM), which states that the individual uses common sense in order to construct lay theories (Ward et al 2009:04). Furthermore, the Common Sense Model states that the individuals' experience differs depending on the age, gender, race, cultural background, ideas, attitudes and beliefs. This meant that the students' views and whether they would like to come and work at the centre after completion might and might not differ. Information shared by participants solemnly depended on the individuals' uniqueness and again what made sense unto them.

The issue of confidentiality was explained that in any case their names would not be mentioned in the study and this, in the researcher's opinion, was reassuring enough for the participants. Students who were willing and interested in the study submitted the signed consent form with a witness signature, as a form of giving permission to take part in the study without being forced. Students were explained that taking part in this study was voluntarily and they had a right to refuse or withdraw from the study at any time without giving any reason. This will not impact on their studies or clinical placement after completion by any means.

## 3.5.2 Effectiveness of approaches

Full details of the study were explained to students who showed interest to take part in the study. The students who were verbalised interest to participate in the study then signed a written consent (Annexure F). The explanation about participation in the study was given in person and all concerns clarified before participants signed the consent. The researcher also gave participants opportunity to ask questions in order to identify any barriers to the recruitment. The sample size of this study was twelve (12) participants, which was 20% of the target population. Each participant who gave written consent to take part in the study was given a file package with information letter, grand tour question to be asked and the reflective diary. This file package was a token of appreciation to participants who volunteered to participate in the study. To those who volunteered to participate in the study, the researcher expressed words of appreciation on a regular basis. By doing so, the researcher was hoping to encourage the researcher to hold on and not to quit until the research was completed and well done. The researcher's intention was to enhance the retention for engaging in the research study. Participants were expected to reflect on their daily experiences and thereafter they handed in their diaries post clinical exposure. After handing in the reflective diaries, digitally recorded one to one in depth interviews were conducted at a private place. The date and time of the interviews were discussed first with the participants to avoid inconvenience and participants pulling out of the study. Participants were not forced to come for interviews and the researcher tried to be flexible enough to accommodate participants so as to retain the research participants. The full procedure of what was expected from the students during data collection was reflected on the information letter given to the students for them to refer. The issue of confidentiality and freedom to

withdraw at any time of study was clarified throughout the research process in order to gain cooperation and to retain the research participants.

### 3.5.3 Recruitment time

The recruitment time was from January to June 2014 that is, five months. Two weeks before clinical exposure to the clinical site, students were given information letters and consent forms. Those who were interested in taking part in the study were requested to sign the written consent form and to give their names and telephone numbers for contact purposes only. Before signing the consent form, the participants had to answer the questions on the consent form that stated that they understood what was involved in the study and they voluntarily agreed to participate in this study. Three participants were randomly chosen as part of the pilot study. Three participants for the pilot study were recruited from January to March 2014 that is; three months. These three participants were excluded from the sampled research participants. From January to June 2014 that is, five months, 20% out of fifty six (56) students placed at the centre from 08-21 June 2014 were sampled to participate in this study. 20% of the fifty six students amount to twelve (12) students. Twelve (12) students were the sample size of this study, but this was depended upon the data saturation.

### 3.6 SAMPLING METHOD

Sampling is the process of selecting a portion of the population to represent the entire population so that inferences about the population can be made (Polit & Beck 2008:339; Walliman 2011:93). In this case, few participants were selected from the group of 4<sup>th</sup> year student nurses to represent the entire group. Non probability sampling method was used.

## 3.6.1 Non-probability sampling method

Non-probability sampling method was appropriate as the study was having an explorative and descriptive purpose. Using non-probability sampling method means that the researcher has no way to estimate the chance of participants to be included in the study (Botma et al 2010:125). In this case, fewer participants were purposively selected from a group of 4<sup>th</sup> year student nurses to gain in depth information of the event and

situation being studied. One-to-one in-depth interviews were conducted until data saturation was achieved. Generalisation and findings were limited as all 4<sup>th</sup> year student nurses could not be included in the study.

# 3.6.1.1 Purposive/judgemental sampling

Purposive sampling is the one whereby people from a pre-specified group are purposely sought out and sampled (Gerrish & Lacey 2010:149). The sampling is based on the belief that the researcher's knowledge about the population can be used to hand-pick sample members. A particular individual is purposefully chosen because he or she illustrates some feature or process that is of interest for a particular study or because he or she is seen as knowledgeable or as an expert about issues under study or the lived experience (Botma et al 2010:201). Maximum variation sampling will also be used by selecting participants with diverse views and perspective or heterogeneous (Polit & Beck 2008:365; Bless et al 2013:178). In this study, the sampling considered the different wards where these students were placed in order to obtain different opinions and divergent data. Students had a variety of experiences and this was evident during data collection. Participants shed different views and opinions which added value to the aims, purpose and findings of the study.

Most of the student nurses were black females with varying training experiences. Few were male nurses. In this study, including whites and male nurses was of great importance in order to obtain maximum rich data. In this study two participants were black males and one white female nurse formed part of the pilot study.

Volunteer sampling was used. A volunteer sampling, persons come forward voluntarily and this may facilitate the task of the researcher and accelerate the process (De Vos et al 2011:344). However, the researcher should acquire the motives behind of voluntarily joining the research in order guard against possible hidden agendas. The main purpose was to collect rich, wide and diverse range of information. Out of the fifty six students that were placed per group in the six wards, 20% which was twelve (12) students were purposively chosen in order to maintain rigour in the study. A sample size of 20% was accurate enough to cover for no shows (Botma et al 2010:211). The researcher used students' allocation list to pick every fifth student who was included in the study.

## 3.7 DATA COLLECTION

Data collection refers to the way data and information will be collected in qualitative studies (Botma et al 2010:204). The approach of data collection was a triangulation of reflective diaries, participatory observations, open ended questions, tape recorded in depth interviews and field notes. This tendency to use a variety of sources and variety of sources data collection is described as bricolage (Botma et al 2010:2014) or bricoleur (Polit & Beck 2008:219).

Information gathered was transcribed, analysed and interpreted into thematic categories. Qualitative data used names or labels rather than numbers (Wood & Ross-Kerr 2011:120).

### 3.7.1 Reflective diaries as a data collection method

Reflective diaries are "self-report instruments used repeatedly to examine on-going experiences. They offer the opportunity to investigate social, psychological, and physiological processes, with everyday situations" (Bolger, Davis & Rafaeli 2003:580 as cited in Thupayagala-Tshweneagae & Molokomme 2012:27). For this particular study, the diaries gave participants opportunities to reflect on their thoughts, challenges, barriers, feelings, experiences in caring for mental health care users with profound intellectual disabilities in a care and rehabilitation centre and to state whether they would like to work at the care and rehabilitation centre after completion. Participants were given small notebooks to serve as diaries. Participants recorded their thoughts, feelings and challenges as informed by the experiences on a daily basis in order to promote self-expressive practices, critical reflection, and therapeutic value of writing and to determine the truth and reality. The value of reflective diaries was pilot tested first with three participants in order to check its effectiveness.

Participants were allowed to write in their diaries during their own down times, in a relaxed quiet place to exercise letting go of negative emotions of anger, frustrations and anxiety in order to heal thyself (Connor 2002:76). The grand tour question asked in the reflective diaries was:

What are your experiences as a fourth year student nurse in caring for mental health care users with profound intellectual disabilities? This question was followed by other probes such as: What are your thoughts about working with health care users with profound intellectual disability? Participants' diaries were checked and read by the researcher.

The purpose of this is to examine the participants' entries for focus and to gain multiple realities that could not be shared with face to face interview. Participants were asked to use false names in order to maintain the anonymity. Participants handed in their diaries after their clinical exposure. More information was shed in the reflective diaries. Participants appreciated its therapeutic value and it was a form of stress relief to reflect in the diaries daily during their clinical exposure.

# 3.7.2 Participant observation

Participation observation is described as a qualitative research procedure that helps one study the natural and everyday set-up in a particular community or situation (De Vos et al 2011:329). In participant observation the focus is on every day and natural experiences of the respondents.

The researcher should strive at all times to gain feelings and impressions, and experience the circumstances of the real world of participants by living alongside them, and by interpreting and sharing their activities. The researcher's intention is to gain a 'feel' for the setting, the participants, how activities are conducted and the context in which they occur (Gerrish & Lacey 2010:386-387). In terms of this study, during students' clinical accompaniment the researcher spent considerable time at the centre with participants observing how and what the students experienced. By getting closer to participants when they care for mental health care users, the researcher was able to establish rapport and to familiarise themselves with the participants. By so doing, the researcher was able to put the participants at ease. It was evident during data collection that it was easier for participants to open up and express their thoughts and feelings freely.

The researcher took field notes to note all that was seen and heard. On the other hand, if people know that they are being observed and studied, their natural behaviour

changes and the researcher might not achieve the purpose of the study objectively. Therefore, it is of paramount importance that the researcher uses all senses during participation and to take a passive role (De Vos et al 2011:331), in order to reduce the threat to Hawthorne effect. Hawthorne effect means that the participants may react differently than they would in real life simply because they know they are participating in a research study (De Vos et al 2011:155). In this study, participants were able to share both negative and positive experiences without any fear. This was evident during data collection where participants shared their divergent data and multiple realities without any fear.

# 3.7.3 In-depth interviews

It is one of the data collection methods and is also referred to as the unstructured interviews. Kvale and Greeff (2005:287) cited in Botma et al (2010:207) define the indepth interview as 'an attempt to understand the world from the participant's experiences [and] to uncover the participant's lived world prior to scientific explanations. For the purpose of this study, the root of the one to one in-depth interview was interested in understanding the student nurses' experiences in caring for mental health care users with profound intellectual disabilities and the meaning attached. The idea was to allow the participants to open up, express, explore and describe their experiences and focus on issues being discussed. Indeed, recorded in-depth interviews shed realities and rich data experienced by participants whilst they were caring for mental health care users with profound intellectual disabilities. It was evident from the data collection that information differed according to individual's experiences, attitudes, beliefs, preferences, gender and age. Indeed, it was evident during data collection that the Common Sense Model does have an influence on the individual experiences. According to Ward et al (2009:04), the Leventhal's theory of Common Sense Model states that the individual uses common sense beliefs in order to construct lay theories. Furthermore, the Common Sense Model states that the individuals' experience differs depending on the age, gender, race, cultural background, ideas, attitudes and beliefs.

# 3.7.3.1 Pilot testing

According to De Vos et al (2011:241), the purpose of pilot study is to improve the success and effectiveness of the study. Pilot study is defined as a procedure for testing

and validating an instrument by administering it to a small group of participants from the intended test population (Barker 3003:327-328 cited in De Vos et al 2011:237). In this study, three participants were selected as part of the pilot study in order to identify any flaws during the in depth interviews. The one to one in depth interviews was digitally recorded as part of the pilot testing. The grand tour question was asked: "What are your experiences as a fourth year student nurse in caring for mental health care users with profound intellectual disabilities". This was done to check if the data collection method and instrument is of value or not. Indeed, the question was easy to follow and participants were able to express their thoughts and views openly. Subsequent questions were asked following the participant's response. The results of the pilot study showed that most follow up questions were leading and were hence rephrased in the actual study.

Pilot studies are of paramount importance to the research standard practice and to maintain rigour in the study. These three participants were excluded from the sampled research participants.

The format of the interviewing process was as follows:

## 3.7.3.1.1 Preparation phase

The researcher introduced the study to all fourth year nursing students who rotate at the care and rehabilitation centre and invited them to be part of the study. A register was left in the classroom so that those who are interested in taking part in the study may write their names and contact details. The researcher contacted the research participants telephonically to find out the convenient meeting times and dates. Almost all the participants chose to be interviewed at the college office which is normally used for consultation with students. Most of the participants chose weekdays after school and the researcher found it was also convenient for her. Short messages were sent to students a day prior to the interviews as a reminder for the appointment. Before the commencement of the interview, the researcher ensured that the venue was clean, warm, well ventilated, and free from noise and with adequate lighting. A meeting in progress sign was also placed outside the door to avoid any disturbances. Seating arrangement was prepared in such a way as to allow for involvement and interaction. According to De Vos et al (2011:350), the researcher should provide the seating

arrangements that encourage involvement and interaction. In this study, the researcher's office was utilised and participants were familiar with the researcher's office.

The digital recorder with standby batteries were connected in preparations for the use during one to one in depth interviews. Participants were prepared for unstructured interview and the grand tour question was given to each participant prior to the interview. According to Bless et al (2013:204), depending on the circumstances, the type of respondent, and the topic, a questionnaire should take between 15 and 90 minutes to answer. Bottles of water and box of tissues were made available for the participants during the interview. In this study most of the interviews lasted from 15-30 minutes.

# 3.7.3.1.2 Introductory phase

Firstly, the establishment of rapport is of paramount importance in order to encourage the participants to open up. The participants were welcomed and greeted by the researcher. A word of appreciation for honouring the appointment was stated. The researcher then introduced herself to the participant. Participants were allocated numbers and their real names were not used. All participants preferred English to be used during interviews.

The interview was opened with introductory pleasantries. Small talk was initiated not related to the research topic to create a friendly and relaxed atmosphere. Respect and non-judgemental attitude was maintained by the researcher throughout the interview process not to interrupt or harm the participant by any means.

The purpose and objectives of the study were stated. The role of the interview in meeting the aims and purpose of the study was emphasised. The duration/length of the interview that is, 45-60 minutes as well as the confidentiality of the information were emphasised. The interviews took place in the school's consultation room which was quiet without any interruptions and the issues of digital recording and taking field notes during the interview were explained to all participants prior to the interviews.

Signed voluntary consent was confirmed on the digital recorder during the interview and the participants were continuously reminded that they have freedom to withdraw at any time. The participants were made aware of the availability of the counselling and debriefing should the interviewer trigger any emotional harm or discomfort for support (Greeff 2005:295 cited in Botma et al 2010:207). The participants were reassured to feel free to answer the questions and that there are no wrong answers. The purpose of the interview was to get their personal views and to integrate the Common Sense Model.

# 3.7.3.1.3 Interviewing phase

During the interview, a grand tour question was asked followed by subsequent questions. A grand tour is also referred to as central/broad question. A grand tour question is defined as the open ended question posed by the researcher during an indepth interview that asks for an exploration of the central phenomenon in a study (Botma et al 2010:207). The researcher stayed focused during the interview process in order to achieve the purpose of the study.

The grand tour question for this study is: 'Please tell me about your experiences in caring for mental health care users with profound intellectual disabilities'. The main point of this open ended question was to allow the participant to open up, express ideas and tell the story. Thereafter subsequent questions were asked guided by the responses from the grand tour question.

The researcher tried not to rush in order to allow the participants a chance to answer. The researcher exercised empathetic response to show support and understanding of the participant's feelings. During the interview, the researcher ensured that the participants did 90% per cent of the talking, in order to encourage the participants to tell their stories (De Vos et al 2011:343). The researcher used clear and simple language easy to be followed. The researcher took notes during the interview for later use and common words/phrase that each participant used. Several communication techniques were used by the researcher to encourage participants to open up and narrate their stories. The following techniques were used (De Vos et al 2011:345):

- Minimal verbal responses: such as. "mm-mm, yes, I see" were be used in order to show that the researcher was listening.
- Paraphrasing: for example, stating the participant's words in another form with the same meaning.

- Clarification: "Please tell me more about your experiences"; "you seemed to be saying that you were scared to see users with profound intellectual disabilities".
   This was asked in order to get clarity. This key question was repeated.
- Probing: "What exactly made you feel scared"? This was asked to deepen the response to a question and to obtain rich in depth data.
- Reflection: By allowing the participant to expand on the idea that had just been said.
- Comments: "I always thought that student nurses do not want to work at the centre". This was asked in order to stimulate the participants to tell more.
- Spur: "But is it not true that this centre was often chosen as the last resort when given the choices where you would like to be placed after completion of training".
   This was asked in order to tease, spur or challenge the participants to tell more.

# 3.7.3.1.4 Ending phase

The researcher stayed alert in order to end the interview at a reasonable time.

The interview should wind down and not end abruptly (Botma et al 2010:2018).

In this case, the researcher notified the participant about the time remaining to end the interview gradually.

The researcher summarised main points discussed with the participants. [Since these are points, let's number them].

The summary included: experiences, challenges, reactions, feelings, ideas, thoughts and recommendations.

Participants were allowed to add on to the summary.

Follow-up question was asked such as "Tell me if there's anything you would like to say that you feel is important".

Participants were allowed opportunity to ask any questions related to the research topic.

The researcher asked the participant how they felt about attending the interview.

The researcher thanked the participants for active participation and for attending the interview.

Participants were asked if they needed any referral to the counselling department.

There were no referrals made. The participants did not see any need to be referred for counselling and they were re-assured that this was done free of charge. No follow up interviews were made; all twelve participants gave sufficient data relevant to the aims and objectives of this study. The digital recorder was turned off.

## 3.7.4 Digital recording

Digital recording is one of the data collection methods in this study. It is concerned with recording the interviews on the digital recorder and is used for data capturing (De Vos et al 2011:359). Furthermore, a digital recorder allowed a much fuller record than notes during the interview. It also meant that the researcher could concentrate on how the interview was proceeding and where to go next. Signed voluntary consent was confirmed on the digital recorder and participants were reminded that they were free to withdraw at any time (Botma et al 2010:209).

The researcher then took field notes after the interview to note any information of significance. The participants were given an opportunity to listen to the recorded interview after the session.

The digital recorder was kept confidential in a safe place and recorded interviews were labelled without using the real names. During the digital recording, the need for referral to counselling and debriefing was confirmed should participants experience any emotional discomfort and harm. Participants who felt unhappy being taped and wish to withdraw were allowed to do so without any victimisation. De Vos et al (2011:359) state that the tape recorder should be placed carefully so as not to unnerve the participants.

The digital recorder was first pilot tested on the small population study before recording the sampled population in order to check its quality and effectiveness. The outcome was positive and the researcher was able to use digital recorder with no difficulties. The digital recorded interviews were easily transferrable to the researchers' personal computer and they were audible enough.

#### 3.7.5 Field notes

Field notes are referred to as the process of making full and accurate notes of what goes on, jotting down your impressions after the interview and observation. Field notes are a written account of the things the researcher hears, sees, experiences and thinks about in the course of interviewing (De Vos et al 2011:359). The process of taking field notes during the participant observation, interviewing and tape recording was explained. A signed voluntary consent was confirmed on the tape recorder.

Field and Morse (1994:79-82) cited in De Vos et al (2011:359) state that the critical points to be followed when writing field notes in order to minimise loss of data, was to find a quiet place to write; set aside adequate time to complete the notes; sequence events in the order that they occurred; letting the events and conversation flow from the mind onto the paper. Record what you "know" has happened and what you "think" has happened that is, your emotions, preconceptions, expectations and prejudices. Field notes were kept in a safe place. In this study, the researcher jotted emotions, expressions and prejudices stated by the participants in order to ensure that no information was left behind and to maintain rigour.

#### 3.8 TRUSTWORTHINESS

Trustworthiness is the degree of confidence qualitative researchers has in their data. It is assessed using criteria of credibility/authenticity, transferability, dependability and conformability (Botma et al 2010:232). In qualitative research, trustworthiness is recognised in terms of how much trust can be given to the research process and findings (Bless et al 2013:236). Lincoln and Guba's framework was used to establish the truth value of a qualitative research (Polit & Beck 2008:539-540).

## 3.8.1 Credibility

Credibility refers to confidence in the truth of the data and interpretation of them. Qualitative researchers must strive to establish confidence in the truth of the findings for the particular participants and contexts in the research. It involves two aspects: first, carrying out the study in a way that enhances the believability of the findings, and second, taking steps to demonstrate credibility to external readers. According to De Vos et al (2011:420) and Lincoln and Guba (1999:245), outline various strategies for increasing the credibility of qualitative research:

## 3.8.1.1 Prolong engagement and persistent observation in the field

According to Polit and Beck (2008:542), prolonging engagement is the investment of sufficient time collecting data to have in-depth understanding of the culture, language or views of the people and to ensure data saturation of important categories. Prolonging engagement was essential for building trust and rapport with the participants, which in turn made it more likely that useful, accurate and rich information be obtained. It is an important step in establishing rigour and integrity in qualitative studies. According to Polit and Beck (2008:542), high quality data collection in the field of study also involves persistent observation, which refers to the researcher's focus on the characteristics or aspects of a situation or a conversation that are relevant to the phenomena being studied. If prolonging engagement provides scope, persistent observation provides depth.

Field notes were taken during the prolong engagement and persistent observation to note what transpired in the field.

The researcher spent considerable time observing participants whilst they cared for mental health care users with profound intellectual disabilities in order to obtain rich information and in depth understanding of the 4<sup>th</sup> year student nurses in caring for mental health care users with profound intellectual disabilities. In this study, most student nurses expressed feelings of sadness and anxiety when they were taken round to various wards as part of the orientation purposes.

## 3.8.1.2 Triangulation of different methods

According to Polit and Beck (2008:543), method triangulation involves using multiple methods of data collection about the same phenomenon. In this study, the researcher used a rich blend of unstructured data collection methods e.g. tape/digital recorded oral interviews, grand tour question, observations, reflective diaries and field notes to maintain rigour.

Triangulation of different methods was used to capture and collect data until data saturation is reached. First participants were given reflective diaries to reflect on the experiences and whether they would like to be placed at the centre after completion. Thereafter digital one-to-one interviews were conducted in the researcher's office at different times whereby a grand tour question was asked. The grand tour question for this study was "What are your experiences in caring for mental health care users with profound intellectual disabilities. This single grand tour question was initially asked to encourage participants to open up and express their experiences and the meaning they make thereof. The interviews were digitally recorded and a signed voluntary consent was confirmed in the digital recorder.

In this study, field notes were taken throughout the research process to note any critical issues that the researcher has observed, heard and seen. The field notes were regarded as a memory book that the researcher utilized and referred to later during data analysis in order to maintain rigour in this study.

## 3.8.1.3 Peer review and debriefing

It was done by discussing with the peers not involved in the study. It is another quality enhancement strategy and it involves sessions with peers to review and explore various aspects of the injury (Polit & Beck 2008:548-549). In peer debriefing, the researcher presented the research question, written or oral summaries of the data collected, categories, emerged themes, researcher's interpretations of the data and even digitally recorded interviews to the peer debriefers who were experts in qualitative research. Peer debriefing and review were used to enhance accuracy of the account and for objective assessment of the study (Botma et al 2010:232). The researcher launched a formal audit of the researcher process scrutinised by an independent external auditor

not in the study. The peer debriefing was of great importance to this study. The peer debriefer was both a quantitative and qualitative expert. Furthermore, the peer debriefer was also a specialist in early childhood disorders and had more advanced knowledge with the intellectual disability.

## 3.8.1.4 Member checking

Lincoln and Guba considered member checking as a particularly important technique for establishing the credibility of qualitative data, in which researchers provide feedback to study participants about emerging interpretations, and obtain participants' reactions. Member checking was carried out in an on-going way to allow participants opportunities to scrutinize the researcher's interpretations/findings. Member checking was done by taking the final report back to the participants in order to determine the accuracy of the findings. A follow-up interview and discussion were done with the participants either in writing and/or face-to-face discussion. In this study, performing member checking was of great importance to verify if the results reflect participants' views. Participants were given opportunities to listen to the digitally recorded interviews. Further discussions were more than welcomed by the participants, more especially because most participants felt this was crucial in order to express the negative feelings experienced. Participating in the study provided stress relief.

The researcher was aware of the fact that some may decline to engage in this process. In this study, the researcher ensured that member checking was done voluntarily in order to maintain high ethical principle of (non-maleficence) which is ethical responsibility not to do any harm and (beneficence) which is duty to maximise possible benefits.

#### 3.8.2 Dependability

Here the researcher asks whether the research process is logical, well documented and audited (De Vos et al 2011:420). Dependability refers to the stability (reliability) of data over time and over conditions. Credibility cannot be achieved in the absence of dependability. A dependability audit was kept which entails the detailed thick and contextual description of the research, the people who participated in the study, the sampling method in detail, the experiences and processes observed during the

collection of data. Multiple methods used on how the researcher acquired the information were noted that is reflective diaries, traceable variability ascribed to identifiable resources, stepwise replication, thick and dense description of the methodology, triangulation, peer examination and co-recode/co-coder (Botma et al 2010:234). Furthermore, Bless et al (2013:237) state that when a researcher describes exactly how data were collected, recorded, coded and analysed, and can present good examples to illustrate this process, then the results will be considered of high quality and dependable. In this study, a triangulation of data collection methods was used to collect information. The methods include: reflective diaries, digitally recorded in depth interviews, observation, questionnaires and field notes. The information collected was then coded, analysed and themes emerged. The results and findings of this study maintained high quality and dependability.

## 3.8.3 Transferability

Transferability refers to the ability to generalise from the findings to larger populations, that is, the extent to which the findings can be transferred to or applicability in other settings, situations and groups (Botma et al 2010:233). The findings were applicable to students on training and clinical nursing practice. Findings of this research formed basis for further research which may ultimately improve patient care and job satisfaction in the care and rehabilitation centre setting. The responsibility of the researcher was to provide sufficient descriptive data in the research report so that consumers can evaluate the applicability of the data to other contexts.

The provision of sufficient descriptive data enabled someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility.

## 3.8.4 Conformability

Conformability refers to the extent to which the findings are a function solely of the participants and conditions of the research, not of other biases, motives or perspectives (Botma et al 2010:233). It is similar to replicability, and requires that other researchers or observers be able to obtain similar findings by following a similar research process in a similar context. The researcher is also expected to present a critical evaluation of the

methodology used by means of a conformability audit. When another researcher understands precisely what you did, why you did it, and in what context you did it, he or she should be able to replicate the study in another context and predict if, and how, the results might be different (Bless et al 2013:237). In this study, the credibility, dependability, transferability and conformability were all applied and the study is considered of high quality and highly trustworthy.

#### 3.9 DATA ANALYSIS

A prerequisite of data analysis is to know how to summarize, interpret and report data (Bruce et al 2011:385). For the purpose of this study an interpretive analysis of Terre Blanche et al (2006) as cited in Botma et al (2010:226) was used. The five basic steps of interpretive analysis are as follows:

#### 3.9.1 Familiarisation and immersion

Familiarisation and immersion began while gathering the data with the researcher developing ideas and theories about the phenomena under study. The researcher read through the reflective diaries, filed notes and other materials many times. The researcher did brainstorming or draw diagrams in order to facilitate thoughts.

## 3.9.2 Development of themes

The researcher tried to stay within the language of the participants while reading through the reflective diaries and listening to tape/digital recorded interviews. The researcher then identified main and subthemes at the same breath trying to be creative.

#### **3.9.3 Coding**

Coding began when the researcher started identifying themes. The data were coded and linked to one of the identified themes which include a phrase, a line, a sentence or even a paragraph. The researcher cut and pastes to code and link the codes to themes or uses one of the computer programs available on the market.

#### 3.9.4 Elaboration

In this way the researcher tried to find similarities and noticed finer nuances of the meaning in the reflective diaries and other materials. Some of the information found in the reflective essays, could not be used for the development of themes. The information was shelved for later use in the findings and recommendation.

## 3.9.5 Interpretation and checking

The researcher interpreted the analysed text and compiled a written account of the interpretations. However, the researcher steered clear from just summarising data but brought richness and deeper understanding of the meaning to the description. Information obtained was verified by doing literature control.

#### 3.10 CONCLUSION

Chapter 3 gave the research design, research methodology, a triangulation of different data collection methods, population of the study, recruitment, sampling methods, measures to ensure trustworthiness, data analysis method, significance, limitations of the study and integrated the Common Sense Model in the study.

## **CHAPTER 4**

## RESULTS, INTERPRETATION AND DISCUSSION

#### 4.1 INTRODUCTION

The purpose of this chapter was to provide the results and their interpretation. The results of this study were informed by written, verbal and nonverbal communication shed by the participants. According to Bless et al (2013:339), data analysis takes place in the form of spoken or written words. In this study, the researcher used a variety of data collection methods that is, field notes, observation, reflective essays and digital recorded in depth interviews to arrive at the findings, interpretation and discussion from a sample size of twelve participants. According to Mouton (2013:124), chapter 4 entails: results of the fieldwork, organised in one or more chapters, nature of the study, the research objectives, the complexity of the research design and the amount of data collected. In this chapter, the demographic profiles of participants, presentation of the results in tables and, thematic content analysis and literature control, significance of the study and conclusion of the results were discussed in detail.

### 4.2 DEMOGRAPHIC FINDINGS

There were 12 participants who were interviewed. Out of the 12 participants 10 of them were females and all the participants were in their final year of training. Ten of the participants had never experienced working with persons with profound intellectual disability. Seven of the participants were single and five of them were married their ages ranged between 21 and 30 years and one of them were between 31-40 years of age. All the participants were blacks, Christians and had the equal opportunities to care for mental health care users with profound intellectual disabilities during the clinical placement at one of the care and rehabilitation centre in Gauteng province Metsweding district. The demographic profile of participants is not surprising as nursing is known to be female dominated (Thupayagale-Tshweneagae & Rapaeye 2009:65).

Table 4.1 Demographic profiles of participants

Criterion	Characteristics	Frequency	Percentage
Gender	Female	10	83
	Male	02	17
Ethnic group	White	None	0
	N Sotho	05	42
	S Sotho	01	8
	Ndebele	02	17
	Seswati	01	8
	Zulu	01	8
	Tswana	01	8
	Tsonga	01	8
Ages	21-30	06	50
	31-40	04	33
	41-50	02	17
Level of training	4 <sup>th</sup> year	12	100
Marital status	Single	07	58
	Married	03	25
	Divorced	01	8
	Widower	01	8
Religious	Christian	12	100
denomination			
Personal encounter	Any	02	17
with individuals	contact/experience		
suffering from	prior to clinical		
intellectual disability	placement		
in the community	No contact prior to	10	83
	clinical placement		

## 4.3 CATEGORIES, THEMES AND SUB-THEMES

Five categories and five major themes emerged from the study. Out of the five categories are: experiences of student nurses, caring for mental health care users with profound intellectual disabilities, profound intellectual disabilities, care and rehabilitation centre and career options of working with mental health care users with profound intellectual disabilities, five themes and sub-themes emerged. The five major themes were emotionally challenging, communication difficulties, lack of knowledge on the nature of intellectual disability, burden of care and mixed feelings. The categories, themes and subthemes are outlined in table 4.2.

Table 4.2 Categories, themes and sub-themes

Categories		Themes	Sub-themes
1	Experiences of student	Emotionally challenging	Anxiety
	nurses		Fear
			Scary
			Frustration
			Overwhelming
			Depression
			Conflicting feelings
2	Caring for mental health care users with profound intellectual disabilities	Communication difficulties	Impaired communication
3	Profound intellectual disabilities	Lack of knowledge on the nature of intellectual disability	Difficulty carrying out activities of daily living
			Poor comprehension of what
			profound intellectual disability
			is
4	Care and rehabilitation	Burden of care	Poor job satisfaction
	centre setting		Stressful work environment
5	Career options with	Mixed of feelings	Avoidance
	mental health care users		Acceptance
	with profound intellectual		
	disabilities		

## 4.3.1 Experiences of student nurses

The experiences of student nurses when caring for mental health care users with profound intellectual disabilities emerged as the first category. Under this category, emotional challenging emerged as a major theme with seven sub-themes.

#### 4.3.1.1 Emotional challenging

Participants experienced mixed feelings when caring for mental care users with profound intellectual disabilities. The mixed feelings indicate the uniqueness of each individual participant. In integrating the Common Sense Model, the Leventhal's theory postulated that individuals use common sense based on the ideas, attitudes and beliefs formed by experience, cultural traditions, formal education and stories from family and friends (Ward et al 2009:04). In this study, the emotional challenges shed by the

participants were based on the unique ideas, attitudes and beliefs formed by the experiences. The seven sub-themes will be discussed individually.

## **Anxiety**

The majority of participants reported that they were anxious. Their anxiety was related to the fact that most of the users had both mental and physical disabilities and was not comfortable looking after them. Some of the quotes that showed their anxiety were as follows:

"It is so scary to treat an older person like a child."

"I felt uncomfortable having to put a nappy on a person my mom's age - is not cultural."

When participants mentioned this some were rubbing their hands or tapping their feet.

According to Van Vuuren (2012:165), anxiety is a consequence of perceived uncertainty and unpredictability. It is often caused by extrinsic factors such as being faced with a new or different situation where we have inadequate information. Whereas, Townsend (2012:651), defined anxiety as a "vague uneasy feeling of discomfort or dread accompanied by an autonomic response (the source often nonspecific or unknown to the individual); a feeling of apprehension caused by anticipation of danger". In this study, anxiety was aggravated by lack of understanding and first time exposure to users with profound intellectual disabilities coupled with other multiple disabilities such as sensory and physical impairment.

#### **Fear**

The majority of participants reported the complexity situation that they found themselves in and with no point of escape. Rooms and wards were just the same. Most reported that they even felt homesick. One reported that he took a lot of breaks during the routine just to relief the fear. Student nurses during their clinical placement were accommodated at the centre's nurses' home. Some of the quotes that showed their fear were as follows:

"I was so fearful of them, seeing them all at once."

"The first time they saw us (student nurses) entering the ward, they were so overwhelmed, and one user chased me. I guess she/he could sense that that I was not at ease."

"It was so difficult, what made me so fearful, was the fact that others made funny noise and sounds like animals. Although I know they are just human beings like us but their behaviours differ completely from ours."

Others raised their eyebrows [Meaning?] when they were trying to explain the complexity of the situation. According to Uys and Middleton (2014:318), the fear is out of proportion to the actual danger posed within the sociocultural context. The fear can be out of losing control, not being able to cope and of physically being harmed. Whereas, Townsend (2012:652) fear is defined as the "response to perceived threat that is consciously recognized as a danger". In this study, students were fearful because of the unusual behaviour by patients such as making funny noises like animals. Furthermore, the self-destructive behaviours displayed by some of the users who were banging themselves against the wall instilled some fear into the participants.

#### Scary

Although being scared could be used synonymously with fear. In the study context it came out clearly as a sub-theme on its own as demonstrated by these quotes:

"I was so scared; I never thought I would see these kind of people. This was something that I was unprepared for."

"I'm even scared to fall pregnant, what if I give birth to a child with intellectual disability."

"When I think about those users, I feel as scared as they did not choose to be like that. They look innocent and some is due to the nurses' fault and negligence".

It can be quite scary to see users with profound intellectual disability for the first time. Effective coping strategies are necessary to deal with the scary feelings. According to Uys and Middleton (2014:318-319), effective coping strategies include problem-focused coping whereby an individual takes direct action to modify or eliminate the source of threat such as physical and interpersonal withdrawal. Even deep breathing to relieve the scare and tension is of paramount importance. Furthermore, emotion-focused coping includes responses with the primary function of managing the affect aroused by stressful situations. Behaviour such as crying, hyperactivity and talking about the experience and seeking help are examples of this type of coping. This was evidenced when participants reported that by being involved in the study it helped in stress relief and even expressing their thoughts and feelings. Participants appreciated the idea and this was true as all participants were very cooperative to be involved in the study.

#### **Frustration**

Most of the participants vented their frustrations. They reported the difficult situation they found themselves in. Some even reported that if it was not for the achievement of the clinical learning outcomes, they were going to absent themselves and avoid being placed at the centre. Some of the quotes that showed their frustration were as follows:

"First day when we were taken round to different wards, I found myself crying as the situation was so overwhelming."

"If it happens, that I'm placed again in the centre after completion of training, I would really need counselling on a daily basis."

"I could not wait for the clinical placement to be over. On the last day I was so happy to having finished and completed the learning outcomes."

Some frowned when they were explaining the situation and their experiences.

The frustration was brought by the fact that they could not communicate properly with users. Most of the users had sensory impairment such as vision, hearing and communication impairment. According to Van Vuuren (2012:165), anger is a common reaction to a stressful situation which may lead to aggression; individuals often become angry and exhibit aggressive behaviour when they experience frustration. Furthermore, the frustration-aggression hypothesis assumes that whenever a person's efforts to

reach a goal are blocked, an aggressive drive is induced that motivates behaviour designed to injure the object or person, thereby caused the frustration.

## Overwhelming feelings

Most of the participants reported that it is not easy to care for users with profound intellectual disabilities. One will never get used to caring for mental health care users mainly because they are unpredictable and you will never know what they will do next.

Some of the views that showed their overwhelming feelings were as follows:

"It was so overwhelming seeing so many users with deformities and others looking like kids but old in terms of years."

"I am overwhelmed by their disruptive and self-injurious behaviour. One would spit sputum and thereafter eats that. Others bang their heads and bites other."

Most of the participants felt lost and emotional during clinical exposure when they care for users. It is important that student nurses display empathy when they care for users. Empathy it is the ability to listen to, recognise and acknowledge the feelings of another person without experiencing those same emotions. Empathy offers support, builds trust and paves the way to greater participation.

#### **Depression**

Most participants reported that the situation was so depressing that they had nightmares. Imagine if I was placed there for good, this could have been suicidal to my career. Some of the quotations that showed their depressed mood were as follows:

"I felt so depressed every day when I woke up, thinking I'm going to the same situation that was in yesterday."

"The first week of my placement was much worse; I could not sleep and eat. It was just a terrible situation. I could not cope with situation."

"You end up crying and feeling pity for them by just looking at them. Form me it was very depressing."

Some showed sad faces as they were trying to explain their thoughts and feelings. According to Uys and Middleton (2014:359), depression is a condition, in which a person feels extreme sadness, withdraws socially, feels guilty and expresses self-deprecating thoughts. In this study most participants uttered that avoidance is the positive way to deal with the stressors. Furthermore, talking about their experiences and feelings really helped in relieving the sadness and depressed mood.

## **Conflicting feelings**

Even though most of the participants reported the negative feelings, there were few positive feelings out of the experiences. Participants reported few positive feelings compared to negative once. This shows that participants had conflicting feelings when they were dealing with users with profound intellectual disabilities.

Some of the quotes that showed their conflicting feelings were as follows:

"Having to stimulate users with different problems was very interesting and satisfactory for me; I could not get it in any placement."

"I have learnt to face my fears on my own and to look at life differently."

"I stimulated users to drink from a cup without spilling. This was interesting and eye opening for me as we have one family member with intellectual disability."

"After stimulating the users, seeing the smiles on their faces, it felt like I have won a trophy."

"One further said; two weeks was not enough. We should rotate to the other wards and get to know how it feels like."

Some mentioned these positive thoughts with smiles and relaxed facial expressions. According to Marijean (2008:04), although few enjoyed a profound sense of privilege

and derive deep satisfaction in this role, frustration, overwhelming, depression, scary, fear and anxiety were common reactions reported.

Participants reported that these negative thoughts and feelings were due to the fact that it was for the first time in their entire four years of training seeing this type of users. Furthermore, they reported that in the communities where they come from they have never come across so many intellectually disabled at once. According to the participants, if they could see a video and be sent to the centre before the real clinical placement they would be more psychologically prepared. Pre-orientation of some sort would help minimise the psychological trauma. Participants did acknowledge that they have been taught in class but that was not enough as they did not have a clue what those users looked like. Furthermore, they reported that upon placement, the first day was full day orientation, they were even taken round to all the wards so that they were psychologically prepared. Participants reported that this was not enough as there was no break. The following day they were expected to be back on duty fully functioning. There was no time for them to work out through the negative emotions. In this study, more negative experiences were shed more than the positive experiences. Eight participants (67%) reported negative experiences and four participants (33%) reported positive experiences.

The positive experiences indicated by the student nurses were interesting and eye opening. One participant mentioned that after stimulating the users and seeing their smiles from the users it felt like I have won a trophy. This was even reflected on their facial expression with a smile and nodding of the head.

The participants reported that even though they experienced negative feelings and thoughts at first, after some when they have trained users self-care skills and users masters that. They were happy making a difference unto them and bringing a smile unto their faces. They reported that seeing a smile from those users gave them fulfilment and happiness which they could not achieve in any placement. Although few at first reported the positive feelings, mostly at first reported the negative feelings and lastly the positive feelings after a week. Few that reported the positive feelings, were females who were married, and had a family member with a history of intellectual disability. This indicated and emphasized the importance of pre-orientation to enable student nurses to adjust and cope. Furthermore, this indicated the value of Common Sense Model in the study,

as participants gave different perspectives. In this study, less positive experiences that is 33% were shed compared to the 67% negative experiences. According to Gaede and Surujlal (2011:344), the study indicated that individual with disabilities, regardless of whether physically or intellectually disabled, are often stigmatized, encountering attitudinal and physical barriers in daily life (Murphy & Carborne 2008). According to the study conducted in Tanzania, McNally and Mannan (2013:01) reported that positive experiences were not easily identified by participants. This means that positive experiences are very rare in the present study.

#### 4.3.2 Caring for mental health care users with profound intellectual disabilities

The caring for mental health care users with profound intellectual disabilities emerged as the second category. Communication difficulty emerged as a theme and impaired communication as a sub-theme.

#### 4.3.2.1 Communication difficulties

## Impaired communication

The majority of participants reported that most users had impaired communication. This was related to the complex nature of the disability. Participants had difficulties communicating with the users leading to impaired communication. Some of the quotes showing were as follows:

"Some users are unable to communicate and express themselves."

"Users are just lost, live in their own world and can't hear properly. They are unable to follow instructions."

"Some coos like doves."

"Others make funny noises that are difficult to be followed."

Student nurses experienced caring as more challenging and complex. The challenges emerged due to the fact that most users had multiple disabilities such as

communication, hearing, physical and visual impairment besides the profound intellectual disability. Furthermore, the centre has very few equipment's to assist with users stimulation and there is total dependence of users on nurses and self-destructive behaviours displayed by the users makes caring for them to be difficult at times. Challenges are described as 'lifeline' and caring for them is complex, although the relationship is formally professional as compared to the very close relationships e.g. mother/child and sibling relationships (Martin, Connor-Fenelon & Lyons 2012:71). In this study, participants quoted different quotes to highlight their endless challenges they came across.

"Stimulating the MHCUs to drink from a cup in took us two weeks, took a lot of efforts, repetitions and patience. It was never easy at all."

Communication remains a challenge to users with profound intellectual disabilities as they use non-verbal communication. Most users are faced with sensory impairment which makes caring more complicated and complex. According to the study conducted in Ireland, Marin, Connor-Fenelon and Lyons (2012:69-70) believed that if you know the person, communication can be successful. If communication is unsuccessful it may be due to the unfamiliarity of the people involved in communication. Furthermore, the study stated that interventions such as speech and language therapy may be used to deal with the communication challenges. The current state of affairs is that the centre does not have speech and language therapy in place. Participants were not familiar with the users as they were only at the centre for the period of two weeks clinical exposure.

Besides the intellectual disabilities, users are confronted with other physical life limiting illnesses such as progressive cancer (Bekkema, Veer, De Albers, Hertogh, Onwuteaka-Philipsen & Francke 2014:495). In this study, other participants mentioned that some had cancer of the breast.

Limited equipment remains a problem in state institutions. This has an impact on the stimulation of users to obtain optimal functioning. Nurses do not have time to train users on self-care skills in order to promote independence as it takes time to train users with profound intellectual disabilities. According to Uys and Middelton (2014:551), stimulation includes early stimulation of all senses and teaching self-care. They learn by repetition and a nurse should be patient with them. Institutions are faced with nurse shortages

both locally and globally. This was supported by the study done in Taiwan, which stated that despite the fact that the nursing profession is growing and becoming more sophisticated, human resource issues have not changed in a dramatically significant way in the past generation (Tzeng & Yin 2009:19). Furthermore, according to the study conducted in California, which stated that the retention of registered nurses (RNs) is an on-going concern for health care organisations due to the enduring nursing shortage and high turnover rate (Cohen, Stuenkel & Nguyen 2009:308). According to the study conducted in South Africa (Venda), Mudhovozi et al (2012:148) reported that there is lack of resources and qualified professionals were scarce.

According to the study conducted in Belgium, Lambrechts et al (2009:620), staff members are faced with the challenging behaviour of users who displayed self-injurious behaviour, stereotyped behaviour and/or aggressive/destructive behaviour. Martin et al (2012:69), reported on the 2003 report by Bray which stated that misinterpretation can lead to frustration and tantrums in people with intellectual disability which may impact upon the person's quality of life. This implies that users display self-destructive behaviour in order to relief their frustrations. This poses a lot of challenges to staff members as they often misinterpreted these behaviours as being rude and aggressive.

There is increasing evidence that the needs of people with intellectual disabilities are not met, including the health needs and unidentified pain or illness (Martin et al 2012:70). Furthermore, the study stated that it is important that service-users have someone who can understand them as they try to communicate their problems. Numerous studies have chronicled the stress and burnout associated with caring for a person with intellectual disability, with carers often presenting lower morale and greater levels of depression than the general population (Blancher, Neece & Paczkowski 2005; Blacher & McIntyre 2006 cited in Aldersey 2012:02). Furthermore, caring for people with intellectual disabilities entailed both the burden and stress. Calitz (2011:66) mentioned that users are particularly exposed to peril because of their lifelong dependence on caregivers, relatively powerless position in society, emotional and social insecurities, and lack of education regarding sexuality and sexual abuse.

Profound intellectual disability has a heavy or total dependence on personal assistance for physical care, education, stimulation and recreation (Tadema & Vlaskamp 2009:42).

This means that this is very demanding for student nurses. As a result this may lead to negative attitude and avoidance to work at the centre to avoid the stress and burden.

#### 4.3.3 Profound intellectual disabilities

Profound intellectual disabilities emerged as the third category. The following themes and subthemes emerged. According to Calitz (2011:66), defining mental retardation of intellectual disability is a complex nature. Definition of profound intellectual disability emerged as a theme and characteristics of profound intellectual disabilities as a subtheme.

## 4.3.3.1 Lack of knowledge on the nature of intellectual disability

## Difficulty carrying out activities of daily living

The majority of participants reported that most of the users cannot carry out activities of daily living (ADL). The inability to meet ADL was related to the fact that most of the users had both mental and physical disabilities and they were unable to do that without any assistance. Some of the quotes that showed the difficulty carrying out activities of daily living were as follows:

"Nurses had to assist users with ADL as they cannot talk and walk."

"Due to their physical disabilities they are unable to feed themselves, at first I found it difficult to feed them but after some time I was taught how they feed them by other staff in the wards."

"Most of the users are not toilet trained, they are on nappies due to physical disabilities. They are paraplegic and on a wheelchair."

"Some could not drink from a cup; we had to stimulate them to drink from the cup without spilling."

"Most of the users, cannot bath themselves due to the physical disabilities and lack of stimulation."

Some were frowning as they were trying to explain their thoughts and experiences.

## 4.3.3.2 Poor comprehension of what profound intellectual disability

The majority of participants expressed poor comprehension of what profound intellectual disability is. The poor comprehension was related to the fact that it is a complex term. Some of the quotes that showed poor comprehension were as follows:

"It is neither a health threat nor an illness, they are just mentally challenged."

"It is a health threat and further said the worst part of intellectual disabilities, they are super slow. They are exposed to threat such as rape, abuse and burns because they cannot advocate for themselves. It is not all about witchcraft; users cannot express themselves and do anything for themselves."

"It is both a health threat and illness. Health threat as they cannot do simple things like bathing and illness because they have an IQ of below 20 and some have cerebral palsy as a result they cannot walk."

"It is a generalised disorder characterised by an IQ below 20 with significant cognitive impairment, congenital abnormalities, maladaptive functioning, self-care deficits and they behave like small children."

"It is a health threat for the mere fact that they cannot think properly. They are prone to injuries and infections."

Others used non-verbal communication and silence when they were trying to share their thoughts of what profound intellectual disability is. According to Aldersey (2012:02), disability is a cultural creation: disability status depends less on the nature or degree of a person's impairment and more on societal standards for normative bodies, mind, behaviours, and roles (Armstrong & Fitzgerald 1996; Ingstad & Whyte 1995).

This had been evidenced in this study where participants gave different perspectives about the definition of profound intellectual disability. It was also evidenced that explaining profound intellectual disability is a complex issue. One participant reported that in their family there is one family member who is suffering from intellectual disability

and the family thought it was all about witchcraft. Two of the participants stated that profound intellectual disability is a representation of both an illness and a health threat and they substantiated their answer based on facts as discussed in the participants' quotations. Most of participants (50%) reported that profound intellectual disability is more of a representation of a health threat than an illness, with 33% reporting that is just a disorder. According to Ambikile (2012:01), it is estimated that world-wide up to 20% of children suffer from debilitating mental illness which include learning disorder. This implies that profound intellectual disability is both an illness and disorder too. To support that profound intellectual disability is a representation of health threat, according to the study conducted in Netherlands Tadema and Vlaskamp (2009:42) stated that apart from the cognitive, motor and sensory impairments, they are at risk of developing several additional health problems such as chronic respiratory disorders, epilepsy, gastro-oesophageal reflux, contractures, constipation, osteoporosis and dysphagia.

In integrating the Common Sense Model, PID is regarded as a representation of both a health threat and an illness. According to Uys and Middleton (2014:538), the term intellectual disability refers to significant sub-average intellectual functioning associated with concurrent impairments in adaptive behaviour manifested during the developmental period (Molteno & Wetway, in Robertson, Allwood & Gagiano 2001:345). Furthermore, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5tm), profound intellectual disability is one of the four subtypes reflecting the degree of intellectual impairment. It is characterised by an IQ below 20 or 25 with limited motor and speech development; may develop very limited self-help skills; requires total care for life. According to Mental Health Care Act No. 17 of 2002 (South Africa 2002:section 01), profound intellectual disabilities, means arrange of intellectual functioning extended from partial self-maintenance under close supervision, together with limited selfprotection skills in a controlled environment through limited self-care and requiring constant aid and supervision, to severely restrict sensory and motor functioning and requiring nursing care. Much as caring for users with profound intellectual disability is not easy, explaining profound intellectual disability was also a complex issue. According to the study conducted in South Africa (Bloemfontein), explaining the term mental retardation or intellectual disability is complex in nature (Calitz 2011:66).

## 4.3.4 Care and rehabilitation centre setting

The care and rehabilitation centre setting emerged as the fourth category. According to Sechoaro, Scrooby and Koen (2014:02), rehabilitation is a goal-oriented process, with the aim of enabling intellectually-disabled people to reach an optimum mental, physical and/or social functional level, thereby providing them with the tools required to change their lives (Department of Health South Africa 2000:31). Users with profound intellectual disabilities are sent to care and rehabilitation centre in order to receive care, treatment and rehabilitation. According to Ambikile and Outwater (2012:02), living with children with learning disorder can be very stressful for the caregivers in the family and they experience various psychological, emotional, social and economic challenges. Therefore, this kind of children is admitted in the care and rehabilitation centre in order to relieve families from the stress and burden. Under the fourth category, the following themes and subthemes emerged. The Burden of care emerged as the theme and poor job satisfaction and stressful work environment.

#### 4.3.4.1 Burden of care

## Poor job satisfaction

The majority of participants reported poor job satisfaction. This was related to the fact that most of the users had both mental and physical disabilities and they were not comfortable looking after the users. Some of the quotes that showed the poor job satisfaction were as follows:

"It is quite a life time challenge to care for users who cannot talk and walk."

"It is tiring and quite hectic as users cannot walk due to cerebral palsy."

"Strain to the nurses to bath users being few."

"It's quite strenuous doing everything for users and others their body frame is long and heavy."

"MHCUs are fully dependent on nurses for Activities of Daily Living (ADL) like bathing, feeding, toilet training and mobility". Constantly the MHCUs have to be reminded of ADL."

Users depended on nurses 24 hours, it's like parenting and mothering."

"They are lost and others can't see properly and they don't look like human beings and they are quite different. I was in female ward but I thought users were males."

Some showed sad faces when they were trying to explain their thoughts and feelings.

#### 4.3.4.2 Stressful work environment

The majority of participants reported that working at the centre is a lifetime stress. The stressful working environment was related to the fact that most of the users had both mental and physical disabilities and nurses were not comfortable looking after them. Moreover, there was a shortage of resources. Some of the quotes that showed the stressful work environment were as follows:

"I have noticed there is severe shortage of nurses, in a day you found there are two professional nurses and staff nurses to bath eighteen (18) users. Professional nurses were not doing bed bathing. There is shortage of resources especially nappies and gloves."

"If they can employ more nurses to practice one to one it will be better."

"It is far from everything, in the rooms and wards are just the same, you have nowhere to go. It is just another world."

"The place is boring with poor mobile network connections."

"It's just a waste of time and talents for professional nurses to work there. All what they do they give medication and supervise activities. The place is rural far from everything with no transportation."

"They throw tantrums, bang themselves and throw themselves on the floor as a form of attention seeking behaviours."

"They behave strangely. One would spit sputum and thereafter eat it."

"Other users have even been dumped by their own families for the past 20-40 years. The centre is like a home for them no longer a rehabilitation centre."

Some participants frowned to display their emotions and feelings.

Martin et al (2012:71) recognised the upheaval and confusion service of users living in long term care setting. Therefore, the study recommends the move towards community based living will be of great importance as the community will have in-depth knowledge and close relationships with users in order to prevent stigma and discrimination.

According to Ryan, McEvoy, Guerin and Dodd (2010:566) people with intellectual disabilities are among the most excluded and vulnerable groups as indicated in this quote:

"It's rare to meet individuals with intellectual disabilities; they are hidden from the society."

"They are stigmatised and not allowed to socialise within the community."

In this study, this has been evidenced with the centre being far from the community with poor mobile network connections. The issue is if intellectual disabilities is not infectious and they are treated as innocent, why was it situated far from the community but next to the prison or correctional services. Siska (2010:501) concluded that people with intellectual disabilities face typical and specific risks of discrimination in all European countries and in all areas of life.

Participants found the centre to be more stressful due to the burden of care needed. Most users rely on nurses for the activities of daily living. According to Marijean (2008:02), activities of daily living include bathing, getting dressed, walking, getting out of bed, eating and taking medication (Pandya 2005). In this study, these activities for the student nurses were tiring and hectic and they contributed to the burden of care as it

is difficult to do them on a daily basis. The burden was more profound due to the users' physical, mental and sensory impairment. Most users could not follow instructions due to the communication difficulties. According to the study conducted in Dar es Salaam, (Aldersey 2012:02), it was stated that caring for people with intellectual disabilities combine ideas of both the 'burden' and stress. It was evidenced from the quotes of the participants that caring for the users with profound intellectual disabilities causes physical and psychological strain.

"If they can employ more nurses to practice one to one it will be better."

"MHCUs are fully dependent on nurses for Activities of Daily Living (ADL) like bathing, feeding, toilet training and mobility". Constantly the MHCUs have to be reminded of ADL."

Users depended on nurses 24 hours, it's like parenting and mothering."

## 4.3.5 Career option of working with mental health care users with profound intellectual disabilities

Career option of working with mental health care users with profound intellectual disabilities emerged as the fifth category. Under the fifth category, the following themes and subthemes emerged. Mixed feelings emerged as the theme and avoidance and acceptance emerged as the sub-themes.

#### 4.3.5.1 Mixed feelings

#### Avoidance

The majority of participants reported that they will avoid working with users with PID. Their avoidance was related to the fact that most of the users had both mental and physical disabilities and they were not comfortable looking after them. Some of the quotes that showed their avoidance were as follows:

"I wouldn't want to be placed at the centre, it was emotional for me."

"One said "No" with laughter."

"If it happens that I work there, I would need counselling on a daily basis."

Others shook their heads to emphasise that they would rather avoid working at the centre after completion of training.

## Acceptance

Very few participants (4) showed interest of working with users' with PID after completion of training. Participants who reported an interest of working with users with PID reported that they have accepted that people are not the same and that each and every person has the right to health care. Some of the quotes that showed their acceptance were as follows:

"I would consider working at the centre, it is not about chasing a career but doing something that is closed to my heart."

"I wouldn't mind volunteering during my spare time even if not placed after completion of training. It was interesting and eye opening for me as we have one family member with PID."

"After stimulating the users, seeing the smiles on their faces, it felt like I have won a trophy". Participant further said "two weeks is not enough. We should explore other wards and get to know how it feels like."

One participant mentioned interest and passion for working with users with profound intellectual disability with a smile.

In this study, eight participants (67%) reported said "no" they wouldn't want to work at the centre after completion of training. 33% that is four participants reported positive feelings about working at the centre after completion of training. According to a study conducted in India, Vijayalakshmi et al (2013:66) stated that worldwide mental illness including profound intellectual disability receives negative publicity and stigma. Furthermore, a positive attitude towards profound intellectual disability and mental illness is a prerequisite for the provision of holistic care. Four out of twelve participants reported interest and passion in working at the centre after completion. However,

persistent negative attitudes and the social rejection of people with mental illness have prevailed throughout history, users face widespread stigmatisation, discrimination, violence, neglect and avoidance. Eight out of twelve participants reported no interest in working at the centre after completion of training. This is attributed to lack of awareness about mental illness which encourages discrimination and stigmatisation. In this study it is evidenced that student nurses avoid working at the centre and this may have a negative impact on users achieving positive quality of life and general well-being. Due to this effect, users will not achieve better life for all and Government's vision of "A Long and Healthy Life for All South Africans" will not be achieved.

#### 4.4 DISCUSSION OF THE REFELCTIVE DIARIES

Reflective diaries as a data collection method were used to as a self-report instruments to repeatedly examine the on-going experiences, which offers the opportunity to investigate social, psychological, and physiological processes, with everyday situations (Bolger et al 2003:580 as cited in Thupayagale-Tshweneagae & Molokomme 2012:27). The results of the reflective diaries indicated the less interest of participants to work at the centre that cares for mental health care users with profound intellectual disabilities. This was also evidenced in the digital recorded in depth interviews, reflective diaries, observation and field notes during data collection. In integrating the Leventhal's theory of Common Sense Model in this study, the results indicated that each and every participant used unique opinions to clarify, justify and rationalise the choice of whether to work at the centre after completion or not. Data collected were in the form of written and spoken words shed by pilot study participants. The study integrated the Common sense Model (CSM) to analyse the results twelve participants who did form part of the research participants. The value of reflective diaries was uttered by participants that it helped them in dealing and expressing negative experiences. Most of the information written in the diaries were more or less the same with the information obtained from the in depth interviews. What was of great importance was that participants wrote in the reflective diaries whilst the information was still fresh in their minds.

The following quotations were highlighted in the reflective diaries:

"The feeling that I had on the first day of exposure of apprehension was now gone as now was no longer emotional, I got used to the conditions of the users. "No" I would however not live or work at the centre because it is emotionally draining."

"Caring for users with profound intellectual disabilities is emotionally draining because users cannot speak for themselves, as student nurses we have to figure out on our own what they want to say. "No" I won't consider working at the centre."

"The day was very long for me and with shortages of staff in the ward it became worse, especially because not even one user is able to bath self. They needed total care and supervision. "Yes" The only reason I can go back and work at the centre is just to use the time that is available to further my studies while I am doing community services, then move to another place after studying."

I did not have much challenges, it was interesting when we started with the daily routine. I felt sorry for the staff members because they work so hard and they are short staffed. "Yes" I would consider working with users with intellectual disabilities, but not at this centre."

"Talk about toddler's behaviour I have really learnt a lot for being exposed to these kind of users, learning has taken place and I feel proud of the work that I do. One major concern is that users are not going to have this kind of attention and again the stimulation programmes won't be continued. It will be done again by the next group of students next year 2015, that's the reality. "No" I wouldn't work at the centre after completion of training."

"I will be glad to see the centre being closed down and the place used as a state hospital for people around the area to benefit from it. "No" I wouldn't consider working at the centre after completion of training."

"Well they say, one day the emotions will end and freedom will reign. The centre was one of the institutions I have learnt that my nursing career is important and needed by my community. The way the centre took me by my prior knowledge

surprise and works on my emotions, "No" I wouldn't want to work there in any other day in my life or nursing career."

"Thanks God it was our last day and I will never ever come back to this place again. "No" I will never work at the centre."

"No", I personally would not like to be placed there to work permanently. The users there have made me appreciate life a lot, but I do not like to see people like that. To me it seems as though they are suffering although I know for a fact that they are not, that is how they are and have lived that way most of their lives. I believe in helping someone and seeing them walk out of a hospital normal, not as those users are in the centre."

Even though I love nursing and would like to make a change in the centre, "No" I do not think I am the right person for this boring job and centre. The users in the ward are so innocent and true it was a privilege to work with these angels."

"The centre is isolated and far from everything. "No" My personal life and happiness outweighed that and I cannot work there if it was somewhere in Pretoria/Centurion I would honestly choose it first choice."

"It was indeed an honour caring for users with profound intellectual disabilities. As much as I love Psychiatry, the field of intellectual disability is not something I am passionate about "No" I would not choose to work at the centre, it is very far from the existing world and it is very cold in winter."

It is evident from the report given that student nurses are less passionate about the field of intellectual disability. Out of 12 reflective diaries issued, two participants' reported that they would consider working at the centre whereas the other ten participants reported that they would not work at the centre after completion of training. Mostly they reflected about the negative experiences they encountered when they were caring for users with profound intellectual disability. Nurse shortage and unhealthy work environment remained the major challenges. Cohen et al (2009:308) stated that the provision of healthy work environment for nurses is one factor that has been linked to staff nurse satisfaction and in turn contributes to the retention of competent, qualified nursing staff. Furthermore, Tzeng and Yin (2009:315) stated that a satisfied RN workforce will improve the quality of patient care, the most important professional nursing standard.

## 4.5 DISCUSSION OF FIELD NOTES

Field notes as a data collection method, Field and Morse (1994:79-82) cited in De Vos et al (2011:359) stated that the critical points to be followed when writing filed notes is to minimise loss of data, is to find a quiet place to write; set aside adequate time to complete the notes; sequence events in the order they occurred; letting the events and conversation flow from the mind onto the paper.

In this study, the field notes helped in capturing the non-verbal and facial expressions. The following were noted during data collection:

"It was emphasised with a smile."

"Before explaining, participant raised eyebrows."

"Fist emphasised with non-verbal communication, frowned and displayed sad faces."

#### 4.6 DISCUSSION OF OBSERVATION

Observation as one of the data collection methods is described as a qualitative research procedure that studies the natural and everyday set-up in a particular community or situation (De Vos et al 2011:329). Observation made by the researcher during data collection was that student nurses showed less interestedness in working at the centre after completion. This was observed by the sad face and frowning when asked whether they would like to work at the centre after completion. Few smiled to work at the centre after completion. The observations made were captured as follows:

"It was emphasised with a smile."

"Before explaining, participant raised eyebrows."

Fist emphasised with non-verbal communication, they frowned and display sad faces."

#### 4.7 SIGNIFICANCE OF THE RESULTS

## What is already known about this topic

- Caring for mental health care users with profound intellectual disabilities is more challenging.
- An advanced knowledge and more skilful personnel are needed to improve the quality of life for people living with intellectual disabilities.
- People with intellectual disabilities remain one of the marginalised in terms of heath care service delivery.
- Stigma and discrimination is more in people living with intellectual disabilities,
   they are not allowed to marry and do things that normal people do.
- They are socially excluded from the people in the community, they are prone to abuse and neglect by their own families.
- Recollected experiences of mothers, parents, teachers and nurses see them as a burden and strain as they need 24 hour care.
- There is more negativity towards people living with intellectual disabilities due to the complex nature of their needs.
- Explaining profound intellectual disability was a complex situation and never easy.
- The causes of intellectual disabilities are variable.

#### What this study adds towards this topic

- Very few studies exists about the student nurses experiences of this particular nursing college in caring for mental health care users with profound intellectual disabilities when they are clinically placed at one of the care and rehabilitation centre in Gauteng province.
- The underlying reasons that made students nurses ill prepared to work at the centre were unknown. The centre even recommended research after doing situational analysis seeing that the situation was escalating.
- The integration of Leventhal's theory of Common Sense Model was recommended for further research in mental health and moreover intellectual disabilities.

- Caring for mental health care users with profound intellectual disabilities is compared to mothering and parenting.
- Profound intellectual disability is seen as the worst case of profound intellectual disability and is both a representation of health threat and an illness depending on the cause of the intellectual disabilities.

#### 4.8 CONCLUSION

This chapter discussed the results and findings of the study that emanated from twelve participants that took part in this study. The purpose of the study was to explore on the experiences of student nurses in caring for mental health care users with profound intellectual disabilities. A triangulation of data collection methods were used to explore the student nurses experiences which included reflective diaries, digitally recorded in depth interviews, field notes and observation. Out of the data collected five categories emerged which are experiences of student nurses, caring for mental health care users with profound intellectual disabilities, profound intellectual disabilities, career option for working with mental health care users with profound intellectual disabilities and care and rehabilitation centre setting. Out of the five categories, themes and sub-themes developed which were earlier discussed and literature control was conducted to verify the facts and findings of this study.

In the next chapter, the study will discuss the conclusions, implications, recommendations and limitation of the study.

#### **CHAPTER 5**

# CONCLUSIONS, RECOMMENDATIONS, LIMITATIONS AND DISSEMINATION OF THE RESULTS

#### 5.1 INTRODUCTION

The purpose of this chapter was to provide the overview of the conclusions, recommendations, limitations and dissemination of the results. The conclusions of this study were informed on the basis of written, verbal and non-verbal communication shed by the participants. Furthermore, the conclusions were also informed by the emerged five categories and literature control that emanated from chapter 4 as already discussed. In this chapter, the conclusions of the study including experiences of student nurses, caring for mental health care users with profound intellectual disabilities, profound intellectual disabilities, care and rehabilitation centre setting and career options of working with profound intellectual disabilities' users, recommendations, limitations and dissemination of the were discussed in details in order to ensure trustworthiness and to maintain rigour in the study.

## 5.2 CONCLUSION OF THE STUDY

Shortage of staff in the centres caring for mental health users with profound intellectual disabilities (PID) is well recorded in literature (Gaede & Surujlal 2011:344; Murphy & Carborne 2008:333). Despite this noted shortages very few studies have looked into why nurses do not want to work with mental health care users with PID. However, nurses and other health care workers find working with these patients to be difficult as discussed in the reviewed literature in chapter 2.

Evidence from this study suggests that completing nurses find working with PID to be emotionally challenging and that negative experiences outweigh the positive experiences, resulting in their reluctance to want to work with PID. It is therefore incumbent upon policy makers and hospital administrators to take cognisance of these

negative feelings so that ways of minimising these frustrations and promoting the wellbeing of nurses caring for mental health users with PID are promoted.

In conclusion, the study fills a significant knowledge gap by illuminating the reasons why completing nurses do not want to work with mental health care users with PID. The study suggests how places that care for persons with PID can be made more attractive to nurses.

#### 5.3 RECOMMENDATIONS

Users with PID continue to suffer stigma, discrimination and neglect due to the complex nature of their needs. In order to improve quality of life and quality patient care the study makes the following recommendations:

#### 5.3.1 Recommendations for the care and rehabilitation centre administrators

The following recommendations for the administrators of centre looking after persons with PID.

- The centre should be made more attractive as a means to stimulate interest and joviality among the clients and nurses alike.
- More community integration and awareness programme to be put in place to break silence, stigma and discrimination about intellectual disability.
- Open days to be celebrated on an annual basis so that the community is aware of the services provided by the centre.

## 5.3.2 Recommendations for nursing education and training

It has been evidenced from the participants' feedback that the students did not like the idea that the centre's clinical placement was placed in the last year of study. Therefore, it is important that the students be taken for an educational tour in their third year before the real placement so that they are emotionally and psychologically prepared. This will minimise the negative feelings experienced. Due to this effect, students can develop more interest to work at the centre after completion.

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Some form of counselling should be provided to students' pre and post clinical placement in order to offer psychological support to the students.

Nurse educators may consider a longer duration like four weeks instead of two weeks for placement. The importance of longer placement period will assist students in knowing and understanding users in order to minimise frustrations and to promote successful communication. Knowing a person plays a major role in successful communication.

#### 5.3.3 Recommendations for nursing educators

It has been evidenced from the students' feedback that students need more support from the nurse educators when placed at the centre in order to offer more emotional support. The availability of full time mentors will assist in offering emotional support and ensuring that the centre is conducive for students to achieve their learning outcomes.

#### 5.3.4 Recommendations for clinical practice

It has been recommended that the unavailability of resources both material and human resources were the main challenges that impacted negatively on the quality of care. Stimulation was not being done due to lack of availability of staff. Due to this effect, users could not achieve quality patient care and improved quality of life. Most of the uses that were institutionalised in the care and rehabilitation centre relapsed more than progressing. Furthermore, staff exhibited low morale and burnout which ultimately led to high staff turnover and high absenteeism. The recommendations for clinical practice are:

• The centre to introduced service awards by nominating sister of the month and ward of the month to recognise service excellence. Prizes, certificates and awards to be issued to recognise excellence service delivery. Furthermore, service certificates to be issued to staffs who have never been absent for a period of a year. Service awards to be awarded to staff who has worked at the centre from as early as five years because is never easy taking care of users with profound intellectual disabilities.

- The staff must also be rotated in different wards on a three year basis to minimise stagnation and resistance to the changes.
- The centre to recruit more matured nurses and even retired nurses with passion for intellectual disabilities to work at the centre in order to minimise high staff turnover and reduce shortage.
- The centre to take emotional wellbeing of the staff into consideration. The implementation of employee wellness programme to assist with the well-being of the employees.
- Collaboration with the psychologists to offer emotional support and counselling to employees who experience psychological trauma of dealing with users on a daily basis.
- Employment of speech and language therapists to assist with the communication difficulties experienced by nurses when they care for users with communication challenges.
- Employment of social workers to assist with the family traces as some of the users have been dumped and neglected with no family contacts. The centre has become a home and no longer rehabilitation setup.
- More in-service training on sign language and stimulation programme to be introduced to the staff to promote general wellbeing of the users with intellectual disabilities in order to encourage autonomy and independence among users.

#### 5.3.5 Recommendations for the Gauteng Department of Health

It has been evidenced that the centres that deals with profound intellectual disabilities are separated far from the community. It is recommended that the centre be placed within the community where it will be easily accessible and within reach. It is recommended that the centre be not treated in isolation but be integrated with other bigger psychiatric institutions in order to minimise high staff turnover.

Furthermore, it is recommended that more incentives be given to staff working at the centre with profound intellectual disabilities to attract more nurses because it is never easy taking care of users with profound intellectual disabilities. Caring for users with profound intellectual y to be regarded as a speciality which needs special care and attention.

More programmes and awareness campaign to be put in place to support individuals, communities and institutions dealing with intellectually disabled users. More funds to be allocated so that intellectual disability receives much attention like any other chronic illness.

#### 5.3.6 Recommendations for nursing research

It is recommended that furtherance of research be done in order to effect changes in caring for users with profound intellectual disabilities. It is recommended that support programmes, policy formulation and conceptual framework be researched to improve quality of life with people living with intellectual disabilities so that they too could achieve that great sense of general well-being and happiness.

#### 5.4 LIMITATIONS

The study was only limited to 4<sup>th</sup> year students who were registered for the Diploma in Nursing (General, Psychiatric and Community) and Midwifery R425 at a specific nursing education institution in Gauteng province who have been exposed to caring for mental health care users with profound intellectual disabilities in one of the care and rehabilitation centre in Gauteng province. Furthermore, the study specifically concentrated only to the profound intellectual disabilities without including other categories of intellectual disabilities. The results of the study were based on the small sample of twelve participants. Although a triangulation of data collection methods were used to arrive at the conclusions and findings, its generalisability will be limited even though conditions of rigour were upheld.

#### 5.5 DISSEMINATION OF THE RESULTS

The results of this study will be shared to others. They will be presented to the research conferences and seminars. A completed theses or book will be presented to the institutions where the student did her master's studies. Other copies will be presented to the centre where students underwent clinical placement and the nursing colleges where students where undergoing nursing education and training. The other copy will be presented to the Gauteng Department of Health so that results and findings are made known to the department to consider the recommendations and to effect the changes.

#### 5.6 CONCLUSIONS

A triangulation of data collection methods was used to explore the student nurses' experiences. Methods used were reflective diaries, digitally recorded in depth interviews, field notes and observation. Out of the data collected five categories emerged which are experiences of student nurses, caring for mental health care users with profound intellectual disabilities, profound intellectual disability, career option for working with mental health care users with profound intellectual disabilities and care and rehabilitation centre setting. Out of the five categories, themes and sub-themes developed which were earlier discussed and literature control was conducted to verify the facts and findings of this study.

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## ANNEXURE A

ETHICAL CLEARANCE CERTIFICATE: UNIVERSITY OF SOUTH AFRICA, HEALTH STUDIES HIGHER DEGREES COMMITTEE

## ANNEXURE B

PERMISSION TO CONDUCT STUDY: GAUTENG PROVINCIAL DEPARTMENT OF HEALTH

OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)

## ANNEXURE C

LETTER TO ADMINISTRATION OF CULLINAN CARE AND REHABILITATION CENTRE

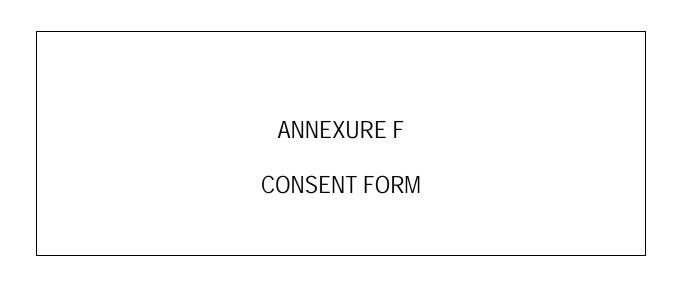
APPROVAL TO CONDUCT RESEARCH FROM CULLINAN CARE AND REHABILITATION CENTRE

## ANNEXURE D

PERMISSION TO CONCDUCT STUDY AT SG LOURENS NURSING COLLEGE

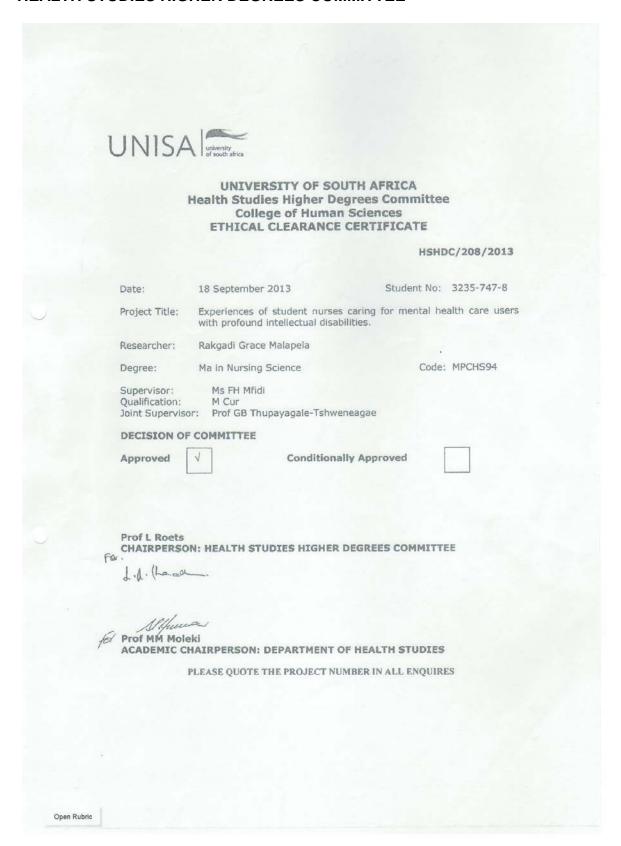
APPROVAL TO CONDUCT RESEARCH FROM SG LOURENS NURSING COLLEGE

# ANNEXURE E INFORMATION FOR STUDY PARTICIPANTS



#### **ANNEXURE A**

# ETHICAL CLEARANCE CERTIFICATE: UNIVERSITY OF SOUTH AFRICA, HEALTH STUDIES HIGHER DEGREES COMMITTEE



#### ANNEXURE B

# PERMISSION TO CONDUCT STUDY: GAUTENG PROVINCIAL DEPARTMENT OF HEALTH

19 July 2013

**Deputy Director** 

**Nursing Education Department** 

Department of Health

Private Bag X085

**MARSHALLTOWN** 

2107

RE: Permission to conduct research with fourth year student nurses of SG Lourens Nursing College

Dear Sir/Madam

I am writing to seek permission of the study I would like to conduct within the fourth year student nurses of SG Lourens Nursing College. The topic of my research is experiences of student nurses caring for mental health care users with profound intellectual disabilities during clinical placement at Cullinan Care and Rehabilitation centre in Metsweding district Gauteng province.

**Title of the study** is experiences of student nurses caring for mental health care users with profound intellectual disabilities

The purpose of this study is to explore the experiences of fourth year nursing students on caring for mental health care users with profound intellectual disabilities.

#### Objectives of the study:

- To describe the experiences of fourth year nursing students on caring for mental health care users with profound intellectual disabilities.
- To explore the meaning attached to caring for mental health care users with profound intellectual disabilities.

• To recommend best practice for retaining and attracting nurses to care for people with profound intellectual disabilities.

#### Research instrument:

Participants will be given reflective diaries to record daily about their experiences, thoughts and feelings regarding caring for mental health care users with profound intellectual disabilities.

In depth interviews will be conducted and captured in the tape recorder. Field notes will be taken during the interviews.

#### Confidentiality:

A participation information leaflet, explaining title, background, purpose, procedure, benefits, risks, freedom to withdraw, voluntary participation, anonymity and confidentiality status of the research will be distributed to the participants.

#### Data collection:

Data will be collected from the fourth year student nurses of SG Lourens Nursing College at Gauteng province Tshwane district through reflective diaries and one to on in-depth interviews.

**Findings of this study** will be presented to the academic staffs at the completion of the study. This study is not intended to impact government resources. My anticipated start date is September 2013. I will not proceed until I have received ethical approval. I will also provide you with a copy of the letter of ethics approval for your files.

I appreciate your time and attention to my research study. I look forward to hearing from you. Please do not hesitate to contact me at 082 598 6881 and work telephone 012 319 5769 email <a href="mailto:gmai

Supervisor: Ms FH Mfdi

University of South Africa

Tel: 012 4296731

E-mail: mfidi@unisa.ac.za

Co-supervisor: Prof G Thupayagale-Tshweneagae

University of South Africa

Tel: 012 429-2195

E-mail: tshweg@unisa.ac.za

Sincerely

Ms Rakgadi Grace Malapela, (Researcher)

Master in Nursing Science student, University of South Africa,

Student number: 3235-747-8

### **OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)**



## OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)

Researcher's Name (Principal investigator)	Ms. Rakgadi G. Malapela	
Organization / Institution	SG Lourens Nursing college	***
Research Title	Experiences of student nurses caring for m profound intellectual disabilities	nental health care users with
Protocol number	P090314	
Date submitted	03/03/2014	
Date reviewed	19/03/2014	
Outcome	APPROVED	
Date resubmitted	N/A	
Date of second review	N/A	
Final outcome	N/A	

It is a pleasure to inform that the Gauteng Health Department has approved your research on "Experiences of student nurses caring for mental health care users with profound intellectual disabilities."

The Provincial Protocol Review Committee kindly requests that you to submit a report after completion of your study and present your findings to the Gauteng Health Department.

Approves / not approves

Dr Bridget Ikalafeng

Provincial Protocol Review Committee, Chairperson

Date #07 104/2014

#### ANNEXURE C

# LETTER TO ADMINISTRATION OF CULLINAN CARE AND REHABILITATION CENTRE

19 July 2013

Chief Executive Officer

Cullinan Care and Rehabilitation Centre

Private Bag X1005

Cullinan

0001

Tel: 012 734-1038

Fax: 012 734-1040

RE: Permission to conduct research with fourth year student nurses of SG Lourens Nursing College placed at your institution

Dear Madam

I am writing to seek permission and support for a study I would like to conduct within the fourth year student nurses of SG Lourens Nursing College placed at your institution. The topic of my research is experiences of student nurses caring for mental health care users with profound intellectual disabilities.

The purpose of this study is to explore the experiences of fourth year nursing students on caring for mental health care users with profound intellectual disabilities.

Findings of this study will be presented to you and the nursing staff at the completion of the study. This study is not intended to impact your resources. My anticipated start date is September 2013. I will not proceed until I have received ethical approval. I will also provide you with a copy of the letter of ethics approval for your files.

I appreciate your time and attention to my research study. I look forward to hearing from you. Please do not hesitate to contact me at 082 598 6881 and work telephone: 012 319 5769 email <a href="mailto:gma

Supervisor: Ms FH Mfdi

University of South Africa

Tel: 012 4296731

E-mail: mfidi@unisa.ac.za

Co-supervisor: Prof G Thupayagale-Tshweneagae

University of South Africa

Tel: 012 429-2195

E-mail: tshweg@unisa.ac.za

Sincerely

Ms Rakgadi Grace Malapela, (Researcher)

Master in Nursing Science student, University of South Africa,

Student number: 3235-747-8

# APPROVAL TO CONDUCT RESEARCH FROM CULLINAN CARE AND REHABILITATION CENTRE



#### CULLINAN CARE AND REHABILITATION CENTRE

Enq: Matshidiso Nyatlo

**2**: 012 734 7004

Cell: 082 777 3208

Fax: 086 612 2871

email: matshidiso.nyatlo@gauteng.gov.za

TO:

MS RG MALAPELA

FROM:

MS MPO NYATLO

CHIEF EXECUTIVE OFFICER

DATE:

19 JUNE 2014

SUBJECT:

PERMISSION TO CONDUCT RESEARCH

This is to inform you that permission to conduct research in Cullinan Care & Rehabilitation Centre has been granted.

Please ensure that all ethical consideration and confidentiality of users' information is protected at all times.

Your cooperation will be highly appreciated

Wish you success in your studies.

Regards

MPO Nyatlo

CEO: CCRC

DEPARTMENT OF HEALTH
Cullinan Care & Rehabilitation Centre

1 9 JUN 2014

Private Bag X1005, Cullinan, 1000 DEPARTMENT OF HEALTH ANNEXURE D

PERMISSION TO CONCDUCT STUDY AT SG LOURENS NURSING COLLEGE

19 July 2013

The Principal

SG Lourens Nursing College

Private Bag X755

Pretoria

0001

Tel: 012 319 5600

RE: Permission to conduct research with fourth year student nurses of SG

**Lourens Nursing College** 

Dear Madam

I am writing to seek permission and support for a study I would like to conduct within the fourth year student nurses of SG Lourens Nursing College. The topic of my research is experiences of student nurses caring for mental health care users with

profound intellectual disabilities.

The purpose of this study is to explore the experiences of fourth year nursing

students on caring for mental health care users with profound intellectual disabilities.

Findings of this study will be presented to you and the academic staffs at the

completion of the study. This study is not intended to impact your resources. My

anticipated start date is September 2013. I will not proceed until I have received

ethical approval. I will also provide you with a copy of the letter of ethics approval for

your files.

I appreciate your time and attention to my research study. I look forward to hearing

from you. Please do not hesitate to contact me at 082 598 6881 and work telephone

012 319 5769 email <a href="mailto:gmalapela@gmail.com">gmalapela@gmail.com</a> if you would like further information.

Supervisor: Ms FH Mfdi

University of South Africa

Tel: 012 4296731

E-mail: mfidi@unisa.ac.za

Co-supervisor: Prof G Thupayagale-Tshweneagae

University of South Africa

Tel: 012 429-2195

E-mail: tshweg@unisa.ac.za

Sincerely

Ms Rakgadi Grace Malapela, (Researcher)

Master in Nursing Science student, University of South Africa,

Student number: 3235-747-8

# APPROVAL TO CONDUCT RESEARCH FROM SG LOURENS NURSING COLLEGE



To ; Ms GR Malapela

From : SG Lourens Research Committee

Date : 20.11.2015

Subject: Permission to conduct research

I hereby respond to your request to conduct research in this institution for you Masters degree study. Permission is granted and you are advised to take note of the following:

- You will be required to collect data on your own
- You are requested to furnish us with results of your research at the end of your study

Thank you,

Mrs Rakubu

Date



#### **ANNEXURE E**

#### INFORMATION FOR STUDY PARTICIPANTS

**Title:** Experiences of student nurses caring for mental health care users with profound intellectual disabilities.

**Principal Investigator:** Ms RG Malapela, Masters in Nursing Science student, University of South Africa, (3235-747-8)

Background and purpose of the study: Student nurses during their four year course of training leading to Diploma in Nursing (General, Psychiatric and Community) and Midwife, which is in accordance with SANC regulation R425 (3C) are expected to render care and rehabilitation to the mental health care users with profound intellectual disabilities as part of the learning outcomes to be achieved during psychiatry placement. In reading their reflective essays post exposure to caring for mental health care users with profound intellectual disabilities, students reported that it is a burden and a traumatic experience to take care of these mental health care users.

The purpose of this study is to explore the experiences of student nurses caring for mental health care users with profound intellectual disabilities in a care and rehabilitation centre incorporating the Common Sense Model (CSM).

**Procedure**: 4<sup>th</sup> year student nurses who are on training at SG Lourens nursing college in Gauteng province will be given reflective diaries during the two weeks of clinical exposure at a care and rehabilitation centre. They will reflect on their thoughts, experiences, feelings, challenges and whether they would like to work in the care and rehabilitation centre after completion of their training. Thereafter, they will hand in diaries post exposure and in depth interviews will be conducted in a researcher's office A303-2 to ensure privacy. The interview will be tape recorded and field notes will be taken during interview. Those interested in taking part in the study, more information will be explained in full. If you are interested in take part, you will give a written consent by completing the consent form. Questions will have to be answered before signing the consent. If you have trouble understanding any of the questions, the researcher will be available to answer your questions. If you agree to

participate, please complete the question sheet and sign the consent. Return the consent form within two weeks in a provided envelope with address at any time.

At any time, you may refuse to answer any questions, or if you choose, you may withdraw from the study.

**Benefits:** If you take part in this study, there may be no immediate, direct benefit for you. You will not receive any payment for taking part in this study. Participants will be issued with note books for reflective practices. However, by taking part in this study, the researcher hopes to learn more about their experiences. Results of this study may lead to further research that may enhance student experiences, clinical practice and nursing education.

**Risks:** There are no direct risks to you by taking part in this study. During interview questions asked may be upsetting to you, and this is considered to be an indirect risk. Participants will be referred to counselling department with prior arrangement should any indirect risk be experienced. There are no monetary costs to you associated with taking part in this study.

**Confidentiality:** Every attempt will be made to maintain your confidentiality during and after the study. As part of maintaining confidentiality, you will be identified by a number. All information will be held confidential, except when professional code of ethics or legislation requires reporting.

The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e., locked filing cabinet). Your name and any other identifying information will not be attached to the information you gave. Your name will never be used in any presentation or publication of the study results.

The information gathered for this study may be looked at again in the future to help answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

The results of this study may be included as part of a thesis or published in a scientific journal. Your name will not be mentioned in any of these documents. No participant in this study will be identified by name in either a presentation or publication.

Freedom to withdraw: If at any time you do not wish to continue in the study, for whatever reason, you may withdraw. You do not have to give a reason for no longer continuing in the study. If you withdraw from the study, it will not impact your employment.

You have the right to learn about the results of this study.

Should you have any question or problems feel free to contact Ms RG Malapela at 082 598 6881 and alternative office number at work 012 319-5769 Monday to Thursday 07h00-16h00 and Friday 07h00-13h00 only.

Signature of research participant	Printed name	Date
Signature of the Researcher	Printed name	Date

.

#### **ANNEXURE F**

#### **CONSENT FORM**

**Title:** Experiences of student nurses caring for mental health care users with profound intellectual disabilities.

**Principal Investigator:** Ms RG Malapela, Masters in Nursing Science student, University of South Africa, (3235-747-8)

#### **Questions:**

Signature of witness	Printed name	Date			
I believe that the person signing th and voluntary agrees to participate		volved in	the stu	dy	
Researcher's signature	Printed name	Date			
Signature of research participant	Printed name	Date			
I agree to take part in this study.					
This study was explained to me by	/:				
Do you understand who will have access to your information?					
Has the issue of confidentiality been explained to you?					
Do you understand that you are free study at any time? You do not have employment.				No	
Have you had the opportunity to ask questions and discuss the study?					
Do you understand the benefits an study?	nd risks involved in taking part i	n this res	search Yes	No	
Have you read and received a cop	y of the attached information s	heet?	Yes N	lo	
Do you understand that you have I	been asked to be in a research	study?	Yes N	lo	