



**KNOWLEDGE, PERCEPTIONS AND PRACTICES OF MEMBERS OF THE  
HEALTH CARE TEAM INVOLVED IN STEM CELL TRANSPLANTATIONS IN THE  
WESTERN CAPE**

**by**

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## ABSTRACT

Stem cell transplantation has become one of the standard methods of treatment for patients with malignant and benign blood disorders. The multidisciplinary team interacting with these patients and their families, must be knowledgeable concerning the appropriate quality health care. The objectives of the study were to explore the knowledge of the members of the health care team in terms of the processes that need to be adhered to with stem cells transplantation, as well as exploring the perceptions amongst the health care team members and their reactions towards patients undergoing stem cell transplantation. An exploratory research design with a qualitative approach was employed. Data collection took place at two stem cell transplant units in the Western Cape, using non-probability purposive sampling technique. The health care team members included a medical doctor, dietician, physiotherapist, social worker, radiographer and nursing staff. Data was collected by face-to-face personal interviews which were transcribed and analysed by using coding and thematic analysis. The majority of the professional participants could identify the processes for stem cell transplantation, which affirmed their knowledge. The non-professional health care team member, could also identify the types of methods and processes of stem cell transplantation. Participants stated that the health care team members had passion for this treatment option. Some participants felt it to be emotionally challenging to work in the environment, especially with paediatric patients and the dying. However, some health care team members could detach themselves emotionally from the patients. The team stated that the stem cell transplanted patients need special care to overcome all challenges experienced, but were positive about treatment. It is evident that management of stem cell transplanted patients is complicated and the health care team members must have knowledge, skills and the appropriate attitude to practice in these units. This study emphasised how vital it is that stem cell transplantation be included in the training programs of the multidisciplinary team. Health care practitioners in the field must stay abreast with stem cell research in order to effectively conduct health promotions for patients and staff. In addition, hematology and transplant awareness campaigns should also be conducted in order to educate society and suggest referrals if necessary.

Key words: stem cells, transplanted patient, knowledge, perceptions, practice.

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## DEDICATION

This research was done for all the patients whom we lost and those whom we helped to recover to be functional and to enjoy life. For all the participants who are the care givers of these patients, who never mind to even take them home, just to make a difference in their lives in their time of sickness. And for our families whose lives are influenced by us, the health care team members.

## GLOSSARY

### DEFINITION OF TERMS

<b>TERM</b>	<b>DEFINITIONS</b>
Stem cell	The main cell which will change into normal blood cells in our bodies, such as red blood cells, white blood cell, platelets
Red blood cells (erythrocytes)	Carries oxygen and nutrients to all cells in the body
White cells (leukocytes)	Protectors of the body
Platelets (thrombocytes)	For clotting purposes
Hematology	The study of blood and blood disorders
Allogenic	This is where donor stem cells are used for stem cell transplantation
Attitude	Psychologists define attitudes as a learned tendency to evaluate things in a certain way. This can include evaluations of people, issues, objects or events. Such evaluations are often positive or negative, but they can also be uncertain at times. For example, you might have mixed feelings about a particular person or issue.
Autologous	This is where the patient's own stem cells are used for stem cell transplantation
Health care	This is organized assessing, planning and implementation of activities in the community to ensure optimal health and care for people and their families.
Health care team members	These are the people who are trained to provide that care. They work together in a multidisciplinary team, each with their own specialty.
Knowledge	This is to be familiar with someone or something. This can be things that you know like facts, descriptions and skill, which you have obtained through experience and training.
Practice	This means to carry out or to apply. It is also to do or perform repeatedly to become good in what you do.

Private Hospital	This type of hospital is owned by a private institute
Hematology unit	A patient care ward set out specifically for the treatment of patients with blood disorders
Work-up for stem cell transplantation	This is where the patient receive treatment which could consist of chemotherapy, radiation, as well as a white blood cell enhancer before the collection of the stem cells
Public hospital	This type of hospital is owned by the department of Health

## ABBREVIATIONS

<b>Abbreviation</b>	<b>Explanation</b>
ACGME	Accreditation Council for Graduate Medical Education
HSC	Hemopoietic stem cell
HSCT	Hemopoietic stem cell transplantation
PN	Professional nurse
SANC	South African Nursing Council
WHO	World Health Organisation
QOL	Quality of Life



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## CHAPTER 1

### ORIENTATION TO THE STUDY

#### 1.1 INTRODUCTION

Hematology refers to the study of blood and blood disorders (Bunn & Aster, 2010: 36). Stem cell transplantations are procedures where the hemapoeitic stem cells are used to engraft in bone marrow in order to treat patients with blood disorders (Trounson & DeWitt, 2016: 194).

Patients with blood disorders are usually treated in hematology wards until they recover or die. All anatomical areas of the human body can be affected by the hematology system, hence caring for patients with disorders of this system can be challenging. These patients have distinct problems specific to their disease, with intermittent symptoms. The nurses who care for them must have a good understanding of the pathophysiology of hematological disorders. The interpretation of laboratory tests is very important in the assessment of the patient, so it is imperative that the nurse concerned, be knowledgeable about blood cells and the anatomy and physiology of the bone marrow (Smeltzer & Bare, 2012: 728).

Hematology units are very specialized areas of practice. In the hospital the diagnosis of a patient's disease, relating to hematology, starts at a physician's office, where the initial complaint and symptoms are investigated. The patient is then referred to a hematologist, where he or she is met by the nursing staff. Further tests are executed to confirm the diagnosis. Some of the procedures, such as a bone marrow biopsy, are carried out in the clinic on an outpatient basis, while for other procedures, such as intense chemotherapy, the patient has to be admitted to the hospital.

Some hematological diseases, such as leukemia, involve specific abnormalities in the blood. The hematological team should be able to interpret the laboratory results, identify the patient's condition, assess the patient's needs and formulate a treatment plan accordingly (Smeltzer et al., 2010:904). The professional nurse, as part of the team, needs to orientate the patients and their families about the procedures and routines in the isolation unit where the patients will receive their stem cell transplants.

The importance of stem cell transplantation was confirmed by an article written in a journal by a nurse who stressed the importance of the care of a patient who had a hemopoietic stem cell transplant. The author stated that a definite treatment plan is necessary, which will consist of chemotherapy and then at times radiation and biotherapy. The care of these patients includes the balance of antirejection medication, protection against infection and the monitoring of long term effects of this type of treatment. The protection from sources of infection includes excessive hand washing procedures, care of wounds and intravenous lines, as well as the observation of skin rashes and diarrhea, which can be a sign of the rejection of the graft (Walden, 2010:56).

## 1.2 BACKGROUND

Thomas, Till and McCulloch (1954), as cited in Bunn and Aster (2011:314), stated that stem cell transplantation (HSCT) began in 1950. The procedure for stem cell transplantation was first tested on animals. Swift, Taketa and Bond (1954:241), working at the Naval Radiological Defence Laboratory in San Francisco, did an experimental study on mice, by exposing the mice to whole-body radiation (Bunn & Aster, 2011:314). The results of the tests showed that multi-potent stem cells exist. The transplantation of unfractionated bone marrow cells saved the animals from bone marrow failure. These results led to further studies that confirmed that the process would certainly benefit the immune system of some cancer-diagnosed patients (Bunn & Aster, 2011:314).

A stem cell is an immature cell in the bone marrow, which can develop into different blood cell types such as white blood cell, red blood cell and platelets (National Cancer Institute, 2017). Stem cell transplantation is a life-saving treatment for patients with leukemia, lymphoma, and other blood disorders. The patient's own bone marrow is destroyed with cytotoxic chemotherapy and radiation (Pallister & Watson, 2011:193).

The patient's own cells or a donor's healthy cells can be given directly into the patient's bloodstream and the cells will multiply and function as normal blood cells. The patient's body can only accept the donor's cell if their tissue type match. Unrelated bone marrow donors are sought on the registries if there is not a related match in the family (National Marrow Donor Program, 2017). A registry is a list of potential bone marrow donors and donated cord blood. The registries functioned under federal contracts by the National

Marrow Donor Program®. The C.W. Bill Young Cell Transplantation Program, also called the “Be The Match Registry”® in the United States, is a worldwide program available in mostly all the countries in the world. In South Africa, we have the South African Bone Marrow Registry. The Sunflower fund is the program where funding will be raised for patients and their donors (National Marrow Donor Program, 2017).

Rizzo et al. (2006) state that more than 50 000 stem cell transplants are performed worldwide each year for malignant and non-malignant diseases. Many diseases have only stem cell transplantation as an option for remission.

More than 50,000 patients are stem cell transplanted worldwide and the amount is still increasing. Of this amount, 53 percent are autologous and 47 percent are allogeneic, 50 percent occur in Europe 28 percent occur in America and 19 percent occur in the Asia Pacific Region. Three percent occur in the East Mediterranean Region. According to the (National Marrow Donor Program® (NMDP) and Be The Match® 2015), stem cell transplantation has improved since scientist, clinicians and nurses are working together in collecting data, doing the procedure with an expected positive outcome (National Marrow Donor Program. 2017).

Some stem cell transplantations are autologous, where patients receive their own cells. The other methods used include allogeneic, bone marrow or cord cells from related or unrelated donors (Pasquini & Wang, 2011:212).

Rak, Foster, Potrzebowska, Talkhonchek, Miharada, Komorowska, Torngren, Kvist, Borg, Svenson, Bonnet, and Larson (2017: 954) completed a study on how Cytohesin 1 regulates homing engraftment of human hemapoietic stem cells and progenitor cells. Rak et al. (2017:955) identified that Cytohesin 1 (CYTH1) is an important mediator of human hemapoietic stem cells. This plays an important role in how the hemapoietic stem cell lodge in the bone marrow and engraft. This information add to our understanding of mechanisms involve in regulating Hemapoietic stem cells and the importance in regulating hemapoietic stem cell function (Rak et al., 2017: 956).

There are a few cell surface role players in the interaction of the bone marrow microenvironment such as Intergrins as well as Integrin  $\beta$ 1. More information is necessary in the roles played intracellular. Cytohesin is a guanine- nucleotide



exchange factor. This factor forms a complex with  $\beta 1$  and Integrin  $\alpha L$  to mediate adhesion to ICAM 1. This leads to Rho activation in dendrite cells. In this manner, natural killer cells are regulated thru migration (Io Celso, 2017: 921).

Rak et al. (2017: 957) and his colleagues reason that stem cells and progenitor cells are difficult to study and that they will rather identify the genes which helps with adhesion of the stem cells. Future studies are recommended, as the hemapoietic system is still highly understudied (Rak et al., 2017: 958).

According to Gross and Pulsipher (National Cancer Institute, 2017)) the rationale for hemapoietic stem cell transplant in children includes the following: developing more marrow space, restrain the patient's immune system in order to impaired graft rejection, and also for severe treatment of hemapoietic blood cancer ([www. childhood-cancer/chils-hct-hp-pdg](http://www.childhood-cancer/chils-hct-hp-pdg)).

The physicians decide which type of transplant procedure to perform, whether autologous, allogenic or cord blood, depending on the patient's condition and availability of stem cells, if it is allogenic or cord blood. Neuroblastomas, lymphomas and brain tumours are mostly treated by autologous stem cell transplantation. Diseases such as leukemia in children are treated with allogenic bone marrow transplants, which will give the patients a better survival chance. Some diseases can be resistant to high doses of chemotherapy and radiation, which will mean that the patient's own cancerous bone marrow will not be destroyed in order for the stem cells to grow into new blood cells. Hemapoietic stem cell transplantation offers children who are at high risk of relapse with chemotherapy, a better chance to survival. Hemapoietic stem cell transplantation has become the preferred choice of treatment for such high risk patients, but only if a Human Leucocyte Antigen- matched donor is available. It is stated that this topic is poorly researched (Scrauder, von Stackelberg & Scrappe, 2008: 234).

Hemapoietic stem cell transplantation can be very successful, but patients can still die in different stages of the procedure. The multidisciplinary team's assessment in the pre-transplant period is very important. This is usually followed by the conditioning of the patient with the high doses of chemotherapy, followed by the aspiration of the stem cells and the infusion of it. The patient has to undergo a period engraftment of the

stem cells into the bone marrow and has to remain in this time in the isolation unit. The patient may experience complications such as dermatological, gastrointestinal, ophthalmology and respiratory morbidities. These conditions will require intensive care from the nurses, other health care team members and the family and friends of the patient. The multidisciplinary team members plays an important role in planning, guidance and training of staff and family, in order to implement patient-centred care. There must be good teamwork between the multidisciplinary team members and the team members with the patient and family. The nurse is the bond between the other team members and the patient. This is because the nurse have the skills to establish this bond because of his/her interaction with the multidisciplinary team members and then with the patient and the family (de Azevedo, 2016: 755)

### 1.3 THE CONTEXT OF THE HEALTH CARE TEAM

The multidisciplinary team in the stem cell transplant unit, also called a hematology unit, comprised of health care team members, such as doctors, nurses (different categories), radiographers, physiotherapists, dieticians and social workers. The hematology unit is responsible for drawing up standard operating procedures for all unit staff on stem cell transplant related procedures and treatment. Each one of the team members has an important, though different role to play in the care of a transplanted patient. Doctors prescribe the treatment, while the professional nurses implement prescriptions. The auxiliary nurse practiced in the public hospital, while the caregiver practiced in the private hospital. However, their duties are similar with regard to doing the following procedures such as urine testing, blood glucose monitoring and the vital signs observations.

The dietician intervenes if a transplanted patient presents with symptoms of nausea, vomiting and excessive diarrhea, which prevents them from eating. She re-assesses the nutritional needs of the patients and suggests what type of feed is important in order for the patient to reach optimal nutritional status.

The physiotherapist intercedes when side effects such as lung problems occur and the patients need chest physiotherapy in order to improve the recovery process. The social work ensures that the entire family is cared for holistically, regarding social grants and housing. The radiographer's role is to interact with the patients when they need chest x-rays. The radiographer makes use of a mobile x-rays machine and a

designated radiographer to ensure the patients comfort, but most of all, to control or prevent infection.

Stem cell transplantation has become one of the traditional treatments after surgery, radiation and chemotherapy for patients with blood disorders (Smeltzer, Bare, Hinkle & Cheever, 2010). Thus the researcher hopes to explore the knowledge, perceptions and practices of the health care team members at a public and a private hospital where stem cell transplantation takes place.

The study was conducted in two hospitals situated in the Western Cape, one Government-funded and the other private. The two hospitals are headed by the same Medical Specialist in hematology. Each hospital has a unit with six beds to treat and nurse hematology patients. The unit managers oversee and manage the units. The categories of nurses make up the biggest component of the health care team who practices with the patients 24 hours a day, seven days a week. The professional nurses implement most of the prescriptions given by the medical staff, dieticians, physiotherapist and radiographer. According to Muller (2009:8) and Searle, Human and Mogotlane (2009:12), it is evident that knowledge and the perception of how health care team members practice, are the essential requirements in the education and training procedures for professional nurses. The role of the other team members such as the dietician, radiographer, physiotherapist or social worker, might be prominent, or come to an end at some time during the recovery process, but all the nursing staff members will remain with the patient until discharge or death.

Taylor, Lillis and Le Monte (2001:291) further mentioned that nurses co-ordinates the inputs of the health care team. They are the link between patients and family members and the health care team. Muller (2009:10) maintains that the attributes of a nursing practitioner must include being compassionate, competent and skilled, as well as committed and empathetic to improving the practice of caring. Thus all members of the health care team must have a positive attitude to their work, with their knowledge and skills (Muller, 2009:10). Pera and Van Tonder (2011:78) confirmed this statement by adding that health care is complicated and that various skills from different health care team members are necessary in the clinical area. These authors further emphasize that all members must cooperate in order to provide quality care.

The Scope of Practice (SANC, Regulation 2598) prescribes the duties for professional nurses. At the end of their education and training, nurses make the nurse's pledge of service (Muller, 2009:4), which emphasizes treating all patients with dignity and respect. Nurses are governed by the South African Nursing Council, a body responsible for protecting the interests of the public. The other health care team members, such as the doctors, dieticians, social workers, radiographers and physiotherapists, are governed by the Health Professionals Council of South Africa (HPCSA).

The Hematopoietic Stem Cell Transplant Society is one of the associations to which nurses can belong to for further education and training in hematology. This group plans yearly conferences and practiced mostly in hospitals in Johannesburg and Cape Town. This group operates in the public and private hospitals. They started the society where they first held a clinical symposium and later yearly conferences on stem cell transplantations. They have links with the Centre for International Blood and Marrow Transplant Research European Group for Blood & Marrow Transplantation, the National Marrow Donor Program, The Sunflower Fund, The South African Bone Marrow Registry, The South African Society of Hematology and The South African Children Study Group. The nurses can also individually belong to each of these groups. They are sponsored by Roche pharmaceutical company ([www.sascets.co.za](http://www.sascets.co.za)).

#### 1.4 PROBLEM STATEMENT

Stem cell transplantation is a very sensitive choice for patients, as a stem cell transplant can help some patients and it can cure some of them, but it is not an easy decision to make to undergo a stem cell transplantation. The patient is the person to make the final choice whether to have a stem cell transplant or not. Patients are being referred from various clinics and day hospitals in the Western Cape to these centres for treatment. Stem cell transplantation cured thousands of people, but there are risks and complications involve which can be life-threatening. Risks and benefits must be discussed with the multidisciplinary team, who will take into consideration the stage of the cancer, the patient's age, time from diagnosis to transplant, donor type and the patient's health and nutritional status (Campbell, 2011: 18)

For most of the sick patients suffering from a hematological disease, it could be the last option. Stem cell transplantation has become a treatment option for many patients with blood disorders. According to Rak.et al (2017), this is a very under research topic and needs further research. The health care team *practicing* in these units need to have the appropriate education and training in stem cell transplantation in order to acquire the *knowledge* and skills to *practice* quality care in these units. Quality treatment is important, as it can be the only option which can prolong a haematological diagnosed patient's quality of life or increase their life span (Cancer Association of South Africa).

Members in the health care team have different roles in the transplant units and should have the necessary *knowledge*, to advice patients on the implications, treatment and care of their condition. They should have a positive *perception* on recovery of the patients, while providing adequate *practices* that requires adequate *knowledge* (de Azevedo, 2016: 1755). However, little is known around the *knowledge, perceptions and practices* of health care team members involved with stem cell transplanted patients. Stem cell transplantation is specialized and complicated and the multidisciplinary team practicing in Hemapoietic Stem Cell Transplantation, should have expert knowledge to meet the patient's health needs in this difficult time. The health care team members in the service of stem cell transplantation should constantly learn interventions and share knowledge to provide high quality care for these patients (de Azevedo, 2016: 1755).

## 1.5 RESEARCH QUESTIONS

The research questions stated from the problem statement are:

- What knowledge do the members of the health care team have in terms of the processes that need to be followed when stem cells are transplanted?
- What are the perceptions of the members of the health care team pertaining to how other health care professionals react towards patients undergoing stem cell transplantation and the death of these patients?
- What are the roles of the members of the health care team involved in practicing in stem cell transplantation and how do the different members plan the care of these patients?

## 1.6 PURPOSE OF THE STUDY

The purpose of this study is to gain insight into the knowledge, perceptions and practices of the health care team members regarding stem cell transplantation.

## 1.7 OBJECTIVES

The objectives of this study are to explore:

- The knowledge of the members of the health care team in terms of the processes that need to be followed when stem cells are transplanted.
- The perceptions of the members of the health care team pertaining to how other health care professionals react towards patients undergoing stem cell transplantation and the death of these patients.
- The roles of the members of the health care team involved in practicing in stem cell transplantations and how do the different members plan the care of these patients?

## 1.8 THEORETICAL FRAMEWORK

The nursing theory of Virginia Henderson (1997), as cited in (George 2014; 104) was used as departure to explore the knowledge, perceptions and practice of the health care team in two hematology units in two hospitals in the Western Cape who were involved with stem cell transplantation. The framework is appropriate to this study, as it brings out the concept of the stem cell transplanted patient as a whole, or in a holistic manner. The main assumptions in Henderson's theory emphasized the following four major concepts: the individual, the environment, health and nursing. These concepts are all relevant to the health challenges of a stem cell transplanted patient (George 2014; 104).

### 1.8.1 THE INDIVIDUAL

A person such as a patient or health care team member, has a mind and a body. The individual consists of biological, psychological, sociological and spiritual aspects. This theory of Henderson presents the individual holistically, in the light of all the basic needs (Watson, 2008:40). Henderson saw humans as having basic needs, all of which are included in her 14 essential components of care (George, 2014:91). She mostly

talked about patients as individuals, but also saw them in the family and community context (George, 2014:92).

The fourteen (14) components consist of the following: Stable breathing; eat and drink enough; get rid of body waste; movement and maintenance of good postures; sleep and restoration of the body; the best way to dress; keep body temperature normal, by adding or removing clothes and to change the environment; to maintain good hygiene to protect the skin; keep away from danger and also not to harm others; keep communications with others, by expressing emotions such as what you fear or need, or even what you think; your religion and how you worship; work to achieve things; be involve in recreation; and be curious about normal development and health, as well as which health facilities are available (Watson, 2008:40).

The individual patient has basic needs and in certain circumstances such as stem cell transplants, needs help from health care team members to maintain her or his health to become independent until s/he dies. Henderson wanted the health care team members to display their knowledge of clinical experience, in inter alia health care facilities (Henderson, 1966:45 as cited in George, 2014:92).

They should have knowledge on how to practice nursing care as well as how the environment can influence the care of a patient (George, 2014:92). The stem cell transplanted patient may experience nadir, which will expose them to infections of every kind, such as pneumonia. The issues which a stem cell transplanted patient will struggle with include their basic needs, as they may be so weak as not to be able to attend to these themselves. The health care team working with them should be aware of this (Garrett & Yoder, 2007).

Individuals view religion as important, and believe in a Higher Being. Their religion is very important when they come close to death experiences, or working hard to achieve recovery goals when movement is at times impaired. There are many individual factors of the patient, which can have an effect on good health, such as age, cultural background, physical and mental capacities, and also emotional balance (Watson, 2008:40).

### **1.8.2 THE ENVIRONMENT**

Hematological transplantations require that patients be placed in isolation, while they are on high doses of chemotherapy or radiation and post transplantation (Tomblyn et al., 2009:1143). They are also isolated in order to prevent infections and maintain good hygiene in order to protect the skin. The isolated environment assist the patient to keep away from danger and not harm others, as they can become very confused in the healing process and most of the times are not aware of their actions (Sharma et al., 2011: 1003).

Henderson focuses on an environment that contributes to sleep and restoration of the body as well as peaceful rest (Watson, 2008:40). Sleep and rest are very important elements post-transplant.

### **1.8.3 HEALTH**

Health is connected with the individual's ability to function on their own, thus independently (Laffan & Biedrzycki, 2006: 787). The health care team aims to guide the patient towards health. Patients that underwent a stem cell transplant experience elimination problems, and they will have either diarrhea or constipation. Urination is also a problem, and they might have a urinary catheter to assist with that function. Patients can experience major lung complications; hence the importance here of Henderson's component of "stable breathing" (Laffan & Biedrzycki, 2006: 787). Nurses and other members of the team must promote health for patients to function on their own, in order to educate the individual on the prevention of further infections or other illnesses.

Henderson believed that health is related to how a patient functions. For this study it was also believed that good health might be challenging and it might be difficult for the nurse to help the patient obtain it (Henderson, 1997, as cited in George, 2014:105). Different factors such as age, background, the body and mind can affect one's health. These factors affect the patient's basic needs, and the nurse should strive to maintain and meet these needs for the patient (George, 2014: 106).

### **1.8.4 HEALTH CARE AND NURSING**

A team member assists a patient who does not have the strength, to meet his or her basic needs. The individual will be assisted until she or he can be independent again. Health care team members are involved in leading the patient to recovery after the



stem cell transplantation. The health care team's function is to serve patients until they have fully recovered (Ezzone & Pokorny, 2007:33).

According to McCray (2009:23), Henderson has redefined nursing as a role in which a patient has to be assisted whether sick or well, until they recover or die, with the necessary knowledge and skills. The main assumption of this theory also accepted for this study is that nurses attend to patients until they can care for themselves, or die peacefully (Watson, 2008:40).

In this study it is assumed that

- The nurse has the role to educate the stem cell transplanted patients about the normal development of their own health, as well as about what health facilities are available.
- Nurses implements prescriptions given by physicians, but they also have to be creative in planning the care of each individual.
- Nurses must have the knowledge to practice. They must be able to render services which are unique to each person, the care should be humane, and problems should be solved systematically.

Henderson believed that the nature of nursing is such that the nurse should be close enough to the patient to assist him in terms of strength, will and knowledge, according to his needs (Watson, 2008:40).

Henderson believed that educated nurses are important, as it provides nurses with the experience to deal with accompaniment of patients on the health continuum. She claims that it is difficult for nurses to rehabilitate patients e.g. stem cell patients or the prevention of relapse of their disease, if they do not have the necessary knowledge or experience in practice (George, 2014:92). Competent nurses are required as Garrett and Yoder (2007:183), point out that the stem cell transplant patient needs complex procedures, such as blood transfusion during and after their primary treatment. It is assumed that the nurse should be able to educate the patient and family, not only in the hospital, but also in follow-up care (Garrett & Yoder, 2007:183), on the health continuum.

Henderson believed strongly that knowledge is important for nurses to practice (George, 2014:92). Therefore it can be assumed that the health care team working with stem cell transplanted patients should have the proper training to provide them with the information they require. Henderson's theory, in Watson (2008:40) insists that nurses should not only serve willingly but should also be trained at university level in arts and science in order to become knowledgeable and skilful.

## 1.9 RESEARCH SETTING

According to Polit and Beck (2010:2130), the research setting is the physical location in which data collection takes place. The location where the researcher collected data was two hospitals where stems cells are being transplanted in the two hematology units in these hospitals. One is a hematology unit in a public hospital and the second one is a hematology unit in a private hospital. These two hospitals are in close proximity of each other and are spearheaded by the same specialist, who takes charge of both these health care facilities.

## 1.10 RESEARCH DESIGN

Brink, van der Walt and van Rensburg (2015:121) define qualitative research as where various designs and methods are utilize to study a phenomena which we do not understand. These designs and methods focus on discovering new knowledge. A qualitative exploratory contextual design was used, which allowed the researcher to investigate human experiences and allowed close contact with participants in the collection of data (Moule & Goodman, 2009:171).

## 1.11 POPULATION AND SAMPLING

### 1.11.1 Population

According to Brink (2013:132), a "population" is the group of people that the researcher wants to study. In this study one private and one public facility offering stem cell transplantation services in the Western Cape were included. The population in this study consisted of all the health care workers who practice in the hematology units in these two health facilities. This health care team included doctors, dieticians, physiotherapists, social workers and nurses of all ranks (professional nurses, enrolled nurses, enrolled auxiliary nurses and caregivers).

### **1.11.2 SAMPLING**

Brink (2013:133) defines a sample as a part of the population that the researcher chooses for her research.

Non-probability purposive sampling technique was used, which is also called 'judgmental sampling' (Burns & Grove 2013:313). The researcher used her judgment of who she can use in her study, to best shed light on the phenomenon (Brink, Van der Walt & van Rensburg, 2015:141). Eligibility criteria were used to select the participants. Sampling will be elaborated on in Chapter 3.

## **1.12 METHOD**

### **1.12.1 ACCESS TO THE FIELD**

As mentioned under Point 1.11.1, from all the hematology units in the Western Cape, only two facilities were selected to collect data. These two facilities were selected based on two reasons. Firstly, it was more accessible to the researcher. Secondly, senior staff members with a work experience were placed in these two hospitals and lastly, convenient access, and gaining permission for access to the staff in the unit, could be facilitated by the person in charge of the unit, as he thought it was a much needed research study. He first motivated and gave the researcher a support letter, and together with the ethical clearance certificate from CPUT, the researcher was able to gain ethical permission from the Provincial Administration in Cape Town to access the public hospital staff. The ethics committee of the University of Cape Town gave permission to gain access to the private hospital.

### **1.12.2 DATA COLLECTION**

Qualitative data was collected by means of face-to-face semi-structured individual interviews. The data collection was conducted using an interview guide (Annexure G). According to Polit and Beck (2010: 341), this method of data collection involves the interviewer asking verbal questions and the interviewee responding verbally. The interviews took place in an office of one of the managers. Each interview took 45- 60 minutes. Interviews were recorded with a digital recorder that was in working order. Field notes was taken by the moderator, who accompanied the researcher to the interviews.

### 1.13 DATA ANALYSIS

A private, independent transcriber was employed to do the transcriptions of the data. All data was transcribed into a Microsoft Word document. Thereafter, coding of the transcriptions was done and thematic content analysis was applied. An independent coder was used to analyse the data in order to reach consensus with the researcher regarding the formation of themes, categories and subcategories (Holloway & Wheeler, 2010:235). In Chapter 3 the process will further be described.

### 1.14 RIGOR IN QUALITATIVE RESEARCH

Trustworthiness, credibility and conformability was discussed in detail in Chapter 3 (Refer to 3.12).

### 1.15 ETHICAL CONSIDERATIONS

The Health and Wellness Faculty ethics committee at CPUT in Bellville granted the researcher permission to complete the study. Permission number given was CPUT/HW-REC 2014/H13 (Appendix G). Ethical principles such as respect, beneficence and justice were applied in this study and will be discussed in detail in Chapter 3.

### 1.16 CHAPTER DIVISIONS

The study comprises the following components:

Chapter 1: Contextualization and orientation of the study

This chapter introduced the reader to the topic researched, the background which led to the study and the history of stem cell transplantation. The aims and objectives, the problem statement and questions, and the conceptual model were discussed.

Chapter 2: Literature review

Literature from books, journals and the internet on stem cell transplantation, nationally and globally, is presented and commented on.

Chapter 3: Methodology and design

An exploratory, qualitative design was selected to explore the knowledge, perceptions and practice of the health care team practicing in stem cell transplantation. Semi structured interviews were conducted with all the team members. These were transcribed and thematic content analysis and coding were employed.

#### Chapter 4: Implementation analysis and interpretation of data

This chapter presented and discussed the results from the interviews. The themes and subthemes that emerged are presented, discussed and interpreted.

#### Chapter 5: Limitations, recommendations and conclusions

This chapter will conclude by highlighting the limitations of the study and the recommendations made on the basis of its findings.

#### 1.17 SIGNIFICANCE OF THE STUDY

The findings of this study can inform nurses practicing in transplant units and the other members of the health care team in the two institutions on stem cell transplantation on the challenges to be addressed in the practices of members of the health care team. It is important to have *knowledge* around stem cell transplantation, as stem cell transplantation is a very complex treatment option, which has a number of facets, where a patient's hematological condition can either improves, or the patient can die. Positive *perceptions* around stem cell transplantation are essential for all members of the health care team so that it could lead to effective practices.

#### 1.18. SUMMARY

This chapter provides an overview of the study and starts with an introduction, background to and overview of the research study, and the importance of a health care team. It provides a statement of the research problem and the research questions posed, and explain the reasons for the study. The chapter also provides a description of the aims, objectives, theoretical frameworks of the study, including an explanation of terms and definitions. This is followed by a brief account of the research design, methodology and methods of data collection, ethical considerations and data analysis.

The researcher also highlighted the ethical principles which will be adhered to throughout the duration of this study. The chapter concludes with an outline of the subsequent chapters in the study. The following chapter (2), a literature search on the topic was conducted.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

This literature review will focus on previous studies of the knowledge, perceptions and practices of the members of the health care team involved in stem cell transplantation. It will also discuss the history of stem cell transplantation, haematological diseases which qualify for stem cell transplantation, incidence rate worldwide, in developing countries, as well as in South Africa. Studies which were done, particularly on knowledge, perceptions and practices of members of the health care teams caring for transplanted patients, will be discussed.

#### 2.2 ORIGIN AND FORMATION OF STEM CELLS

Blood science is the study of blood, of which hematology is a part of which in turn studies blood and its disorders, which will include their treatment options such as stem cell transplantation. Blood science was studied from the early 19<sup>th</sup> century and disciplines such as microbiology and histology was developed which led to the founding of the Institute of Biomedical Science in 1912. This society included biomedical and clinical scientist. Biomedical science developed in the last 200 years and disciplines such as bacteriology and urology was added. Biomedical science included three groups of pathology laboratories, namely infection science, cellular science and blood science (Blann & Ahmed, 2014: 1).

The ultimate goal of these pathology laboratories is to provide true results to the physician for a particular analysis they require. Blood science included biochemistry, hematology, blood transfusions, immunology and molecular genetics. Blood is an important fluid in the transport system and the regulator of which interlinks with organs and tissues. It ensures the physiology and homeostasis of the whole body. Any adverse changes to blood will have life-threatening consequences. The functions of blood include carrying oxygen, nutrients to the cells and body tissues. Other functions include defence of the body against infection, regulation of the balance between thrombosis and haemorrhage, distribution of heat and also carries waste products to the kidneys and lungs for removal from the body (Blann & Ahmed, 2014: 1).

### 2.2.1 HAEMATOPOIESIS

This is the most important part to the health of a person. It is the process where the blood cells are produced to exercise their function as described in an earlier text. Haematopoiesis occurs in the bone marrow of adults, but can occur in the liver, lymph nodes and spleen. Mature blood cells have their origin in the bone marrow, where the stem cells, which give rise to the blood cells, are found. The major sites for haematopoiesis in adults are the sternum and the iliac crest. Other sites include the skull, vertebrae and the ribs. This is called intramedullary haematopoiesis. Haematopoiesis can occur outside the bone marrow as in some diseases such as haemoglobinopathy, myelofibrosis and severe haemolytic anaemia. The process of haematopoiesis is regulated and balanced by cytokines, growth factors and environmental factors such as oxygen. The value for blood cell production is  $5-10 \times 10^{11}$  each day. This production of cells is the same which the body loses when the cells come to the end of their life span. Any irregularities in this production of blood cells will lead to disease, of which some can be life-threatening such as leukaemia, aplastic anaemia and hemoproliferative diseases. The mature cells consist of red and white blood cells, which grew with lineage-specific growth factors as they go through stages which includes several blast stages (Blann & Ahmed, 2014: 53)

The following figure will display the long bone, where the process of **hematopoiesis** occurs.



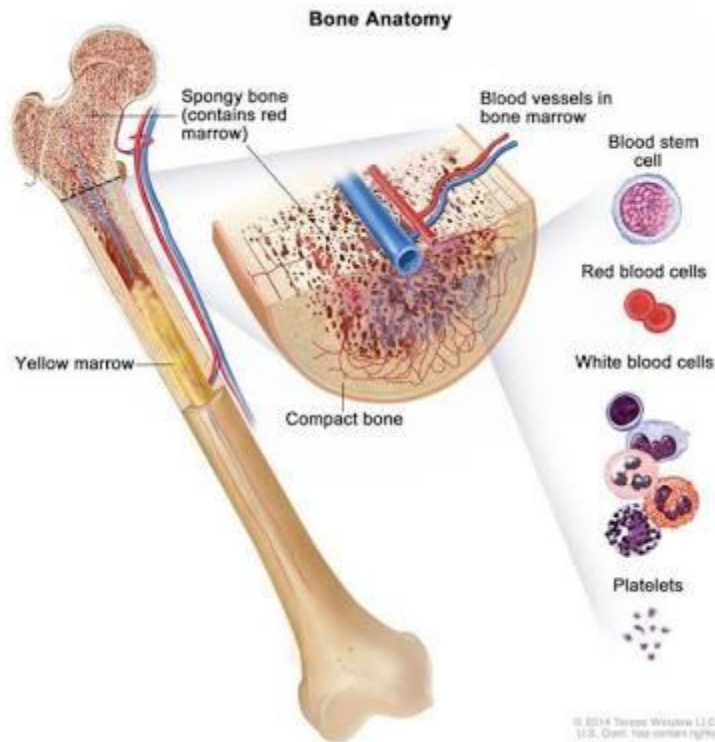


Fig 2.1: The long bone

Figure 1 displays the production of red blood cells as it occurs in the bone as previously mentioned in the text. Blann and Ahmed (2014: 52) described the functions of the long bone as such; support and pivot points for muscle, ligaments and tendons and also protection for delicate structures such as the brain and also physical support for body organs. All this physical functions raised from the fact that the bone is strong and hard connective tissue. The hollow spaces within the bone is the host for hematopoietic tissue and blood vessels which supply the bone with blood. This complicated microenvironment has three components namely, hemapoietic tissues consisting of stem cell and their progeny, sinuses and cells that support and produce growth factors. These cells are stromal cells which make the scaffolding that support other cells, macrophages make the growth factor which promotes erythropoiesis, store iron and remove debris and adipocytes, which stores energy in the form of fat (Blann and Ahmed (2014: 52).

Waugh and Grant (2008: 385) further describe that the long bone is covered by a vascular membrane, the periosteum. The periosteum has two layers, the outer layer of which protects the bone underneath. The inner bone has osteoblasts and osteoclasts which are responsible for bone production. Red marrow is present in flat and irregular bone (Waugh and Grant, 2008:385). The life span of most blood cells is

short, so the body needs to produce blood continuously to meet its needs. There are three types of blood cells, erythrocytes, thrombocytes and leukocytes (Smeltzer et al., 2010:904).

This figure explains the entire process of how haematopoiesis occurs

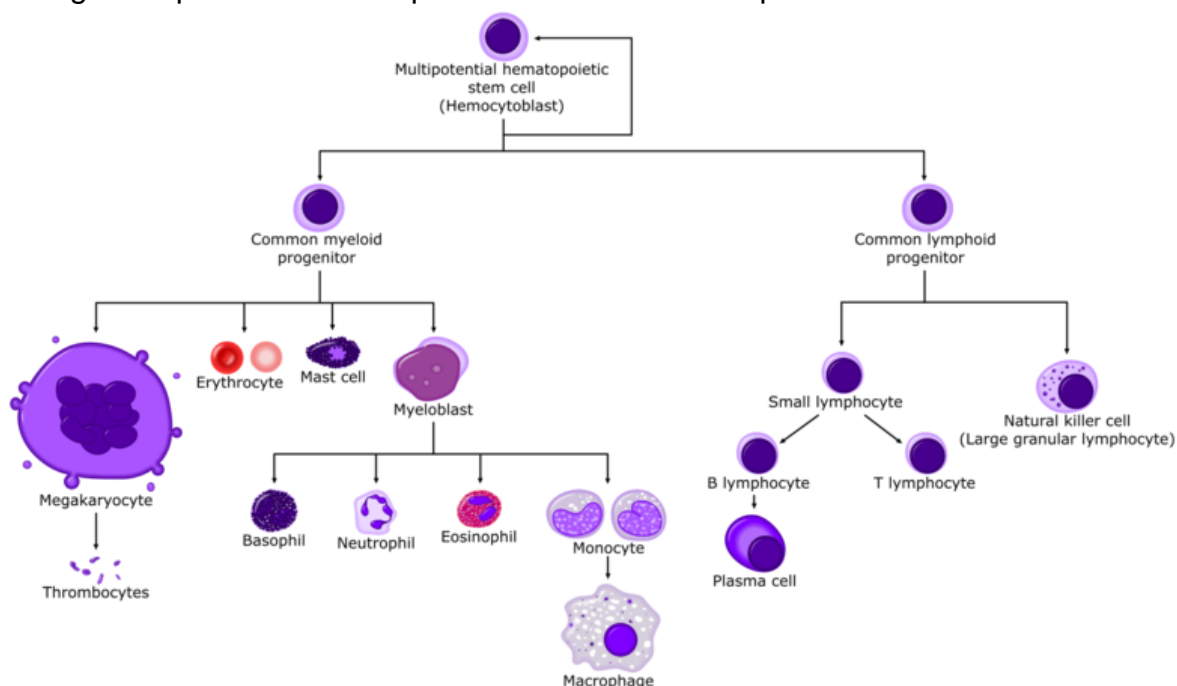


Fig. 2.2: The process of haematopoiesis

Figure 2.2 explains the process where the multi-potential hematopoietic stem cells can change into myeloid or lymphoid cells. Stem cells undergo various processes to change into these normal cells before they are released into the blood stream. The myeloid is responsible for the production of red blood cells, platelets and non-lymphoid white blood cells. Each process has a different growth factor for each cell. The stem cells may lose their function and fail to respond when the body needs them to, or may respond in excessive amounts and out of control, as in leukaemia (Smeltzer et al., 2010:904).

### 2.2.2 THE ROLE OF STEM CELL TRANSPLANTATION

The role of stem cell transplantation in the treatment of malignant and benign diseases of the bone marrow, has grown (Smeltzer et al., 2010:12). Healthy stem cells are given to the patient to restore blood cell production (Campbell, 2011:6). Stem cell transplantation can utilize the patient's own stem cells. Healthy stem cells can also be

obtained from a donor. This donor can be a brother, sister or unrelated person. A donor provides a more positive survival rate from a malignant hematological disease.

Stem cells can also be obtained from the umbilical cord and placenta of a newborn infant. The number of cells obtained is very small and this form of transplant is mostly used in children. The best match for stem cell transplantation is when an identical twin is used. A related donor is a cell-donating family member, such as a brother, sister, or even parent or child (Ljungman et al., 2006).

It is rare for a child or a parent to be used as a donor, as this form of transplantation has a very low rate of one in three patients who will be suitable (Campbell, 2011:6). A match unrelated donor is where a non-family member is a suitable donor for the patient. These types of donors can be allocated or identified through the National Donor Bank (Garrett and Yoder, 2007). Stem cell transplantation is not dangerous, but is only allowed for certain diseases, and age is also a factor. Some transplant centers only transplant the patient's own cells until 55 years of age and donated cells until 70 years of age (Campbell, 2011:7).

Stem cell transplantation involves the infusion of hematopoietic stem cells through a transfusion into the peripheral blood to reconstitute hematopoiesis. Resources for stem cell transplantation are bone marrow, the umbilical cord blood of newborn babies and peripheral blood (Bunn & Aster, 2011:26).

Langhorne, Fulton and Otto (2007:388) describe transplantation as a process in which damaged bone marrow is replaced by new bone marrow. This method of treatment for malignant or nonmalignant diseases is now a recommended treatment after surgery, radiation and biotherapy.

Stem cells have three valuable properties: they can divide and renew themselves for long periods; they do not have a specific function, which make them unspecialized; yet they can develop into specialized cell types, through differentiation, which makes them useful in the treatment of diseases (Next Bioscience, 2015).

## 2.3 INCIDENCE OF HEMATOLOGICAL DISEASES

### 2.3.1 WORLDWIDE

The World Health Organisation (WHO) has recognised the fact that the transplantation of cells, tissues and organs is an important medical task. Information was very scarce. A study was conducted by Gratwohl et al (2015) to document these activities worldwide, from the beginning of transplantation. Data for hematopoietic stem cell transplantation activities were collected between 1 January 2006 to 31 December 2014 by the Worldwide Network for Blood and Marrow Transplantation. It was collected from the 194 WHO member states. 953 651 hematopoietic stem cell transplantations were reported by 1516 transplant centres in 75 countries. 553 350 (58%) were autologous and 400 301 (42%) were allogenic. Exclusive criteria for the collection of stem cell transplantation data included countries with fewer than 300 000 inhabitants, areas less than 700 km<sup>2</sup> and also areas where people earns an income of 1260 American dollar per person. Hematopoietic stem cell transplantation increased to almost 10 000 in 1985 since 1957 when the first transplant was done. 100 000 transplants were done by 1995 and an estimated 1 million transplants by December 2012. The number of allogeneic transplants have increased in the past 35 years. More transplants were done in countries where there were more resources, more transplant teams and unrelated donor registries. Findings showed that there is still unmet needs, more guidance need to be given for decisions to be made, access for patients, donor registries and guidelines.

The table below gives an indications of the findings of the study.

Table 2.1: Stem cell transplantation findings

	1957-70	1971-85	1986-91	1992-95	1996-2005	2006-12	Total
Pan-American total	..	2422	14 975	33 734	126 212	119 140	296 754 (31%)*
Allogeneic	..	2375 (98%)†	7242 (48%)†	12 092 (36%)†	51 347 (41%)†	54 437 (46%)†	127 764
Autologous	..	47	7733	21 642	74 865	64 703	168 990
South East Asian and Western Pacific total	..	505	3349	9120	53763	73 342	140 079 (15%)†
Allogeneic	..	450 (89%)†	2508 (75%)†	5061 (55%)†	30 340 (56%)†	44 607 (61%)†	82 966
Autologous	..	55	841	4059	23 423	28 735	57 113
Eastern Mediterranean and African total	..	33	300	441	5104	9625	15 503 (2%)*
Allogeneic	..	32 (97%)†	239 (80%)†	357 (81%)†	3821 (75%)†	5968 (62%)†	10 417
Autologous	..	1	61	84	1283	3657	5 086
European total	..	6088	21 152	35 660	222 470	215 941	501 315 (53%)*
Allogeneic	..	4165 (68%)†	10 570 (50%)†	12 869 (36%)†	68 970 (31%)†	82 576 (38%)	179 154
Autologous	..	1923	10 582	22 791	153 500	133 365	322 161
<b>Total</b>							
Allogeneic	275 (100%)†	7022 (78%)†	20 559 (52%)†	30 379 (38%)†	154 478 (28%)†	187 588 (45%)†	400 301 (42%)*
Autologous	0	2026	19 217	48 576	253 071	230 460	553 350
<b>Total HSCT</b>	275	9048	39 776	78 955	407 549	418 048	953 651 (100%)*
Cumulative numbers of unrelated donors	..	0	741 994	199 8172	10 777 966	22 346 551	..
Cumulative numbers of cord blood products	..	0	0	2345	275 669	645 646	..

Data are total HSCT by main donor type (allogeneic or autologous HSCT), during the respective timeframe, by WHO region, and the development of cumulative numbers of registered unrelated donors and cord blood products during the same time. All regions are WHO-defined regions. Retrospective allocation of transplants to the respective WHO region is not possible in details. Most procedures were done in the USA and in Europe. HSCT=haemopoietic stem-cell transplantation. \*Represents column percentages of total HSCT per WHO region. †Represents proportion of allogeneic HSCT during the respective timeframe in the respective WHO region.

Table 1: Milestones in the development of HSCT, 1957-2012

Pan- America started in 1971 with stem cell transplantation. More allogeneic stem cell transplantations was done in comparison with autologous stem cell transplantations in the same year frame. Autologous stem cell transplantations have increased over the years and by the end of 2012 more autologous stem cell transplantations was performed than allogeneic transplantations (Gratwohl et al, 2015). In South East Asian and Western Pacific area, more allogeneic transplantations were performed than autologous transplants throughout the time frame of 1971 to the end of 2012. They did transplant far less patients than Pan- America (Gratwohl et al, 2015).

The Eastern Mediterranean and Africa areas also started to exercise transplantations in the time frame of 1971-1985. They also started with one autologous stem cell transplantation and 33 allogeneic stem cells. Allogeneic stem cell transplantations continued to be more in total than autologous stem cell transplantations until the end of 2012 (Gratwohl et al, 2015). Europe appears to have transplanted more patients than the former states. They started to transplant more patients with allogeneic

transplants, in 197, more than autologous, but at the end of 2012, autologous transplantations exceeded the amount of allogeneic transplantations (Gratwohl et al, 2015).

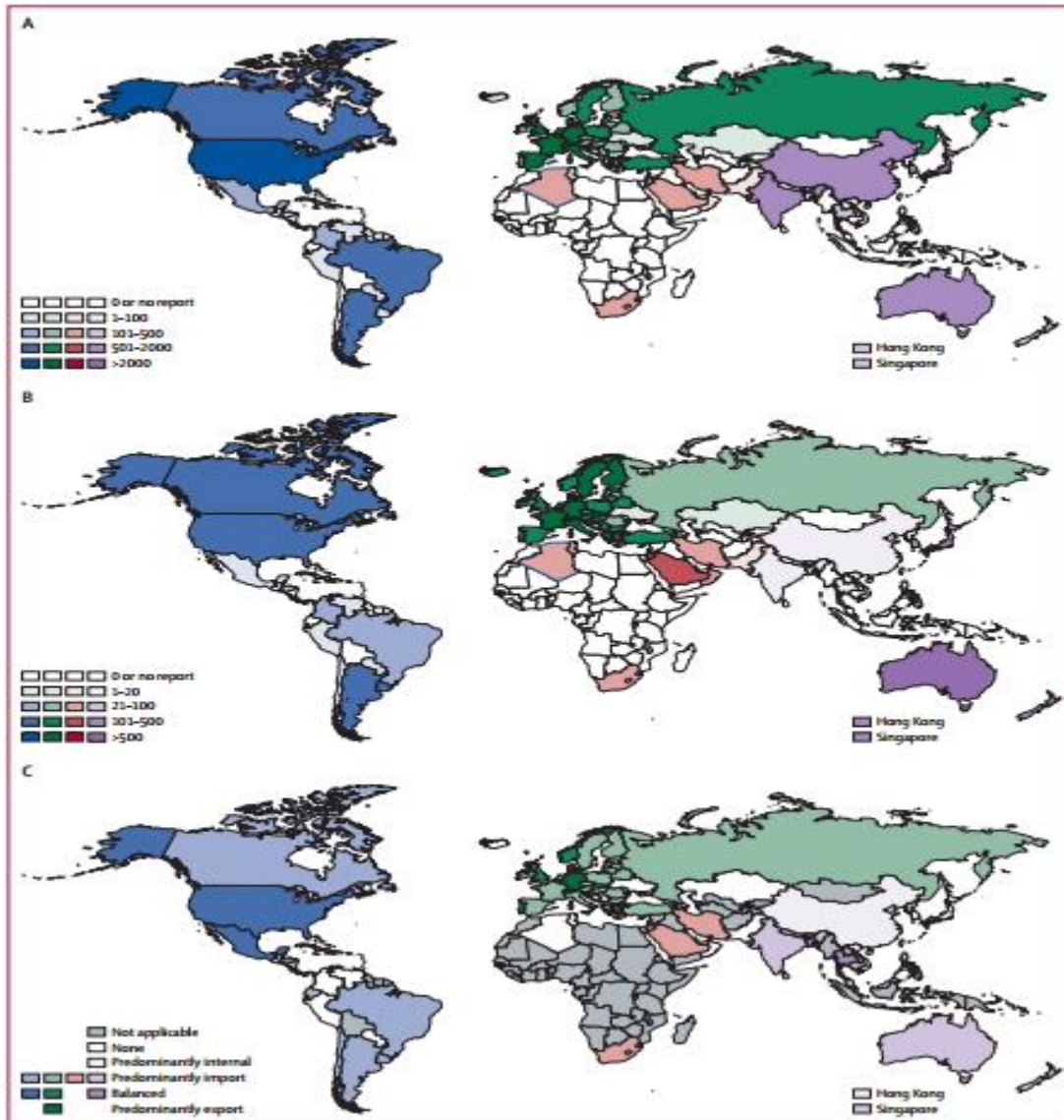


Figure 2: Global HSCT activity in 2010

Figure 2.3: Hematopoietic stem cell transplantation done in 2010

Figure 2-3 showed the global view of hematopoietic stem cell transplantations in 2010. The codes in Sketch A showed that some countries had no transplants done. Some of the countries such as America, showed an amount from up to 200 transplants. In sketch B, showed amounts of decreased numbers of stem cell transplantations. In sketch C no report was given in some countries and the areas which was not applicable, were those countries which was included. The exclusive criteria of the reports to be handed in (Gratwohl et al, 2015).

TABLE 2-2

	Allogeneic Donor			Autologous Donor (n = 28 901)	Total (N = 50 417)
	Family (n = 11 928)	Unrelated (n = 9588)	Total (n = 21 516)		
Leukemia	8122 (68.1)	7088 (73.9)	15 210 (70.7)	1839 (6.4)	17 049 (33.8)
Acute myeloid leukemia	3907 (48.1)	3119 (44.0)	7026 (46.2)	1372 (74.6)	8398 (49.3)
Acute lymphoblastic leukemia	1799 (22.1)	1850 (26.1)	3649 (24.0)	216 (11.7)	3865 (22.7)
Myelodysplastic, myeloproliferative syndromes	1151 (14.2)	1248 (17.6)	2399 (15.8)	60 (3.3)	2459 (14.4)
Chronic myeloid leukemia	877 (10.8)	519 (7.3)	1396 (9.2)	14 (1.0)	1410 (8.3)
Chronic lymphocytic leukemia	336 (4.1)	269 (3.8)	605 (4.0)	175 (9.5)	780 (4.6)
Other leukemia	52 (1.0)	83 (1.2)	135 (1.0)	2 (<1.0)	137 (1.0)
Lymphoproliferative disorders	2088 (17.5)	1414 (14.7)	3502 (16.3)	23990 (83.0)	27 492 (54.5)
Plasma cell disorders	546 (26.1)	287 (20.3)	833 (23.8)	11 877 (49.5)	12 710 (46.2)
Hodgkin disease	270 (12.9)	235 (16.6)	505 (14.4)	3275 (13.7)	3780 (13.7)
Non-Hodgkin lymphoma	1109 (53.1)	708 (50.1)	1817 (51.9)	7943 (33.1)	9760 (35.5)
Other lymphoma (type unknown)	163 (8.0)	184 (13.0)	347 (10.0)	895 (4.0)	1242 (5.0)
Solid tumors	113 (1.0)	40 (<1.0)	153 (<1.0)	2772 (9.6)	2925 (5.8)
Neuroblastoma	22 (19.5)	8 (20.0)	30 (19.6)	615 (22.2)	645 (22.1)
Germinal cancer	3 (3.0)	2 (5.0)	5 (3.3)	518 (18.7)	523 (17.9)
Breast cancer	13 (11.5)	4 (5.0)	17 (11.1)	273 (9.8)	290 (10.0)
Ewing sarcoma	17 (15.0)	6 (20.0)	23 (15.0)	176 (6.3)	199 (6.8)
Other	58 (51.3)	20 (50.0)	78 (51.0)	1190 (42.9)	1268 (43.4)
Nonmalignant disorders	1512 (12.7)	884 (9.0)	2396 (11.1)	197 (1.0)	2593 (5.1)
Bone marrow failures	879 (58.1)	457 (52.0)	1336 (55.8)	0	1336 (51.5)
Hemoglobinopathies	348 (23.0)	54 (6.1)	402 (16.8)	3 (1.5)	405 (15.6)
Immune deficiencies	216 (14.3)	241 (27.3)	457 (19.1)	3 (1.5)	460 (17.7)
Inherited diseases of metabolism	63 (4.0)	122 (13.8)	185 (7.7)	2 (1.0)	187 (7.2)
Autoimmune disorders	6 (<1.0)	10 (1.1)	16 (1.0)	189 (96.0)	205 (8.0)
Other	93 (1.0)	162 (2.0)	255 (1.2)	103 (<1.0)	358 (1.0)

<sup>a</sup>Values are expressed as number (column percentage of total and within subgroup). Percentages may not equal 100% due to rounding.

This table above indicates the number of stem cell transplants done in 2006, worldwide. The statistics cover diseases such as leukemia, lymphoma, solid tumors and noncancerous diseases. The table also distinguishes allogeneic transplants from autologous transplants. In the allogeneic stem cell transplants, both family members and unrelated donors were used. The statistics show that there is more related stem cell transplants performed on leukemia patients than in the case of any other disease or type of stem cell transplant. According to WHO (2014), the success rate for allogenic stem cell transplantations in various leukemia patients are higher in comparison with autologous stem cell transplantations for these patients.

Stem cell transplantation was mostly done for patients who had a family-matched donor, comprising 30% of all patients. Those patients requiring unrelated donors are put on a register, where their chances of ever getting a matched donor are very slim (in the region of 1:500 000). Cord blood has also been used, with more than 20 000 cord blood transplants performed annually for patients without donors. Stem cell transplantation has become so important that a federation has been convened, the

World Wide Network for Blood and Marrow Transplantation (WBMT). It consists of eighteen scientific and professional societies (WHO, 2014).

Table 2-3

	Allogeneic			Autologous	Total
	Family	Unrelated	Total		
<b>Leukaemias*</b>	41 615	43 935 (51%)†	85 550 (92%)‡	6970 (8%)‡	92 520 (35%)§
Acute myeloid leukaemia*	19 972	20 257	40 229	5352	45 581
Acute lymphoblastic leukemia*	10 291	10 742¶	21 033	842	21 875
Chronic myeloid leukaemia*	3 291	2 425	5 716	32	5 748
<b>Myelodysplastic and myeloproliferative neoplasia*</b>	6 247	8 191¶	14 438	204	14 642
Chronic lymphocytic leukaemia*	1 533	1 836¶	3 369	493	3 862
Other leukaemia*	281	484¶	765	47	812
<b>Lymphoproliferative disorders</b>	9 421	8 006 (46%)†	17 427 (13%)‡	120 959 (87%)‡	138 386 (53%)§
Plasma cell disorders	2 483	1 622	4 105	61 266	65 371
Hodgkin's disease and non-Hodgkin lymphoma	6 938	6 384	13 322	59 693	73 015
<b>Solid tumours</b>	467	2 55 (35%)†	722 (8%)‡	12 901 (92%)‡	13 623 (5%)§
<b>Non-malignant disorders*</b>	8 614	5 711 (40%)†	14 325 (92%)‡	1 176 (8%)‡	15 501 (6%)§
Bone marrow failures*	4 727	2 635	7 362	10	7 372
Haemoglobinopathies*	2 176	512	2 688	10	2 698
Immune deficiencies*	1 144	1 364¶	2 508	24	2 532
Inherited diseases of metabolism*	309	683¶	992	17	1 009
Autoimmune disorders	57	47	104	1058	1 162
Other non-malignant disorders*	201	470¶	671	57	728
<b>Others§</b>	335	423 (56%)†	758	237	995
<b>Total</b>	<b>60 452 (51%)</b>	<b>58 330 (49%)†</b>	<b>118 782 (46%)‡</b>	<b>142 243 (54%)‡</b>	<b>261 025</b>

Appendix shows the list of participating teams. \*Significantly more allogeneic than autologous haemopoietic stem-cell transplantation (HSCT) for this indication (p<0.0001). †Proportion of patients with an unrelated donor allogeneic HSCT. ‡Proportion of patients with an allogeneic or autologous HSCT. §Column percentages. ¶Significantly more unrelated than family donors in allogeneic HSCT for this indication (p<0.0001). ||Neutral distribution between family donors and unrelated donors for allogeneic HSCT.

Table 2: Global numbers of HSCT by main indication and donor type undertaken by 1516 teams in 75 countries, 2006-10

This table is an update version of the table above, table 2-3. The leukemias still show more allogeneic stem cell transplantations than autologous stem cell transplantations, as the success rate to increase overall survival rate for these patients are better in allogeneic stem cell transplantation. Unrelated allogeneic transplantations are more prevalent in the acute leukemias than in chronic myeloid leukemia, where they rather used a family member (Gratwohl et al, 2015).

More autologous stem cell transplantations than allogeneic stem cell transplantations were used in the lymphomas, plasma cell disorders and lymph proliferative disorders. More allogeneic stem cell transplantations were done in Non-malignant cancers then autologous stem cell transplantations. More autologous stem cell transplantations were done in solid tumours in this time frame then allogeneic stem cell transplantations (Gratwohl et al, 2015).



### 2.3.2 INCIDENCE RATE IN DEVELOPING COUNTRIES

Most of the studies done regarding stem cell transplantation in developing countries, focus on the cost involved.

Barr (2002: 76(1); 365) did a study regarding the importance of lowering cost of stem cell transplantation in developing countries. Health care systems can be assessed how effective and efficient they are, by looking at the cost and outcomes of treatments. Cost mostly included accommodation, nursing care, medical doctor's fee, tests and treatments. Patients are unemployed at the time of hospitalisation and that might add to their burden. Stem cell harvesting from peripheral blood is very expensive and thus, a shorter stay in hospital will be more cost effective. The conclusion was made that stem cell transplantation will cost less when done in the early stages of remission. Despite the fact that some patients may be treated on an outpatient basis, there are still cost involved (Barr, 2002: 76(1); 365).

The cost of stem cell transplantation was confirmed by a study done by doctors in Mexico. Jaime-Perez, Heredia- Salazar, Cantu-Rodriguez, Gutierrez-Aquirre, Villareal-Villareal, Mancias-Guerra, Herrera-Garza and Gomez-Almaguer (2015) wanted to determine the cost structure for the hemopoietic stem cell transplantation program model which was utilized at the public hospital. These doctors also wanted to assess the clinical outcomes associated with that cost structure. The data was collected from January 2010 to February 2011 from adult and paediatric patients, who received allogeneic hemopoietic stem cell transplantations. The cost of laboratory tests, medical procedures, chemotherapy drugs, other drugs such as antibiotics and inpatient costs were perused and cost were calculated per person. There was no calculation of physicians charge, as it was a public hospital. The results has shown that some diseases are more expensive to manage than others. The components which carried the most cost, were laboratory tests and the drugs used. The conclusion was that the cost structure was affordable for patients in developing countries (Jaime-Perez et al., 2015: 20(4):386).

Stem cell transplantation in India was addressed by Chandy (2008: 42, 581). Data was collected in September 2005 from six transplant centres in India. 1540 transplants were done where over one billion people live. From October 1986 to December 2006, 620 transplants were done in 595 patients. 28 patients were transplanted more than

once. The diseases which were transplanted, included Thalassemia, acute myeloid leukemia, acute lymphocytic leukemia, aplastic and fanconi anaemia, myelodysplasia and miscellaneous treatments, which could be any type of other treatment, such as autoimmune diseases. Thalassemia made out a third of these transplants. There is over 20 million carriers of this disease in India, of which 10 000 children are born each year with the disease. The average cost of stem cell transplantation was 15 000-20 000 dollar, which is lower than in the West.

The conclusion was that India needs more transplant centres, with trained personnel, as that is a great need to provide quality care for the patients. The improvements in the economy will mean that more people will be able to afford stem cell transplants. According to this author, 70% of patients in India can't afford a transplant, unless it is provided by the public hospital, but in which case the state will first assess the more urgent cases. (Chandy, 2008:42, 581).

### **2.3.3 HISTORY OF STEM CELL TRANSPLANTATION IN SOUTH AFRICA**

Stem cell transplants started in the 1980s in university hospitals in Johannesburg and Cape Town. Mostly autologous stem cell transplantation was performed. Allogeneic stem cell transplantation has only been done since 1990 in Cape Town. Allogeneic stem cell transplantation is done more frequently in the private sector than in public hospitals. There are three major hospitals in South Africa where stem cell transplantations are carried out. Transplants are generally done peripherally and with bone marrow, but cord blood stem cell transplantation is becoming more popular internationally and in South Africa. Fifteen transplants were done with cord blood at these centers, of which two were on adults and thirteen on children. Engraftment was successful (Next Bioscience, 2015).

In an article by Jacobs and Wood (2008: Aug; (42) 1:125), it was stated that the first bone marrow transplant which was done in South Africa, was done with bone marrow as graft source. The hematologist used rabbits in an experiment to establish the technical details and also introduced this procedure into a formal program at one of the largest universities which was based in one of the largest hospitals in 1972. There was no infrastructure, but this was overcome when the first continuous-flow cell separator in the sub-Sahara was acquired to provide granulocyte transfusions. A donor panel for platelets was created, as well as specialized laboratory for clonogenic essays, flow cytometry, program freezing and adding cryopreservation. The team were

guided by and encouraged by Professors such as Professor E Donnell Thomas, who did the first bone marrow transplant in 1953.

In 1995, the same team who did the first transplant, relocated to a private facility and continue their research there. The bone marrow transplants were expensive and contained high profile procedures and had to be reported to the International and Autologous registries, which are still continuing to the Centre for Bone Marrow Transplant Research who are concurrent with the European Bone Marrow Registry. This approach was disciplined, but had to keep in line with the accreditation which was unbroken since 1953. There were challenges in the finding of sibling donors and that is why the South African Bone Marrow Registry was created. Jacobs and Wood concluded their article by stating that a specialized multidiscipline team approach can be cost effective (Jacobs & Wood, 2008: Aug; (42) 1:125),

It is concluded that a properly constituted and functioning multidisciplinary team can cost-effectively carry out immune-hematopoietic stem cell grafting even in an under-resourced country with an outcome approximating that reported from recognized First World reference centres. The caveat is that, outside such comprehensive units, results may be less impressive, thereby arguing for resource allocation being directed to academically designated, rather than incentive-driven, preferred providers.

## **2.5 TYPES OF STEM CELL TRANSPLANTATIONS**

Allogeneic stem cell transplantation is an established treatment option for haematological diseases and can be collected from bone marrow, peripheral blood or umbilical cord blood. Thorough donor investigations, such as a medical history, are required before donation, physical examination, ECG, chest x-ray, blood count and coagulation screening are required in order to minimize risks. Testing for infectious diseases are also done. Donors signed informed consent for donation of stem cells and must have all the information in order for them to make that decisions (Bojanic, Cepulic & Mazic, 2009 Jun;63(3):237).

### **2.5.1 PERIPHERAL BLOOD STEM CELL TRANSPLANTATIONS**

This is the most common form of stem cell transplantation and can be allogeneic or autologous. The cells are infused after being removed through apheresis from either

the patient self or a donor. The number of stem cells is increased in the bloodstream by using growth factors (Watson, Barrett, Spence and Twelves, 2006:147).

Mohammadi, Malek Mohamadi, Nikbakht, Norooznejhad, Alimoqhaddam and Ghavamzadeh, (2017 Jan 1; 11(1):78) confirmed that peripheral blood stem cell transplantation is effective for the treatment of malignancies of the hematology system. Mobilization can consist of the growth factor alone, chemotherapy with the growth factor or adding Plerixafor with any of the two approaches. Different approaches has been tested to determine the correct method for mobilization, it is all still in process. The success of mobilization in peripheral stem cell transplantation depends on the cost effectiveness of the procedure and the optimal stem cell mobilization regimen (Mohammadi et al., 2017 Jan 1; 11 (1):78).

Bojanic, Cepulic and Mazic (2009 Jun; 63(3):237) has concluded that peripheral blood stem cell transplantation has become more popular in utilization then bone marrow transplants. This type of transplant offer faster recovery of the patient and decrease transplant-related morbidity and mortality. The incidence for acute graft- versus -host disease is not different from those in bone marrow stem cell transplants, although chronic graft –versus- host disease is increasing. The reason for this is that the T-cells and Natural killer cells of the donor, is collected with the peripheral blood stem cells and re-infused in the patient, which the body will see as a foreign object and react to it. (Bojanic, Cepulic & Mazic, 2009 Jun; 63 (3):237).

### **2.5.2 BONE MARROW STEM CELL TRANSPLANTATIONS**

Stem cells are obtained from the bone marrow. The procedure to obtain the stem cells is performed under general anesthetic. The bone marrow is stored while the patient receives high doses of chemotherapy, and is then re-infused through a vein into the body. This method encourages the stem cells to make new cells faster, making the recovery of the blood cells more rapid. The patient will still experience a period of myelo-suppression and the risk of serious infections (Watson et al., 2006:147).

According to Bojanic, Cepulic and Mazic (2009 Jun; 63(3):237), multiple bone marrow aspirates from pelvic bones are required in this type of transplant and that the donor must stay at least one night in the hospital. Marrow donations are usually safe, but the donor can experience effects such as pain at the collection site and fatigue. There can

also be major complications which is life-threatening, such as mechanical injury to bone, anesthesia-related events and injury to the sacroiliac and sciatic nerve (Bojanic, Cepulic & Mazic (2009 Jun;63(3):237).

However, there is evidence for increased chronic Graft-versus-Host disease (GvHD), which is in part related to the higher number of T-cells and Natural Killer (NK) cells that are collected with peripheral blood stem cell collection (PBSC) and re-infused into the patient.

### **2.5.3 UMBILICAL CORD BLOOD STEM CELL TRANSPLANTATIONS**

In cord blood transplantations, pregnant mothers would donate the umbilical cords for collections of stem cells. The blood from these cords are frozen and stored in a cord blood bank until it is necessary for utilization in transplants (Umbilical Cord Stem Cell Transplantation). A New York blood center facilitates a program of umbilical cord blood stem cell transplantation. The cord blood procedure is possible when some blood remains in the blood vessels of the placenta and the part of the umbilical cord that is still attached to it. The baby does not need this blood anymore and it is called placental blood or umbilical cord blood (National Cord Blood Program, 2017).

Cord blood has white blood cells, red blood cells, platelets and plasma. Like bone marrow, cord blood has hematopoietic stem cells and can be used in transplantation. One unit contains 20ml of cord blood, which has white cells, including the hematopoietic stem cells, and 5ml of cryo-protectant solution. It is frozen in a liquid nitrogen freezer until it is time to be used for stem cell transplantation. Cord blood stem cell transplantation has been used in patients with blood and immune system diseases, as well as genetic and metabolic diseases, which amount to more than 80 different diseases that can be treated with umbilical cord blood (National Cord Blood Program, 2017).

Studies are been done to determine whether cord blood can be used to treat diseases in the nerves or the heart. Subsequently, a study conducted regarding cord blood donation, 650 questionnaires were distributed at the antenatal clinics in regional hospitals. 68% of women responded. 70% responded that they had very little information regarding cord blood donations. 68% wanted physicians and health care

team members to provide them with information regarding the collection, testing and transplantation of cord blood. The interpretation was that most women in the study supported the donation of cord blood to cord blood banks (Fernandez, Gordon, Van den Hof, Taweel and Baylis, 2003:251).

#### **2.5.4 MESENCHYMAL STEM CELLS**

These cells are a type of immature multi-potent adult stem cell. They can renew themselves in various specialized cells of human tissue. These cells include osteoblasts, chondrocytes, adipocytes, cardio-myocytes and also neurons. The sources of the cells and their availability are still under investigation. The cells can be found in many organs, but most of these sites are not realistic for harvesting and to attempt this can cause organ damage. The cells were discovered recently in Wharton's Jelly in cord tissue, as well as in adult adipose tissue. Benefits include the fact that it can be widely applied and easily isolated and expanded; also the risk of cancer formation is low (Next Bioscience, 2015).

#### **2.5.5 HUMAN EMBRYONIC STEM CELLS**

These are donated eggs fertilized in a laboratory, and they do not come in large numbers. They are pluripotent stem cells, which comes from the inner cell mass of a blastocyst, before implantation of the embryo. The embryos become blastocyst 4-5 days after fertilization, and contain 50-150 cells (Thomson, Itkowitz-Eldor, Shapiro, Waknitz, Swiergiel, Marshall and Jones, 1998).

Baldwin (2009, 10(4):299) confirmed that there are more than 220 cell types in the adult body. The embryonic stem cells can differentiate in more cells than the adult stem cell, which is multipotent and their production of cells are limited. These cells are used for stem cell transplantation, because of its capacity to self-renewal, and is also utilized for regenerative medicine and tissue replacement after damage or injury to tissue.

### **2.6 THE STEM TRANSPLANT PROCESS**

#### **2.6.1 TESTS AND PROCEDURES PRE-TRANSPLANT**

Various tests and procedures are completed in order to assess the patient before the actual process of stem cell transplantation. It can take up to several days. An access line will be inserted into the patient by a radiologist. This device remains in situ for the

duration of the treatment. The hemapoietic stem cells, intravenous medication and blood products will be transfused through this line (Next Bioscience, 2015).

### **2.6.2 THE CONDITIONING PROCESS**

This is the period where chemotherapy and possible radiation will be administered. The reason for this treatment is to destroy cancer cells, and to suppress the immune system in order to make it susceptible for the apharesed stem cells, whether in autologous or allogeneic stem cell transplantation. There is important factors to consider before this treatment. Factors to consider includes the type of haematological disease, the overall health of patient or recipient and the type of transplant planned. The possible side effects from these treatments consists of nausea and vomiting, diarrhoea, mouth sores and ulcers, hair loss, infections, bleeding, infertility and sterility, anaemia, fatigue, cataracts, organ complications in the heart, liver or lungs. Prophylactic medication will be given to minimize this type of side effects (Next Bioscience, 2015).

### **2.6.3 REDUCED-INTENSITY CONDITIONING**

This is where a patient's dose of chemotherapy or radiation is lowered, depending on their age and health condition, in order for them to tolerate the treatment. With the reduced treatment, only some of the cancer cells are destroyed and the immune system is not suppressed completely. When the donated cells are infused in the body, it will replace the cells in the bone marrow. The immune factors in the donated cells will destroy the cancer cells (Next Bioscience, 2015).

### **2.6.4 COLLECTION OF HEMAPOIETIC STEM CELLS FOR TRANSPLANT**

For autologous transplantation, the patient will undergo apheresis for the collection of the stem cells after the patient had high doses of chemotherapy. The patient have to receive daily injections of growth factors to increase stem cell production and to move the stem cells in the circulating blood in order to be collected. For this procedure, a femoral is inserted in the femoral vein. During apheresis, blood is drawn from the patient and circulated through a machine. Blood in this machine, is separated into different parts. The stem cells are separated and collected in a bag, which is frozen to be utilized late. The rest of the blood is returned to the body (Umbilical Cord Stem Cell Transplantation, 2016).

A donor is necessary in allogeneic transplantation. The donor would either donate stem cells, or bone marrow, depending on the decision of the hematological team. The procedure is the same as for the autologous, but in this case, it is the donor who will receive the growth factor injections and from whom stem cells will be harvested. The growth factor the donor will receive is Recombinant human granulocyte colony stimulating factor, also called G-CSF, four to five days before the process of apheresis. This growth factor is given in the form of a subcutaneous injection, at a dose of 10mg/kg. Vascular access is obtained through the ante-cubital vein. Citrate is used as an anticoagulant, which is used to keep the patient's blood thin while it is rotating through the apheresis machine. The patient would be receiving chemotherapy and full body irradiation. There might be more collections necessary of the stem cell in order to collect an adequate graft. Age and the effect of the G-CSF plays a role in donors' mobilization of the peripheral stem cell. Effects from the G-CSF injections include symptoms such as bone pain, myalgia, headaches and fatigue (Bojanic, Cepulic & Mazic (2009 Jun; 63 (3):237).

## 2.7 THE STEM CELL TRANSPLANTED PATIENT

The patient will receive high doses of chemotherapy and/or radiotherapy before the transplant. This process is called myelo-ablation. This type of treatment is to destroy the damaged bone marrow. Stem cells can be transplanted in the form of bone marrow, or peripheral blood (Kolb, Gidwani and Grupp, 2006:406).

According to Anders, Soler, Brandao, Vendramini, Bertagnolli, Giovani, Carvalho, Suen, Marchini and Voltarelli (2000; 33: 463) all these treatments can be risky for the patient's health, which means that the patients need specialized care to overcome problems in this regard. Hospitalization can range from one month to longer. The bone marrow itself will take six to twelve months to recover, but complications may still appear. The emotional trauma which the patients suffer can also be challenging in this process. This was concluded in a study done to review the aspects of nursing, nutrition, physical therapy and social services in bone marrow transplantation. The patients has multiple and complicated needs and the assistance of the health care team, such as the medical staff, nursing teams, dietician, social worker and physiotherapist were discussed (Anders, Soler, Brandao, Vendramini, Bertagnolli, Giovani, Carvalho, Suen, Marchini and Voltarelli, 2000; 33: 463).



In an article by Lima and Bernadino (2014, 23(4):14), the statement was made that the nursing care in a stem cell transplanted unit is different from other departments and units. They completed a descriptive qualitative study to identify the care activities of nurses in a stem cell transplant unit. Systematic observations and content analysis was utilized to collect data. The maintenance of life care for patients and environmental hygiene, the general technique with an instrument, drugs, patient assessments and specialized care with specific procedures such as bone marrow collection, infusion of graft, central catheter care, blood transfusions and chemotherapy, were the main focus of the study. The conclusion was that care for stem cell transplanted patients are specialized and can be managed through additional training and expertise.

These patients experience a number of side-effects and complications. Allogeneic transplants have the risk of graft-versus-host disease, which can be fatal. This effect is when the body of the recipient is reacting against the donor stem cell. Other side-effects include infection, bleeding, anemia, mucocitis, graft failure, lung damage, liver complications, cataracts, and reproduction impairment (Campbell, 2011:22).

## 2.8 CARE OF THE FAMILY OF A TRANSPLANTED PATIENT

Caring for the family is also part of the health care team's responsibility. This is especially important where knowledge and the carrying over of information to the family members needs to happen. In the case of a child, the parent is the ultimate decision-maker and has to be informed all the time what is happening with a child's progress. With adults, it is either themselves, their partners or their children who are involve and who has be informed regarding taking care of their family member. The financial part, housing or any social activities which must be addressed, of the patients and families, are mostly managed by the social worker. A psychologist will be involved once psychological challenges are faced (Langhorne, Fulton and Otto, 2007:620)

## 2.9 SPIRITUAL CARE

Spirituality is one of the many facets of man. It is also a belief in a greater power then oneself. A person has to have an understanding of this concept to know that it is important to a patient's illness (Rieg, Mason and Preston, 2006, 31 (6): 249).

Regarding the spiritual care of patients, Emmamally (2013, 38 (4): 24) stated in a South African journal, that spirituality helps the patient to cope with the disease and also to face death. It assists them to recover from their illness and promote health and healthy behaviours. Spirituality influence positive body system functioning, as stress is relieved and optimism enhanced (Emmamally, 2013, 38 (4): 24).

Van Leeuwen and Cusveller (2004) stated that nurses are always intervening in ways to improve the spirituality of their patients, as they are going through emotional trauma of pain, loneliness and hopelessness during their illness period. Van Leeuwen, Tiesinga, Post and Jochemsen (2006) added to that statement that patient's uncertainty in these times attune them to seek spiritual guidance and comfort from their faith. Spirituality is part of the holistic care provided for the patient. Patients are often challenged to look at their past and to rediscover the purpose and new meaning in their lives. Nurses' role in supporting patients and family is imperative, as they are close to the patient and family. Spiritual care is supported by listening, touching and does not always require formal planning (Van Leeuwen et al, 2006).

Spirituality begins with the nurse first, where she has to embrace her own spirituality and have a worldview, which will have an input on her practice as part of a health team. Spiritual care are mostly neglected and is not given the same recognition as the other dimensions of care (Emmamally, 2013, 38 (4): 24).

## 2.10 ADVANTAGES OF THE DIFFERENT METHODS OF STEM CELL TRANSPLANTATION

The advantages of stem cell transplantation are numerous (Bunn and Aster, 2011:316). Patients who suffer from diseases like Severe Combined Deficiencies, Thalassemia, sickle cell diseases, monocytosis and or macrophages will benefit from this form of treatment. Stem cell transplantation also combats the effects of the high doses of radiation and chemotherapy in cancer treatment (Bunn and Aster, 2011: 25). These advantages are the same for children, as more marrow space can be developed, the patient's immune system can be restrained in order to impair rejection of graft and serve as severe treatment of hematological diseases (Gross & Pulsipher (2015).

In cancers like myeloid leukaemia, it is beneficial to generate the graft versus tumour effect. During this procedure, the patient builds up great immunity and resistance

against the cancer. When an organ, for example a kidney or liver, is transplanted, a haematopoietic stem cell transplant will be the preferred choice of treatment to avoid rejection of the organ (Bunn & Aster, 2011:25). Stem cell transplantation patients do experience side effects before they can finally reach recovery. Some of the side effects and complications are unbearable for the patients and they may die. The adverse reactions of peripheral stem cell transplantation can start as early as in the collection process, which can include complications related to the venous access and also citrate toxicity. The platelet count can be decrease because of the use of G-SCF, as it is a mild side effect of this growth factor. Paediatric donors are more tolerable to the collection process than adult donors. (Bojanic, Cepulic & Mazic (2009 Jun; 63 (3):237).

The following side effects and complications will now be discussed.

## 2.11 SIDE EFFECTS

### 2.11.1 INFECTION

The infections that the recipients of hematopoietic stem cell transplant patients struggles with is bacterial infections. Balletto and Mikulska (2016) completed a study where they have investigated this phenomena in these patients. The bacterial infections are mainly in the bloodstream, followed by pneumonia and gastrointestinal infections, such as typhlitis and *Clostridium difficile* infections. Pathogens such as coagulase negative staphylococci and Enterobacteriaceae are about 25% of bloodstream infections. Enterococci, *P. aeruginosa* and viridans streptococci follows after these infections. The resistance of these infections differs in the different transplant centres. In some centres, there are multi-drug resistant gram-negative rods, and in some Vancomycin resistant enterococci. This increasing risk of resistance to antibiotics have been questioned, especially how effective flouroquinolone is as prophylaxis and standard treatment of febrile neutropenia. Proper evaluation of each situation should be done in order cover resistant bacteria before the transplant. This would include screening for resistant bacteria, application of isolation and contact precautions. Anti-microbial stewardship programs should be implemented (Balletto and Mikulska, 2016)

A virus which is struggled with mostly post transplantation, is the cytomegaly virus (CMV). It can be a late onset. Patients are treated with Ganciclovir for the first three

months after stem cell transplantation, which means that reconstitution of the T-cells are slow. Patients at risk for this infection should have prophylactic antiviral treatments and should be monitored closely. Patients with nausea and vomiting, may be experiencing early signs of this infection. It can be diagnosed by drawing blood samples for CMVpp65 and PCR (de Azevedo et al, 2015).

Another infection, with which post-transplant patients can struggle, is Varicella Zoster. This infection occurs in 40-50% of patients in the first year, which is more evident in the second to eighth month, when patients do not have acyclovir. The infection start with abdominal distension or pain in the abdomen or back. Liver functions will also be raised, before the skin lesions appear. Treatment consists of fluids with high doses of acyclovir. Renal functions are monitored closely, as acyclovir must be decreased if abnormal renal functions are detected (Dos Santos, e Souza, Atalla & Hallak- Neto, 2016)

### **2.11.2 GRAFT VERSUS HOST DISEASE (GVHD)**

This is a symptom which will occur after allogeneic transplantation. GvHD is a side effect which will occur when the donor's immune system attacks the recipient's body. The skin, liver and colon are the areas which are mostly affected. Acute and chronic GvHD can be distinguished. The difference is marked in the first 100 days after transplantation. Acute GvHD is within the first 100 days after transplantation and chronic GvHD is after 100 days of transplantation (Nowlin, 2005).

Straffas, Burgos, da Silva and van den Brink (2017) completed a study of the intestinal micro biota in allogeneic hematopoietic stem cell transplantation and the graft versus host disease. As previously mentioned in other studies, hematopoietic stem cell transplantation is utilized as a treatment option in hematopoietic malignancies, deficiencies and immune diseases. In allogeneic hematopoietic stem cell transplants, donor derived T-cells are seen as foreign objects, which causes graft-versus-host disease. This affects morbidity and mortality. The gastro-intestinal tract is mostly affected. This will cause loss of intestinal bacteria diversity and the growth of opportunistic pathogens belonging to phylum Proteo-bacteria and Enterococcus genus. Loss of intestinal diversity is common in hematopoietic stem cell transplantation and is associated with the development of GVHD. It is usually treated with broad spectrum antibiotics. Experimental studies in animals have shown that

prebiotics and probiotics strategies are preferable as prophylactic treatment. Continuous studies are advised to show the relationship between microbiota features and hematopoietic stem cells transplantation outcomes (Straffas et al, 2017).

#### 2.11.2.1 Acute graft versus host disease

This reaction occurs in the first 100 days of transplantation. Severe rash, nausea, vomiting, diarrhoea and jaundice are typical signs of this period (National Marrow Donor Program: 2004).

There are some factors which will increase the risk of GvHD, which include the age of the donor or patient, if the donor was pregnant in the past, had a blood transfusion, if the immunosuppressive drugs were reduced after transplant, and if the tissue matches between the donor and recipient was not 100%. It can be classified from grade I to grade IV, depending on how severe the condition is. The condition is treated by administering more intensive drugs to suppress the immune response, but this action can lead to the risk of opportunistic infections. T-lymphocytes can also be removed from the graft, but this will lead to graft rejection, more infections and also relapse. Treatment might include steroids, such as Atgam, which is an anti-hymocyte globulin. A drug like this will assist in reducing the numbers of T-lymphocytes, which are the cause of the GvHD reaction (Campbell, 2011: 17).

#### 2.11.2.2 Chronic graft versus host disease

This reaction may occur three to six months post allogeneic transplant and may affect the lungs as well as the skin, liver and colon. Risk factors for this reaction include the (increased) age of the donor or patient, previous contraction of acute GvHD, an infusion of donor lymphocytes, as well as an infection of the Herpes zoster virus. Drugs of choice for this reaction include high doses of steroids, Cyclosporine or Tacrolimus. The most common cause of death is infection, which is typically treated with antibiotics (Nowlin, 2005:51-52).

#### **2.11.3 NAUSEA**

Nausea sets in often, but can be resolved relatively early. Other complications such as mucocitis, which can be resolved with mouthwashes, injections and painkillers, also contributes to nausea. Mouth care programs are commenced before any treatment (Nowlin, 2005:51).

#### **2.11.4 DIARRHEA**

Diarrhoea is a side effect which might also be associated GvHD or the Cytomegaly virus. Clostridium difficile infection is more frequent in allogenic transplantations than autologous, and affects about 15% of stem cell patients. This condition is treated with anti-diarrheal medication, but further management is necessary if it continues. Clinically, diarrhoea are diagnosed with regards to its duration, volume, consistency, whether blood is present in the stools, or the diarrhoea is associated with fever. A history must be taken to rule out any foreign travelling, or the exposure to children at a day-care centre, or magnesium supplementation. In this case, Magnesium will be administered intravenously. Continued management of this complication will include that the patient should remain nil per mouth, be given replacement fluids, to prevent dehydration and also to receive immunosuppressive medications intravenously. Cyclosporine or Tacrolimus levels, together with creatinine must be monitored closely. Patient should continue with oral medication once this complication has been resolved. However, if not resolved, other tests such as C. difficile and adenovirus, or rotavirus for children recommended (Campbell, 2011:18).

#### **2.11.5 LUNG COMPLICATIONS**

Gram- negatives are predominant in bacterial pneumonia, which is frequent after hematopoietic stem cell transplantation (Balletto and Mikulska, 2016).

These complications will be diagnosed with diagnostic tests such as chest x-ray, lung CT scan, blood cultures, together with symptoms such as coughing, pyrexia, desaturation, shortness of breath and tachypnea. This complication is worse when the patient was a previous smoker. In severe cases specimens are taken to identify if the complication is bacterial, fungal or mycobacterial. Sensitivity tests will be send away to recognize for which antibiotic the complication is sensitive for. Patients are treated on continuous oxygen, via 40% or 60%mask, or in extreme cases, being ventilated. Pneumocystis' Carinii Pneumonia is one of the infections identified which can cause lung complications. Patients had to be prophylactically treated with trimethoprim sulfamethoxazole. Fluid hydration is important and the vital sign monitoring (Campbell, 2011:20).

Yue, Kang, Ai, Xu, Wu, Pan, Yan, Liu and Liu Q (2016), completed a study in which they wanted to explain the phenomena of a viral infection which facilitates the

development of severe pneumonia in transplanted patients with hematologic malignancies. Severe pneumonia are associated with the high mortality rates in patients who had a hematopoietic stem cell transplantation. This type of infection indicated a poor prognosis in stem cell transplanted patients. 68 allogeneic transplanted patients were included in the study. Peripheral and blood and oropharynx swabs were done to assess for the Cytomegalovirus (CMV) and Respiratory syncytial virus. Data was collected 180 days after transplantation. Association of CMV and RSV co-infection with severe pneumonia and mortality were made. Incidence of CMV and RSV co-infection was 26.5%. Severe pneumonia was diagnosed in 61%, 10% were monoinfections or there were no infection. CMV and RSV showed that it is associated with pneumonias. The death of five patients was associated with these viruses. The conclusion was that CMV and RSV can cause severe pneumonia in hematopoietic stem cell patients with malignant diseases, in allogeneic stem cell transplantation (Yue et al, 2016)

A pilot study was done by Wilson, Jacobson and Fields (2005) regarding home-based aerobic exercise program for sedentary patients who had a hemapoietic stem cell transplant. The study included 17 adult participants post hematopoietic stem cell transplantation who did not any treatment for six (6) months. The criteria for the program consists of physical activity less than 20 minutes per day and less than three (3) times a week. Baseline assessments were done for aerobic fitness and fatigue symptoms, as well as for quality of life. The exercise program was 20-40 minutes, heart rate 40-60 beats per minute, 3-5 sessions for 12 weeks. Electronic heart rate monitors were given to the participants, they had to maintain weekly telephone contact and had to keep exercise diaries. 32 of the 42 participants consented, 17 kept their appointments and four (4) did not complete. No exercise related events were reported. Scores on aerobic fitness, fatigue and severity and physical wellbeing improved. The conclusion was that individually prescribed home-based aerobic exercise is an acceptable, safe and potentially effective intervention for physical improvement of fatigue in hemapoietic stem cell transplanted patients (Wilson, 2005).

The studies associated with knowledge, perceptions and practices of health care team members will now be discussed in the following paragraphs.

## 2.12 KNOWLEDGE

The *Concise Oxford English dictionary* (2009:789) defines knowledge as something which can be known to someone. This statement can include facts, information, how it is described and what skills you need to acquire through experience or education. It can refer to theory or to a practical understanding of a subject. Knowledge can be implicit, which means it is inseparable from practical expertise, or explicit, when one understands the theory of a subject, in a formal or systematic way (*Concise Oxford English dictionary*, 2009:789).

Bruce, Klopper and Mellish (2011) invoke Bloom's taxonomy in considering forms of knowledge. They maintain that nurses should be able to analyse, think critically, solve problems, make decisions, synthesise, evaluate and apply the results of these processes. These are thinking skills, which will empower nurses to gain knowledge and to reason with it (Bruce et al, 2011: 144). Knowledge is based on experience, but it can become outdated (Bruce et al, 2011:145).

In an article by Fox and Khan (2010:83), they advocate for evidence base research, whenever health care professionals are involved. It also shows that various approaches are capable of bringing about change, although they are likely to be barriers to attempted changes (Fox and Khan, 2010:83). The following study proved how education and training of the health care team influenced their knowledge base.

The ACGME (Accreditation Council for Graduate Medical Education) in the United Kingdom is the council responsible for the accreditation of postgraduate medical training programs. Accreditation is accomplished through a peer review process and is based on established standards and guidelines. The ACGME has a program in place to meet the Requirements for Graduate Medical Education in Hematology. It was important to the ACGME that health care professionals working with hematology patients possess the appropriate knowledge and the right attitude. It is a one-year program and has been effective from 1 July 2013 (Accreditation Council for Graduate Medical Education, 2016).

Initially, the program in hematology did not include issues pertaining to the practice and attitudes of health care team members. When the curriculum was revised, issues



of attitude, knowledge and practice were incorporated, as medical training can be physically, emotionally and intellectually demanding. It is expected of medical students to manage patients and their families, under the guidance and supervision of their professors and faculty members. They have to develop the skills, knowledge and attitudes to practice quality care with hematology patients and their treatment (Accreditation Council for Graduate Medical Education, 2016).

Lee, Bell, Singh and Hicks (2012:325) completed a survey to determine the knowledge of hematologists and oncologists regarding screening for Hepatitis B before administering chemotherapy to their patients. In their findings they discovered that (in Canada) knowledge among hematologists and oncologists regarding hepatitis B screening was very low and that it had an effect on their screening rates.

Hepatitis B is one of the screening tests conducted before the patient receives chemotherapy prior to stem cell transplantation. This study proved that each health care professional must have extensive knowledge of the procedures recommended for stem cell transplanted patients. Smeltzer et al. (2012:1141) confirms that the occurrence of Hepatitis B after blood transfusions was reduced after donors were screened for Hepatitis B.

A study was conducted by Chaturvedi, Suri, Pant and Rusia (2006:381- 384) to determine laboratory personnel's knowledge and practice regarding blood collection procedures in hematology. Blood collection is a very important part of hematology. A questionnaire consisting of 37 questions was handed to the staff for completion. Twenty of the questions were related to knowledge, which included essential knowledge and desirable knowledge, while ten of the questions related to practice. The study concluded that the staff's knowledge and practice had deficiencies that needed to be rectified. These deficiencies included the fact that they had little knowledge regarding blood collection procedures and the management of blood products. A recommendation was made that such studies be conducted among nursing and medical staff, as they are also involved in blood collection procedures (Chaturvedi et al, 2006:381).

It is imperative that the procedures involved in stem cell transplantation are linked to standards, and that studies are conducted to improve the ongoing quality care

provided to patients. Blood transfusions are a vital part of stem cell transplantation. The study of Chaturvedi et al., (2006:382) is important because it provides an indication of how important it is for health care professionals to be knowledgeable about procedures such as blood transfusions.

Ger, Lee, Wong, Chao, Wang and Ho (2003:105) conducted a survey among 97 physicians and 78 fifth-year medical students. The survey focused on the effects of education and clinical practice on knowledge of and attitudes towards the use of analgesics for cancer pain. The research was conducted to address the concern that physicians and medical students were under-treating cancer patients for pain. The conclusion was that knowledge regarding cancer pain management was limited among general physicians, but was adequate in anesthesia and hematology/ oncology specialists (Ger et al, 2003: 107).

Patients undergoing stem cell transplantation receive high concentrations of chemotherapy and radiation, which can lead to life-threatening complications. Nurses must possess knowledge of evidence-based treatment options for these types of hematological cancers, so as to be able to identify complications when they emerge (Rimkus, 2009:129). A qualitative study was conducted in Sweden to describe what is necessary for an oncology pediatric nurse to be an expert in oncology care (Enskar, 2012). The results of the study revealed that the health care professional needs to have the necessary knowledge and skills to render quality care. A professional nurse also needs to practice with the correct attitude, as hematology nursing is a highly specialized area (Enskar, 2012).

Azzazy and Mohamed (2016) conducted a study in Saudi Arabia regarding the effect of educational interventions on knowledge and attitude of nursing students regarding stem cell therapy. They stated that stem cell therapy can be a cure and treatment for many diseases and that new technologies in science proved that. They further stated that nursing curriculums should be adapted to include such information, which will equip them with the required knowledge to practice safely. The study aimed to evaluate how effective educational interventions are on knowledge and attitude of nursing students towards cell therapy. A quasi experimental design was utilized with pre and post testing. 53 students participated. The results showed that the students had poor knowledge regarding stem cell therapy in the pretest, it was improved in the post test.

Knowledge was poor, but their attitude was positive. The study concluded that the educational interventions to improve nurses' knowledge and attitude regarding stem cell therapy, was effective (Azzazy and Mohamed, 2016).

Sickle cell anemia is one of the diseases where technology has improved and the disease can be corrected by stem cell transplantation. Sickle cell anemia is an inherited disease where the hemoglobin polymerizes and deform the red blood cell and the red blood cell appears as a sickle in shape. The shape of the red blood cell in this form, causes blocked blood flow, which will lead to pain, organ damage and stroke. Children are born with this condition and can die before the age of five years. Allogenic stem cell transplantation appears to be a cure for this disease (Adediran, Kagu, Wakama, Babadoko, Damulak, Ocheni and Asuquo, 2016).

A study was done to determine the level of awareness, knowledge and acceptance of hemapoietic stem cell transplantation for sickle cell anemia in Nigeria. This cross sectional study was conducted in 2015 in seven tertiary hospitals in Nigeria. A pretested questionnaire was distributed to participants 18 and above and to the parents or guardians of children below the age of 18. 265 participants responded, consisting of 120 males and 145 females. The results showed that the awareness in Nigeria is low in comparison with developing countries. It also display that their knowledge and acceptance of this procedure is poor. The solution appears to be adequate information, improved education and psychological support (Adediran, Kagu, Wakama, Babadoko, Damulak, Ocheni and Asuquo, 2016).

### 2.13 PERCEPTION

The Concise Dictionary (2009:971) described 'perception' as where a concept is recognized by the senses, of a phenomenon or an object from outside.

Tseng, Wang and Weng, (2013 (29) 161) explored the perceptions of the students towards nursing and what their experiences were. Semi-structured interview guides and unstructured face-to-face interviews were used to collect data. It was a qualitative study and purposive sampling was used with a snowball effect. 30 nursing students participated in the study. The themes recognized in the study were that the nurse recognized nursing in a deeper meaning, recognized the meaning and value of life and the decision conflicts of nurses. The findings of the study assisted the managers

in recruiting and train new nurses, but also to understand the effect of education in clinical practice (Tseng et al, 2013 (29) 161)

Fifteen (15) quantitative studies from 1990 to 2012 were used to explore how anxiety has an impact on the attitude of nurses, particularly in how they care for patients at the end of their lives. The statement was made that nurses had much to do with death in their care of the patients. Their personal attitude towards death and the dying may have an influence on their quality of care of these patients. Nurses needed skills and experience to exercise control over these fears. Nurses, who are not comfortable about their own feelings regarding death, will not be able to provide quality care to the dying. The themes identified, were the nurses' level of anxiety, death anxiety and attitudes towards caring for the dying and death education necessary. The results showed that level of anxiety is not particularly high, especially in areas such as in oncology, general, renal, hospice and community care. It was determined that younger nurses feared death more and had negative attitudes. Studies in some countries has shown that a program on the issues of death and dying at the worksites are necessary for all nurses (Peters, Cant, Payne, O'Connor, McDermot, Hood, Morphet & Shimoinaba, 2013).

A similar study on nurses' perception on death and dying was done by Leung, Esplen and Peter (2012) in Ontario, Canada. The study tends to explore how the hematological nurses' experience the threat of patient's dying. This study was done, as even patients who had bone marrow transplants as a treatment intervention, may still die. An interpretive phenomenology study was done with 19 frontline registered nurses, from two in-patient bone marrow transplant units. Focused observations and individual interviews were done. Data was collected between April and August 2007. The findings emphasized the fact that nurses struggled with their own conflicts, while trying to help patients with the disease. The study revealed that nurses wanted to help patients to accept the idea of death and to let go of the idea that they could be cured. The results also showed that nurses should have more capabilities to prepare patients and family for the dying process (Leung et al, 2012)).

Paddy (2011) explored the understanding of patient's and nurses' perception of a 'good death'. Health care and social care team members' goals are to ensure that patients are pain and symptom free when they are busy dying and that they should at

all times be treated with dignity and respect. It is important that the patients were e involve in decision-making regarding their stage of health and that they should be prepared to accept death with family members around them. Patients, however, may have a different idea of their disease process. This is why the health care team must have an understanding of the different types of patients, as not to install their own views of death on a patient. It was concluded that nurses are the best care givers when it comes to death and dying (Paddy, 2011).

According to Gross and Pulsipher (childhood-cancer/chils-hct-hp-pdg) the rationale for hemapoietic stem cell transplant in children includes the following:

- Develop more marrow space
- Restrain the patient's immune system in order to impaired graft rejection
- Also for severe treatment of hemapoietic blood cancer

The physicians decide which transplant procedure to perform, whether autologous or allogenic, depending on the patient's condition. Neuroblastomas, lymphomas and brain tumours are mostly treated by autologous stem cell transplantation. Diseases such as leukemia in children, are treated with allogenic bone marrow transplants, as some diseases are resistant to even high doses of chemotherapy. Hemapoietic stem cell transplantation offers children who are at high risk of relapse with chemotherapy, a better chance to survival. Hemapoietic stem cell transplantation has become the preferred choice of treatment for such high risk patients, but only if a Human Leucocyte Antigen- matched donor is available. It is stated that this topic is poorly researched (Scrauder A, von Stackelberg A, Scrappe M, 2008, 41(2): 571)

## 2.14 PRACTICE

The *Concise Oxford English dictionary* (2009:1011) defines practice as the performance of one action as a norm; or an activity which is repeated continuously to master that activity (*Concise Oxford English dictionary*, 2009:789). This definition is applicable to health care teams in the different duties involved in working with stem cell transplanted patients

Searle, Human and Mogontlane (2009:60) quote *Websters Dictionary* in giving a description of practice as the embodiment of knowledge. There are certain theories which underwrite the practice of nursing. Searle et al. (2009:61) make use of Virginia Henderson's theory of nursing to emphasize this. Nursing practice is recognized by law: nurses' practise in terms of the Nursing Act and under the South African Nursing Council (SANC) (Searle et al., 2009:60). Searle et al. (2009: 312) claim that health care facilities should have policy manuals and written guidelines in place, to emphasize how standards should be met. The desired standards should be identified by the SANC (Searle et al., 2009:312). The practice of nursing is so important that a Scope of Practice for each nursing category is set out in the Nursing Act of 2005. The Scope of Practice sets the boundaries within which a nurse is allowed to practise (Searle et al., 2009:171).

The Regulations in the Scope of Practice were authorized by the Minister of Health. These regulations define the scope of practice of registered nurses and conditions under which they may practice. The control of SANC over the practice of registered persons and the inspection of nursing education institutions are also defined under these regulations (Searle et al., 2009:172). The other health care professionals (doctors, social workers, radiographers and physiotherapists) practise under the regulations of the HCPSA. Thus all health care professionals have guidelines within which they have to practise, guidelines that entail also knowledge and attitudes.

The treatment of children in hematology poses a challenge for hematologist and health care professionals. Research into the attitudes and practice of pediatric oncology providers regarding fertility issues revealed that pediatric oncologists do have an understanding of fertility issues pertaining to pediatric patients. However, oncologists need more resources and open communication between themselves and the doctors in reproductive medicine and endocrinology (Goodwin, Oosterhuis, Kierman, Hudson and Dahl, 2007:80).

New information and treatment protocols in stem cell transplantation are being tested all the time. Clinical trials are always in progress to improve practice in providing quality care for patients, which can be very challenging. This area of practice is highly specialized and nurses must be aware of the protocols pertaining to hematological diseases and the treatments available. Obtaining this knowledge can be difficult, for experienced nurses as well as for new oncology nurses. Nurses' knowledge and

professional education should be updated constantly, to ensure safe and effective patient care (Brown and Faltus, 2011:401).

A cross-sectional survey was conducted by physicians in America to determine the attitude of health care providers regarding quality of life (QOL) for patients after hemapoietic stem cell transplantation (Blood, 2004:2194). 180 (24%) responses were received from physicians in 29 countries. 72% of these physicians reported that their patients consented to the stem cell transplantation, even if their quality of life was poor afterwards. 28% of them said that QOL is discussed with their patients in the program. The conclusion was that 55% of physicians should change their practice, using QOL results to render the best care for their patients (Lee, Joffe, Kim, Socie, Gilman, Wingard, Horowitz, Cella, and Syrjaka, 2004:2194).

## 2.15 THE HEALTH CARE TEAM

McCray (2009:8) describes a multi-professional or disciplinary group as consisting of various professionals working together to care for patients and their families. Each of the members will have the knowledge and skills relevant to their group in order to perform their function. However, they need to share the same values and beliefs, as well as joint responsibility for the patient. They have to form a team to provide quality care to the patient (McCray 2009:8).

According to Smeltzer, Bare, Hinkle and Cheever (2010), the nurse functions interdependently with other health care professionals. Team members will get together to discuss the treatment plan of the patient to ensure quality care. The multidisciplinary team monitors and supports the physical and the psychosocial needs of the patient (Smeltzer et al., 2010:12).

## 2.16 SUMMARY

In this chapter literature was reviewed regarding stem cell transplantation. The chapter also explored the history of stem cell transplantation and how stem cell transplantation is done today, nationally and globally. It has become one of the conventional forms of treatment for hematological diseases. There are different methods of transplantation, each with its own risk factors and complications. The role of the health care team, together with their knowledge, perceptions and practice skills, involved with the transplanted patient, was discussed in detail. The care of the patient and the family

were also expedited. The history of stem cell transplantation and the incidence thereof was discussed globally, in developing countries as well as in South Africa.

In the following chapter, namely chapter 3, the research methodology and design will be discussed.



## CHAPTER 3 METHODOLOGY

### 3.1 INTRODUCTION

According to Hesse-Biber and Leavy (2011), methods are tools which researchers use to collect data in order to make sense of reality. The data is collected from people, artefacts or texts. These methods may include interviews, observations, text or visual data. The purpose of the study and the method must complement each other. They also stated that the methodology brings out the philosophical standpoint and method together (Hesse-Biber and Leavy, 2011).

Methodology serves as a guide. This is the process where researchers collect the data, to analyse, describe and to explain the phenomena (Maree, 2016). Sandelowski (2010) stated that in methodology there has to be some knowledge of the world, which included theory, method or paradigm. The methodology employed in this study is discussed below under the following major headings: qualitative research; research design; population and sampling; method of data collection, rigor and trustworthiness.

### 3.2 QUALITATIVE RESEARCH

Qualitative research sheds light on the questions that health care professionals ask about a situation they would like to understand better. Qualitative studies open the story behind the numbers of quantitative studies. Data is obtained using language in the form of feelings, behaviours, thoughts, insights and actions, rather than numbers (Botma et al, 2010: 182). Qualitative methods focus on aspects such as meaning, feelings and understanding, aspects of human experience as seen from the participants' point of view (Brink et al, 2012: 119).

The use of qualitative research in the health care was discussed by Holloway and Galvin (2017: 12). They stated that qualitative a researcher's perspective is on people and on a holistic approach to the phenomena to be studied. This is important, as health care members focus on care, communication and interaction with people. Through this perspective, nurses and other health care members obtain knowledge and insight about human beings, whether it is patients or colleagues. In qualitative research, researchers focus on human beings in their social and cultural context. They know the phenomena to be studied, which consist of emotions, perceptions and actions. Health care members can get back to these perspectives on care and treatment if they focus

on their emotions, perceptions and actions. This will give them an opportunity to evaluate their management of illness and health from the health care members and patient's perception (Holloway and Galvin, 2017:12).

### 3.3 RESEARCH DESIGN

A, qualitative exploratory contextual design was used to gather information in this research project. This design was employed in order to establish the participants' own understanding of their knowledge, perceptions and practice skills, when caring for patients who had undergone stem cell transplantation. Exploratory studies are designed to increase knowledge, especially in a specialized field (Grove et al., 2013:370). This was confirmed by Botma et al (2010), who stated that exploration is conducted in depth to understand or explain the phenomenon researched in the study. They suggested that in an exploratory study, the researcher will attempt to collect new data if little or no previous research is known about a phenomenon. In a descriptive study the data is fact-centred and based on personal experiences as recounted by the participants attempting to explain a phenomenon (Botma et al., 2010)

Describing contextualisation, Holloway and Calvin (2017: 12) stated that a researcher should be sensitive to the context of the study they do, as they should be deeply known and involve in the research setting and situation of the study. According to Holloway and Calvin (2017:12), participants' behaviour are affected by their lives or work and researchers must realise that they have a history of themselves. Researchers have to consider the total context of participants' lives, but also the context of themselves.

Koro-Ljungberg (2008), made the statement that participants have their own values and beliefs, as they are connected to their environment, which would have an influence in how they interact with the researcher. Context and culture is important and should be respected by the researcher. The researcher will be able to see the perception of individuals if he/she understands the context.

According to Holloway and Galvin (2017:12), the researcher must be familiar with the participants' world, to understand their experiences. The researcher has been practicing in hematology with stem cells transplantation, for twelve years (12), hence she is familiar with the environment that these health care team members and stem cell transplanted patients find themselves in.

### 3.4 THE RESEARCH SETTING

According to Polit and Beck (2010:2130), the research setting is the physical location in which data collection takes place. The setting where data was collected in this study comprises of two (2) hematology units in two (2) hospitals in the Western Cape where stem cell transplantation is being performed. One is a public hospital and the second one is a private hospital. These two hospitals are in close proximity of each other and are spearheaded by the same specialist, who takes charge of both these health care facilities. Each hospital has one unit, which consists of (6) six beds each. However, the same professor heads both hospitals. One hospital is a public facility and the other a private hospital. Amounts of transplants differ each year in both hospitals. In the private hospital, 35-40 transplants are done of which 15- 20 transplants are autologous and the rest allogeneic and cord blood transplants. 1-3 of these transplants are performed on children in the public hospital and 4-6 children are been transplanted in the private hospital (Pillay, 2016). According to Pillay (2016), the most common diseases treated in adult and children in both hospitals, are acute and chronic myeloid leukemia, acute lymphoblastic leukemia, Hodgkin's and non-Hodgkin's lymphoma, thalassemia and Neuroblastomas. Deaths in both institutions varied from year to year. It ranged between 3-5 adults and 1-2 children in both the units together. In some years, no deaths occurred, but patients who relapsed, came back to the two (2) institutions.

At both these hospitals, the health care teams consist of medical practitioners, social workers, dieticians, physiotherapists, professional nurses, staff nurses, enrolled nursing auxiliaries. However, caregivers work in the private unit only.

#### 3.4.1 PRIVATE HOSPITAL

Hematology treatment for benign and malignant blood-related disorders has been available for patients at this hospital since 2004, when the professor in charge moved from another hospital in a distant town. Diseases treated include aplastic anaemia, paroxysmal nocturnal hemoglobinuria, myelodysplastic syndromes, pure red cell myelofibrosis, chronic myeloid leukaemia, acute leukaemia, coagulation disorders, and sickle cell anaemia (Shields, 2015).

Cases are referred from all over the country, as well as internationally. The stem cell transplant programs are well developed and the facility is one of the largest on the

continent. Different types of transplant methods have been employed at the hospital, such as allogeneic, autologous and cord blood.(Shields, 2015).

### **3.4.2 PUBLIC HOSPITAL**

This hospital is linked to the Division of Hematology in the Faculty of Health Science at a university in the Western Cape. The services fall under the umbrella of the Department of Internal Medicine, and the diagnostics under the Department of Clinical Laboratory Science and the National Health Laboratory Service (NHLS). There is also a new Leukaemia unit, which focus on hemapoietic stem cell studies. Diseases such as haemophilia, genetic anemias and haematological malignancies are treated here. Bone marrow stem cell transplantations are performed on patients nationally, as well as paediatric cases referred from a children hospital. Interaction with nurses, doctors and other health care professionals occurs on a daily basis to share information about the patients (Division of Hematology, 2015).

## **3.5 POPULATION AND SAMPLING**

### **3.5.1 POPULATION**

Brink et al., (2015:131) defined population as the group of people whom the researcher wants to study. Other authors, such as Burns & Grove (2011) referred to the population as the entire group of people or objects which is of interest to the researcher or meets the inclusive criteria.

The population in this study was the health care team practicing in the two hematology units in the hospitals in the Western Cape. The health care team included doctors and nurses of all ranks (professional nurses, enrolled nurses, enrolled nursing auxiliaries and caregivers). Dieticians, physiotherapists and social workers also formed part of this team. All the health care professionals who agreed to participate and met the inclusive criteria, were included in the study.

This table below is an indication of the health care professionals who participated in the study.

Table 3.1

Health care team member	Public Hospital	Private Hospital
Professional Nurse	2	4
Enrolled Nurse	No enrolled nurses practiced in the public hospital at the time	4
Enrolled Nurse Auxiliary	1	None
Caregiver	none	1
Dietician	Practiced in the public and private hospital	
Physiotherapist	Practiced in the public and private hospital	
Social worker	Practiced in the public and private hospital	
Doctor	Practiced in the public hospital	
Hematologist	1	Was not available

### 3.5.2 SAMPLING

Sampling involves “a researcher choosing a part of the population to focus the research on”. A small sample exhibiting the characteristics of the group from which it is taken, can be used to represent the population (Maree, 2016:192). Members of the health care team, who practiced in these units, participated in this study.

A non-probability purposive sampling technique was used, which is also called judgmental sampling (Burns and Grove, 2011:313). The researcher used her judgment of who she can use in her study, to best shed light on the phenomenon (Brink, 2015: 141). Holloway and Galvin (2017:144) agree that purposeful sampling is based on the researcher’s judgment.

The researcher did not know before the time how many participants she would need, but continued collecting data until data saturation was reached. Saturation of data is the point where no new data will appear (Brink et al, 2015:141).

An advantage of this form of data collection is that the researcher can collect the data based on the knowledge of the phenomenon. Disadvantages are that sample bias is

possible, that a sample can be used which does not represent the population and results cannot be generalized (Brink et al, 2015:141).

The sample size was sixteen health care team members, in both the units who cared for patients in stem cell transplantation.

#### 3.5.2.1 Inclusion criteria

- Members of the health care team involve in stem cell transplants
- 19 years and older
- At least one year experience in their current position
- Able to understand and speak English and Afrikaans

#### 3.5.2.2 Exclusion criteria

- Agency staff working in the hematology unit was excluded from the study
- Members of the health care team practicing in their current position for less than a year
- Under 19 years of age at the time when the study was conducted
- All team members who were practicing on night duty

#### 3.5.3 RECRUITMENT OF PARTICIPANTS

The participants were recruited after ethical approval was obtained from the Ethical Committee of the Health and Wellness Faculty at the Cape Peninsula University of Technology (Appendix G).

The two unit managers at both the private and public hospitals introduced the project during their respective staff meetings. Both were enthusiastic and supported this project. Hence, they informed all the health care team members in the facility regarding this project and sorted permission from all team members on behalf of the researcher. Health care team members were given the information letter (refer to appendix A) and they could make their informed decision to participate voluntary. The researcher was granted permission to address all members of the team at one of their staff meetings.

She then explained the information letter and consent form (refer to appendix A) to all staff.

The health care team agreed that whoever is on duty, on the day that the researcher would start collecting data, would voluntarily participate in the research. The researcher located the dietician, social worker, radiographer and the medical officer involved, afterwards. This was done to ensure that data was collected from all categories of health care providers, who were involved in stem cell transplantation. The researcher negotiated that all members of the health team on day duty would be approached to participate. Night duty staff were not considered, as they were very short staffed on night duty and not all the health care team members do night duty, for example, the dietician, social worker, physiotherapist and the nurse managers were not available on night duty.

The researcher set up appointment dates and times for interviews with the participants that suited them. All information regarding the research was attached to the consent form. The researcher's as well as the supervisor's details were written on the information leaflet and consent form, in case the participants needed clarification about the intended study (Appendix A).

## 3.6 METHOD OF DATA COLLECTION

### 3.6.1 INDIVIDUAL INTERVIEWS

The method of data collection can range from in-depth, semi-structured to unstructured individual interviews, depending on the information the researcher is searching for (Polit and Beck, 2010: 341). For this research project, semi-structured interviews were utilised, using an interview guide (Annexure J), consisting of seven (7) questions. According to Polit and Beck (2010: 341), this method of data collection involves the interviewer asking verbal questions and the interviewee responding. The purpose of qualitative semi-structured individual interviews is to find out how the participants experience a certain situation, or what they think about it (Moule and Goodman, 2009: 294). Semi-structured interviews help to ensure that the relevant topics are covered in the course of the interview (Polit and Beck, 2010:341). Data was collected by means of individual interviews, meaning that the researcher interviewed one person at a time. The interviewer asked semi- structured questions in a personal contact session with the interviewee (Moule and Goodman, 2009:294).

According to Holloway and Galvin (2017:90), the semi-structured or focused interviews allowed the researcher to focus on the issues at hand and the area of interest could easily be explored. Hence, this was chosen for this study, so that the researcher could explore the knowledge, perceptions and practice through setting particular questions for the participants in the interview guide. The advantage is that the sequence of the questions does not have to be the same for all participants, yet similar types of data could be collected from all the individual participants (Holloway and Galvin, 2017:90) Probing, prompting and summarizing was the manner in which the interviews were conducted. The purpose of these techniques allow for elaboration on certain discussions, as well as giving more meaning or reasons. It also assist to reduce anxiety between the researcher and the participant Holloway and Galvin, 2017: 90).

#### 3.6.1.1 Advantages of individual interviews

Individual interviews are flexible and enable researchers to ask in-depth questions to make sure that the questions are understood, and that the required information is obtained. It is also more cost-effective than questionnaires (Moule and Goodman, 2009: 300). The researcher used her interpersonal skills to motivate the participants to give additional information. The responses of participants are richer in interviews than in questionnaires as they have the latitude to give a more comprehensive account of their experience. This allows for a better overview of the phenomenon that is being studied (Burns et al., 2013: 405).

#### 3.6.1.2 Disadvantages of personal interviews

Interviews take more time than questionnaires. Power play could affect data collection. The researcher needs good interpersonal skills to conduct effective interviews (Moule and Goodman, 2009:300). Interviews obtain information directly from participants, so the researcher has no option but to assume that the information given is the truth. The sample size may have to be smaller because of the time involve (Burns et al., 2013:405).

#### 3.6.1.3 Interview Guide

The researcher developed an interview guide (Appendix K) in order to maintain consistency during the interviews. The same questions were asked to all participants. However, the advantage is that the sequence of the questions does not have to be the same for all participants, yet similar types of data could be collected from all the



individual participants (Holloway and Galvin, 2017:90). Probing, prompting and summarizing was also utilised where necessary.

The following questions were asked:

Knowledge:

- When performing stem cell transplantation, there are certain processes/steps to be followed. From your point of view, what are these processes/steps?

Perception:

- In your view, how do other health care professionals react towards patients undergoing stem cell transplantation?
- What is the general attitude of health care professionals toward children undergoing stem cell transplantation?
- What is the attitude of health care professionals regarding the death of a patient who had stem cell transplantation?

Practice:

- What are the roles of the health care professional responsible for looking after patients undergoing stem cell transplantation?
- As a health care professional, describe your role regarding stem cell transplantation.
- How do you plan the care of a patient undergoing stem cell transplantation?

### 3.7 PROCESS OF DATA COLLECTION

Data were collected during July and August 2015, on different days, because of shift changes involving the health care team. Each interview lasted 45 to 60 minutes. The interviews were conducted with those health care team members who were available and had voluntarily consented to participate after reading the information letter. The purpose and aims of the study were explained to each participant individually, with the researcher highlighting the information on the information sheet, before the commencement of the interview. The place and time for each interview was organized by the researcher, at a time convenient for the participants. The interviews were held in a soundproofed room at the hospital, where only the researcher, the moderator and the participant were present.

The participants, who were practicing in the two units, were Afrikaans, English or Xhosa speaking. They had a choice to respond in the language in which they were comfortable. The Xhosa speaking participants preferred responding in English, as that was the language which is being used in the workplace. It was also one of the inclusive criteria that the participant must respond in English or Afrikaans. Five (5) of the participants responded in Afrikaans.

Interviews were recorded with a digital hand recorder, as indicated on the consent form. Written permission was obtained from all participants, before recording took place. The researcher was aware that some participants might be resistant to being recorded; hence written permission was obtained prior to the interviews. Fortunately, in this study, none of the participants objected being recorded. Recording contain the exact words of the interview. This could also include questions and answers given during the interview. While recording takes place, the researcher can maintain eye contact and pay attention to what is said by the participants. The researcher therefore can remember important answers or statements made by the participants which will assist her in formulating probing questions, if required (Holloway and Galvin, 2017:96). Codes such as P1 or P2 were used, for Participant 1 and Participant 2 to protect the identity of participants. The consent form was signed by the participants on the day of the interview. The researcher thanked each participant after each interview for contributing towards the study.

Data was collected until saturation took place. This means that all the important aspects related to the agenda of this research emerged and concepts were obtained. According to Holloway and Galvin (2017: 152), no specific rules or guidelines exist pertaining to saturation, so researchers have to decide for themselves when this has happened. (Morse, 2012 as cited in Holloway and Galvin, 2017: 152) is of the opinion that sampling methods need to be chosen carefully, as this could assist to achieve saturation.

### 3.8 THE MODERATOR

A moderator was present during the collection of data. According to Minhat (2015: 213), anybody can be a moderator provided they exercise good listening and observational skills. The moderator was a professional nurse who was never involved in stem cell transplantation. She did not participate in the interview, but made notes

which was later compared with the recorded interviews. The role of the moderator in the interview sessions was to make sure that each participant was treated fairly and that the researcher did not lead a participant in answering the questions to the researcher's advantage.

Krueger (1998) and Bloor, Frankland, Thomas and Robson (2001) agreed with Minhat (2015; 213) regarding the characteristics of a good moderator. A moderator should guide and not participate in the discussion during the interviews, or, put slightly differently, a moderator should facilitate the interview process and not lead it (Gill et al., 2008: 291). Moderators should have a calming effect on the participants, helping them to feel relaxed while the interviews are in progress. The moderator also plays a role in ensuring that the researcher treats all participants fairly (Kreuger, 1998). The registered nurse who acted as a moderator in this study, acted professionally and she related well to all the participants. Participants felt at ease and trusting relationships were formed between the researcher, moderator and participant.

This interviewer-moderator-participant relationship was based on mutual respect and a position of equality as human beings. Holloway and Galvin (2017: 98) encourage this type of relationship and warn, particularly health professionals, against the position of power relationships. Throughout the interviewing process, the moderator ensured that a relationship of equality was maintained.

### 3.9 DATA PROTECTION AND MANAGEMENT

Holloway and Wheeler (2010: 274) specify that data management involves transcribing the interviews, organizing and developing categories and coding the data. The researcher used a thematic content approach as a framework to guide the data analysis process for this study (Balls, 2009:31). Themes included the knowledge, perception and practice of the health care team members.

The transcribed documents were checked by the researcher against the recordings in order to ensure that the correct information was transcribed. The tapes of the interviews are stored securely for five years in a lock-up safe in the Nursing Department on the Bellville campus of the Cape Peninsula University of Technology.

### 3.10 DATA ANALYSIS

According to Maree (2016: 109), in qualitative data analysis, the researcher will try to determine how participants make meaning of a specific phenomenon, by analysing their perceptions, attitudes, understanding, knowledge, values, feelings and experience.

Seidel (1998), as cited in Maree (2016) concurs with Maree that the process of data analysis consists of noticing, collecting and reflecting. Qualitative data consists of words and observations and the aim of the researcher is to make sense of it, hence, noticing and reflecting is interlinked and a cyclical process, which means that while the researcher reflect over the data, he or she will notice gaps in the data and then go back to collect it (Maree, 2016: 109).

In this study, it was not necessary to go back and recollect data again after the initial individual interviews which was conducted and recorded with the participants, because data saturation was reached. The researcher followed certain steps according to Maree (2016) in order to achieve a successful data analysis. The following steps were introduced in the data analysis process:

#### **3.10.1 PREPARATION OF DATA ANALYSIS**

Miles and Gilbert (2007) stated that you must check and audit the steps of the analysis. Data collection and the analysis thereof, is an interactive process and the researcher must be able to trace results back to the actual data (Maree, 2016: 114).

#### **3.10.2 DESCRIBING THE SAMPLE AND PARTICIPANTS**

There were 16 (sixteen) participants from different categories of the health care team practicing in two haematological units in Cape Town. They were from a private and a public hospital. The health care consist of one haematologist, six registered nurses, four enrolled nurses, one enrolled nursing auxiliaries and one caregiver, a dietician, a social worker and a radiographer. These participants were all experienced in this field. Their years of practicing in hematology with stem cell transplantation, ranged from 2–30 years. There ages ranged from 24- 60 years. Twelve of the participants were females and four of them were males. The social worker was married, but no children, two registered nurses were married with children, one registered nurse was single, but

had a child, one male enrolled nurse participant had a child, but was not married and the other participants were single.

Four of the participants had formal training in hematology and the other twelve only had their specific training to their category. The social worker, radiographer, dietician and two registered nurses had a degree. The other four registered nurses had a diploma in nursing, enrolled nurses, enrolled nursing auxiliaries and the caregiver, had certificates in nursing and the haematologist had doctorates.

#### **3.10.4 TRANSCRIBING DATA**

As noted by Holloway and Galvin (2017), verbatim transcription provides fuller and richer data. In this regard, the data were transcribed verbatim by a professional transcriber who transcribed the recordings at the end of each interview session into a Microsoft Word document, which was printed by the researcher, who listened again to the recordings and compared it to the printed document. This allowed the researcher to be immersed in the data and engage with the data, at the same time make any corrections to any words that the transcriber had misspelt or misunderstood (Holloway and Galvin, 2017). The interviews that were conducted in Afrikaans were translated into English by a professional translator. The researcher back translated the translations from English into Afrikaans, as the researcher is well versed in both English and Afrikaans.

This was also a means of checking accuracy of the translation. The researcher used the printed copy of each recorded interview to read and make notes. Data analysis and data collection were done concurrently, with data analysis starting as soon as the first interview was completed. This assisted in identifying more aspects to explore in the subsequent interviews (Holloway & Galvin, 2017).

#### **3.10.5 Ordering and organizing data**

Maree (2015: 114) emphasized the fact that data requires intensive attention to make sense of it. He also stated that it takes organizing skills to take the heaps of words from the data and to put it in a final report. The researcher took the data from the interviews and the observations of the moderator and combined it in a final report. Each participant was given a number, in the order, in which they were interviewed.

### **3.10. 6 CODING**

Coding is the process where the researcher will go through the data intensively and divide it into units which can be analysed (Maree, 2016: 116). The responses of the health care team members were grouped into themes by the researcher, with the assistance of the supervisor. Thematic content analysis was applied with colour coding to interpret the data.

### **3.11 REFLEXIVITY**

Reflexivity is a reflection of what has been done in a study. It places the researcher in the project. Locke et al., (2013) mentioned that one of the characteristics of a researcher is that he or she is intense involve with the participants. This can introduce personal and ethical issues in the research process.

The researcher has been practicing for eighteen years as a nurse of which twelve years were in hematology. She has developed a passion for this specialist field of nursing. The researcher was the clinical technologist in collecting stem cells via apheresis, as well as the clinical nurse specialist involved in training and education. According to Creswell (2014), these experiences of the researcher might have an influence in the interpretations of the data. The researcher worked closely with the participants and according to Glesne and Peshkin (1992) as cited in Creswell (2014), this may influence the researcher's interpretations of the study. The researcher has been in an academic role and not clinically involve in stem cell transplantation for four years now, hence she was able to bracket herself outside of the study particularly during data collection.

### **3.12 RIGOR IN QUALITATIVE RESEARCH**

Rigorous qualitative research requires the researcher to keep an open mind regarding the phenomenon being studied (Burns et al., 2013: 39). Findings obtained with scientific rigour are seen as more valuable. The assessment of rigour is mostly based on the design of the study, how the data is collected and how thorough the analysis was (Burns et al., 2013; 39).

The manner in which rigor is established in qualitative research, is different from that in quantitative research (Brink et al, 2012: 126). In qualitative research, trustworthiness is established through consistency, dependability, conformability, audibility, recurrent

patterning, credibility and transferability (Corbin and Strause 2008) as cited in Brink et al., 2012:126).

This research proposal was also peer reviewed by four (4) academics prior to acceptance at the university's institutional research and ethics committees. This is a rigorous review process with input from all the committee members on both the research and ethics committees. The researcher also used personal interviews which are a well-known data collection method in qualitative research (Burns et al., 2013).

All the transcriptions will be kept in a locked-up safe in the nursing department, which will serve as an audit trail wherever it will be needed by the researcher and supervisor.

Streubert and Carpenter, (2011:48) stated that there is other ways to describe these processes to ensure that trustworthiness is enhanced. Credibility, transferability, dependability and conformability is the criteria which can apply to qualitative research (Streubert and Carpenter, 2011:48).

These concepts will now be discussed to illustrate how trustworthiness was applied and maintained throughout this study during the research process.

### **3.12.1 CREDIBILITY**

Accuracy in qualitative research relates to credibility, and authenticity. Credibility is achieved by being in the area of research for a long time (Brink et al., 2012: 171). This was achieved through prolonged engagement, as the researcher collected data for two months, and in that period, the researcher went to the setting multiple times. These continued visits to the setting also provided the opportunity to interact with the participants in the study and member checking was done, as the researcher discussed the progress of the data collection with the participants. Member checking was also done by summarising, paraphrasing and repeating the participant's words. It was also done by talking about their understanding of their words and actions (Holloway and Galvin, 2017:311)

Credibility concentrates on how accurate or truthful scientific findings are (Le Compte and Goetz, 1982, as cited in Brink et al, 2012: 171).

Authenticity can be described as the meaningful descriptions which are obtained through the participant's experiences as expressed in the interviews (Brink et al., 2012: 171). Each transcription was done by a professional transcriber and checked by the researcher in this study, which could be regarded as authentic.

### **3.12.2 TRANSFERABILITY**

This means that the results of the project can be transferred to situations outside of the research study. The readers can then correlate the findings of the study meaningful and can compare it with their own experiences (Brink et al, 2012:171). The findings of this study will be applicable to use in the hematology units as the knowledge, perceptions and practice of the health care team relating to stem cell transplantation do have an influence in the hematology units.

### **3.12.3 DEPENDABILITY**

According to Shenton (2004:63), dependability refers to how true or consistent the research findings would be in the event that the study was to be replicated in a similar context. The data presented and findings obtained must be able to stand true through time. The dependability of the study will be enhanced by aligning the theory, methodology and analytical processes of the study, as discussed in Chapter 4.

### **3.12.4 CONFORMABILITY**

Polit and Hungler (2010) assert that conformability is measured by the research findings in comparison with the data collected. In this study, conformability was achieved by associating objectives with the interview questions. Patel (2008: 82) agrees that this helps to ensure the objectivity and neutrality of the data collected.

## **3.13 ETHICAL CONSIDERATIONS**

The research proposal was reviewed by the institutional ethics committee at CPUT. Permission and support letters obtained from the hospital managers, Head of the Hematology department, and the Unit Managers (Annexure B, C, D and E) of each department where the study was conducted, all formed part of the submission to the ethics committee at CPUT for approval. Data collection commenced after ethical approval was obtained (Appendix H and I. Ethical principles such as respect, beneficence and justice were considered in this study.



Ethical considerations were formally set out in the Declaration of Helsinki by the World Medical Association (the global representative body for physicians). This is an official policy document which was adopted in Helsinki, Finland, in June 1964, to protect human participants in research. The document was revised in several countries, including South Africa in 1996 (World Medical Association, 2008). Brink et al., 2012; 31), describe these principles as follows:

### **3.13.1 AUTONOMY**

Respect for autonomy means that participants must make a free and informed choice to participate (Polit and Beck, 2010: 93). All the participants in this study participated out of their own free will. The participants had to give consent for the use of a digital recorder to be used for the recording of the interviews, for transcription purposes. Each participant signed a consent form before data collection commenced.

### **3.13.2 BENEFICENCE**

Beneficence means maximizing good outcomes for participants and minimizing harm (Holloway and Wheeler, 2010:52). One should not do any harm to any participant. The researcher explained to the participants that there would be no harm done to them. The only intention was to generate new information, which would be of future benefit to health care professionals and society as a whole. Participants were informed that the data collected would be kept in a lock-up safe in the Department of Nursing at CPUT. The researcher and her supervisor would be the only persons with access to the stored data, which would be destroyed five years after the study. While each participant had the right to access their own information, the results of the study would be available to everyone without exposing any individual's personal details. Anonymity and confidentiality would be upheld and safeguarded at all times.

### **3.13.3 JUSTICE**

The principle of justice includes participants' right to fair treatment and privacy. The researcher exhibited fairness in the selection of participants (Polit and Beck, 2010; 90). All health care professionals who were available and would potentially benefit from the findings were included in the study. No benefits or financial incentives were given to participants during this study. Participants were protected through each interview being labelled with a significant anonymous identification code. All data was handled confidentially and all completed interview tapes and data sets were stored in a safe at CPUT. The researcher ensured that the selection of participants was based

on the requirements of the research and agreements made with the participants. All participants were treated equally without discrimination.

#### **3.13.4 NON-MALEFICENCE**

Non-maleficence means avoiding or minimizing unnecessary harm or risk. This is related to beneficence and the balancing of risks towards the patient. Health care providers should take great care not to harm their patients and researchers should behave similarly with respect to their participants (Pera and van Tonder, 2011: 55). Participants were subjected to no risks in this project.

#### **3.13.5 RIGHT TO PRIVACY AND CONFIDENTIALITY**

Confidentiality was maintained throughout the research process. Participants were assured that no information would be made accessible to any persons not involved in the study (Leedy and Ormrod, 2005). Pera and van Tonder (2011) agreed that no information should be given to a third party, except in the case of contagious disease, a gunshot wound or child abuse. No names were linked with the interviews, and the participants were informed that while quotes would be included in the data, there would be no association between the data and their names. The participants' names were replaced with numbers in the order in which they were interviewed, e.g. P 1, 2, 3.

Grace (2009: 98) declares that privacy is a broader subject than confidentiality. Confidentiality is broken when information about a person is given to another person. Privacy is broken when someone else gains access to another person's personal information (Grace, 2009:98). The consent forms (Appendix A) will be kept safe for five (5) years and then destroyed. Findings were reported in such a way that there was no link to any participant. No names were written on any documents in the study. A psychologist practicing at the private hospital was on stand-by to assist any participant who might get distressed and need counselling services (Appendix F). Fortunately, none of the participants required any referral as they coped well with the interview questions.

#### **3.14 INFORMED CONSENT**

Informed consent is described by Beauchamp and Childress (2001: 78), as cited in Pera and van Tonder (2011: 72), as having two meanings. The first meaning is invoked when a person is required to agree to experience something through an act of informed consent. The second meaning is linked to the formal permission that institutions have

to give for any form of research to proceed (Ethical Committee of the Cape Peninsula University of Technology, Appendix G).

Pera and van Tonder (2011: 73) point out that there is information which the researcher must give to participants prior to their giving their consent. The information consists of data relating to the participants' health, benefits, risks and costs, as well as the right to refuse. Butts and Rich (2008: 43) discuss the competency of a participant. Consent given by the participant can be verbal or written but must be understood by the participant. Berglund (2012: 119) insists that consent must be voluntary and free of constraint or coercion. Grace (2009: 81) remarks that participants' who gave their consent on the basis of unspoken expectations does not comply with the standards of informed consent. The method of obtaining consent for this study was explained in 3.5.3.

### 3.16 SUMMARY

This chapter has focused on the research methodology and design used in the study. The research setting and sampling were described. The method of data collection and the procedures used to analyse data were discussed. Finally, the ethical considerations applicable to the study were described. Consideration was given to conformability, dependability and trustworthiness, which are all important in qualitative research. The next chapter will discuss the findings of the interviews.

## CHAPTER 4

### RESULTS

#### 4.1 INTRODUCTION

This chapter presents the findings from the interviews conducted in this study. This section demonstrates the experiences of participants based on the research questions that were answered. This study was conducted at two hospitals in the Western Cape (Refer to Chapter 3). Sixteen participants were interviewed. Chapter 4 gives an interpretation of the findings.

The aim of the study was to “explore the knowledge, perceptions and practices of the health care team involve in stem cell transplantation”.

#### 4.2 BIOGRAPHICAL DATA

In this study the biographical background of the participants comprised of their years of service in the profession, their qualifications in nursing and their training in hematology (Table 4.1). They alluded to their years of experience in working in the transplant units and their level of applicable knowledge.

Table 4.1: Participants

Professional nurses	Seven (7)
Enrolled nurse	Three (3)
Care worker	One (1)
Dietician	One (1)
Physiotherapist	One (1)
Radiographer	One (1)
Social worker	One (1)
Doctor	One (1)

Table 4.1 presents the outlay of the participants. There were seven (7) professional nurses, three (3) enrolled nurses, one (1) care worker, one (1) dietician, one (1) physiotherapist, one (1) radiographer, one (1) social worker and one (1) doctor.

Table 4.2 Participant's biographical data

<b>PARTICIPANTS</b>	<b>RANK</b>	<b>YEARS OF EXPERIENCE</b>	<b>ONCOLOGY/HEMATOLOGY TRAINING</b>
P 1	Professional Nurse	Two years	Trained
P 2	Caregiver	Five years	Untrained
P 3	Professional Nurse	Six years	Trained
P 4	Dietician	Three years	untrained
P 5	Professional Nurse	Twenty-five years	Trained
P 6	Enrolled Nurse	Five years	untrained
P 7	Professional Nurse	Thirty years	Trained
P 8	Enrolled Nurse	Ten years	Untrained
P 9	Professional Nurse	Three years	Untrained
P 10	Professional Nurse	Three years	untrained
P 11	Enrolled Nurse	Fifteen years	untrained
P 12	Physiotherapist	Ten years	untrained
P 13	Radiographer	Three years	untrained
P 14	Professional Nurse	Three years	untrained
P 15	Social worker	Fifteen years	Untrained
P 16	Doctor	Five years	Trained

The years of experiences of the professional nurses working in the two hematology units varied between (two) 2 years and (thirty) 30 years. One of the professional nurses had been practicing in the bone marrow transplant unit for thirty (30) years and was also the unit manager of the public hospital, while another professional nurse had

twenty-five (25) years of service. One professional nurse had been practicing there for two (2) years and three (3) of the professional nurses for three years.

Four enrolled nurses participated in the study. One enrolled nurse had been working in the unit for fifteen (15) years. She had more experience with stem cell transplanted patients than most of the professional nurses with higher qualifications than hers. The physiotherapist's ten years of experience working with stem cell transplanted patients made her knowledgeable in this regard. She was the only designated physiotherapist for the stem cell transplanted patients and her experience of practicing with such patients, emerged in the interviews.

The radiographer had three (3) years and the doctor had four (4) years of experience in the field of stem cell transplanted patients, whereas the social worker had fifteen (15) years of experience. The dietician had been practicing for two (2) years attending to the nutritional needs of the stem cell transplanted patients.

Of the sixteen (16) health care professionals, four (4) were formally trained to manage stem cell transplanted patients. There is a postgraduate oncology course at one of the universities in the Western Cape for professional nurses, but there is no formal course in hematology or oncology available for enrolled nurses, care givers, social workers, dieticians and physiotherapists in South Africa.

#### 4.3 INTERVIEW RESULTS

The interviews conducted in this study were individual interviews. A semi-structured interview schedule (refer to appendix J) was used in this study. Transcriptions were done by a professional transcriber (refer to 3.10.4). Thematic content analysis was employed to analyse the data. Coding was done by the researcher. The researcher interpreted the data, but liaised with an independent person, when she deemed it necessary. Data were categorized and arranged into themes and subthemes. Three (3) themes and eight (8) subthemes emerged (Table 4.3)

Table 4.3: Themes and subthemes

Themes	Subthemes
1. Knowledge of health care team members	<ul style="list-style-type: none"> <li>• Knowledgeable about different types of transplants methods and processes</li> <li>• Knowledgeable about decision-making and information</li> </ul>
2. Perceptions of Health care team members	<ul style="list-style-type: none"> <li>• Various perceptions of caring for different stem cell transplanted patient</li> <li>• Positive thinking about the treatment option, stem cell transplantation, and stem cell transplantation for children</li> <li>• Sadness about death in stem cell transplantation and in children being sick during stem cell transplantation</li> </ul>
3. Practice	<ul style="list-style-type: none"> <li>• Participation in the team</li> <li>• Differentiation of roles of team members</li> <li>• Holistic delivery of care</li> </ul>

#### 4.3.1 THEME 1: KNOWLEDGE OF HEALTH CARE TEAM MEMBERS

This was confirmed by the Oxford English dictionary, which explain that you can obtain facts, information and skills thru experience and education. It also include the understanding of theory and practical (<https://en.oxforddictionaries.com> Accessed 20 September 2017). The Merriman-Webster dictionary describe knowledge as “to know a fact or a condition which was learned through experience or association. It can also be an acquaintance or understanding of a science, art or technique or to be aware of something” (Merriman-Webster Dictionary, 2017)

The knowledge of the health care team members with regard to different types of transplants methods and processes emerged in two subthemes, namely knowledgeable about different types of transplants methods and processes and knowledgeable about decision-making and information.

#### 4.3.1.1 Knowledgeable about different types of transplants methods and processes.

There are different methods of stem cell transplantation each with their own processes depending on the condition of the patient:

*“well, I think, don’t think in that case they really choose whether they want. I want my own cells. It depends on the condition and what type of Leukemia or type of cancer. Lets make an example. Mostly multiple myelomas, they are going for auto transplant, and AML, they cannot choose. They are only getting allogenic. So it is not a matter of choosing. It’s a matter of what is the condition, does it lead you to get auto or allo.”(P8)*

Professional nurses mentioned the differences between donating own stem cells and using those of a donor:

*“So it’s usually patients, they use their own stem cells, it’s their own that they harvest from when they are in remission. The other stem cell transplant, it’s when the patient is getting stem cells from a donor. Usually it’s a sister or someone that it is a match”. (P3)*

*“There is two options. It is of you as a person, a lot of brothers and sisters and all before the stem cell transplant is tested and one of them is compatible, just one. So cells, tissue type, ma en pa come together. I do not have an example now, but there is certain DNA matching which they must first view and get compatibleness for 100% and then you are happy. Then is there ALO. ALO is tried when your donor is prepared through Neupogen, which is given to the donor and that is to produce more stem cells, to be taken off with the plasma machine to be transplanted on the recipient. Then autograft or autologous stem cell transplant is where the patient do not have a donor (P7)*

Other participants also mentioned these two options of donating cells:

*There is two options. your option is either with your own marrow or from a donor. Somebody who can give you stem cells. (P2)*

*“..then that donor’s stem cells are transplanted over in you (P9)*

*“the auto, that means the patient’s own stem cells”(P10)*



*autologous is where the patient get his own (P12)*

A caregiver mentioned the time frame linked with donating stem cells:

*If it is their own cells, then they are done in the clinic, then they must come in a couple days before the time, their cells are harvested and then they will come to F4 for the stem cell transplant*

Participants mentioned the precautions before stem cell transplantation:

*“ so the patient will come, lets say they are coming for stem cell transplant, so we have a J-line, of which we do dressing” (P1)*

This was confirmed by other participants:

*“Usually our patients have central lines inserted, so we must be able to access the lines, to work with the lines and then I must have knowledge, because usually before the transplant they get chemotherapy” (P..)*

*“They get Neupogen injections over the weekend and then again the last one on a Monday so three o’ clock, four o’clock, the a blood count to see the cells, what is the number, person is connected to the plasma machine and a line is inserted” (P7)*

Participants mentioned the importance of blood tests:

*“...every morning we take bloods, daily bloods for the patient” (P1)*

*“Some blood tests that needs to be done to see if the patient will be able to get any donor” (P6)*

*“taking bloods, on a daily basis we take bloods, pre-transplant and post-transplant (P11)*

Another participant pointed out the different routes to be taken:

*Everybody is tested before stem cell transplantation to see who is compatible, so cells and tissue type, some DNA matching for 100% compatibility. Then it is the Also, when you have a donor” (P7)*

The procedure followed with a donor before transplants was outlined:

*“especially if they have a donor, then they will insert a femoral line. Well the donor has to get injections for days” (P9)*

The flow of activities during stem cell transplants were described:

*“yes, a bone marrow biopsy. After that then they go through a process of chemo (P 6)*

*“at this stage, did they have the chemo and all those things” (P 7)*

*Then the patient who gets chemo then gets discharged, they get Neupogen, afterwards they go to the clinic where they can harvest the patient. Then when the patient is receiving the stem cells from another person, then the person is getting chemo, then the person who is going to donate attends the clinic, they give the Neupogen to raise the stem cells, then they will do the harvesting (P10)*

Participants were aware of procedures after the stem cell transplant process:

*“lets say if the blood pressure is normal, then I will do two hourly” (P8)*

*“say that for the next six hours you will observe the patient for reaction, after the transplant” (P12)*

4.3.1.3 Decision making about stem cell transplantation and information by health care team members to guide stem cell transplanted patients

In this subtheme it was evident that patients had to take difficult decisions, and that it was important for them to have the correct information to make those decisions. The health care team were required to inform patients about the effects of the stem cell transplants.

The care worker thought that it was the decision of the patients to decide whether they wanted the stem cell transplantation:

*“for me, from what I have seen, then it is for many a benefit, and for many it is a disadvantage, but we cannot tell the patient, because look, this is their decision and so on” (P2)*

One of the professional nurses was negative about the patient's decision regarding stem cell transplantation:

*I would never do stem cell transplant and I know it is not giving somebody a second chance, and that decision is also not for me" (P5)*

The professional team members were the ones who will give information to the patients about stem cell transplantation:

*"So we inform the patients of what to expect of the transplant, so we are not scarring the patients, but like if they know what to expect. It's so much. I've noticed it's much less traumatic for the patient. So we will first explain the transplant, because they ask how long does it take. We just tell them it's a procedure of about 30- 45 minutes. After that, we tell them, maybe after a week or so, your white cell count will drop, so there will be a time when you are going to feel sick, where you will have no immunity to fight infection. So during that time, your temperature, you will have fevers, your temperature will spike, you will have loose stools, you will also begin to have mucocitis (P1)*

*Blood and platelets, we need to tell them that it is part of the treatment (P5)*

*"this is how you inform the patients on day one, that they must know that certain systems is in place, such as the care and the do-good" (P7)*

*is to first reassure the patient, explain according to my level of education so be there with the patient, I mean reassure all the time, answer, but no false promises (P8)*

*indications for the transplant and so on, but in general, naturally, to give good information and naturally keep your clinical part aside (P16)*

The social worker agreed that the patient must have all the information:

*I will have to sit down and explain the whole process (P15)*

In each of the subthemes the participants displayed knowledge regarding the stem cell transplanted patient. They were aware of the information regarding the availability of donors and also the type of treatments available for stem cell transplanted patients. The participants were aware what information they had to give to the patients regarding stem cell transplant procedures, in order for these patients to make informed decisions.

The Merriman-Webster dictionary explained perception as “the way you think or understand something (Merriman-Webster Dictionary, 2017).

This was confirmed by the English Oxford Dictionary which defines ‘perception’ as using your senses or the way you understand or interpret something (Oxford Dictionaries, 2017).

The next theme identified was the perceptions of the health care team members.

#### **4.3.2 THEME 2: PERCEPTIONS OF HEALTH CARE TEAM MEMBERS**

The subthemes which was identified, was various perceptions of caring for different stem cell transplanted patients, positive thinking about stem cell transplantation, and stem cell transplantation for children and sadness with death in stem cell transplantation and in children being sick during stem cell transplantation

##### **4.3.2.1 Various perceptions of caring for different stem cell transplanted patients**

The participants had all different feelings regarding the stem cell transplanted patient and the effect of the transplant.

A professional nurse thought about the type of patients they nurse:

*“I think the most of them, they understand what kind of patients we have. It’s a 50/50 chance that they might, you cannot cure, but there is a 50% chance that after the transplant or chemotherapy, they can still, we don’t prolong it, but just- I don’t know the word to say” (P1)*

Another agreed with that statement

*“but the general attitude here, because people have been working here for years, it’s not one year, two years, it’s years, so I think they are quite happy with stem cell transplant and things like that (P5)*

The dietician thought that it can emotional:

*first, it’s very emotional. You get more emotional with the patient (P6)*

This was supported by another participant

*sometimes you will feel not so sorry, but you know, if this was my family member, I would say I mean to be there for that patient all the time (P8)*

One participant felt that they feel more if the patients are poor

*they feel a lot for some patients, especially patients who does not have money and things (P 9)*

One of the participants thought that the participants wanted association with the patients

*it's like they want to associate themselves with those patients (P10)*

One of the participants felt that they think differently about patients

*it depends with each patient that comes in, then we will have different views for the patient (P11)*

One participant thought that your age makes a difference if you are transplanted:

*Sometimes the people will say that they wonder if this person was not too old to be transplanted (P12)*

Other participants thought that they can see from a patient's condition whether stem cell transplant was the treatment option of choice:

*"it depends with each patient that comes in, then we will have different views for the patient. But from the start when the patient comes in, all the nurses, all of us will say, oh, this patient maybe will make it through the transplant, this patient won't make it through the transplant, why is this patient being transplanted " (P11)*

*but it's only if the patient is not doing well, then you find that people will say no, this was not supposed to be done, then you know already that this was not going to work, why force it (P15)*

One of the participants felt that health care members are excited about these types of patients:

*"the people who are working with it, is thrilled about it. It becomes an absolute passion, and if it is in your blood, then you can't get away. They become closely involve with patients in this condition (P16)*

#### 4.3.2.1 Positive thinking about stem cell transplantation, and stem cell transplantation for children

Some participants felt positive about stem cell transplantation:

*so I think they are quite happy with stem cell transplant and things like that (P5)*

*they respond good to it (P13)*

One participant saw the stem cell transplant as a solution to cancer

*And this sort of cure, the transplant is cure (7)*

Some participants saw stem cell transplantation as supportive and preventative:

*it is supportive care, its treatment and management, and maintenance of good health through the procedure (P4)*

*I think it is largely fits around supportive treatment and preventative treatment (13)*

Some of the participants felt that the health care team members feels good about children stem cell transplantation:

*so I mean I will say their attitude is good (P3)*

Some participants agreed that the children recover in a shorter period than the adults:

*we feel positive as the staff because kids, they recover so quickly when they are having the transplant (11)*

Another participant agreed:

*they do much, much better than adults. They recover quickly, the children (P15)*

Some of the participants believed that this type of treatment gives children a second chance at life:

*for children, I will say it's very difficult if it's them, but I feel like at least they need another chance. They are still young so for them it's positive (P10)*

*shoo. This is a wonderful opportunity to be and a second chance on life, and I must say they tolerate the transplants so much better than adults (P16)*

#### 4.3.2.2 Sadness with death in stem cell transplantation and in children being sick during stem cell transplantation

A participant responded that they cannot get use to death:

*we can't get used to it. It's very sad (P1)*

Some participants were sad for families losing loved once after a transplant.

*for me, according to me I can say it touches n person a lot (P2)*

*it is not so easy, because you get used to the patient and so on (P5)*

*it's very sad.*

*it is so sad and a person do get tears in your eyes (P16)*

For the majority of the participants it was sad to lose their patients.

*we get close to them all, and so if the patient dies, then I do feel it very badly (P12)*

One participant responded how difficult it is to deal with death:

*but dealing with that, death, it's very, very sad (P3)*

whereas another participant thought that you must have experience in your career in order to manage death:

*it also depends how mature you, according, I mean to your experience...A sudden death is always not a nice feeling (P8)*

The participants were emotional about the children who are going through the transplant procedures:

*it is always quite emotional (P4)*

*it's not very pleasant. I mean, you don't want any child to be sick (14)*

*I feel it with the parents and some children do not actually know what is going on (P12)*

One participant agreed that it can be emotional, but he knows not to get attached to the patients emotionally

*It is always very emotional with kids especially, but I know where to draw the line. I will never get too attached (P5)*

The three subthemes which emerged, was various perceptions of caring, positive thinking and stem cell transplantation for children as well as sadness brought about with children being sick during stem cell transplantation. There were various statements from the participants regarding stem cell transplantation. Some of the participants found that it was a treatment option which could be a chance for a patient with blood disorders to live. Some of the participants felt that some of the patients might be too old for transplantation. All of the participants were positive about this second chance, especially for children. It was sad for the participants to experience the suffering of the patients through the recovery process of stem cell transplantation. The participants formed an emotional link with the patients and could not bear their physical challenges through the recovery process.

#### **4.3.3 THEME 3: PRACTICE**

The Merriman-Webster dictionary describe practice as something which have to be done repeatedly in order for a person to become experienced and competent in it (Merriman-Webster Dictionary, 2017).

The English Oxford dictionary describe 'practice' as the actual application of an idea or method, or to apply or exercise a profession or practicing an activity or skill (Oxford Dictionaries, 2017).

This is the third theme which emerged from the interviews. The subthemes consist of participation in the team, holistic delivery of care and differentiation of roles of team members.



#### 4.3.3.1 Participation of the health care team members in the team

This theme emerged from all the interviews about how participants perceived their participation and roles in caring for stem cell transplanted patients. Each one of the participants were also aware of the duties of the other health care team member.

Some of the participants felt strongly that they had a specific duty to fulfill in the stem cell transplant process:

*and I must be able to look after them. Usually our patients have central lines e inserted, so we must be able to access the lines, to work with the lines and then I must have knowledge, because usually before the transfer they get chemotherapy (P1)*

*going to be there supporting them emotionally and physically, and also at the same time making sure as our duties as the nurses (P3)*

*if the patient has dressings, like J-line, I change the dressing as a nurse, then to deal with emotional support at times (P10)*

*see that the planning of the care is prescribed for the day and that basic care such as washing, hair information and medication is prescribed whatever treatment, platelets, antibiotics the patient must get (P7)*

Some participants, such as the social worker, were aware of the role of the other team members:

*nurses as well, who see to the patient, that they get their medication on time (15)*

The careworker was also aware of her participation in the team:

*this is now the observations, the weight and height and the observations and anything that is normal, then I will report it to the sister (P2)*

One of the professional nurses felt except caring for the patient, that the whole family is involve:

*it's a lot more supportive and caring, and involving the whole family (P4)*

The part of the doctor seem to be more challenging:

*to mobilize the stem cells and the harvesting of the cells (P16)*

#### 4.3.3.1 Differentiation of roles of team members

The participants were knowledgeable about the roles of the health care team members:

*the roles of the health care workers are to make sure that the patient understands the process of stem cell transplantation (P3)*

*the doctor, the social worker, the nurse, the clinic people, before things, hopefully first the clinic and then Prof will follow up (P9)*

*the roles of the health care professionals is to make sure you do the vital signs and while you are doing the procedure. It's Prof, then it's the doctors, the doctor who is working with her, it's the sisters who are working on the unit, staff nurses, social workers. They are there to oversee the patient and also the dieticians are there, and the physiotherapist also (P10)*

*the whole team is the registered nurse, the staff nurse, the ENA, the carers and the doctors as well (P11)*

*like us as radiographers, our role is to take x-rays in the wards of the patients and also ultrasounds, like help the doctors with the ultrasounds and do the scans for the patients (13)*

*it is a team, a team effort and each one has his own role which he plays (P16)*

The physiotherapist saw the cleaners also as part of the health care team:

*the doctor, the nursing sisters, ENA assists and the chemo clinic's people, yes they also play a role and even the cleaners (P12)*

One of the participants thought that the role of the health care team includes been supportive and preventative:

*you obvious has the doctor giving input, the nursing staff providing the care for the patient and the allied health care professionals providing support for the patient, all fitting in a supportive and preventative role (P14)*

Some of the participants saw the roles of the health care team members as part of a team:

*that includes the doctors, the physios, the nurse. It also includes the dietician. What else can I say, social workers. It is a team effort (P6)*

One participant thought that the family is part of the team

*I think the role players are, we all are a team, a multidisciplinary team. It is the doctors, the pathologist, and the family (P7)*

#### 4.3.3.2 Holistic delivery of care

The planning of care could be done by every member of the health care team.

The participants were knowledgeable about the care of the stem cell transplanted patient

*I must be able to manage or how they react when they are going through the treatment of stem cell transplantation (P1)*

*see to it that their care is planned for the day, the basic needs such as washing of hair, information and medication prescribed, whatever treatment, platelets, antibiotics that the patient also gets (P7)*

*so we give them the care they need (P11)*

One professional nurse responded that the patient must be looked after in each aspect:

*going to be there supporting them emotionally and physically, and also at the same time making sure as our duties as the nurses (P3)*

Another professional nurse agreed with the previous response and also included the care of the whole family:

*it's a lot more supportive and caring, and involving the whole family (P4)*

The social worker agreed that the whole family must be cared for in all aspects, as she provides financial assistance with the counseling and education:

*I am here to support the patient and the family...now there won't be any income, so I need to assist with that. If maybe there would be income from work, or UIF, sick benefit...counselling, support, education, yes all that stuff (P15)*

Practices is the third theme which was identified in the interview responses. The subthemes which emerged from this theme was participation in the team, holistic delivery of care and differentiation of roles of team members. The health care team members had each one a specific role to play in the stem cell transplant process. Each one of the participants were also aware of the roles of the other members of the health care team.

#### 4.4. SUMMARY

This chapter presented the results obtained from the data collected in the interviews. Biographical data pertaining to the qualifications and experience of the participants were presented in bar graphs. The themes and subthemes which emerged from the transcribed data were presented. In the following chapter, the results from the study will be discussed and related to the literature review and the theoretical framework of the study. Conclusions, limitations and recommendations will be discussed in chapter 5.

## CHAPTER 5

### DISCUSSION OF RESULTS

#### 5.1 INTRODUCTION

In this chapter the results of the interview responses were discussed. This study aimed at exploring the knowledge, perceptions and practice of the health care team members in the field of stem cell transplantation. The result of the interviews were presented in themes and subthemes.

#### 5.2 PARTICIPANTS BIOGRAPHICAL DATA

Sixteen (16) health care team members participated in the research to explore the knowledge, perceptions and practice of the health care team members relating to stem cell transplantation in the Western Cape. The participants consisted of seven (7) Professional nurses, three (3) enrolled nurses, one (1) caregiver, one (1) dietician, one physiotherapist, one (1) radiographer, one (1) social worker and one (1) doctor. Their years of experience in practicing in stem cell transplanted patients, range from two to thirty years. One (1) of the professional nurses in the private hospital was oncology/hematology trained, and four (4) professional nurses were not trained in either oncology or hematology. Two (2) professional nurses in the public hospital were oncology/hematology trained. None of the enrolled nurses or the caregiver was oncology/ hematology trained and no one of the physiotherapist, the radiographer or the social worker was oncology/hematology trained. The doctor did his specialty in hematology.

#### 5.3 THEME 1: KNOWLEDGE OF THE HEALTH CARE TEAM MEMBERS

##### **5.3.1 KNOWLEDGEABLE ABOUT DIFFERENT TYPES OF TRANSPLANTS METHODS AND PROCESSES.**

The health care team members' knowledge regarding the processes for stem cell transplantation was expressed in their responses during the personal interviews.

The ACGME (write out) identified that education in haematology was important, as the health care professionals working with patients, should possess the appropriate knowledge. Henderson also claimed that it is difficult for nurses to achieve the rehabilitation of patients or the prevention of disease, if they do not have experience and knowledge (George, 2014:92).

This was confirmed by Garrett and Yoder (2007, 184), who pointed out that the stem cell transplanted patient needed many treatments, such as blood transfusion during and after their primary treatment. The nurses working in these units should be able to educate the patient and family, not only in the hospital, but also in follow-up care facilities (Garrett and Yoder, 2007:189).

Hence, they need to be equipped with the necessary knowledge and skills. The majority of the health care team members could identify the processes for stem cell transplantation, which is an indication that they did have knowledge, as suggested by Henderson and Garrett and Yoder.

Participants (P3 and P7) also displayed enough knowledge regarding the different stem cell transplantation methods. Watson et al (2006: 147) stated that peripheral stem cell transplantation can be allogeneic or autologous and the cells are removed through aphaeresis from a donor or the patient self. This is in line with what the participants revealed in the interviews that stem cell transplantation can be allogeneic or autologous and that you need a donor for allogeneic stem cell transplantation

Mohammadi et al (2017: 78) confirmed that peripheral stem cell transplantation is effective in treatment for hematology diseases. The care worker (P2), who was not a professional health care team member, was also aware of the different types of methods and processes of stem cell transplantation. The social worker (P15), the physiotherapist and the radiographer expressed knowledge regarding the processes for stem cell transplantation, although they only came to the unit periodically.

Some of the participants expressed knowledge regarding bloods to be taken before the stem cell transplant. Bojanic et al (2009: 237) stated that there are several investigations to be done before any stem cell transplantation procedure, such as a blood count, with coagulation screening, medical history, physical examination, ECGs, chest X-ray and several other test could be performed. Blann & Ahmed (2014:1) describe the importance of blood and that it is a transport system, as well as a link between organs and systems, to ensure homeostasis of the whole body. Any adverse change or abnormality will have life-threatening consequences. The participants realised the importance of these functions of blood in hematology diseases and could relate it to an important procedure in stem cell transplantation.

A study conducted by Chaturvedi et al., (2009: 381) was to determine if laboratory personnel have knowledge regarding blood collection procedures in hematology. This concurs with this study that nurses must have knowledge, as they are constantly involve in blood collections with stem cell transplanted patients.

Participants (P6, P7, and P10) were aware of the flow of activities during stem cell transplantation. They were knowledgeable that patients needed Neupogen, which is a Recombinant human granulocyte colony stimulating factor days before the transplant, in order to stimulate the bone marrow to produce more stem cells for collection and transplantation. Partakers responded also that patients may need chemotherapy before stem cell transplantation and/ or radiation. Bojanic et al., (2009: 237) confirmed this information to be the normal procedures for the activities during stem cell transplantation and that all nurses should be up to date with these procedures and activities. Hence they need to be knowledgeable.

Participants were also aware of the side-effects and complications that these patients experienced. Some of these complications included graft versus host disease in allogeneic stem cell transplantations, where the recipient reacts against the donor cells. This can result in death. Other side effects included infection, bleeding which led to anaemia, mucocitis, graft failure, lung damage, liver complications and reproduction impairment. This is in line with what Campbell (2011: 22) said of the side-effects and complications these patients experienced.

Henderson requires that health care workers display their knowledge of clinical experience regarding stem cell transplantations, not just in health care facilities where these take place, but also in the home (Henderson, 1966:45). Henderson's focused was mostly on nursing care for the sick. However, she implicitly stated that nursing should be practiced in the wider context of the family and the community. She reiterated that nurses should be knowledgeable on how to practice nursing care in the patient's own environment. This is to ensure that the environment can influence the care of a patient positively. Knowledge of interacting with the family and involving the family in the care of the patient, was evident in this study.

### **5.3.2. KNOWLEDGEABLE ABOUT DECISION MAKING AND INFORMATION**

The majority of the health care team members were knowledgeable about the difficult decisions which the patients had to make and they were up to date about the information to be given to the patients in order for them to make important choices. However, nursing staff admitted that patients were left to make these difficult decisions. One professional nurse alluded to the fact that she would never take the responsibility of making the decision on behalf of the patient, particularly if she knows that it will not be giving the patient a second chance. The health care team were also aware that they had to give accurate information to the patients, which could assist them to make informed choices.

Anders, et al., (2000; 33) confirmed how challenging the stem cell transplant process can be for the patients and their families. Lima and Bernadino (2014: 14) conquered with Anders (2000; 33) how the nursing team in the stem cell transplanted units provide more specialized care than those in other departments and units. Hence, they need to be knowledgeable in giving accurate information to patients, in order to make the correct, informed decisions.

## **5.4 THEME 2: PERCEPTIONS OF THE HEALTH CARE TEAM MEMBERS**

### **5.4.1 VARIOUS PERCEPTIONS OF CARING FOR DIFFERENT STEM CELL TRANSPLANTED PATIENTS**

The health care team members responded differently to the question about the attitude of health care professionals towards stem cell transplantation. Some of the participants (P11 and P15) felt that stem cell transplantation were not necessary for certain patients. Participants (P1 and P5) felt that because health care providers work so long in the unit, they get use to the type of patients who are treated there. Participant (P3) found that the health care team members, who are practicing in these units where stem cell transplantation is performed, had an absolute passion for this type of treatment option.

Participants (P6 and P8) shared that it was emotional to work in these transplant units and (P1) felt that the patient needed support. Anders et al., 2000; 33: 463 confirmed that stem cell transplantation is complicated for patients with haematological diseases. However, stem cell transplantation remains a treatment option for patients suffering



from haematological diseases. The participants agreed that the stem cell transplanted patient needs special care to overcome all the health and emotional problems. A study was done by Anders et al. (2000) to view the aspects of nursing, nutrition, physical therapy and social services in stem cell transplantations. The results concluded that the patients experienced multiple and complicated needs and require the assistance of the health care team. This is in line with the findings of this study.

A participant (P12) had the perception that age played a major role in the stem cell transplanted criteria, as they thought that some older people should rather not have been transplanted. Bojanic et al. (2009: 237) as well as Watson, (2008:40) agreed that age, plays a major role in the stem cell transplantation procedure, when it comes to the collection of stem cells for mobilization. The older the patient, the longer it will take for stem cells to be collected. Henderson believed that the nature of nursing is such that the nurse should be knowledgeable and skilful enough in order to assist the older patients in terms of strength and will, according to their needs (Watson, 2008:40). These older patients should be assisted, until they well enough to be independent again. In this study all the members of the health care team perceived this to be true and of utmost importance to the recovery of the patient or until the patient died.

#### **5.4.2 POSITIVE THINKING ABOUT STEM CELL TRANSPLANTATION FOR CHILDREN.**

This subtheme emerged after the participants were asked how the health care providers felt about stem cell transplantation as a treatment option for children. Dealing with transplanted children, can be very challenging for the nurses. Participants (P1, P2, P4, P5, P12, P14 and P16) expressed that it was an emotional experience for them to nurse these children through the recovery process. However, despite the emotional experiences of nursing these children, the majority of the participants (P3, P4, P5, P7, P10, P11, P15, and P16) displayed a positive attitude towards stem cell transplantation for children. This could afford sick children suffering from hemapoietic blood cancers, a second chance for survival. Gross and Pulsipher (2015) established that stem cell transplantation is an advantage for paediatric patients, as more marrow space is developed to restrain the patient's immune system to prevent rejection of the stem cells. In the light of the aforementioned, these sick children normally recover much quicker than adults.

According to Henderson's components of health, sleep and rest are very important post-transplantation, as well as the maintenance of good hygiene (George, 2014). The entire health care team plays a major role in ensuring that children's pain are under control or that they are pain free in order to have enough sleep and rest. The nurses in this team, plays a major role in maintaining good health in these children post transplantation in order for them to recover timeously. In children this is essential. This is connected with the individual's ability to function on their own. However, children cannot function independently, particularly because they are so young and too sick.

Adediran et al (2016) agreed that allogeneic stem cell transplantation is a cure for sickle cell anaemia in children, who are born with this disease and can die before they reach the age of five years. Bojanic et al (2009: 237), agreed with Adediran et al (2016) and Gross and Pulsipher (2015) that paediatric patients are more tolerable than adults. This is also in line with the positive thinking of the participants in this study regarding stem cell transplantation as a cure for children.

#### **5.4.3 SADNESS WITH DEATH IN STEM CELL TRANSPLANTATION AND IN CHILDREN BEING SICK DURING STEM CELL TRANSPLANTATION**

This subtheme emerged when the participants were asked how the health care providers reacted when a patient died. In contemplating on this question, most of the participants revealed that they felt very sad. Henderson's (George 2011) component of communicating different feelings and needs, are very applicable here, as the team members voluntarily revealed their feelings of sadness to the interviewer

Peters et al., (2013) stated that nurses have much to do with death while caring for these patients. The majority of the participants felt that they grew close to the patients and find it extremely challenging when a patient died. Participant (P3) emphasized that dealing with death is sad and difficult. Leung et al (2012) conducted a study to explore how haematological nurses experience the threats of a dying patient. The study confirmed that nurses' struggle with their own conflicts while trying to help the patients with their disease and to help them to let go of the idea that they could be cured.

The health care team should all play a role in assisting the patients to come to terms with their illness, particularly if they reach the terminal stage post transplantation. Terminally ill patients should be guided according to their religious values, as stipulated in Henderson's components, to accept death. However, in contrast to the majority of the participants, who found it difficult to cope with the death of a patient, an enrolled nurse (P5) felt that he was not emotionally attached and that he knows "where to draw the line between him and the patients". By this he meant that he could detach himself from the patient who is dying.

Another participant (P8) felt that a person will be able to handle death better if they are experienced in looking after stem cell transplanted patients. Peters et al (2013) emphasized the fact that nurses need skills and experience to be able to deal with dying patients and death. Leung's findings corresponds with the results in this study on the subject of how nurses cope with their inner conflicts with regard to dealing with dying patients (Leung, 2012).

## 5. 5 PRACTICE

### **5.5.1 PARTICIPATION IN THE TEAM**

Each participant had to identify their role within the health team. Each one of the participants could describe their role in the team as well as in relation to each other. They all participated in the care of the patients, who underwent stem cell transplantation. McCray (2009:8) stated that each member of the multidisciplinary team must have relevant knowledge and skills in order to perform their function.

From the interviews it was also clear that it was the nurses who were with the patients most of the time and devised care plans in conjunction with the other team members. The social worker (P15) in the team commended the nurses for their role they played regarding caring and the administration of medication to the transplanted patients. The care worker (P2) reported that she reported all observations to the professional nurse in the unit on her shift. This is another indication of the important role that the professional nurses play within this team. Professional nurses (P4) also revealed that they not only have a caring role, but also a supportive one, as they also needed to support the entire family. Smeltzer et al., (2010:12) confirmed that nurses function interdependently with other team members and play a major role within this team nursing these patients.

Some of the professional nurses responded that the whole family is involved in caring for the patient. This was confirmed by Langhorne, Fulton and Otto (2007: 620) where they agree that the family formed a formidable part of the care of the patient, together with the health care team. In the case of the paediatric patient, it will be the parents who play a major role in caring for the child. It will be the partners and their children with the extended family that will participate in caring for the transplanted adult patient.

The doctor within this health care team seemed to have the most challenging tasks, which involves the process of mobilisation and harvesting of the stem cells. Mohammadi et al (2017: 78) confirmed that this procedure is complicated, but very important. The doctor has to decide when the nurses, who are doing the harvesting, have to stop or continue with mobilisation or harvesting of the stem cells. Within the team, the doctor therefore fulfils a pivotal role in the mobilisation and harvesting of stem cells for the patient.

### **5.5.3 HOLISTIC DELIVERY OF CARE**

This subtheme emerged when participants were asked how they plan the care of the patients. The human being's mind and body are one. Thus, an individual consist of biological, psychological, sociological and spiritual aspects. Henderson's theory presents the patient holistically, in the light of all these needs (Watson, 2008: 40).

The majority of the health care team members knew how to plan the care of the patients, taking into account their biological, psychological, sociological and spiritual needs. Their religion (spiritual needs) is important, because these patients come so close to death. They draw strength by believing in a Higher Being. This is in line with Henderson's focus on the spiritual needs of patients. Patients need to be taken care of spiritually as well. They have to work hard to achieve recovery goals, as movement is at times impaired due to the weakness of the physical body. Henderson's environmental concept is very relevant in this study. After hematological transplantations, patients are nursed in isolation, while they are on high doses of chemotherapy or radiation (Tomblyn, Chiller, Einsele, Gress, Sepkowitz, Storek and Boeckh, 2009:1143). This complies with Henderson's insistence on sleep and restoration of the body. Post transplantation, these patients should be made comfortable in order to sleep and rest peacefully. They are cared for in isolation in order to prevent infections. Patients are encouraged and taught how to maintain good

hygiene in order to protect their skin, as prescribed in the components of Henderson's theory (chapter 1.8).

This isolated environment, in which these patients are being cared for, ensures that they are protected from danger. It also prevents them from harming other persons, as they can become very confused in the healing process. The isolated environment and the harm prevention, are part of Henderson's components that are applied in this study. However, they are unaware of their actions most of the time, while they are in this confused state of mind (Sharma et al., 2011:1003). The health of the patient is compromised in many ways and it determines the individual's ability to function on their own. Patients experience elimination problems, and they will have either diarrhea or constipation. A urinary catheter would be inserted to assist with the urinary complications. Patients can experience major lung complications; hence the importance here of Henderson's component of "stable breathing" (Laffan and Biedrzycki, 2006:787).

This has a major negative effect on the psyche of the patient According to George 2014, Henderson, theory claims that the team should encourage the patients to communicate with them regarding their fears and needs. Patients should also be allowed to express their emotions such as what they think. Here the attendance of the councilor and social worker in the health team plays a major role, as expressed in this study.

The care worker could identify her role and who she reported to. However, she did not compile specific nursing care plans for the patients. The majority of the participants agreed that they have to be supportive and caring, not only to the patients, but to their families as well. Smeltzer et al (2010:12) confirmed that the multidisciplinary team monitors and supports the physical and psychosocial needs of the patient. Van Leewen et al (2006) agreed that part of the nurses' role is supporting the patients and family, as they are close to them most of the time.

A participant (P7) pointed out the importance of including the family members as part of this team. Henderson's theory mostly talked about patients as individuals, but also saw them in the family and community context. Hence this finding is in line with the theoretical framework that was applied in this study. All the participants were aware of

the role of the other members in the team. They emphasized how important the role of each member was.

McCray (2009:8) described that the multidisciplinary team consist of various members working together to care for the patient and their families. They have to form a team to provide quality care for the patient. Yet, it is important that each team member's role is clearly defined, but that they complement each other in order to give comprehensive and quality care to the patient. The radiographer is responsible for the radiology, the physiotherapist plays a role in the mobilization of the patient and the dietician needs to ensure that the patient receives and consume a well-balanced nutritious diet. All health care professionals are involved in recreation, in which the patient is led to recovery after the stem cell transplantation. The nurse's main function is to serve patients until they have fully recovered (Ezzone and Pokorny, 2007:33).

However, all the participants conquered that they have to be part of the care plan and treatment decision-making of the patient, in order for the patient to be restored back to health. One of the team players thought that the care plans of the patients should also include preventive and supportive care. Even the lower categories of nurses, such as care workers, had a major role to play in nursing the transplanted patient back to health. According to McCray (2009:23), Henderson has redefined nursing as a role in which a patient has to be assisted whether sick or well, until they recover or die, with the necessary knowledge and skills. The main assumption of this theory is that nurses attend to patients until they can care for themselves, or die peacefully (Watson, 2008: 40).

The patient therefore should be treated holistically by all the team members. This was evident in this study and it conquers with Henderson's main assumption that nurses have to care for patients and assist them to get back to health or until they die. Each individual has basic needs which are aspects of health, and they would need help to maintain this health and independence until they die.

## **6. SUMMARY**

This chapter discussed the findings of the study. The findings were compared with the literature which was reviewed and the theoretical framework of Henderson which was applied to this study. Knowledge, perceptions and skills to practice were found to be

invaluable to each member of the team dealing with the transplanted patient. Every team member has an important role to play in nursing this patient back to health or to support and care for them until death sets in. Holistic care is imperative for these patients.

## CHAPTER 6

### CONCLUSIONS, RECOMMENDATIONS AND SUMMARY

#### 6.1 INTRODUCTION

The purpose of this study was to gain insight into the knowledge, perceptions and practices of the health care team regarding stem cell transplantation.

The objectives of this study were to explore:

- The knowledge of the members of the health care team in terms of the processes that need to be followed when stem cells are transplanted.
  
- The perceptions of the members of the health care team pertaining to how other health care professionals react towards patients undergoing stem cell transplantation and the death of these patients.
  
- The roles of the members of the health care team involved in practicing in stem cell transplantations.

The first chapter gave an overview of the research study. A comprehensive literature review relevant to the study was discussed in the second chapter. The third chapter discussed the research methodology and design. Analysis of the findings was presented in Chapter 4. In chapter 5 the results were discussed. In this Chapter limitations were highlighted. The study will be concluded and recommendations will be made.

#### 6.2. CONCLUSIONS

##### **6.2.1 OBJECTIVE ONE**

The first objective was “To explore the knowledge of the members of the health care team in terms of the processes that need to be followed when stem cells are transplanted. “

From the findings of the study:

- The participants were knowledgeable that there are different types of transplant processes.



- They were knowledgeable of the treatment available for the patients before stem cell transplantation.
- They were knowledgeable about the difficult decisions which the patients sometimes have to make and the information they have to provide the patients with, in order for them to make informed decisions.

The theory of Virginia Henderson was used to confirm how important it was that the health care professionals must possess knowledge in order for them to provide quality care for the stem cell transplanted patients. Henderson wanted the health care team members to display their knowledge of clinical experience, in inter alia health care facilities (Henderson, 1966:45). They should have knowledge on how to practice nursing care as well as how the environment can influence the care of a patient (George, 2014:92).

The stem cell transplanted patient may experience nadir, which will expose them to infections of every kind, such as pneumonia. The issues which a stem cell transplanted patient will struggle with include their basic needs, as they may be so weak as not to be able to attend to these themselves. The health care team working with them should be aware of this (Garrett & Yoder, 2007). The health care team members practicing with stem cell transplanted patients should have the appropriate training to enable them to impart this information.

Based on the discussion above, the first objective was met.

### **6.2.2 OBJECTIVE TWO**

The second objective was ‘To explore the perceptions of the members of the health care team pertaining to how other health care professionals react towards patients undergoing stem cell transplantation and the death of these patients.’

From the findings:

- The health care team members had various perceptions of caring for different stem cell transplanted patients
- The health care team members displayed positive thinking towards transplantation as a treatment option for hematological diseases and for children for the same type of diseases.
- The health care team members displayed sadness at the death of a patient who died during the recovery process after stem cell transplantation.

Virginia Henderson believed that health care team members must be able to remain humane and that they should be close to the patient. Every member of the team should be able to render services which are unique to each person. The health care team should be able to apply critical thinking and problem solving skills in order to treat every patient holistically. Henderson (in Watson,2008:40) believed that the nurse should be the caregiver most involved with the transplanted patient, hence these nurses should assist these patients in terms of strength, will and knowledge, according to their needs on the way to recovery, or until they die. Based on the findings and the theoretical framework applied, the second objective was met.

### **6.2.3 OBJECTIVE THREE**

The third objective was “To explore the roles of the members of the health care team involved in stem cell transplants and how the different members plan the care of these patients?”

- The health care team members displayed participation in the team
- The health care team members displayed differentiation in the different roles that they play/perform within the team.
- The health care team members displayed holistic delivery of care and they understood the different roles of every team member

Virginia Henderson has identified the role of the nurse in her theory and believed that the health care team aims to guide and assist the patient towards health. According to McCray (2009:23), Henderson has redefined nursing as a role in which a patient has to be assisted whether sick or well, until they recover or die, with the necessary knowledge and skills. The main assumption of this theory is that nurses attend to patients until they can care for themselves, or die peacefully (Watson, 2008:40).

Henderson stated that the nurse has the role to educate the stem cell transplanted patients about the normal development of their own health, as well as about what health facilities are available. Nurses implements prescriptions given by physicians, but they also have to be creative in planning the care of each individual. Nurses must have the knowledge to practice.

The individual patient has basic needs and in certain circumstances such as stem cell transplants, needs help from health care team members to maintain her/his health to become independent or until death occurs (George, 2014).

The most important notion that derived from this theme was that patient care was linked to every member of the health care team. Every individual's particular needs were considered and care plans were devised for each patient with the input of every team member. It was clear that the participants realised how important the care and planning of care was for stem cell transplanted patients and their families. The participants were also aware of the importance of each team member's role within the multidisciplinary team in order to develop comprehensive care plans according to the needs of each patient.

Based on the conclusion and confirmation above, the third objective was met.

## 6.3 BENIFITS OF FINDINGS FOR HEALTH CARE TEAM MEMBERS IN STEM CELL TRANSPLANT UNITS

### 6.3.1 THE HOSPITAL

All hematology units attached to a hospital will benefit from this study, as the knowledge obtained in the study can contribute to the improvement of nursing and medical care of all patients. Each health care member's role, involved in caring for the transplanted patient, has been highlighted. The importance of every team member's contribution was significant.

### 6.3.2 THE CLIENT

- For the client, the myths regarding stem cell transplantation will be reduced or even disappear, as the health care team consist of adequate knowledge to dispel these myths and to give the patients and family member's adequate knowledge to equip them to make inform decisions regarding their treatment options.
- Patients who are diagnosed with a blood disorder will know that stem cell transplantation is the answer to most chronic conditions which were only previously treated with conventional chemo - and radiation therapy.

- Families of younger patients will be motivated to use this form of treatment if they know and are informed that there are standards linked to the overall care of patients in the unit. Families will be included in the care of patients, particularly families of children, who needs to be transplanted.

### **6.3.3 THE PROFESSION**

- Knowledge, practice and attitude of health care team members dealing with the stem cell transplanted patient, can be integrated in the basic training for health care professionals, especially if they want to specialize in the field, of bone marrow stem cell transplantations.
- This study will help make staff aware of deficiencies in their practice, regarding knowledge and skills, which will encourage them to ensure quality of care and continuous development and training.
- Continuous Professional Development programs (CPD) monitored by the South African Nursing Council (SANC) are in progress for nurses. A suggestion would be to commence a program for members of the HPCSA as well.
- There is no hematology course for enrolled nurses, care givers, social workers, dieticians, physiotherapist, social workers and radiotherapists. Each of the courses only has a few hours of basic hematology knowledge in their programs. A short course in hematology could be added to the training of these professionals, enrolled nurses and caregivers, in the relevant training programs offered at universities and nursing schools.

### **6.4 LIMITATIONS**

One of the limitations of the study was the fact that one study focussing on the topic, cannot give thorough understanding of the phenomena explored. The other limitation of the study was the translation of the interviews from Afrikaans to English.

### **6.5 RECOMMENDATIONS OF THE STUDY**

- Standard operating procedures should be compiled to ensure consistency in care for stem cell transplantation patients in all hospitals, where hematological transplants take place.
- Continuous education and training programs should be implemented in the health services to equip health care professionals with knowledge and thus improve their service to stem cell transplanted patients.

- Continuous awareness and health promotion programs in the communities are necessary to make patients and their families aware of the option of stem cell transplantation for blood disorders.
- Primary health care (PHC) providers should provide education on hematology and the transplanted patient and procedures. Various information pamphlets could be made available at these PHC clinics. The researcher has developed such a pamphlet (refer to Appendix L)
- Information sheets and leaflets on hematology and transplantations should be made available at the library, in the postcard stands in health centers and clinics where all clients can easily have access to it.
- Health education and promotion must be done by oncology specialist in schools, communities and places of public gatherings.
- A hematology course especially for health care professionals is recommended, to provide them with the necessary information to be able to care for stem cell transplanted patients.
- Strategies on how to integrate knowledge, practice and attitude should be included in the basic training for nursing and medical staff regarding specialized fields such as hematology and stem cell transplantation.
- The study can also help to ensure that hematology and stem cell transplantation are integrated with practice and theory in the curriculum of health care professionals such as the dieticians, social workers, physiotherapist and radiographers.
- Training manuals regarding stem cell transplantation should be made available to the nursing profession. Such manuals should be included in the training of all nurses. Medical and supportive staff could also benefit from such a manual.
- More training should be provided for all members of the health care team, but particularly the nurses (as they are in contact mostly with the patients) regarding death and dying.

## 6.6 AREAS FOR FURTHER RESEARCH

The following areas have been identified by the researcher for further research.

- Stem cell transplantation awareness in rural areas.
- Health promotion and education on stem cell transplantation by oncology/hematology specialists who constantly engages in research activities.
- Stem cell transplantation in young children: implications of early detection.

- The importance of debriefing for health care professionals with the death of a stem cell transplanted patient.

## 6.7 CONCLUSION

The aim and objectives of this study have been met. The study has revealed that the health care professionals working with stem cell transplanted patients in the two hospitals in the Western Cape have obtained enough knowledge from their experience to adopt the right attitude to practice. It is nevertheless noted that training can play a greater role in providing them with professional knowledge and skills to practice. The study highlighted the significance of health care workers' knowledge, perceptions and practicing skills in caring for the transplanted patient. The importance of the team having the correct attitude, as well as knowledge on haematological diseases and transplants, in order to care for patients on a regular basis, was highlighted.

The researcher hopes that further research, will be undertaken, particularly in rural areas, in order to educate more families in this regard. More courses on haematology and transplants should be included in other cancer awareness programs in their curricula from primary to secondary school levels in the life skills curricula and at higher education institutions, either in short courses or in degree programs, related to health and para-health studies.

Finally, this study emphasised how important it is for all health care team members to keep updated with new knowledge in order to do health promotion and give advice to patients and family members regarding stem cell transplantation, but particularly, to dispel myths. This is predominantly significant for all the nurses that are part of a health care team involved in transplanted patients. They are the first point of contact with all the patients and are the caregivers that are close to the patients on a daily basis for long periods of time.

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## 8.1 APPENDIX A: RESEARCH INFORMATION SHEET AND INFORMED CONSENT



Bellville Campus,  
P.O. Box 1906  
Bellville  
Website: [www.cput.ac.za](http://www.cput.ac.za)

**Research title:** Knowledge, perceptions and practices of health care team members involved in stem cell transplantation in the Western Cape.

**Researcher:** Barennise Arries

I am a postgraduate student at the Cape Peninsula University of Technology, conducting a study as a partial requirement for my M.TECH nursing degree. I am inviting you to take part in this study which is aimed at exploring the knowledge, perceptions and practices of health care team members involved in stem cell transplantation in the Western Cape.

**Benefits:** Taking part in this study will give you the opportunity to share your view and experiences on knowledge, perceptions and practices relating to stem cell transplantation. The study may also provide further insight on health care team members' knowledge, perceptions and practices relating to stem cell transplantation, which may influence health care policies regarding the health care members' knowledge, perceptions and practices involved in stem cell transplantation.

**Procedure:** The interview will take 45 minutes to 1 hour of your time and it will take place at the ward. You will be asked a few questions related to the research as explained above. You will be asked questions about health care members' knowledge, perceptions and practices involved in stem cell transplantation. All answers will be appreciated. The interview will be recorded. You are allowed to ask questions or to indicate if you want to stop the interview or not to answer some of the questions asked during the interview.

**Risk/ Discomfort:** If you take part in this study there is no physical risk, but some of the questions asked may be sensitive. You have the right to answer or decline to answer those questions or to let me know how you feel. Should you feel that you need counselling afterwards, arrangements are made with Mrs Gill Smith, who is currently the counsellor at the private hospital.

**Time:** The researcher will use approximately 45 minutes to one hour to conduct the interview.

**Cost:** The study does not involve any cost to you as a participant.

**Ethical considerations:** Your participation in the study is voluntary and you can withdraw at any time. You have the right to withdraw from the study at any time or refuse to answer any question and your decision will not affect your relationship with the researcher or the hospital. You can choose not to answer any question at any point and it will not have any effect on your work. There will be an audio taping of the interview and it will be transcribed to paper and all information gathered will be confidential and kept locked.

**Right to privacy and confidentiality:** Your privacy will be protected at all times if you participate in this study. Everything we talk about in the interview will be kept confidential. In the analysis, I will ensure that your identity is not revealed in any part of the final document. The researcher will transcribe the content of the interview and

return to you for clarification and confirmation that the content is consistent with information given. You are free to stop taking part in the interview at any time and you may choose not to answer specific questions, as you prefer.

Participant's agreement form:

I have read the information above or it has been explained to me in a language that I understand. I consent voluntarily to participate as a participant in this study.

Name: .....

Signature: .....

Date: .....

Witness: .....

Signature: .....

Date: .....

## 8.1 APPENDIX B: PERMISSION LETTER FOR HEAD OF DEPARTMENT TO CONDUCT STUDY



PO Box 1906  
Bellville  
26 February 2014

Prof. N. Novitzky  
Head of Hematology Department  
Groote Schuur Hospital  
Anzio Road  
Observatory  
7925  
Dear Professor Novitzky

Re: Permission to undertake a Masters' Nursing Degree research at the clinical wards of the Hematology departments

My name is Barenise Arries. I am currently doing my Master's Degree in nursing at the Cape Peninsula University of Technology in Bellville. I am also a lecturer at the same university. I have been working in the hematology units. My interest of my study comes from there. The title of my proposed Masters' research study is: Knowledge, perceptions and practices of health care team members involved in stem cell transplantation in the Western Cape. There will only be twelve participants according to the inclusive criteria, six from the one hospital and six from the other hospital. My supervisor is Dr Hilda Vember.

Based on my experience and interaction with colleagues, I have noted lack of knowledge to practice quality interventions in all disciplines of health care professionals working with hematology patients. This study will contribute to the improvement of quality nursing and medical interventions for hematology clients. It is anticipated that training manuals could be developed for findings of the study. Furthermore, the outcome of my study would provide directions on strategies to integrate essential KPAs in our basic training to improve the quality of interventions for hematology patients/clients.

I do hope that you will permit me to proceed with this study as it is important that we should have the appropriate knowledge and attitude to provide quality nursing interventions, especially to our immuno-compromised hematology patients.

Yours sincerely



Barennise Arries

074 285 0153 (c); 021 953 8644 (o)

Email:-arriesb@cput.ac.za

Supervisor: Dr H Vember

Email: vemberh@cput.ac.za

### 8.3 APPENDIX C: PERMISSION LETTER TO HEAD OF NURSING IN THE PRIVATE HOSPITAL TO CONDUCT STUDY



P O Box 1906  
Bellville  
7535  
30 December 2014

Netcare Management  
Corner of Maude and West Street  
Sandton  
2010

Dear Sir/Madame

Re: Permission to undertake a Masters' Nursing Degree research at the clinical wards of the Hematology departments

My name is Barennise Arries. I am currently doing my Master's Degree in nursing at the Cape Peninsula University of Technology in Bellville. I am also a lecturer at the same university. I have been working in the hematology units with Prof. Nicholas Novitzky. My interest of my study comes from there. The title of my proposed Masters' research study is: Knowledge, perceptions and practices of health care team members involve in stem cell transplantation in the Western Cape. There will only be twelve participants according to the inclusive criteria, six from the one hospital and six from the other hospital. My supervisor is Dr Hilda Vember.

Based on my experience and interaction with colleagues, I have noted lack of knowledge to practice quality interventions in all disciplines of health care members working with hematology patients. This study will contribute to the improvement of quality nursing and medical interventions for hematology clients. It is anticipated that training manuals could be developed for findings of the study. Furthermore, the outcome of my study would provide directions on strategies to integrate essential KPAs in our basic training to improve the quality of interventions for hematology patients/clients.

I do hope that you will permit me to proceed with this study as it is important that we should have the appropriate knowledge and attitude to provide quality nursing interventions, especially to our immuno-compromised hematology patients.

Yours sincerely  
Barennise Arries

074 285 0153 (c)

021 953 8644 (o)

Email:-arriesb@cput.ac.za

Supervisor: Dr H Vember

Email: vemberh@cput.ac.za

#### 8.4 APPENDIX D: PERMISSION LETTER TO HEAD OF NURSING IN PUBLIC HOSPITAL TO CONDUCT STUDY



P O Box 1906  
Bellville  
7535  
30 December 2014

Dr Bernadette Eick: COO  
Western Cape Government; Health  
Groote Schuur Hospital  
G46 Management Suite  
Old Main Building  
Observatory  
7925

Dear Dr Eick

Re: Permission to undertake a Masters' Nursing Degree research at the clinical wards of the Hematology departments

My name is Barennise Arries. I am currently doing my Master's Degree in nursing at the Cape Peninsula University of Technology in Bellville. I am also a lecturer at the same university. I have been working in the hematology units with Prof. Nicholas Novitzky. My interest of my study comes from there. The title of my proposed Masters' research is: Knowledge, perceptions and practices of health care team members involve in stem cell transplantation in the Western Cape. There will only be twelve participants according to the inclusive criteria, six from the one hospital and six from the other hospital. My supervisor is Dr Hilda Vember

Based on my experience and interaction with colleagues, I have noted lack of knowledge to practice quality interventions in all disciplines of health care professionals working with hematology patients. This study will contribute to the improvement of quality nursing and medical interventions for hematology clients. It is anticipated that training manuals could be developed for findings of the study.

Furthermore, the outcome of my study would provide directions on strategies to integrate essential KPAs in our basic training to improve the quality of interventions for hematology patients/clients.

I do hope that you will permit me to proceed with this study as it is important that we should have the appropriate knowledge and attitude to provide quality nursing interventions, especially to our immuno-compromised hematology patients.

Yours sincerely  
Barennise Arries

074 285 0153 (c)

021 953 8644 (o)

Email:-arriesb@cput.ac.za

Supervisor: Dr H Vember

Email: vemberh@cput.ac.za

## 8.5 APPENDIX E: RE TO DIRECTOR OF PUBLIC HOSPITAL TO CONDUCT STUDY



P O Box 1906  
Bellville  
26 February 2014

Dr. Bhavna Patel  
Groote Schuur Hospital  
Anzio Road  
Observatory  
7925

Dear Dr. Patel

Re: Permission to undertake a Masters' Nursing Degree research at the clinical wards of the Hematology departments

My name is Barennise Arries. I am currently doing my Master's Degree in nursing at the Cape Peninsula University of Technology in Bellville. I am also a lecturer at the same university. I am currently working in the hematology units with Prof. Nicholas Novitzky. My interest of my study comes from there. The title of my proposed Masters' research is. Knowledge, perceptions and practices of health care team members involve in stem cell transplantation in the Western Cape There will only be twelve participants according to the inclusive criteria, six from the one hospital and six from the other hospital. My supervisor is Dr Hilda Vember.

Based on my experience and interaction with colleagues, I have noted lack of knowledge to practice quality interventions in all disciplines of health care professionals working with hematology patients. This study will contribute to the improvement of quality nursing and medical interventions for hematology clients. It is anticipated that training manuals could be developed for findings of the study. Furthermore, the outcome of my study would provide directions on strategies to integrate essential KPAs in our basic training to improve the quality of interventions for hematology patients/clients.

I do hope that you will permit me to proceed with this study as it is important that we should have the appropriate knowledge and attitude to provide quality nursing interventions, especially to our immuno-compromised hematology patients.

Yours sincerely  
Barennise Arries

074 285 0153 (c); 021 953 8644 (o)

Email:-arriesb@cput.ac.za

Supervisor: Dr H Vember

[Email:vemberh@cput.ac.za](mailto:vemberh@cput.ac.za)

## 8.6 APPENDIX F: REFERRAL LETTER TO PSYCHOLOGIST



P O Box 1906

Bellville

7535

26 February 2014

Mrs Gill Smith  
UCT Private Academic Hospital  
Anzio Road  
Observatory  
7925

Dear Mrs Smith

Re: Permission to refer the participants if counselling is necessary.

My name is Barennise Arries. I am currently doing my Master's Degree in nursing at the Cape Peninsula University of Technology in Bellville. I am also a lecturer at the same university. I have been working in the hematology units with Prof. Nicholas Novitzky. My interest of my study comes from there. The title of my proposed Masters' research is: Knowledge, perceptions and practices of health care team members involve in stem cell transplantation in the Western Cape. There will only be twelve participants according to the inclusive criteria, six from the one hospital and six from the other hospital. My supervisor is Dr Hilda Vember

Based on my experience and interaction with colleagues, I have noted lack of knowledge to practice quality interventions in all disciplines of health care professionals working with hematology patients. This study will contribute to the improvement of quality nursing and medical interventions for hematology clients. It is anticipated that training manuals could be developed for findings of the study. Furthermore, the outcome of my study would provide directions on strategies to integrate essential KPAs in our basic training to improve the quality of interventions for hematology patients/client



The questions in the interviews may be too emotional for some participants. I want to ask permission to refer them to you if the need may arise.

Yours sincerely  
Barennise Arries

074 285 0153 (c) 021 953 8644 (o)

Email:-arriesb@cput.ac.za

Supervisor: Dr H Vember

Email: vemberh@cput.ac.za

## 8.7 APPENDIX G: ETHICAL APPROVAL FROM CAPE PENINSULA UNIVERSITY OF TECHNOLOGY



### HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE (HWS-REC)

Registration Number NHREC: REC- 230408-014

P.O. Box 1906 • Bellville 7535 South Africa  
Symphony Road Bellville 7535  
Tel: +27 21 959 6917  
Email: sethn@cput.ac.za

24 April 2015  
*REC Approval Reference No:*  
*CPUT/HWS-REC 2015/H10*

---

Faculty of Health and Wellness Sciences

Dear Ms Barenise Arries

**Re: APPLICATION TO THE HWS-REC FOR ETHICS CLEARANCE**

Your application for ethics approval has reference. This serves to inform you that approval was granted by the Health and Wellness Sciences-REC on 17 April 2015 to Ms Arries for ethical clearance. This approval is for research activities related to the MTech: Nursing at this Institution.

**TITLE: A study of health car professionals' knowledge, attitude and practice, relating to stem cell transplantation in Cape Town.**

**Internal Supervisor:**

1. Prof D Khalil
2. Dr H Vember

**Comment:**

**Approval will not extend beyond 25 April 2016.** An extension should be applied for 6 weeks before this expiry date should data collection and use/analysis of data, information and/or samples for this study continue beyond this date.

The investigator(s) should understand the ethical conditions under which they are authorized to carry out this study and they should be compliant to these conditions. It is required that the investigator(s) complete an **annual progress report** that should be submitted to the HWS-REC in December of that particular year, for the HWS-REC to be kept informed of the progress and of any problems you may have encountered.

Kind Regards

A handwritten signature in black ink, appearing to read "Navindhra Naidoo".

*Mr. Navindhra Naidoo*  
**Chairperson – Research Ethics Committee**  
Faculty of Health and Wellness Sciences

## 8.8 APPENDIX H: NETCARE HOSPITAL PERMISSION



Netcare Management (Pty) Limited

Tel: + 27 (0)11 301 0000  
Fax: Corporate +27 (0)11 301 0499  
76 Maude Street, Corner West Street, Sandton, South Africa  
Private Bag X34, Benmore, 2010, South Africa

### RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2015-0003

Ms B Arries

E mail: Arriesb@cput.ac.za

Dear Ms Arries

#### RE: HEALTH CARE PROFESSIONALS' KNOWLEDGE, PRACTICE AND ATTITUDE RELATING TO STEM CELL TRANSPLANT IN CAPE TOWN

The above-mentioned research was reviewed by the Netcare Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Netcare UCT Private Academic Hospital, has been approved, subject to the following:

- i) Research may now commence with this FINAL APPROVAL from the Netcare Research Operations Committee.
- ii) All information regarding Netcare will be treated as legally privileged and confidential.
- iii) Netcare's name will not be mentioned without written consent from the Netcare Research Operations Committee.
- iv) All legal requirements with regards to participants' rights and confidentiality will be complied with.
- v) Netcare must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Netcare Research Operations Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.
- vi) A copy of the research report will be provided to the Netcare Research Operations Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date..
- vii) Netcare has the right to implement any recommendations from the research.

---

Directors: M S F Da Costa, J du Plessis, K N Gibson R H Friedland, M B Nkosi, C Pallman, N Phillipson,  
P Warener, D van den Bergh

Company Secretary: L Bagwandeem Reg. No. 1995/012717/07

- viii) Netcare reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/Netcare or should the researcher not comply with the conditions of approval.
- ix) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE STUDY, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully



Prof Dion du Plessis

Full member: Netcare Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Shannon Nell



Chairperson: Netcare Research Operations Committee  
**Network Healthcare Holdings Limited (Netcare)**

Date:

12/2/2015



## 8.9 APPENDIX I: GROOTE SCHUUR HOSPITAL PERMISSION



### GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick

Email: [Bernadette.Schmitz@westerncape.gov.za](mailto:Bernadette.Schmitz@westerncape.gov.za)

Ms B. Arries  
Cape Peninsula University of  
Technology P O Box 1906  
**BELLVILLE**  
7535

E-mail: [arriesb@telkomsa.net](mailto:arriesb@telkomsa.net) / [ArriesB@cput.ac.za](mailto:ArriesB@cput.ac.za)

Dear Ms Arries

#### **RESEARCH PROJECT: Health Care Professionals Knowledge, Practice and Attitude Relating to Stem Cell Transplant in Cape Town**

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research subject to the approval of Professor Nicolas Novitzky, the HOD: Haematology.

Please note the following:

- a) Your research may not interfere with normal patient care.
- b) Hospital staff may not be asked to assist with the research.
- c) No hospital consumables and stationary may be used.
- d) **No patient folders may be removed from the premises or be inaccessible.**
- e) Please introduce yourself to the person in charge of an area before commencing.
- f) Please discuss the study with Professor Novitzky before commencing.
- g) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- h) Confidentiality must be maintained at all times.

I would like to wish you every success with  
the project. Yours sincerely

*Signed by*

**DR AGATA KRAJEWSKI**  
**(Acting) CHIEF OPERATIONAL OFFICER**

**Date:** 16<sup>th</sup> January 2015

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## **8.10 APPENDIX J: INTERVIEW QUESTIONS**

1. What are the roles of the health care team members responsible for looking after patients undergoing stem cell transplantation?
2. As a health care professional describe your role regarding stem cell transplantation?
3. In your view, how do other health care team members react towards patients undergoing stem cell transplant.
4. How do you go about planning the care of a patient undergoing a stem cell transplantation?
5. Describe the process/steps in stem cell transplantation.
6. What is the general attitude of health care team members towards children undergoing stem cell transplantation?
7. What is the attitude of the health care team members regarding a death of a patient undergoing stem cell transplantation?

## 8.11 APPENDIX K - INTERVIEW 15: V0101019

Colour key to subthemes of responses

RESPONSE	SUBTHEME
	Knowledgeable about different types of transplants methods and processes
	Knowledgeable about decision-making and information
	Positive thinking about the treatment option, stem cell transplantation, and stem cell transplantation for children
	Sadness about death in stem cell transplantation and in children being sick during stem cell transplantation
	Various perceptions of caring for different stem cell transplanted patient
	Participation in the team
	Differentiation of roles of team members
	Holistic delivery of care

### Speaker Key

IV Interviewer  
 FI Female Interviewee

IV Okay Participant, I am very happy that you have agreed to take part in this study. As you know, I have explained to you the reason for the study. We want to improve quality care, and you have also signed the consent form. So, do you understand what I have said in the consent form?

FI Yes, I do.

IV Okay, thank you very much. Okay, so now the questions that I want to ask you is what is the roles of the different health care professionals, or with the patients that have been stem cell transplanted?

FI The role of?

IV Yes, the different role players.

FI Like what I think, the doctors, they are here to treat patients, and most of them, of my doctors, are trained to do the bone marrow transplant, and there are nurses as well who see to the patient, that they get their medication on time. They see to their J Line and whatever the patient needs. If there are any complaints, maybe the patient has got a high temperature or there is any query, they call the doctor to find out from the doctor what the doctor needs to do. But there is a doctor on 24 hours in the hospital



premises, and we have also got a dietician who sees to the diet of the patients. She is also here Monday to Friday.

IV Very important people.

FI Yes, and what I also think which we don't have here, I think we need to involve the physios, because I went to a congress over the weekend.

IV SESMO?

FI Yes. There was a physiotherapist who emphasised like exercise is very good for our patients, because our patients, most of the time they feel tired, you find that they don't walk around, whereas they are in isolation. Also, I was questioning myself when would the person start with the exercise, but they say as long as they walk around, they must exercise. They say exercise, eating and your medication are very important. She even said exercise equals medicine. That was the point that I have taken.

IV That's very good, yes. So, these conferences mean knowledge hey [laughs].

FI Yes, but physio, to tell you, it's rare that I see a physio comes, especially to F4 here.

IV Yes, and they are also part of the team.

FI Yes, they are supposed to be.

IV So, what is your specific role?

FI **Me, I am a social worker. I am there to support the patient and the family.** This is from diagnosis, and you find out most of, even the doctors, they don't have enough time to sit down and explain to the patient what is the diagnosis and the treatment and all of that. You find out the patients at times, they are even scared to ask the doctors other questions, then I will have to ask the doctors on behalf of the patients, see that at home everything is okay, because even with the sickness, it was somebody that was working, maybe a sole breadwinner, now there won't be any income, so I need to assist with that. If maybe there would be income from work, or UIF, sick benefits, or a disability grant. There is an organisation also that is called the Benevolent Association. They assist patients with food parcels and also transport while they are waiting for the disability grant, or UIF. There is also like family conflicts that I need to sit with the family and discuss all of those things to help them through.

IV It's quite a role, hey?

FI Yes, counselling, support, education, yes, all that stuff.

IV Shoo, wow. So, how do you think, according to you, how do health care professionals feel generally about transplant?

FI **I think there are positive outcomes,** but it's only if the patient is not doing well, then you find that people will say no, this was not supposed to be done, then you know already that this was not going to work, why will they force it. But I can tell you, most of the time it's a positive thing, and even you, you see them after the transplant when they are coming, and they are still alive after three years, five years. Even now, there is a clinic where Prof is seeing patients that had the transplant, but today it's only, I think they were discharged about three weeks ago, the patients that are here.

IV Okay, so the general feeling actually is more positive than what it is negative.

FI Yes.

IV How do you plan the care of a patient? You follow them up from diagnosis until they go home, so how do you plan that care for them?

FI Like with me, it's like most of the patients that are referred to us, I don't know whether to make an example for somebody, the one that is here today who is from Bloemfontein, he has got no family here, so I am the only support for him. You know, now I must see that he has got accommodation to stay when he is out of hospital, and I make a point that he will have travelling to go back home when it's time for him to go, and when it's time for him to come back to Cape Town. He must also keep in touch with his family, and the Benevolent Association, if it's somebody that's away that doesn't have any family in Cape Town, they can assist maybe for the family to come for two weeks. That support is very important. There is no way a patient will be able to go through this on their own. Also, there are other patients that had the same illness, went through all of that, then I make a point that he meets them, he speaks to them.

IV So you want them to stay positive for the treatment.

FI Yes.

IV That's quite a job hey? So not only are you the social worker, you are the coordinator also for transplants.

FI Yes.

IV Do you know about the different types of transplants that they have?

FI I do, because we had an auto, like this patient that I am talking about now. Even he, they are going to do the harvesting tomorrow. So what they have done, where he is staying, he is staying at Eikenhof, and the driver at Eikenhof will start working round about eight o'clock, so they arrive here nine o'clock, which is going to be too late. So I have arranged for him to sleep over in E7 so that the doctor can start at seven, like tomorrow.

IV Yes, they start early.

FI Yes, so they are going to collect his own cells, so it's going to be auto transplant, because he doesn't have any siblings, you see.

IV Yes, he's alone here from Bloemfontein you said, hey?

FI Yes, and also there is what we call allo, that's when you've got a donor, maybe your brother or your sister. With the donor will have to sit down and explain the whole process, because if they are not from Cape Town, they will have to come from wherever to be in Cape Town for at least a period of three weeks, because the first week, that's when they will be given the Neupogen injection, and also they will be tested if they are fit, tested if they don't have any other illnesses, HIV and all of that, then the transplant.

But they will have to stay in Cape Town for a period of two weeks so that if the transplant is not successful, then they will have to get more cells from the donor, because when they get the cells from the donor, it must be given to the patient the next day, immediately. They can't keep them. There is what they call the hypo now, which is they use the mother.

IV That's new, hey?

FI Yes, I think it's about three years now they have been doing that. But in the three that have been done, one of the patients died. But it is very, very successful.

IV Good hey? Research is going on.

FI Yes.

IV And children, what is the general feeling regarding children that have been transplanted?

FI Children, to tell you, they do much, much better than adults. They recover quickly, children.

IV So you see that is positive.

FI Yes.

IV Okay, so now we are on our last question. How do you feel about the fact that the patients sometimes die after the transplant, they die?

FI Yes, to tell you the honest fact, it's very sad, yes. To me, there are times whereby it depends when did the patient die. If I knew it was coming, there are times whereby I can see, you know, this patient is not doing well, whereas the doctor will tell you they are doing well. Me, it's just to look, then I say uh-uh, this is not what they are. So, if there is that time that I prepare myself, then I came to accept, they have done so much for this patient, maybe this was not meant to be. But if it happened whereby I was not prepared, to tell you, it drains me emotionally. Now, look at that now, this happened and you must also be there with the family. You must support the family.

IV You must stay positive for them.

FI Be there, and you must stay strong. There are times that I feel like, but you must keep strong. Just you must be there to support them. But if it happened like in the week that there would be two people dying, but it's rare that that happens, but there was a time whereby it happened. Then I was like I couldn't, I was crying. Yes, it drains you emotionally. It drains it out of you.

IV You have been working here how long now?

FI I have been working here for eight years now.

IV Okay, that's quite a time, and you don't get used to death.

FI I don't think there is anybody that can get used to that. You can't. There is no way you can, unless you can see that the patient is struggling, then you can say it's a good thing. But if it's somebody that you were talking to on Friday, there was nothing, you come back Monday and they are gone, there is no way. You have to also be prepared.

IV Okay, thank you very much. I appreciate the time you have taken to answer the questions.

[End of sound file 00:14:25]

## 8.12 INTERVIEW 15: RESPONSES LINKED TO THEMES

The table below indicates how each interview was analysed and the themes identified from the responses

Question	Response	Themes
1. What are the roles of the health care professionals responsible for looking after patients undergoing stem cell transplantation	<i>Like what I think, the doctors, they are here to treat patients and most of them, of my doctors, are trained to do bone marrow transplant, and there are nurses as well who see to the patient, that they get their medication on time” They see to their J Line and whatever the patient needs.</i>	<b>Theme:</b> Practice <b>Subthemes:</b> 1.Differentiation of roles of team members  2. Participation in the team  3.Holistic delivery of care
2. As a health care professional describe your role regarding stem cell transplantation	<i>“I am here to support the patient and the family...now there won't be any income, so I need to assist with that. If maybe there would be income from work, or UIF, sick benefit...counselling, support, education, yes all that stuff”</i>	
3. How do you go about the planning the care of a patient undergoing a stem cell transplantation	<i>Most of the patients are referred to us...so I am the only support for him...I must see that he has accommodation</i>	

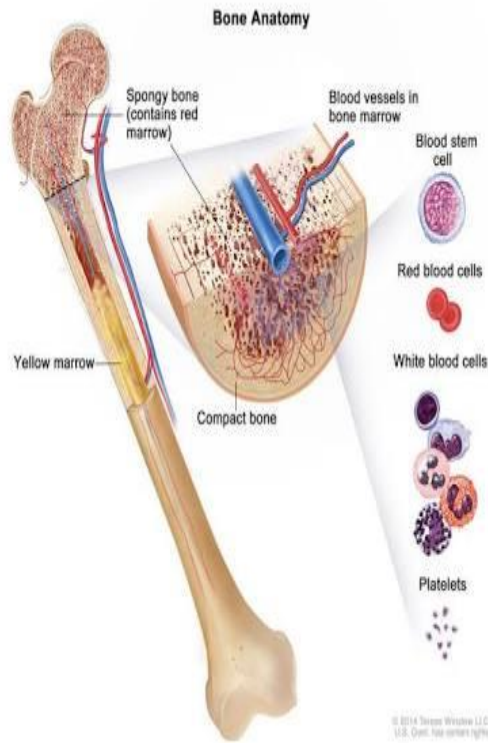
<p>4. Describe the process/steps in stem cell transplantation in each method.</p>	<p><i>They are going to do harvesting tomorrow...they are going to collect his own cells...</i></p>	<p><b>Theme:</b> Knowledge</p> <p><b>Subthemes:</b> 4.Knowledgeable about different types of transplant methods and processes</p>
	<p><i>I will have to sit down and explain the whole process”</i></p>	<p>Knowledgeable about decision- making and information</p>
<p>5.What is the general attitude of health care professionals toward children undergoing stem cell transplantation</p>	<p><i>Children, to tell you, do much, much better than adults. They recover quickly</i></p>	<p><b>Theme:</b> Perception</p> <p><b>Subtheme:</b></p> <ul style="list-style-type: none"> <li>• Positive thinking about the treatment option, stem cell transplantation, and stem cell transplantation for children</li> <li>• Sadness about death in stem cell transplantation and in children being sick during stem cell transplantation</li> </ul>
<p>6.What is the attitude of the health care professionals regarding a death of a patient undergoing stem cell transplantation?</p>	<p><i>“..it is very sad.. you must be there for the family. I was crying.. it drains you emotionally”</i></p>	

7. In your view, how do other health care professionals react towards patients undergoing stem cell transplantation?	<i>“there is positive outcomes”</i>	<ul style="list-style-type: none"><li>• Various perceptions of caring for different stem cell transplanted patient</li></ul>
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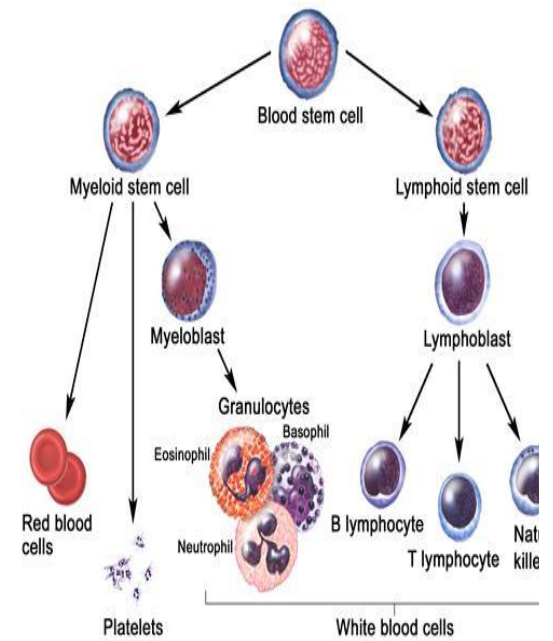
## 8.13 APPENDIX L: PAMPHLET

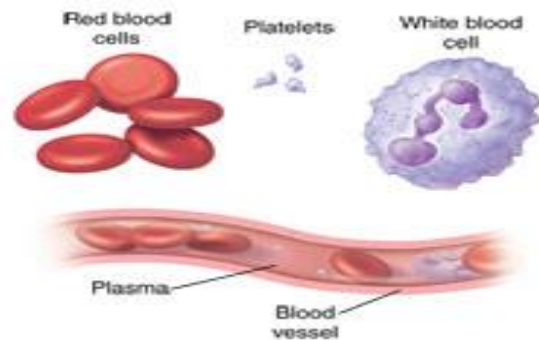
Peripheral Stem cell transplant

*What you need to know*



# Peripheral stem cell transplantation Information leaflet





Stem cell transplantation is the last treatment option for some life-threatening diseases.

**How does stem cells work?**

Other types of cells have a limited lifespan and die after they have divided their predetermined number of times, but a stem cell can reproduce forever. A stem cell can forgo immortality and differentiate. In the process of differentiation, it can turn into an ordinary blood cell, such as a red blood cell, a white blood cell or a platelet. Peripheral blood stem cells go to the recipient's bone marrow spaces and rebuild the damaged bone marrow after the intensive treatment is over. It can reconstitute the entire repertoire of blood cells and restore that portion of the immune system.

Side effects: Infections, flu-like symptoms, nausea and vomiting, diarrhoea, constipation mucocitis, lung complications, graft-versus-host disease,

Where does the stem cells come from for transplantation?

Stem cells are not normally seen in the bloodstream. A Recombinant human glycosylated Granulocyte Colony Stimulating Factor (rhG-CSF) is utilized to lure the stem cells from the bone marrow into the peripheral blood where it is harvested from.

Preparation: The patient receive high doses of chemotherapy and radiotherapy over several days to destroy the damaged cells in diseases such as leukemia, lymphoma, immune system diseases and solid tumours.

Process of stem cell transplantation: The stem cells are given to the patient as a blood transfusion. It is normally infused through a Hickman line, which is tunnelled through the jugular vein to the superior vena cava.

REFERENCE: www.medicinenet.com  
Compiled by Barenise Arries (arries©2017)

Peripheral blood stem cell transplantation entails the harvesting of stem cells from the peripheral blood of the donor. Peripheral blood is your bloodstream. Stem cells are harvested through the process of apheresis.

Autologous transplantation: Patients own cells. Cells are frozen after harvesting. It will be re-infused in the patient after intensive treatment.

Allogeneic transplantation: Donor cells. The stem cells are usually given straight to the recipient after harvesting, but also after the recipient, who is the patient, has received intensive treatment.

These processes does not involve surgery, but are also transplantations.





