

The psychosocial experiences of the patient and family of skin cancer diagnosis and treatment

Mini-dissertation

Submitted for the partial fulfilment of the requirements for the degree

**Master of Social Work in Health Care
MSW (Health Care)**

by

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in the

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DECLARATION OF ORIGINALITY

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DEDICATION

Dedicated to my beautiful blonde boisterous blue eyed blessing

Nicol

Ek wil hê jy moet saam sing
as musiek begin speel
en dans in die somer se reën
En soek vir die reënboog
langs die pad, my skat
Hardloop in die see in met jou jeans aan
Kyk uit vir 'n meermin
en deel in gesprekke oor al die mooi plekke
langs die kus.

K.Zoid

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- To all the participants - my appreciation and respect to those who had suffered losses, who were still willing to participate and make an invaluable contribution to research.
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ABSTRACT

Title: **The psychosocial experiences of the patient and family of skin cancer diagnosis and treatment.**

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Department: **Department of Social Work and Criminology**

Degree: **MSW (Health Care)**

Supervisor: **Dr. CL Carbonatto**

Skin cancer is the most common cancer in South Africa with about 20 000 reported cases every year and 700 deaths. The Cancer Association of South Africa (CANSA) urges all South Africans to be SunSmart to reduce the high incidence of skin cancer in the country. The World Health Organization (2014) reports that between two and three million non-melanoma skin cancers and approximately 132 000 malignant melanomas occur globally every year. South Africa has the second highest incidence of skin cancer in the world after Australia (CANSA, 2014).

Skin cancer is an increasing phenomenon in South Africa and enough is not done to raise awareness. The researcher has a very personal interest in skin cancer, the emotions around it, the needs, thoughts and experiences of patients diagnosed with skin cancer, due to various family members having suffered skin cancer. The researcher also learnt through own experience that there is a lack of support systems for the traumatised family to fall back on, specifically when it comes to skin cancer. Individuals who wish to support the patient may also need education, support and information regarding the condition in order to do so. The latter was confirmed through consultations with a Dermatologist and a Plastic Surgeon with regards to the emotional effects of skin cancer. Both specialists expressed eagerness to learn more in this regard and committed to assist the researcher in this study in finding suitable participants, who were selected and interviewed. It was clear from the first interview that none of the participants had expected skin cancer and many emotions were expressed.

When a person is diagnosed with skin cancer he or she will often experience anxiety which can be very severe. Anxiety may make the pain experienced by cancer sufferers worse. Anxiety is a normal response to stressful events and is part of the process of coming to terms with an illness. Fear of the unknown is often a significant cause of anxiety. Patients may feel less anxious when they are given more information about their illness and their treatment, or when they find out more from booklets available from cancer charities and patient groups or from websites. Patients also usually begin to feel less anxious as they become more accustomed to seeing the doctor and going to hospitals. As they get to know hospital staff they gradually feel more at ease and less threatened by fears of the unknown. (Gillie, 2005:42).

The patient participants had some form of treatment for skin cancer. Various emotions and experiences were observed and expressed by both patient and family participants and it became evident that from diagnosis, through treatment and even post treatment, the participants had a lot of emotions and each phase brought along its own experiences, feelings and needs. This supported theory around the issue of skin cancer and the experience around it being studied.

The emotional effects of cancer may last long after the end of treatment. People often find they continue to feel anxious about minor signs of illness or pain, fearing a recurrence. Regular check-ups may be necessary and these can be very scary times. Permanent changes in lifestyle, as a result of cancer, or bodily changes may be daily reminders of the cancer and cause sadness. As distressing as these emotions may be, they are natural reactions to a cancer diagnosis. Talking to family and friends may be helpful (The Cancer Council of New South Wales' 'Coping with Cancer' (2005:1).

The researcher followed a qualitative approach in this study and attempted to understand the subjective life experience of the participants who suffer from skin cancer and have been diagnosed and undergone treatment. In order to add to the development of insight and a better understanding of the experiences skin cancer patients have in the current South African context, the researcher was able to obtain first-hand information through the use of unstructured interviews as it allowed the participants to share their thought and feelings and experience without guidance from the researcher. The information gathered was in the form of words

and concepts, which gave meaning to the participants' experiences of a skin cancer diagnosis and treatment.

In total 13 participants were selected as part of the study, who included both skin cancer patients and family members. These participants were selected from existing patients and family members of patients of two private medical specialists in Panorama, Parow and Cape Town. Unstructured interviews were conducted with the participants and were voice recorded with their permission. These interviews were then transcribed. The data was then analysed by the researcher and from that, themes and sub-themes were identified. The research findings are presented by the biological profile of all the participants being portrayed and a thematic analysis of the themes and sub-themes. Literature and verbatim quotes were then given in support of the findings.

Five themes were identified as follows:

- Theme 1: Lack of knowledge around skin cancer
- Theme 2: Reaction to diagnosis
- Theme 3: Treatment
- Theme 4: Post-diagnosis mindfulness and behaviour change and
- Theme 5: Support structures. Each theme had sub-themes which were also discussed.

In conclusion, it was eminent that skin cancer patients and their family go through a lot of emotional turmoil and therefore it is of vital importance that the medical personnel or the multi-disciplinary team is aware of this when working with skin cancer patients. It was clear that at the point of diagnosis, patients and their families experience a lot of shock and disbelief which they have to work through. Some even have immediate fears of death, whereas others are oblivious of the severity of the condition. It was mentioned as a need from participants, but also noted in theory that knowledge or a good understanding of a condition and of the treatment lowers anxiety levels. All members of the multi-disciplinary team should ideally be aware and motivated to ensure patients' emotional needs are identified and addressed. Social workers have a vital role to play as their skills to identify needs are highly developed and have a good understanding of the family as a

support system, as well as connecting patients and families with support systems within their environment and community.

LIST OF KEY TERMS

Cancer

Diagnosis

Family

Skin cancer

Patient

Psychosocial experiences

Social work in health care

Treatment

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1. CHAPTER 1: GENERAL INTRODUCTION

1.1 Introduction

According to the University of Texas' MD Anderson Cancer Centre, skin cancer is on the increase with more than one million new cases of skin cancer occurring in the United States each year, the days of the "healthy tan" are over. The problem of skin cancer is epidemic. It was reported that one in six Americans will develop some form of skin cancer and it was estimated that there may be as many as 100 000 new cases of non-melanoma skin cancer annually, and around 7 000 cases of malignant melanoma. The incidence of malignant melanoma has increased more than any other major cancer in the UK, with male rates having quadrupled from around 2.5 in 1975 to 11.0 in 2002, while the female rates have tripled from 3.9 to 12.7 over the same period in Great Britain. This increase in numbers was alarming.

According to Samuels (2007) skin cancer was the most common form of cancer, with over a million people diagnosed each year, according to the National Cancer Institute. About half of all people in the United States have experienced some form of skin cancer at least once by the time they were 65. There were an estimated million new cases in the United States each year and two thousand deaths per year from this disease.

Skin cancer is the most common cancer in South Africa with about 20 000 reported cases every year and 700 deaths. South Africa has the second highest incidence of skin cancer in the world after Australia (CANSA, 2010). Whilst exploring the effects a skin cancer diagnosis and treatment had on patients and their families, Doctors De Goede (Dermatologist) and Smit (Plastic surgeon), who were consulted in this regard, agreed that there is not much information on the effects, despite it being such a common occurrence. This research, on this topic will thus contribute on a gap that exists within this field.

1.2 Definition of key concepts

1.2.1 Cancer

Cancer medically referred to as malignant neoplasm, is a class of diseases in which a group of cells display the traits of uncontrolled growth (growth and division beyond the normal limits), invasion (intrusion on and destruction of adjacent tissues), and sometimes metastasis (spread to other locations in the body via lymph or blood). These three malignant properties of cancers differentiate them from benign tumours, which are self-limited, do not invade or metastasize. Most cancers form a tumour, but some, like leukaemia, do not form tumours (Skin cancer, 2008). According to Meyers (2007) cancer is abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

From the above, cancer is defined as an area where body cells grow different to that of the surrounding cells and without control, potentially becoming a form of cancer.

1.2.2 Skin cancer

Skin Cancer is the most common form of cancer. The two most common types are basal cell cancer and squamous cell cancer. They usually form on the head, face, neck, arms and hands. Another type of skin cancer, melanoma, is more dangerous, but less common, according to Types of Skin Cancer (2007).

According to the National cancer institute (2007) it is cancer that forms in tissue of the skin. There are several types of skin cancer. The skin cancer that forms in melanocytes (skin cells that make pigment) is called melanoma. Skin cancer that forms in basal cells (small round cells in the base of the outer layer of skin) is called basal cell carcinoma. Skin cancer that forms in squamous cells (flat cells that form the surface of the skin) is called squamous cell carcinoma. Skin cancer that forms in neuroendocrine (cells that release hormones in response to signals from the nervous system) is called neuroendocrine carcinoma of the skin. Most skin cancers form in older people on parts of the body that's been exposed to the sun or in people who have weakened immune systems. Skin cancer is cancer that forms in the tissues of the skin. When cancer forms in cells that make pigment, it

is called melanoma. When cancer forms in cells that do not make pigment it may begin in basal cells (small, round cells in the base of the outer layer of skin) or squamous cells (flat cells that form the surface of the skin), as stated by e-Cancer Awareness.com (2007).

Skin cancer is understood as cancer cells specifically forming in the cells or tissues of the skin. It can form in the various layers of the skin and is predominant in areas where the skin was exposed to sun.

1.2.3 Treatment

Treatment is most often used to mean a process of modifying or altering something and depending on context may be used in an unqualified form to refer to any of the following: A type of therapy used to remedy a health problem. Experimental treatment, the levels of treatment factor(s) (variables controlled by the experimenter) applied, according to Treatment (2010). Care provided to improve a situation (especially medical procedures or applications that are intended to relieve illness or injury) (WordNet Search-3.1[sa]).

It is understood from the above that treatment refers to a process to change or improve a situation.

1.2.4 Psychosocial effect

Psychosocial effect refers to Psychology and Sociology of or relating to processes or factors that are both social and psychological in origin (thefreedictionary.com). This term is used to describe the relationship between the personal, internal environment, and the wider social world (i.e. the influence of social factors on an individual's mind or behaviour (Benzeval,, Green,, Ferrell, et al. , 2007).

From the definitions above, it is understood that the concept psychosocial refers to combined influence of psychological and social aspects on an individual.

1.2.5 Diagnosis

Diagnosis is used in many different disciplines, with slightly different implementations on the application of logic and experience to determine the cause and effect relationships. Below are given as examples and tools used by the

respective professions in medicine, science, engineering, business. Diagnosis also is used in many other trades and professions to determine the causes of symptoms, mitigations for problems, or solutions to issues, according to Wikipedia sv 'diagnoses. Identifying the nature or cause of some phenomenon (WordNet Search-3.1[sa]).

It is thus understood from the above that diagnosis means the process of understanding a phenomenon in what it is, what caused it and how to cure or prevent it.

1.3 Contextualisation of topic

As stated by the Cancer Council of New South Wales (Skin Cancer Statistics, 2007), Australia has the highest rate of skin cancer in the world. Almost 1 in 2 people who live here their whole lives will develop some form of skin cancer. There are over 1600 deaths from skin cancer in Australia every year.

In New South Wales, incidence and mortality rates for skin cancer are also high. Over 3,505 new cases of melanoma are diagnosed every year and more than 460 people die. There are also some 147,653 new cases of non-melanoma skin cancers (squamous cell and basal cell carcinoma).

Incidence and mortality are highest in people aged over 50 years. However melanoma also occurs in younger people. In 2005 in New South Wales, melanoma was the most common cancer in males aged 25-54 and in females aged 15-29. It was the second most common cancer in women 30-54 years of age.

There are three different types of skin cancer, namely Basal Cell Carcinoma, Squamous Cell Carcinoma and Melanoma. Basal cell carcinoma accounts for more than 90% of all skin cancers, as described by the University of Texas MD Anderson Cancer Centre (Types of Skin Cancer, 2008). It is a slow-growing cancer that seldom spreads to other parts of the body. However, if left untreated, it can spread to nearby areas and invade bone and other tissues under the skin.

The second type of skin cancer is squamous cell carcinoma. The University of Texas MD Anderson Cancer Centre describes squamous cell carcinoma as less common than basal cell carcinoma. It can be more aggressive than basal cell carcinoma and is also more likely to grow deep below the skin and spread to distant parts of the body. When squamous or basal cell skin cancers are found early, there is nearly a 100% chance for cure (Types of Skin Cancer, 2008).

The third type of skin cancer is melanoma. According to Wikipedia sv 'skin cancer') most melanomas are brown to black looking lesions. Signs that might indicate a malignant melanoma include change in size, shape, colour or elevation of a mole. The appearance of a new mole during adulthood, or new pain, itching, ulceration or bleeding of an existing mole should be checked.

When exploring South African statistics, it was found that among South African whites, nearly 14 out of every 100 000 men and 13 out of every 100 000 women suffer melanoma. Yet, despite a rising incidence in skin cancers, in particular malignant melanoma, South Africa remains a nation of sun worshippers, according to health.iafrica (Skin Cancer, 2007).

The Cancer Association of South Africa (CANSA) states that skin cancer is the most common cancer in South Africa with almost 20 000 new cases every year and over 700 deaths annually (Skin Cancer, 2008). Many social workers do not have a sound knowledge of oncology or skin cancer, even though the incidence rates in South Africa are so high.

During consultation with a Dermatologist from Panorama Medical Centre in Cape Town, Dr F de Goede, (2010), he confirmed the above. The good news is that skin cancer can be prevented if people respect the sun and learn how to be SunSmart by following advice from CANSA. South Africa is a sunny country and a popular holiday destination and the recreational culture is known to be an outdoor one. Many activities synonymous with being South African comprise of being outdoors, especially during sunny days, often all day long. A lot is done to emphasise the importance of using sunscreen lotions, but often for the idle reason that sun damage causes skin to look aged and wrinkled. Also, many people doing work in the outdoors are often over exposed to sunlight. Not a lot of emphasis is put on

the seriousness of being exposed to the sun or using a very good sun block in order to prevent skin cancer caused by exposure to the sun.

According to CANSA (Coping Kit, 2007), most skin cancers can be treated by removal of the lesion, making sure that the edges (margins) are free of the tumour cells. These excisions provide the best cure for both early and high-risk disease. For low-risk disease, radiation therapy and cryotherapy (freezing the cancer off) can provide adequate control of the disease; both, however, have lower overall cure rates than surgery. In the case of disease that has spread or metastasized, further surgical or chemotherapy may be required.

A cancer diagnosis is often seen as synonymous with death and dying, although with an increase in research on treatment, there is now increasing hope of survival. Skin cancer is specifically known as a form of cancer that often has a cure and a higher cure rate, and the researcher therefore believes that this may be why research and intervention in this type of cancer may have been neglected and why it has often taken a back seat to cancer research and intervention in other fields.

Todkill (2006:7) reflects the above by stating that any cancer diagnosis can result in emotional or psychological trauma that can impair your ability to live your everyday life: “The psychic trauma may cause more suffering than the physical lesion itself”

The prospect of having skin cancer can be quite stressful for most people, so it is important to be prepared for any emotional or psychological issues that may occur before or during treatment (How to check for skin cancer, 2005).

According to Todkill (2006:3) the medical literature has long recognised the importance of dealing with scars, from the early half of the last century professionals eloquently realised scars’ “... devastating effects on happiness, mental health and even livelihood of disfigured victims must not be underestimated.” It is to be expected that any type of scar or lesion would be a challenge emotionally and physically to deal with in the world of perfection and

aesthetic pre-occupation that we live in. This is where social work counselling is usually needed.

The diagnosis of a skin cancer can produce emotional scars of two kinds, the first being the initial weight of the diagnosis of a cancer and its implications, the second having to deal with the psychosocial burden of disfigurement and change in body image which – despite recent advances – may last a lifetime. The cancer diagnosis is classically associated with psychological models such as those of Kübler-Ross or Horowitz and the word cancer continues to be associated with fear and pessimism among the general public, perceived as nasty, painful and reducing the life span of a previously healthy individual. Cancer diagnosis has been associated with anxiety, depression, and psychosexual issues and has financial repercussions (Todkill, 2006:12).

The researcher is of the opinion that despite the perception of skin cancer being curable, the patient who gets such a diagnosis is anticipated to undergo some emotional trauma to some extent before treatment has started.

Much research has been done on the impact of burn scars and their psycho-social impact; however, the resultant scars from skin cancer surgery can be equally traumatic. There is a lack of studies looking directly at the impact of scars resultant from elective surgery; instead these are often grouped into the category of disfigurement, along with cleft lip and palate, acne, port wine stains, burns victims, and haemangioma, to mention a few.

The emotional effects of cancer may last long after the end of treatment. People often find they continue to feel anxious about minor signs of illness or pain, fearing a recurrence. Regular check-ups may be necessary and these can be very scary times. Permanent changes in lifestyle, as a result of cancer, or bodily changes may be daily reminders of the cancer and cause sadness. As distressing as these emotions may be, they are natural reactions to a cancer diagnosis. Talking to family and friends may be helpful. If your distress is really troubling, seek counselling and talk to the professional team involved in your care (The Cancer Council of New South Wales' 'Coping with Cancer' (2005) 2005).

It is all very well that a basic information leaflet encourages patients strongly to speak openly about their concerns and fears with regards to their diagnosis and

treatment, because it is vital for emotional support during the process and the prevention of trauma and supporting emotional well-being throughout treatment and recovery. Although, as earlier mentioned, very little research has been done in this specific regard, this research should make a valuable contribution to identifying the treatment needs of skin cancer patients.

The Cancer Council of New South Wales' 'Coping with Cancer' (2005:1) summarizes it well in stating that

No two people with cancer are alike; everyone copes in their own way. The diagnosis may cause you to feel a range of strong emotions such as fear, anger, guilt, denial, sadness or depression and loneliness. You may feel you've lost control of your life. These are all normal reactions. It's also hard not to think about dying, but it's important to focus on living.

The researcher has had personal experiences with the diagnosis of skin cancer within her family. It was ascertained that no emotional support was offered within the multi-disciplinary team context whatsoever. Also, there was no education or information given to the patients/family members, with regards to the type of skin cancer diagnosed, as well as the impact, treatment and prognosis thereof.

Having cancer and dealing with treatment can be time-consuming and emotionally draining.

The motivation for this study was therefore summarised as:

- Skin cancer is an increasing phenomenon in South Africa and enough is not done to raise awareness.
- The researcher has a very personal interest in skin cancer, the emotions around it, the needs, thoughts and experiences of patients diagnosed with skin cancer, due to various family members having suffered skin cancer.
- The researcher also learnt through own experience that there is a lack of support systems for the traumatised family to fall back on, specifically when it comes to skin cancer. Individuals who wish to support the patient may also need education, support and information regarding the condition in order to do so.

- The latter was confirmed through consultations with a Dermatologist and a Plastic Surgeon with regards to the emotional effects of skin cancer. Both specialists expressed eagerness to learn more in this regard and committed to assist the researcher in this study in finding suitable respondents.

From this research, a guideline was drawn up for the social worker and other members of the multi-disciplinary team with regards to the necessary intervention needed in supporting patients with a skin cancer diagnosis and their families.

Edwards & Clark (2004:193) also states that today, though social workers find themselves in a changing health care arena where they become devalued, where even the need for oncology social workers is being questioned. The researcher fully agrees with this statement and values the importance of the oncology social worker to continuously market him-/herself and also the importance and significance of oncology social work. In order to be dynamic in this kind of setting, it is of the utmost importance that social workers must constantly be exposed and updated with regards to new and developing technologies, knowledge, resources and treatments.

This researcher views this research as important and cardinal and aims to contribute to patients, families, organisations and the social work profession. Through effective research, the role of the social worker in the multidisciplinary context was also emphasised.

1.4 Rationale and problem formulation

Counsellors, therapists and other health care professionals are often faced with the difficult task of assisting and supporting patients and families from various cultures that are facing illness, extensive treatment, dying and death within the health care system, as is the case with oncology patients.

Carlier, Voerman and Gersons (2000:88) argue that problems are special kinds of questions that arise for which knowledge is needed. It is further regarded as the need for the study, or the source of the problem. According to Grinnell (1998:109) problem formulation is one of the most important aspects in the research investigation. Singleton as quoted in Strydom (2005:202), states that from a

general idea, one must decide more specifically what one wants to know and for what purpose one wants to know it.

In South Africa there are attempts to raise awareness of risk factors of cancer and specifically skin cancer; however there is very little support structure in place for victims of skin cancer. The researcher therefore hopes to contribute to the understanding of what the patient with skin cancer is experiencing, on the various levels of their functioning and within their different personal and interpersonal systems. There will also be a focus on how the diagnosis, treatment and potential scarring impacts them throughout these phases and the needs and resources that they have and need in order to raise awareness and to be able to contribute to improved intervention and support to these patients.

In a further attempt to explore this, the researcher has also found a significant shortage and lack of information and resources within the immediate environment and theory with regards to the emotional effect and coping strategies of skin cancer patients and/or their immediate families.

Through studying literature on the emotional experience of skin cancer, the researcher was able to detect that not a lot has been done to research this specifically. There was hardly any literature found on this, nor was the role of the social worker in this context to be found. There is a lack of research.

Valuable information and guidelines could be ascertained for the social worker working in an oncology unit or as a member of any multi-disciplinary team within a health care setting through this study.

Problem formulation leads to the research question.

1.5 Research question

Within the qualitative context of this research study, a hypothesis will not be the appropriate approach; however a research question will suit the nature of this approach, as suggested by Fouché & De Vos (2005:103). The research question for the study is: What are the psychosocial experiences of patients and their family of a skin cancer diagnosis and treatment?

1.6 Aim and objectives of the research study

1.6.1 Aim of the study

According to Fouché and De Vos (2005:104) the aim of research is the end to which the effort is directed and the objectives are the particular steps that are taken to accomplish this. It furthermore states that the aim of the study is 'the intended result of the study' (Fouché and De Vos, 2005:105).

The aim of this particular study is: To explore and describe the psychosocial experiences of the patient and family of skin cancer diagnosis and treatment.

This aim would only be achieved once the experience a patient has when going through a skin cancer diagnosis and treatment is explored.

As stated in Lauria, Clark, Hermann and Stearns (2001:199) multidisciplinary studies are so important in psychosocial oncology, and oncology social workers need to play a larger role in research activities. The aim of this research is hereby motivated and confirmed as a need.

1.6.2 Objectives of the study

According to Fouché and De Vos (2005:105), objectives refer to the steps that must be taken in order to achieve the aim. The objectives of this study are:

Objective 1 - To describe the phenomenon of skin cancer, including the various types of skin cancer, causes, symptoms, diagnosis, disease progression, treatment options, as well as the psychosocial aspects.

Objective 2 - To explore the psychosocial experience of a skin cancer diagnosis by patients and significant others.

Objective 3 - To explore the psychosocial experiences of skin cancer treatment by patients and significant others.

Objective 4 – To formulate guidelines for social workers in terms of intervention with skin cancer patients and their families.

1.7 Research methodology

The researcher followed a qualitative approach in this study. The researcher attempted to understand the subjective life experiences of the participants who suffer from skin cancer and have been diagnosed and undergone treatment, in order to add to the development of insight and a better understanding of the psychosocial experiences skin cancer patients have in the current South African context.

Applied research was applicable in this study, since it fell into this category in that it aims at describing and understanding the subjective and very personal experiences of having skin cancer and by that, improving service provision and support to patients and family. In order to explore the psychosocial experiences of skin cancer on patients, the phenomenological design was the most appropriate to use. The proposed study was consistent with the aims of a phenomenological research design in that it aimed to provide an in depth description of the psychosocial experiences of the patient and the family of skin cancer diagnosis and treatment.

For the purpose of this study, the population included all adult patients and their family who had been diagnosed with skin cancer two years prior to the study commencing and were having on-going screenings and or treatment in Cape Town, Western Cape Province at medical specialists in private practice.

The sampling method selected for this study was non-probability sampling, specifically purposive sampling. The reason for this was that not all skin cancer patients and family could be identified, nor interviewed for the purpose of this study. The participants were selected from the practices of two specialists in Cape Town, totalling 13 participants. The inclusion criteria for the sample encompassed:

- age was limited to persons above 18 years
- both males and females
- skin cancer patients, who had had their diagnosis and treatment two years prior to the commencement of the study, from two identified medical specialists' in private practice, in Cape Town

- Participants had to have been diagnosed with skin cancer and willing to participate voluntarily
- Family members of the patients (i.e spouses/life partners, children, parents)

Two specialist medical practitioners, who consented to researcher using their patients for the study, were utilised in identifying potential participants. These medical specialists approached their patients who met the criteria and informed them of the study. An information letter explaining the purpose of the research was given to them to explain the research project to the potential participants, should they be interested. Their contact details were recorded and handed to researcher. Thereafter the researcher contacted the potential participants. Appointments were made with the first 13 persons who met the sampling criteria, in order to discuss the letter of informed consent with each participant. Once they signed the letter and agreed to partake in the study, an appointment for the interview was arranged with them at a place agreed upon by the participant and the researcher, and in all cases it was the home of the participant. A total of 13 participants were included in this study, 7 were skin cancer patients and 6 were family members.

For the purposes of this study, the researcher utilised an unstructured one-to-one interview in order to gather the necessary information on the psychosocial experience of skin cancer from participants.

At the root of unstructured interviewing is an interest in understanding the experience of other people and the meaning they make of that experience. It is focused and discursive and allows the researcher and participant to explore an issue. This method of information collection was therefore suitable to the proposed study which aimed at developing an in-depth understanding of the psychosocial experiences of persons diagnosed with skin cancer and their family.

The researcher tested the tape recorder beforehand, during a pilot study with two persons who had skin cancer, to ensure it works efficiently and is placed in the best place to record effectively. The primary and secondary questions were also tested. The necessary changes were then made to the formulation of the primary and secondary question, before conducting interviews with the selected

participants. The findings gathered during the pilot study for the testing of the measuring instrument was not utilized in the research report.

The tape recorded interviews were transcribed after the interview. Transcription of interview, according to Terre Blanche and Kelly (2002:131-132) enables the researcher to access information easier than on a cassette and facilitates the moving around of information later on in the study. Non-verbal responses were noted in field notes and were also noted on the transcripts. This data was then filed electronically and in hard copy.

1.8 Limitations of the study

Despite the expectation to have sixteen participants, the researcher was only able to select and interview thirteen participants. There were a limited amount of patients and family that were willing to participate.

Two participants were interviewed as part of the pilot study and their information was excluded from the findings. Because of a small sample the participants had varying skin cancer diagnosis and treatment and the findings could therefore not be generalised or transferred.

This study was limited to the view and descriptions of the specific sample. Another limitation was cultural diversity as all the participants were white. Skin cancer is not only limited to people of a particular race and unfortunately the patients of the two practices had only representation of this race and culture.

1.9 Contents of the research report

The research report will be structured as follows:

Chapter 1: General introduction

Introduction, contextualisation of topic, rationale and problem formulation, aim, objectives, research question, research methodology overview, limitations of study and contents of research report.

Chapter 2: Literature Review – Skin cancer and the psychosocial effects on patients and family

A review of literature relating to skin cancer as chronic disease, causes, symptoms, disease progression, diagnosis and treatment and the psychosocial effects on the patient and family.

Chapter 3: Empirical Study

Research methodology and empirical results and the interpretation and discussion thereof.

Chapter 4: Summary, conclusions and recommendations

Summary, conclusions and recommendations.

Chapter 2 follows, focussing on the literature review.

The following chapter will focus on the literature study.

2. CHAPTER 2: SKIN CANCER AND THE PSYCHOSOCIAL EFFECTS ON PATIENTS AND FAMILY

2.1 Introduction

This chapter lends itself to abstracting firstly the theoretical framework of this study, followed by a literature review of the phenomenon of skin cancer. This includes the diagnosis, treatment and the psychosocial effects it has on patients and their families. Furthermore, definitions and an exploration of the different types of skin cancer, diagnosis, treatment options and prevention thereof are discussed.

2.2 Theoretical framework

The theoretical framework that forms the basis of this study will be the biopsychosocial approach.

The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery (Cohen and Brown Clark, 2010):

- Biological, psychological, and social factors exist along a continuum of natural systems.
- Systematic consideration of psychological and social factors requires application of relevant social sciences, just as consideration of biological factors requires application of relevant natural sciences. Therefore, both the natural and social sciences are 'basic' to medical practice. In other words, psychological and social factors are not merely epiphenomena: they can be understood in scientific ways at their own levels as well as in regard to their biological correlates.
- Humanistic qualities are highly valued complements to the biopsychosocial approach, which involves the application of the scientific method to diverse biological, psychological, and social phenomena as related to human health.
- While the biomedical approach takes the reductionist view that all phenomena are best understood at the lowest level of natural systems (e.g., cellular or molecular), the biopsychosocial approach recognizes that different clinical

scenarios may be most usefully understood scientifically at several levels of the natural systems continuum.

To apply the biopsychosocial approach to clinical practice, the clinician should (Cohen and Brown Clark, 2010):

- Recognize that relationships are central to providing health care.
- Use self-awareness as a diagnostic and therapeutic tool.
- Elicit the patient's history in the context of life circumstances.
- Decide which aspects of biological, psychological, and social domains are most important to understanding and promoting the patient's health.
- Provide multidimensional treatment.

As this approach encompasses biological, social and psychological factors as considerations when looking at health care intervention, this model serves to be the most suitable for this study in determining the effects skin cancer has on patients and their families, but also for looking at the role of the social worker as a support to them.

2.3 Cancer

Cancer is medically referred to as malignant neoplasm; a class of diseases in which a group of cells display the traits of uncontrolled growth (growth and division beyond the normal limits), invasion (intrusion on and destruction of adjacent tissues), and sometimes metastasis (spread to other locations in the body via lymph or blood). These three malignant properties of cancers differentiate them from benign tumours, which are self-limited, do not invade or metastasized. Most cancers form a tumour, but some, like leukaemia, do not form tumours (Wikipedia sv 'Cancer') and (Meric-Benstam & Pollock, 2010; Rees, 2004:4; Ross & Deverell, 2004:116; Ross & Deverell, 2010:134). Any number of diseases that include malignant tumours with the capability of growing and invading surrounding tissue (*Medical Dictionary for Allied Health, 2008:56*).

Cancer develops when a cell changes in quality and it is characterized by the uncontrolled division of these abnormal cells (Rees, 2004:5; *Oxford Concise Medical Dictionary, 2010:109*).

According to Meyers (2007) cancer is the abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

From the above, cancer is defined as an area where body cells grow different to that of the surrounding cells and without control, potentially becoming a form of cancer.

2.4 The Skin

The function of the skin is to protect the body from heat, injury, and infection. It also protects your body from damage caused by ultraviolet (UV) radiation (such as from the sun or sunlamps). The skin stores water and fat, and helps control body heat and makes vitamin D (U.S. Department of Health and Human Services, 2010). Figure 2.1 shows the two main layers of the skin as explained by U.S. Department of Health and Human Services, 2010.

2.4.1 Epidermis

The epidermis is the top layer of your skin. It's mostly made of flat cells called **squamous cells**. Below the squamous cells deeper in the epidermis are round cells called **basal cells**. Cells called **melanocytes** are scattered among the basal cells. They are in the deepest part of the epidermis. Melanocytes make the pigment (colour) found in skin. When skin is exposed to UV radiation, melanocytes make more pigment, causing the skin to darken, or tan.

2.4.2 Dermis

The dermis is the layer under the epidermis. The dermis contains many types of cells and structures, such as blood vessels, lymph vessels, and glands. Some of these glands make sweat, which helps cool your body. Other glands make sebum. Sebum is an oily substance that helps keep your skin from drying out. Sweat and sebum reach the surface of your skin through tiny openings called pores.

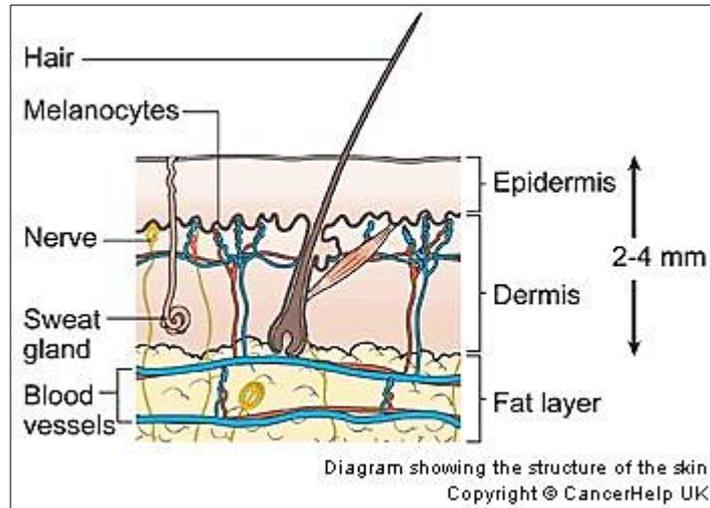


Figure 2.1: The skin and skin cells (Stages of Melanoma, 2014)

Skin cell growth begins deep below the surface of the skin, in the epidermis, where basal cells divide to produce new cells. New cells push mature cells upward to the skin's surface, where they die and flake off. In this way, the skin constantly repairs itself, as new cells grow and multiply in a controlled, orderly manner to replace dying cells. The outermost layer of the skin is made up mostly of flat, scale like cells called squamous cells. The deepest part of the epidermis also contains melanocytes, the cells that produce the pigment called melanin. Sometimes any of these cells may begin to grow in an uncontrolled manner, leading to an overgrowth of tissue, or a tumour. The tumours may be either benign or malignant (Morra and Potts, 2003:653).

2.5 Skin cancer

Skin cancer is the uncontrolled growth of skin cells. If left unchecked, these cancer cells can spread from the skin onto other tissues and organs (Skin Cancer Health Article, 2006). Skin cancer is understood as cancer cells specifically forming in the cells or tissues of the skin. It can form in the various layers of the skin and is predominant in areas where the skin was exposed to sun.

The National cancer institute (2007) refers to skin cancer as cancer that forms in tissue of the skin. There are several types of skin cancer. The skin cancer that forms in melanocytes (skin cells that make pigment) is called melanoma. Skin cancer that forms in basal cells (small round cells in the base of the outer layer of skin) is called basal cell carcinoma. Skin cancer that forms in squamous cells (flat

cells that form the surface of the skin) is called squamous cell carcinoma. Skin cancer that forms in neuroendocrine (cells that release hormones in response to signals from the nervous system) is called neuroendocrine carcinoma of the skin. Most skin cancers form in older people on parts of the body that's been exposed to the sun or in people who have weakened immune systems. Skin cancer is cancer that forms in the tissues of the skin. When cancer forms in cells that create pigment, it is called melanoma. Cancer not only form in cells that create pigment but also in basal cells (small, round cells in the base of the outer layer of skin) or squamous cells (flat cells that form the surface of the skin) (e-Cancer Awareness.com, 2007).

Melanoma, accounts for only about 4 percent of skin cancer cases but 80 percent of skin cancer deaths. Melanoma is more dangerous, but less common. The two most common types are basal cell cancer and squamous cell cancer. They usually form on the head, face, neck, arms and hands (Types of Skin Cancer 2007).

Skin cancer is the most common cancer in South Africa with about 20 000 reported cases every year and 700 deaths. The Cancer Association of South Africa (CANSA) is urging all South Africans to be SunSmart to reduce the high incidence of skin cancer in the country. The World Health Organization (2014) reports that between two and three million non-melanoma skin cancers and approximately 132 000 malignant melanomas occur globally every year. South Africa has the second highest incidence of skin cancer in the world after Australia (CANSA).

Cancer begins in cells, the building blocks that make up tissues. Tissues make up the skin and other organs of the body. Normal cells grow and divide to form new cells as the body needs them. When normal cells grow old or get damaged, they usually die, and new cells take their place. But sometimes this process goes wrong. New cells form when the body doesn't need them, and old or damaged cells don't die as they should. Malignant growths happen when cells physiology changes. Meric-Benstam & Pollock and Serfontein (2010:64) mentions that there are six changes needing to happen. Firstly, the uncontrolled growth of cancer cells happens when their growth signals become self-sufficient. Secondly, the cancer cells do not stop dividing as they become insensitive to the growth-inhibitory

signals, which usually stop division. Thirdly, the genetically regulated process of programmed cell death is by-passed or the sequenced interfered with. Fourthly, the probability for unlimited duplication of cancer cells is then established. Fifthly, the establishment of blood supply encourages growth and deprives other cells of nutrients and finally the invasion of adjacent tissues and metastasis can occur.

The build-up of extra cells often forms a mass of tissue called a growth or tumour. Growths on the skin can be benign (not cancer) or malignant (cancer). Benign growths are not as harmful as malignant growths and are rarely a threat to life and can generally be removed. They usually also do not invade the tissues around them or spread to other part of the body. Malignant growths (such as melanoma, basal cell cancer, or squamous cell cancer) may be a threat to life. It often can be removed but sometimes grow back and may invade and damage nearby organs and tissues or even spread to other parts of the body (U.S. National Health and Human Services).

Any new growth on the skin, a spot or lump that is getting larger, or a sore that does not heal in three months, might be skin cancer and should be examined by a doctor (Gillie, 2005:28).

Cancer of the skin is unique. It is the only cancer that is directly visible to the patient from its early stages and as such, serves as a constant reminder of its presence. Treatment has traditionally meant excision, and – as with any such intervention – resultant of the body’s attempts to heal itself, the patient is inevitably left with a scar. Skin cancer can develop in anyone, not only people with these risk factors. Young, healthy people - even those with dark skin, hair, and eyes - can develop skin cancer (Skin Cancer Health Article, 2006).

It is evident that skin cancer is not always clearly visible and noticeable and could occur on any type of skin or skin tone.

2.5.1 Types of skin cancer

There are three different types of skin cancer (WHO, CANSA, Morra and Potts 2003:62, and U.S. Department of Health and Human Services, 2010). The various

skin cancers are named for the type of cells that become malignant (cancer) (U.S. Department of Health and Human Services, 2010).

The three most common types are:

2.5.1.1 Melanoma

Melanoma begins in melanocytes (pigment cells). Most melanocytes are in the skin. Melanoma can occur on any skin surface. In men, it's often found on the skin on the head, on the neck, or between the shoulders and the hips. In women, it's often found on the skin on the lower legs or between the shoulders and the hips. Melanoma is rare in people with dark skin. When it does develop in people with dark skin, it's usually found under the fingernails, under the toenails, on the palms of the hands, or on the soles of the feet (U.S. Department of Health and Human Services, 2010). According to Morra and Potts (2003:662) melanoma (referred to medically as cutaneous melanoma or malignant melanoma) is the most serious type of skin cancer. It occurs most frequently in white women and men over the age of 40 who have light complexions, red or blond hair, lots of moles on their bodies, and skin that freckles and burns easily. Women most often get melanoma on the arms and legs. In men, it is most often seen on the trunk, head, or neck. There are a number of different types of melanoma – superficial spreading melanoma, nodular melanoma, acral-lentiginous melanoma, and lentigo maligna melanoma. Intraocular melanoma is a type of melanoma affecting the eye. Often the first sign is a change in the size, shape or colour of an existing mole. Or it may appear as new, abnormal lump in normal skin or as a new, ugly looking mole. Early signs in the change of a mole, such as a darkening or a change in colour, an increase in size, or an itching sensation, should be immediately checked by a doctor. Bleeding and ulceration of the mole are later signs of possible problems. Melanoma is best treated when it is found early, as it can spread to other parts of the body through the lymph system or through the blood. Interestingly, Morra and Potts (2003:663) also mention that 10% of all people who have melanoma have family members who also have had melanoma. There appears to be a predisposition to melanoma in some families.

Melanoma is generally first noticed as a dark coloured spot on the skin resembling a mole. A normal mole is an evenly coloured brown, black or tan spot on the skin which may be flat or raised up and may be round or oval. Normal moles generally stay the same size for many years. Melanoma forms a much more irregular spot. Occasionally a normal mole may develop into melanoma (Gillie, 2005:28).

When determining whether a mole is melanoma, Morra and Potts (2003:664), refers to the ABCD that physicians refer to. It is: **A**symmetry, **B**orders that are irregular, **C**olour variability and **D**iameter (greater than 6 mm). Furthermore, they state that a properly performed biopsy is critical in diagnosing melanoma. Ideally the biopsy should be performed in such a way that the complete melanoma is removed and examined for cancer.

According to Harper (2014) it must be emphasised that they are very curable if diagnosed and treated early – over 80% of people survive. They can occur on any part of the body, even in unexposed areas to sun, but more common in sun damaged skin.

- **Non-melanoma skin cancers**

Non-melanoma skin cancers are generally spotted early and are easily treated. They usually appear on parts of the body such as the head and necks, lips and the back of the hands that are most frequently exposed to the sun. They grow relatively slowly and rarely spread far (Gillie, 2005:28). Basal cell carcinoma and squamous cell carcinoma are sometimes called non-melanoma skin cancer (Types of Skin Cancer, 2008).

2.5.1.2 Basal cell carcinoma or Basal cell cancer

Basal cell skin cancer begins in the basal cell layer of the skin. It usually occurs in places that have been in the sun. For example, the face is the most common place to find basal cell skin cancer. In people with fair skin, basal cell skin cancer is the most common type of skin cancer (U.S. Department of Health and Human Services, 2010). Harper (2014) explains that Basal Cell Skin Cancer is the most common, especially on the face, growing slowly over 6 to 12 months when it is very obvious at that stage. Starts as a small round lump, which is red or pale scar like, as it grows becomes an ulcer with bleeding. Morra and Potts (2003:657)

describe basal cell cancer as the most common and least lethal form of skin cancer. Often it will appear as a small, raised bump that has a smooth, pearly appearance. Another type looks like a scar, and it is firm to the touch. Basal cell cancer is very slow growing, may spread to the tissue around the cancer, but seldom spreads to other parts of the body. If not treated properly, however, it can invade and destroy nearby bone and cartilage. Following treatment for basal cell cancer, you should have a clinical examination every six months for five years. Thereafter, yearly examinations should be done. See Figure 2.2.



Figure 2.2: Basal cell cancer on left forehead (Harper, 2014)

2.5.1.3 Squamous cell cancer

Squamous cell skin cancer begins in squamous cells. In people with dark skin, squamous cell skin cancer is the most common type of skin cancer, and it's usually found in places that are not in the sun, such as the legs or feet. However, in people with fair skin, squamous cell skin cancer usually occurs on parts of the skin that have been in the sun, such as the head, face, ears, and neck (U.S. Department of Health and Human Services, 2010).

Morra and Potts (2003:657-358) describe squamous cell cancer as the second most common type of skin cancer, after basal cell cancer. It rarely spreads, but it does so more often than basal cell cancer. Most of the epidermis is composed of squamous cells, which are flat. Squamous cell cancers are faster growing than basal cell. Overall, only about two percent of squamous cell cancers spread to other parts of the body. However, 20 percent of squamous cell cancers that develop on the lips or in burn scars or x-ray scars are known to metastasize.

Squamous cell cancer is two to three times more common in men than in women. Studies indicate that the risk of developing this type of skin cancer is related to the cumulative amount of sun exposure and the degree of skin pigmentation. Since squamous cell cancers can metastasize, if you have squamous cell cancer, you should be re-examined every three months for the first several years and then followed indefinitely at six months intervals. In appearance, squamous cell cancer looks like a raised, smooth, pearly bump on the sun-exposed skin of the head, neck or shoulders. Sometimes small blood vessels can be seen within the tumour. Crusting and bleeding in the centre of the tumour frequently develops. It is often mistaken for a sore that does not heal. In appearance, it is commonly red, scaling, thickened patch on sun-exposed skin. Ulceration and bleeding may occur. When squamous cell carcinoma is not treated, it may develop into a large mass (Skin Cancer, 2007). The more aggressive of these lesions can spread into nerves, blood vessels, lymphatic system and to other parts of the body if not treated early (Harper, 2014). See Figure 2.3.



Figure 2.3: Squamous cell cancer on back of calf (Harper, 2014)

2.6 Risk factors of Skin Cancer

The main risk factor for skin cancer is exposure to sunlight (UV radiation), but there are also other risk factors. A risk factor is something that may increase the chance of getting a disease. People with certain risk factors are more likely than others to develop skin cancer (Cancer research UK, 2014; U.S. Department of Health and Human Services, 2010; Daniel, 2005:408; Gillie, 2005:29).

Sunlight: Sunlight is a source of **UV radiation**. It's the most important risk factor for any type of skin cancer. The sun's rays cause skin damage that can lead to cancer. Ultra violet (UV) rays are part of the light spectrum that reaches the earth.

There are two kinds of UV rays that damage our skin. The broader UVB rays cause the browning reaction that we call 'tanning' and are responsible for the redness of skin, painful burning, skin damage and skin spots and ultimately skin cancer. UVA rays penetrate deeper into the skin and can damage the structure of the cells, causing ageing, as well as increasing the risk of skin cancer – it is currently accepted that UVA rays are the cause of malignant melanoma. Owing to the hole in the ozone layer (known to protect the earth from the sun), South Africa is receiving increased amounts of UVA and UVB rays from the sun (CANSAs, 2014).

Tanning: Although a tan slightly lowers the risk of sunburn, even people who tan well without sun burning have a higher risk of skin cancer because of more lifetime sun exposure. Sunlight can be reflected by sand, water, snow, ice, and pavement. The sun's rays can get through clouds, windshields, windows, and light clothing. Sun Protection Factor (SPF) refers to the extra protection offered by applying a specific sunscreen lotion to the skin. If your skin usually starts to change colour within five minutes, a sunscreen with a Sun Protection Factor (SPF) of 20 protects your skin for 20 times as long, i.e. 5 times 20, which equals 100 minutes. There is no such thing as a 'complete' sun-blocker, as all sunscreen lotions need to be reapplied at regular intervals (CANSAs, 2014).

Other risk factors include:

- **Severe, blistering sunburns:** People having had at least one severe blistering sunburn, are at increased risk of skin cancer. Although people who burn easily are more likely to have had sunburns as a child, sunburns during adulthood also increase the risk of skin cancer.
- **Lifetime sun exposure:** The total amount of sun exposure over a lifetime is a risk factor for skin cancer.
- **Sunlamps and tanning booths:** Artificial sources of UV radiation, such as sunlamps and tanning booths, can cause skin damage and skin cancer. Health care providers strongly encourage people, especially young people, to avoid them as the risk of skin cancer is greatly increased by using sunlamps and tanning booths before age 30.

- **Personal history:** People who have had melanoma have an increased risk of developing other melanomas. Also, people who have had basal cell or squamous cell skin cancer have an increased risk of developing another skin cancer of any type.
- **Family history:** Melanoma sometimes runs in families. Having two or more close relatives (mother, father, sister, brother, or child) who have had this disease is a risk factor for developing melanoma. Other types of skin cancer also sometimes run in families. Rarely, members of a family will have an inherited disorder, such as xeroderma pigmentosum or nevoid basal cell carcinoma syndrome, that makes the skin more sensitive to the sun and increases the risk of skin cancer.
- **Skin that burns easily:** Having fair (pale) skin that burns in the sun easily, blue or grey eyes, red or blond hair, or many freckles increases the risk of skin cancer.
- **Certain medical conditions or medicines:** Medical conditions or medicines (such as some antibiotics, hormones, or antidepressants) that make your skin more sensitive to the sun increase the risk of skin cancer. Also, medical conditions or medicines that suppress the immune system increase the risk of skin cancer.
- **Compromised immune function** (with co-existing leukaemia or lymphoma or when using immune suppressant drugs e.g. after transplants).
- **Radiation:** The area of previous radiation treatment will be more at risk of non-melanoma skin cancer. You should keep the area covered and use high factor sun cream. If you have been exposed to radiation through your job, you will also have a slightly increased risk of non-melanoma skin cancer.
- **Chronic leg ulcers:** Rarely, a longstanding leg ulcer may develop into a skin cancer, usually a squamous cell carcinoma.
- **Occupational exposure** to tar, asphalt, pitch, waxes, heavy oils (including shale oil) and arsenic.
- **A diet** which is low in vitamin A, beta-carotene and vitamin C and high in fat intake.

There are other types of risk factors for Melanoma, specifically (Cancer research UK, 2014; U.S. Department of Health and Human Services, 2010; Daniel, 2005:408; Gillie, 2005:29):

- **Dysplastic nevus:** A dysplastic nevus is a type of mole that looks different from a common mole. A dysplastic nevus may be bigger than a common mole, and its colour, surface, and border may be different. It's usually wider than a pea and may be longer than a peanut. A dysplastic nevus can have a mixture of several colours, from pink to dark brown. Usually, it's flat with a smooth, slightly scaly or pebbly surface, and it has an irregular edge that may fade into the surrounding skin. A dysplastic nevus is more likely than a common mole to turn into cancer. However, most do not change into melanoma. A doctor will remove a dysplastic nevus if it looks like it might have changed into melanoma.
- **More than 50 common moles:** Usually, a common mole is smaller than a pea, has an even colour (pink, tan, or brown), and is round or oval with a smooth surface. Having many common moles increases the risk of developing melanoma.

There are other specific risk factors for both basal cell and squamous cell skin cancers:

- Old scars, burns, ulcers, or areas of inflammation on the skin
- Exposure to arsenic at work
- Radiation therapy

There are further types of risk factors for squamous cell cancer (Cancer research UK, 2014; U.S. Department of Health and Human Services, 2010; Daniel, 2005:408; Gillie, 2005:29):

- **Actinic keratosis:** Actinic keratosis is a type of flat, scaly growth on the skin. It is most often found on areas exposed to the sun, especially the face and the backs of the hands. The growth may appear as a rough red or brown patch on the skin. It may also appear as cracking or peeling of the lower lip that does not heal. Without treatment, this scaly growth may turn into squamous cell skin cancer.

- **HPV** (*human papillomavirus*): Certain types of HPV can infect the skin and may increase the risk of squamous cell skin cancer. These HPVs are different from the HPV types that cause cervical cancer and other cancers in the female and male genital areas.

2.7 Symptoms of skin cancer

Most skin cancers are visible to the eye and are easier to identify early on, more so than many other kinds of cancer. Many people have a number of small, coloured spots on their bodies – moles, freckles, birthmarks, or liver spots, some are present at birth. Others develop at different times throughout life. Almost all of these spots are normal and remain that way. But when there are changes in existing moles and other skin spots or when new spots appear, it is time to take action. Cancer of the skin is the most common form of cancer – and, because it is easy to see, it can be diagnosed and treated at an early stage. Over a million cases of skin cancers are reported annually in the United States. Most of these are categorized as basal cell or squamous cell cancer or non-melanoma cancers. However, about 54 000 of the skin cancers are cutaneous melanomas – serious skin cancers that arise in moles or in the tanning cell of the skin and which, in later stages, can spread or metastasize to other parts of the body (Morra and Potts, 2003:651).

2.7.1 Symptoms of melanoma

Often the first sign of melanoma is a change in the shape, colour, size, or feel of an existing mole. Melanoma may also appear as a new mole. Thinking of “ABCDE” can help you remember what to look for (U.S. Department of Health and Human Services, 2010; Harper, 2014):

- **Asymmetry**: The shape of one half does not match the other half.
- **Border that is irregular**: The edges are often ragged, notched, or blurred in outline. The pigment may spread into the surrounding skin.
- **Colour that is uneven**: Shades of black, brown, and tan may be present. Areas of white, grey, red, pink, or blue may also be seen.

- **Diameter:** There is a change in size, usually an increase. Melanomas can be tiny, but most are larger than the size of a pea (larger than 6 millimetres or about 1/4 inch).
- **Evolving:** The mole has changed over the past few weeks or months. Melanomas can vary greatly in how they look. Many show all of the ABCDE features. However, some may show changes or abnormal areas in only one or two of the ABCDE features. In more advanced melanoma, the texture of the mole may change. The skin on the surface may break down and look scraped. It may become hard or lumpy. The surface may ooze or bleed. Sometimes the melanoma is itchy, tender, or painful. See Figure 2.4 and 2.5.

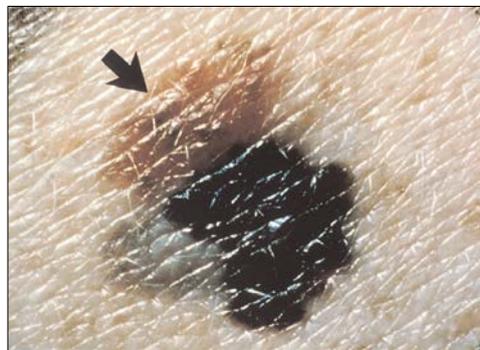


Figure 2.4: An asymmetric melanoma with irregular and scalloped borders (U.S. Department of Health and Human Services, 2010)

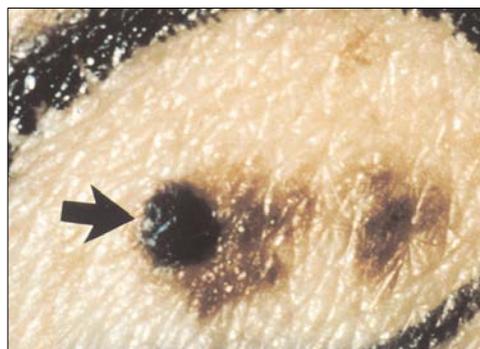


Figure 2.5: A dysplastic nevus with a new black bump that was not there 18 months earlier (U.S. Department of Health and Human Services, 2010)

One half of all melanomas arise in normal skin. A new pigmented lesion growing over 2 to 6 months to over 6 mm in size as flat or a raised lump, you should make your doctor aware (Harper, 2014).

2.7.2 Symptoms of basal cell and squamous cell skin cancers

A change on the skin is the most common sign of skin cancer. This may be a new growth, a sore that doesn't heal, or a change in an old growth. Not all skin cancers look the same. Usually, skin cancer is not painful. Common symptoms of basal cell or squamous cell skin cancer include (U.S. Department of Health and Human Services, 2010):

- A flat red spot that is rough, dry, or scaly and may become itchy or tender
- A red or brown patch that is rough and scaly
- A sore or lump that bleeds or develops a crust or a scab

From the above, it is clear that not all skin cancers look or feel or are alike and is therefore not easily identifiable.

2.8 Diagnosis of skin cancer

Diagnosis means the process of understanding a phenomenon in what it is, what caused it and how to cure or prevent it. Diagnosis is used in many different disciplines, to determine the cause and effect relationships.

According to Morra and Potts (2003:657) and the U.S. Department of Health and Human Services (2010), you cannot tell whether or not a growth is cancerous. Any skin change should be brought to the attention of a doctor, as only a trained physician can determine the nature of an abnormal skin growth, whether it is benign, precancerous or malignant. The opinion of a qualified dermatologist who has had experience dealing with skin cancers should be sought, or of certain plastic surgeons, general surgeons, oncologists, internists and family doctors who have a special interest and training in dealing with skin cancers.

When it is expected that a spot on the skin is cancer, a biopsy is usually done. The doctor may remove all or part of the skin that does not look normal. A biopsy could be either done in a doctor's office or as an outpatient in a clinic or hospital, usually under local anaesthesia. The sample goes to a laboratory for histological testing, the study of the microscopic structure and function of bodily tissues, where a pathologist examines the sample under a microscope, in this case a piece of the

skin, and usually an outcome is available in a day or two (Medical Dictionary for Allied Health, 2008:162).

There are four common types of skin biopsies (U.S. Department of Health and Human Services, 2010; Skin sight, 2014 and Harper, 2014):

- **Shave biopsy:** The doctor uses a thin, sharp blade to shave off the abnormal growth. See Figure 2.6.
- **Punch biopsy:** The doctor uses a sharp, hollow tool to remove a circle of tissue from the abnormal area.
- **Incisional biopsy:** The doctor uses a scalpel to remove part of the growth.
- **Excisional biopsy:** The doctor uses a scalpel to remove the entire growth and some tissue around it. This type of biopsy is most commonly used for growths that appear to be melanoma. See Figure 2.6.



Figure 2.6: Query a basal cell cancer on nose. Shave biopsy in rooms to obtain diagnosis (Harper, 2014)

If the biopsy shows that you have skin cancer, your doctor needs to learn the stage (extent) of the disease to help you choose the best treatment. The stage is based on (U.S. Department of Health and Human Services, 2010):

- The size (width) of the growth.
- How deeply it has grown beneath the top layer of skin.
- Whether cancer cells have spread to nearby lymph nodes or to other parts of the body.

When skin cancer spreads from its original place to another part of the body, the new tumour has the same kind of abnormal cells and the same name as the primary (original) tumour. For example, if skin cancer spreads to the lung, the cancer cells in the lung are actually skin cancer cells. The disease is metastatic

skin cancer, not lung cancer. For that reason, it's treated as skin cancer, not as lung cancer. Doctors sometimes call the new tumour "distant" disease. Blood tests and an imaging test such as a chest x-ray, a CT scan, an MRI, or a PET scan may be used to check for the spread of skin cancer. For example, if a melanoma growth is thick; the doctor may order blood tests and an imaging test. For squamous cell skin cancer or melanoma, the doctor will also check the lymph nodes near the cancer on the skin. If one or more lymph nodes near the skin cancer are enlarged (or if the lymph node looks enlarged on an imaging test), the doctor may use a thin needle to remove a sample of cells from the lymph node (fine-needle aspiration biopsy).

A lymph node is one of the small, roundish bodies of lymphatic tissue that lie along the lymphatic vessels and are the primary producers of lymphocytes' (*Oxford Concise Medical Dictionary, 2010:429*). The lymph is the fluid present within the vessels of the lymphatic system, which bathes the tissues and is derived from the blood and is drained by the lymphatic vessels. Lymph passes through a series of filters and is ultimately returned to the bloodstream via the thoracic duct. It is similar in composition to plasma but contains less protein and some cells mainly lymphocytes (*Oxford Concise Medical Dictionary, 2010:429*).

A pathologist will check the sample of cells from the lymph node for cancer cells. Even if the nearby lymph nodes are not enlarged, the nodes may contain cancer cells. The stage is sometimes not known until after surgery to remove the growth and one or more nearby lymph nodes. For thick melanoma, surgeons may use a method called sentinel lymph node biopsy to remove the lymph node most likely to have cancer cells. Cancer cells may appear first in the sentinel node before spreading to other lymph nodes and other places in the body (U.S. Department of Health and Human Services, 2010).

Knowing exactly what is going on with your situation is critical, especially because the timing of a skin cancer diagnosis makes all the difference in your prognosis. It is important to know what stage the cancer is in. The first stage is highly treatable; the later the stage, the poorer the prognosis (Rodriguez, 2014). Figure 2.7 shows the stages clearly in an article on stages of melanoma (Stages of Melanoma, 2014):

2.9 Stages of skin cancer

2.9.1 Stages of Melanoma NIC

These are the stages of melanoma (Stages of Melanoma, 2014):

- **Stage 0:** The melanoma involves only the top layer of skin. It is called melanoma in situ.
- **Stage I:** The tumour is no more than 1 millimetre thick (about the width of the tip of a sharpened pencil. The surface may appear broken down. Or, the tumour is between 1 and 2 millimetres thick, and the surface is not broken down.
- **Stage II:** The tumour is between 1 and 2 millimetres thick, and the surface appears broken down. Or, the thickness of the tumour is more than 2 millimetres, and the surface may appear broken down.
- **Stage III:** The melanoma cells have spread to at least one nearby lymph node. Or, the melanoma cells have spread from the original tumour to tissues nearby.
- **Stage IV:** Cancer cells have spread to the lung or other organs, skin areas, or lymph nodes far away from the original growth. Melanoma commonly spreads to other parts of the skin, tissue under the skin, lymph nodes, and lungs. It can also spread to the liver, brain, bones, and other organs.

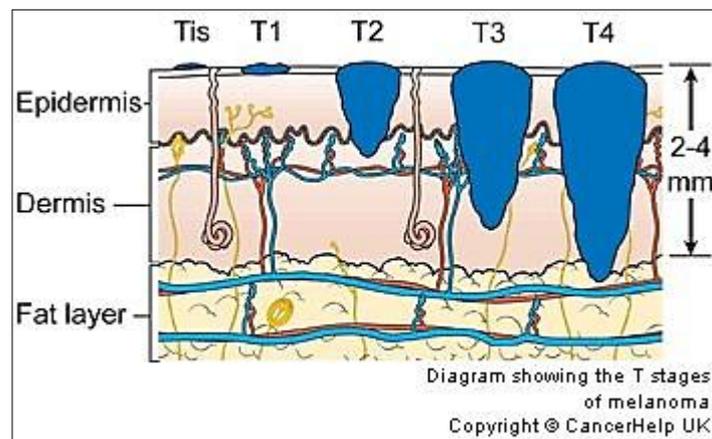


Figure 2.7: The stages of melanoma (Stages of Melanoma, 2014)

2.9.2 Stages of other skin cancer

These are the stages of basal cell and squamous cell skin cancers (Stages of Melanoma, 2014):

- **Stage 0:** The cancer involves only the top layer of skin. It is called carcinoma in situ. Bowen disease is an early form of squamous cell skin cancer. It usually looks like a reddish, scaly or thickened patch on the skin. If not treated, the cancer may grow deeper into the skin.
- **Stage I:** The growth is as large as 2 centimetres wide (more than three-quarters of an inch or about the size of a peanut).
- **Stage II:** The growth is larger than 2 centimetres wide.
- **Stage III:** The cancer has invaded below the skin to cartilage, muscle, or bone. Or, cancer cells have spread to nearby lymph nodes. Cancer cells have not spread to other places in the body.
- **Stage IV:** The cancer has spread to other places in the body. Basal cell cancer rarely spreads to other parts of the body, but squamous cell cancer sometimes spreads to lymph nodes and other organs.

2.10 Treatment of skin cancer

Treatment is most often referred to as a process of modifying or altering something and depending on context may be used in an unqualified form to refer to any of the following: A type of therapy used to remedy a health problem. Experimental treatment, the levels of treatment factor(s) (variables controlled by the experimenter) applied, according to Wikipedia sv 'treatment'. Care provided to improve a situation (especially medical procedures or applications that are intended to relieve illness or injury) (WordNet Search-3.1).

It is also defined as a: 'Process of providing medical, surgical, alternative or psychological care for a disease or disorder or the care itself' (Medical Dictionary for Allied Health, 2008:363).

Skin cancer treatment therefor is the chosen intervention to remove or attempt to remove such a cancer.

Treatment for skin cancer depends on the type and stage of the disease, the size and place of the tumour, and the patient's general health and medical history. In most cases, the aim of treatment is to remove or destroy the cancer completely. Most skin cancers can be cured if found and treated early. Sometimes all of the skin cancer is removed during the biopsy. In such cases, no more treatment is

needed. If you do need more treatment, your doctor can describe your treatment choices and what to expect. You and your doctor can work together to develop a treatment plan that meets your needs. Surgery is the usual treatment for people with skin cancer. In some cases, the doctor may suggest chemotherapy, photodynamic therapy, or radiation therapy. Patients with melanoma may also have biological therapy. The patient may have a team of specialists to help plan your treatment. The doctor may refer the patient to a specialist, or the patient may ask for a referral. Specialists who treat skin cancer include dermatologists and surgeons. Some people may also need a reconstructive or plastic surgeon. People with advanced skin cancer may be referred to a medical oncologist or radiation oncologist. The treatment for melanoma depends upon the location, extent and stage of the disease. The depth to which the skin has been invaded determines the extent of the treatment. Some melanomas that have spread to nearby lymph nodes may be curable with wide surgery of the tumour and removal of the affected lymph nodes. Melanoma that has spread to other areas, such as the liver, lungs, bone, brain and internal organs is more difficult to cure, although surgical removal of the metastasized cancer is sometimes successful (Department of Health and Human Services, 2010; Morra and Potts, 2003:665; National Cancer Institute, 2010).

2.10.1 Surgery

In general, the surgeon will remove the cancerous growth and some normal tissue around it. This reduces the chance that cancer cells will be left in the area. There are several methods of surgery for skin cancer. The method your doctor uses depends mainly on the type of skin cancer, the size of the cancer, and where it was found on your body (Morra & Potts, 2003:665; U.S. Department of Health and Human Services, 2010; Harper, 2014, National Cancer Institute, 2010, Cancer coping kit, 2007).

- **Excisional skin surgery:** This is a common treatment to remove any type of skin cancer. After numbing the area of skin, the surgeon removes the growth (tumour) with a scalpel. The surgeon also removes a border (a margin) of normal skin around the growth. The margin of skin is examined under a

microscope to be certain that all the cancer cells have been removed. The thickness of the margin depends on the size of the tumour.

- **Mohs surgery** (also called Mohs micrographic surgery): This method is often used for basal cell and squamous cell skin cancers. After numbing the area of skin, a specially trained surgeon shaves away thin layers of the tumour. Each layer is examined under a microscope. The surgeon continues to shave away tissue until no cancer cells can be seen under the microscope. In this way, the surgeon can remove all the cancer and only a small bit of healthy tissue. Some people will have radiation therapy after Mohs surgery to make sure all of the cancer cells are destroyed.
- **Electrodessication and curettage**: This method is often used to remove a small basal cell or squamous cell skin cancer. After the doctor numbs the area to be treated, the cancer is removed with a sharp tool shaped like a spoon (called a *curette*). The doctor then uses a needle-shaped electrode to send an electric current into the treated area to control bleeding and kill any cancer cells that may be left. This method is usually fast and simple. It may be performed up to three times to remove all of the cancer.
- **Cryosurgery**: This method is an option for an early stage or a very thin basal cell or squamous cell skin cancer. Cryosurgery is often used for people who are not able to have other types of surgery. The doctor applies liquid nitrogen (which is extremely cold) directly to the skin growth to freeze and kill the cancer cells. This treatment may cause swelling. It also may damage nerves, which can cause a loss of feeling in the damaged area.
- **Simple elliptical skin cancer excision**: The cancer is excised with healthy surrounding skin as an ellipse running along a wrinkle line, and is 2 to 3 times longer than the lesion in order to avoid bunching of the skin at the ends (dog ears) to obtain a flap incisional line. This is a minor operation, under local anaesthetic, with sedation if needed, can be provided performed in a day surgery clinic. See Figures 2.8-2.11.

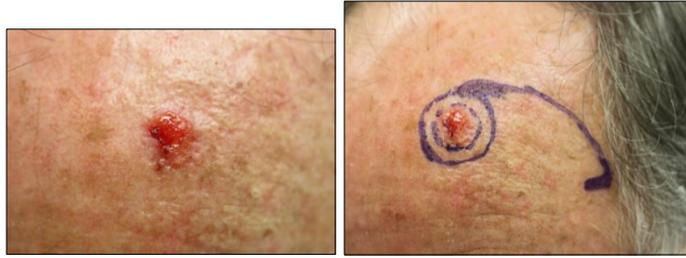


Figure 2.8: Basal cell cancer on left forehead showing excision with a flap repair of the defect after excision (Harper, 2014)



Figure 2.9: Squamous cell cancer on back of calf showing excision with flap repair of the defect after excision (Harper, 2014)

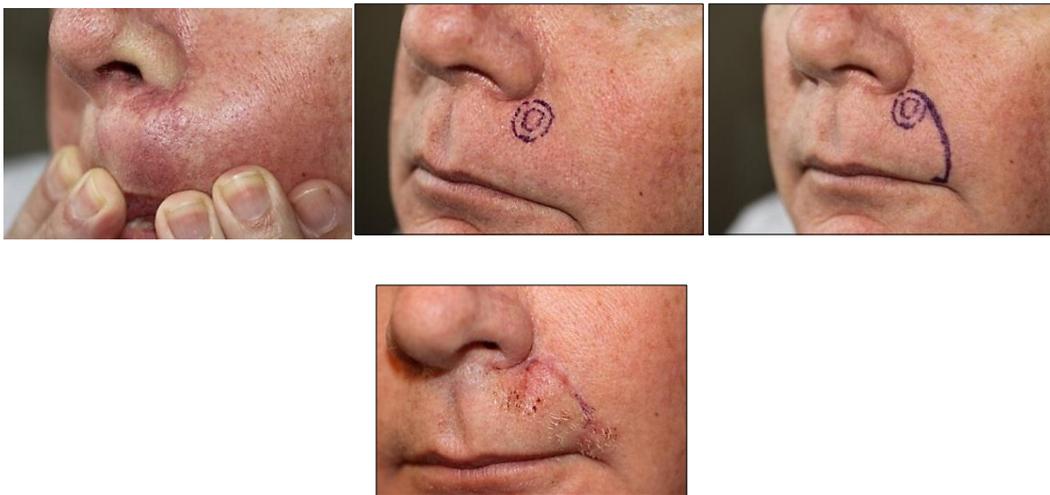


Figure 2.10: Basal cell cancer upper lip with flap to repair the defect (Harper, 2014)



Figure 2.11: Melanoma upper right cheek and a basal cell cancer lower, simple elliptical excision performed (Harper, 2014)

When cancer has spread to the lymph nodes, some or all of the nearby lymph nodes may be removed. Additional treatment may be needed after surgery. If a large area of tissue is removed, the surgeon may do a skin graft, especially if the edges of the skin cannot be pulled together. The doctor uses skin from another part of the body to replace the skin that was removed. After numbing the area, the surgeon removes a patch of healthy skin from another part of the body, such as the upper thigh. The patch is then used to cover the area where skin cancer was removed (see Figure 2.12 and 2.13).



Figure 2.12: Basal cell cancer on helical margin of ear showing excision, with full thickness skin graft repair taken from sulcus of the ear (Harper, 2014)



Figure 2.13: Full thickness skin grafts to nasal tip after excision of skin cancers. Settle well over twelve months (Harper, 2014)

A pressure dressing is placed over the graft and inspected in 7 days. The donor site heals by 14 day, which leaves a white scarred area as shown in Figure 14. (U.S. National Department of Health and Human Services, 2010 and Harper, 2014).



Figure 2.14: Skin split shin graft on lower leg, (and a further Basal Cell Carcinoma developing below it) (Harper, 2014)

There is usually only a little pain and a burning sensation in the area from which the skin was removed and little or no pain at the site where applied. The match of normal and grafted skin depends upon where the graft comes from. The doctor will try to match it as closely as possible – in colour and texture. In a few months, the graft develops sensation. It is wise to protect the skin from the sun as the new skin can become sunburned, but will probably not darken as much as surrounding skin. The new skin will grow hair only if it came from a location where hair was originally growing (Cukier, Gingerelli, Makari-Judson and McCullough, 2005:40).

Thorough healing can take time. The wound graft/or flap may look unsightly at first, but its appearance improves significantly over the next six to nine months. Complications can occur and a patient should be aware of possible complications, so they area is attended to urgently (Harper, 2014). These complications are:

- Infection in the wound and graft.

- Bleeding in the wound/graft.
- Incomplete excision of the cancer and further excision and/or radiotherapy may be required.
- Wound breakdown, or re-opening of wound.
- Loss of skin graft or flap due to variety of factors bleeding/infection. Further surgery may be necessary.

Scarring will occur, but depends on a variety of factors. The majority of results grafts, flaps and incision lines are quite inconspicuous, flat, and soft with patients very happy as they are not too drastic. Some people develop thick scars, wide scars, depressed scars and revision may be necessary for improvement (Harper, 2014).

The emotional and surgical scars of skin cancer can be profound. It is clear that the vast majority of patients receive minor scarring and little long lasting distress resulting from the treatment of their skin cancer, and of those who suffer disfiguring scarring, the majority adapt functionally and emotionally. However, for a small proportion, the effects of scarring can be devastating. Dealing with the cancer, the scar and the emotional burden of an individual requires a health provision team educated in the public's fear of cancer, the difficulties that scar formation can bring, and on a societal front public education and attitude change towards disfigurement and all its causes. Fortunately, the combination of advances in surgical techniques and in the understanding of the biology of scar formation are beginning to combine to reduce the effects of scarring, with recent development, it is possible that scar formation could be removed as a reminder of evolution's remarkable healing process (Todkill, 2006:16).

2.10.2 Chemotherapy

Chemotherapy, in its most general sense, according to Wikipedia sv 'chemotherapy', refers to treatment of disease by chemicals that kill cells, specifically those of microorganisms or cancer. The Cancer Treatment Centres of America (2008) refer to chemotherapy as the treatment of cancer with drugs that can destroy cancer cells by impeding their growth and reproduction. These drugs often are called 'anticancer' drugs. Chemotherapy drugs are given intravenously,

by injection or by mouth. Chemotherapy is often used alone, or in conjunction with radiation therapy or surgery. Chemotherapy for the purposes of this study is understood to be a form of treatment for cancer where drugs or medicine is used to eliminate cancer cell development.

Malignant melanoma is the single most common tumour reported to spontaneously regress, although this occurs in less than one percent of cases. Chemotherapy using isolated arterial perfusion may be used, especially if the cancer occurs on an arm or leg. In this method, in order to allow the drug to reach the tumour directly, chemotherapy drugs are put into the bloodstream of the arms or leg where the melanoma is found. Chemotherapy may also be prescribed after surgery to kill any undetectable cancer cells that might still remain in the body (Morra and Potts, 2003:666).

Chemotherapy uses drugs to kill cancer cells. Drugs for skin cancer can be given in many ways (National Cancer Institute, 2010):

- **Put directly on the skin:** A cream or lotion form of chemotherapy may be used to treat very thin, early-stage basal cell or squamous cell skin cancer. It may also be used if there are several small skin cancers. The doctor will show you how to apply the cream or lotion to the skin one or two times a day for several weeks. The cream or lotion contains a drug that kills cancer cells only in the top layer of the skin:
- **Fluorouracil** (another name is 5-FU): This drug is used to treat early stage basal cell and squamous cell cancers.
- **Imiquimod:** This drug is used to treat early-stage basal cell cancer. These drugs may cause your skin to turn red or swell. The skin may itch, ooze, or develop a rash. Your skin may be sore or sensitive to the sun after treatment. These skin changes usually go away after treatment is over. A cream or lotion form of chemotherapy usually does not leave a scar. If healthy skin becomes too red or raw when the skin cancer is treated, your doctor may stop treatment.
- **Swallowed or injected:** People with melanoma may receive chemotherapy orally or through a vein (intravenous). You may receive one or more drugs. The drugs enter the bloodstream and travel throughout the body.

If you have melanoma on an arm or leg, you may receive drugs directly into the bloodstream of that limb. The flow of blood to and from the limb is stopped for a while. This allows a high dose of drugs in the area with the melanoma. Most of the chemotherapy remains in that limb. The patient may receive chemotherapy in an outpatient part of the hospital, at the doctor's office, or at home. Some people need to stay in the hospital during treatment. The side effects depend mainly on which drugs are given and how much (National Cancer Institute, 2010).

Chemotherapy kills fast-growing cancer cells, but the drugs can also harm normal cells that divide rapidly (National Cancer Institute, 2010):

- **Blood cells:** When drugs lower the levels of healthy blood cells, you're more likely to get infections, bruise or bleed easily, and feel very weak and tired. Your health care team will check for low levels of blood cells. If the levels are low, the health care team may stop the chemotherapy for a while or reduce the dose of the drug. There are also medicines that can help your body make new blood cells.
- **Cells in hair roots:** Chemotherapy may cause hair loss. If you lose your hair, it will grow back after treatment, but the colour and texture may be changed.
- **Cells that line the digestive tract:** Chemotherapy can cause a poor appetite, nausea and vomiting, diarrhoea, or mouth and lip sores. Your health care team can give you medicines and suggest other ways to help with these problems. They usually go away when treatment ends.

Chemotherapy is therefore a combination or variety of different interventions as they are all given and work in a distinct way and are not only limited to one type or application.

2.10.3 Photodynamic therapy

Photodynamic therapy (PDT) uses a drug along with a special light source, such as a laser light, to kill cancer cells. PDT may be used to treat very thin, early stage basal cell or squamous cell skin cancer (Bowen disease). The drug is either rubbed into the skin or injected intravenously. The drug is absorbed by cancer cells. It stays in cancer cells longer than in normal cells. Several hours or days later, a special light is focused on the cancer. The drug becomes active and

destroys the cancer cells. The side effects of PDT are usually not serious. PDT may cause burning or stinging pain. It also may cause burns, swelling, or redness. It may scar healthy tissue near the growth. If you have PDT, you will need to avoid direct sunlight and bright indoor light for at least six weeks after treatment (National Cancer Institute, 2010).

2.10.4 Biological therapy

Some people with advanced melanoma receive treatment called biological therapy. Biological therapy for melanoma is treatment that may improve the body's natural defence (immune system response) against cancer. One treatment for melanoma is *interferon*. It's injected intravenously (usually at a hospital or clinic) or injected under the skin (at home or in a doctor's office). Interferon can slow the growth of melanoma cells. Another treatment used for melanoma is *interleukin-2*. It's given intravenously. It can help the body destroy cancer cells. Interleukin-2 is usually given at the hospital. Other treatments may be given at the same time to prevent side effects. The side effects differ with the treatment used, and from person to person. Biological therapies commonly cause a rash or swelling. The patient may feel very tired during treatment. These treatments may also cause a headache, muscle aches, a fever, or weakness (National Cancer Institute, 2010).

2.10.5 Radiation therapy

Radiation therapy uses high-energy rays to kill cancer cells. The radiation comes from a large machine outside the body. It affects cells only in the treated area. Patients will go to a hospital or clinic several times for this treatment. Radiation therapy is not a common treatment for skin cancer. But it may be used for skin cancer in areas where surgery could be difficult or leave a bad scar. For example, radiation therapy will be used if you have a growth on your eyelid, ear, or nose. Radiation therapy may also be used after surgery for squamous cell carcinoma that can't be completely removed or that has spread to the lymph nodes. And it may be used for melanoma that has spread to the lymph nodes, brain, bones, or other parts of the body. Although radiation therapy is painless, it may cause other side effects. The side effects depend mainly on the dose of radiation and the part of your body that is treated. It's common for the skin in the treated area to become

red, dry, tender, and itchy. (Morra and Potts, 2003:666-667, National Cancer Institute, 2010).

Radiotherapy is defined by the treatment of disease with penetrating radiation, such as X-rays, beta rays, or gamma rays, which may be produced by machines or given off by radioactive isotopes. Beams of radiation may be directed at a diseased part from a distance (see tele therapy), or radioactive material, in the form of needles, wires, or pellets, may be implanted in the body (see brachytherapy). Many forms of cancer are destroyed by radiotherapy (Oxford reference.com, 2014).

Radiotherapy is the medical use of ionizing radiation as part of cancer treatment to control malignant cells (not to be confused with radiology, the use of radiation in medical imaging and diagnosis). Radiotherapy may be used for curative or adjuvant cancer treatment. It is used as palliative treatment (where cure is not possible and the aim is for local disease control or symptomatic relief) or as therapeutic treatment (where the therapy has survival benefit and it can be curative). Total body irradiation (TBI) is a radiotherapy technique used to prepare the body to receive a bone marrow transplant. Radiotherapy has a few applications in non-malignant conditions, such as the treatment of trigeminal neuralgia, severe thyroid eye disease, pterygium, prevention of keloid scar growth, and prevention of heterotopic ossification. The use of radiotherapy in non-malignant conditions is limited partly by worries about the risk of radiation-induced cancers (Wikipedia sv 'radiotherapy').

Radiotherapy, according to Cancerbackup.org (2008), radiotherapy is the use of high energy x-rays and similar rays (such as electrons) to treat disease.

From the above, radiotherapy is understood as a type of treatment for cancer where radiation is used to destroy cancerous cells.

2.10.6 Follow-up Care

After treatment for skin cancer, you'll need regular check-ups (such as every 3 to 6 months for the first year or two). The doctor will monitor your recovery and check for any new skin cancers. Regular check-ups help ensure that any changes in a patient's health is noted and treated if needed. During a check-up, a physical examination is done. People with melanoma may have x-rays, blood tests, and

scans of the chest, liver, bones, and brain. People who have had melanoma have an increased risk of developing a new melanoma, and people with basal or squamous cell skin cancers have a risk of developing another skin cancer of any type. It is advised to get in a routine for checking skin for new growths or other changes. Although changes are not a sure sign of skin cancer they should be examined by a doctor immediately.

2.11 Prevention of skin cancer

According to Harper (2014) and Morra and Potts (2005), early diagnosis is lifesaving and some methods of prevention are mentioned:

2.11.1 Avoiding over exposure to the sun

People with skin cancer are at risk of developing another skin cancer. Limit your time in the sun and stay away from sunlamps and tanning booths. Keep in mind that getting a tan may increase your risk of developing another skin cancer. The best way to prevent skin cancer is to protect you from the sun (CANSAs, 2014; Types of skin cancer, 2008 and Skin Cancer Foundation, 2014):

- Avoiding outdoor activities during the middle of the day. The sun's rays are the strongest between 10 a.m. and 4 p.m. When being outdoors is unavoidable, seek shade wherever possible.
- Protect the skin from the sun's rays reflected by sand, water, snow, ice, and pavement. The sun's rays can go through light clothing, windshields, windows, and clouds.
- Wear long sleeves and long pants. Tightly woven fabrics are best.
- Wear a hat with a wide brim all around that shades the face, neck, and ears. Keep in mind that baseball caps and some sun visors protect only parts of the skin.
- Wear sunglasses that absorb UV radiation to protect the skin around the eyes.
- Use sunscreen lotions with a sun protection factor (SPF) of at least 15 (Some doctors will suggest using a lotion with an SPF of at least 30.) Apply the product's recommended amount to uncovered skin 30 minutes before going outside, and apply again every two hours or after swimming or sweating. Sunscreen lotions may help prevent some skin cancers. It's important to use a

broad-spectrum sunscreen lotion that filters both UVB and UVA radiation. But one still needs to avoid the sun during the middle of the day and wear clothing to protect the skin.

While care must be taken to avoid sunburn, it is important not to avoid sunlight completely. Exposure of the skin to sunlight for about ten minutes per day is desirable to ensure a good supply of vitamin D, which is now believed to protect against certain cancers including melanoma (Gillie, 2005:29).

CANSA in South Africa especially and various other countries like the USA and Australia are advocating sun safety in an attempt to reduce skin cancer rates. Figure 2.15 is an example of one such campaign in America.



Figure 2.15: The U.S. Department of Health and Human Services' (2010) campaign to promote sun safety

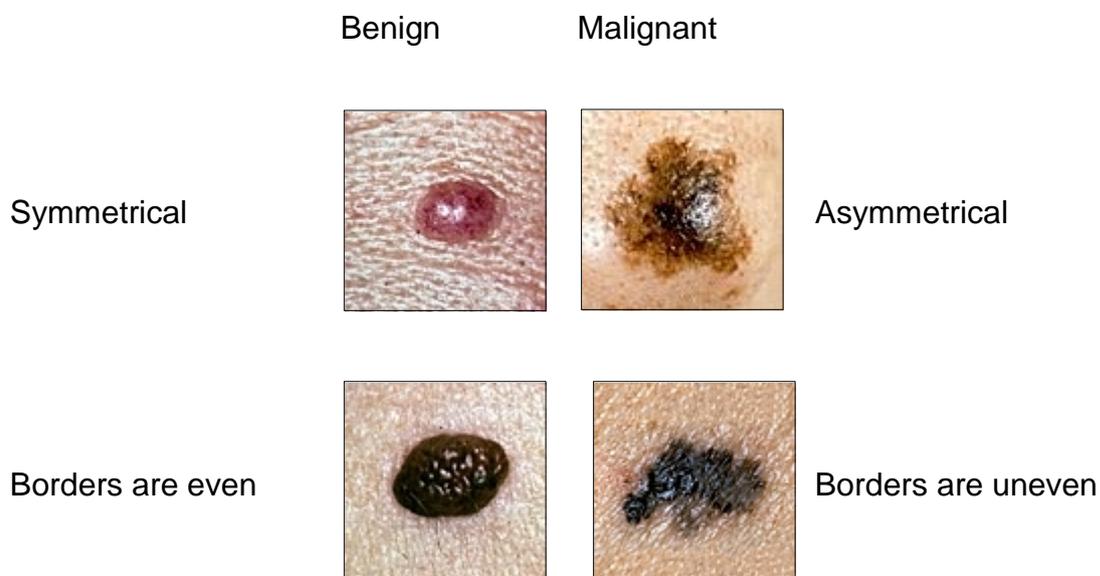
2.11.2 Examine your skin frequently

Practice frequent examinations, either self or a friend, 3 to 4 times a year. Let your doctor know of a change (Harper, 2014). The best time to do this exam is after a shower or bath. Check your skin in a room with plenty of light. Use a full-length mirror and a hand-held mirror. It's best to begin by learning where your birthmarks, moles, and other marks are and their usual look and feel. Any changes must be looked for and a guide is given by the National Cancer Institute, (2010) as to how to look for changes:

- A new mole (that looks different from other moles)
- A new red or darker colour flaky patch that may be a little raised
- A new flesh-coloured firm bump
- A change in the size, shape, colour, or feel of a mole
- A sore that fails to heal
- Scrutinize the body from head to toe:

- Look at the face, neck, ears, and scalp. A comb or a blow dryer could be used to move your hair to see well. A relative or friend could assist as it may be hard to check the scalp alone
- Look at the front and back of the body in the mirror. Raise the arms and look at the left and right sides.
- Bend the elbows. Look carefully at the fingernails, palms, forearms (including the undersides), and upper arms.
- Examine the back, front, and sides of the legs. Also look around the genital area and between the buttocks.
- Sit and closely examine the feet, including the toenails, soles, and between the toes.

By checking the skin regularly, what is normal can be established. It may be helpful to record the dates of skin exams and to write notes about the way the skin looks. If a doctor has taken photos of your skin, you can compare your skin to the photos to assist in identifying changes. If anything unusual is identified, a doctor should be consulted (National Cancer Institute, 2014). Figure 2.16 is a helpful tool provided by the Skin Cancer Foundation (2008).



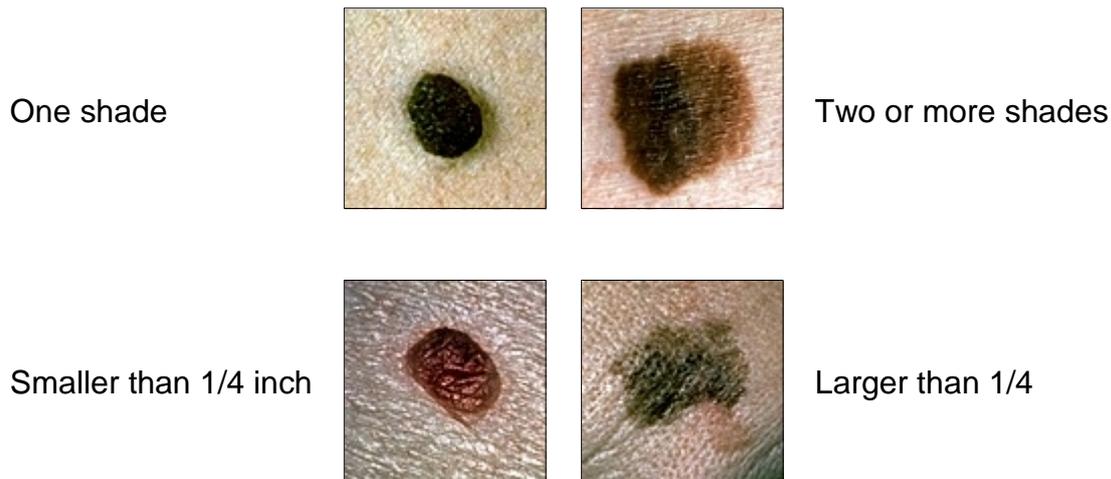


Figure 2.16: A chart to assist in identifying potential skin cancers when self-examining (Skin Cancer Foundation, 2008)

2.12 Psychosocial effects of skin cancer on the patient and family

Psycho social pertains to both psychological and social aspects of behaviour (Medical Dictionary for Allied Health, 2008:298).

Psychosocial effect refers to Psychology and Sociology of or relating to processes or factors that are both social and psychological in origin (thefreedictionary.com). This term is used to describe the relationship between the personal, internal environment, and the wider social world (i.e. the influence of social factors on an individual's mind or behaviour) ((Benzeval M., Green M., Ferrell C, et al. , 2007).

Within skin cancer, the psychosocial effect refers to how people would think or change their thinking around skin cancer and risk factors or their behaviour as contributing or preventative factors.

During the diagnosis phase, as a new patient, the patient and family may be in a state of upheaval. The uncertainty that accompanies the news of a diagnosis can have a ripple effect on the patient's own and family life, employment and financial situation (Szynkarsky, 2011).

Skin cancer can change the life of a patient and the lives of those close to them. These changes can be hard to handle. It's normal for a person and their family and friend to need support in coping with the feelings that such a diagnosis can bring. Concerns about treatments and managing side effects, hospital stays, and

medical bills are common. Concerns about caring for your family, keeping your job, or continuing daily activities could also be experiences. Doctors, nurses, and other members of the health care team can answer questions about treatment, working, or other activities. Social workers, counsellors, or members of the clergy can be helpful if these feelings or concerns need to be expressed. Often, social workers can suggest resources for financial aid, transportation, home care, or emotional support. Support groups also can help. In these groups, people with skin cancer or their family members meet with other patients or their families to share what they have learned about coping with the disease and the effects of treatment (National Cancer Institute, 2010).

When a person is diagnosed as having cancer he or she will often experience anxiety which can be very severe. Anxiety may make the pain experienced by cancer sufferers feel worse. Anxiety can also be a major factor in nausea and vomiting. Nevertheless anxiety is a normal response to stressful events and is part of the process of coming to terms with an illness. Fear of the unknown is often a significant cause of anxiety. Patients may feel less anxious when they are given more information about their illness and their treatment, or when they find out more from booklets available from cancer charities and patient groups or from websites. Patients also usually begin to feel less anxious as they become more accustomed to seeing the doctor and going to hospitals. As they get to know hospital staff they gradually feel more at ease and less threatened by fears of the unknown (Gillie, 2005:42).

The effects of treatment such as nausea and exhaustion may make a person anxious about a further course of treatment. In these circumstances discussion with medical staff will be of great help. Medical and nursing staff may suggest modifying the treatment schedule in some way. This gives the patient an important feeling of control, which in turn may reduce anxiety (Gillie, 2005:42).

Relaxation is also important. The best way to relax varies greatly from one person to another. For one person, listening to music or playing a board or card games with friends may be a good way. For others talking with friends and family about ordinary things may be the best. Special tapes designed to encourage relaxation

can be very effective. Massage and aromatherapy are good ways for other people (Gillie, 2005:43).

Severe anxiety can be brought on by a diagnosis of cancer, or by other life events. Signs of severe anxiety include (Gillie, 2005:43; Sadock & Sadock, 2003:592):

- Intense fears
- Inability to absorb information
- Inability to cooperate with medical staff
- shortness of breath
- sweating
- trembling
- light-headedness or dizziness
- sensation of rapid heartbeat (palpitations)
- restlessness
- diarrhoea
- urinary frequency

It is not easy to tell people bad news. A person with cancer may not feel able to talk about their illness right away. It may take time for a person with cancer to absorb information about their illness and find the right words to be able to tell others. Sometimes patients want their distress to be kept private – especially at the beginning. But it may come as a relief when friends and family do know. The person with cancer can then enjoy receiving greetings and visits from friends which provide what is often a vital lifeline (Gillie, 2005:46).

Friends and family are an important link with the normal world outside hospital. People with cancer want to feel that they are still actively connected and involved with this world even though the hospital ward and treatment isolate them. Patients want to hear good and bad news of family and friends so they do not feel excluded. They often do not want advice and those who give advice often do not know all the circumstances, and even if they are well informed too much advice can just create additional worry. Patients often find it more helpful if friends and family ask questions and listen. Laughter and talking about other things will often

help to make a patients feel normal. Sometimes holding hands and crying together brings people closer and makes everyone feel better (Gillie, 2005:47).

According the experts consulted, Dr Francois de Goede and Dr Christie Smit, there is a need for research on the psychosocial impact skin cancer has on the individual. Dr. De Goede is a dermatologist based at the Panorama Medical Centre and Dr. Smit is a cosmetic surgeon at Panorama Medi-Clinic and they both have a keen interest and vast experience in diagnosing and treating skin cancer. After completing treatment, they stated that it can be both stressful and exciting and although patients are normally relieved to finish treatment, it is hard not to worry about recurrence. If skin cancer does recur, it is most likely to happen in the first five years after treatment. In addition, a person who has had skin cancer is at higher risk for developing another lesion in a different location. It may take a while before one's confidence in their own recovery begins to feel real and one's fears are somewhat relieved. Even with no recurrences, people who have had cancer learn to live with uncertainty.

Scarring and the emotional effects thereof have been researched and it was found that there are distinct differences between a congenital abnormality and disfigurement developed in later life. It is also important to note that the location, severity or size of scarring is not correlated with level of psychosocial sequelae. Some light has been shed on the distribution of those affected – women show higher levels of disturbance than men, and higher levels are also found in those undergoing surgical revision of scars. Some of the psychosocial sequelae of scarring and disfigurement include daily activity disruption, sleep disturbances, anxiety, and depression, loss of self-esteem, stigmatisation and even post-traumatic stress reactions. The effects on body image and quality of life can be profound. Visible disfigurement and difference from societal norms has been equated to a social disability. Persons with facial disfigurements have similar levels of social phobia and agoraphobic avoidance to that of patients diagnosed with social phobia. Social interaction, concerns over meeting new people, long term relationships, accounts of staring, audible comments, avoidant behaviours are also reported (Todkill, 2006:8).

From the above, it is clear that skin cancer patients and their family can be affected in various ways when exploring the psychosocial impact the condition has on them. It varies from the crisis the patient and family face upon diagnosis, anxiety, changes in life style, concerns around scarring and fear of reoccurrence, as well as financial elements. Various support structures could be of assistance in this time, such as friends, family, the multidisciplinary team and other cancer specific resources.

2.13 The role of the social worker

According to Todkill (2006:8) the health care team has a vital role in psycho-social rehabilitation – it extends from the initial treating dermatologist, dermato-surgeon, nurses, physiotherapists and ward staff to the long term care provided by the general practitioner. The charity for disfigurement “changing faces” identifies four factors which health workers can address:

- Ensuring that family and other support systems can provide the background for patients to (re)build their self-esteem and self-belief.
- Enabling patients to overcome their functional limitations.
- Enabling patients to be informed about surgical and other treatment options.
- Enabling patients to acquire effective social skills to manage the reactions of their peers and strangers to their unusual appearance.

Oncology social workers can assist with practical needs such as employment and financial stressors caused by the illness. The social worker is an important link in the chain of communication that takes place in a busy hospital. Social workers accompany patients through all phases of the illness trajectory including diagnosis, treatment, and life after cancer and supportive palliative care. The following sections describe the role of the social worker in more detail along the treatment trajectory (U.S. Department of Health and Human Service, 2010).

Szynkarsky (2011) explains the role of the oncology social worker very well in an article on the Cancer Knowledge Network. She explains that social workers will evaluate the patients’ situation in order to understand the full impact of the illness on them and those around them. During this time, a patient and their family will receive information about the illness, assistance with how to negotiate time away

from work responsibilities, information about medication programs and community and financial resources. A patient will need support both from their social network as well as from their health care team. The social worker in oncology is well placed to be a bridge for good communication with the health care team. Oncology social workers are trained to assess how patients are coping and provide illness adjustment counselling to patients and their loved ones including young children. Social workers will also screen, monitor and refer patients to appropriate services if they are identified as dealing with depression, anxiety, or anticipatory grief. Particular attention is given to assess whether there are other stressors happening in your life during the time of diagnosis such as family conflict, abusive relationship, etc. Doing so can help social workers provide support needed to make living life with treatments somewhat easier. During the treatment phase the social worker's aim is to monitor how patients are coping with changes in life as a result of treatment. This is the phase in which many families find that the instrumental and financial burdens are the highest. With frequent visits to the hospital requiring transportation and days missed from work, the costs can be significant. Social workers can help by finding volunteer or community resources that can take some of the burden off caregivers. Furthermore, social workers can help with the coordination of community provided care. Social workers are often the source of referrals to home care and can be instrumental in mobilizing homecare resources so that the patient can remain at home and avoid unnecessary hospitalizations. If the patient is hospitalized, the social worker will work with the multidisciplinary team to help plan the patients' discharge home so that the transition can be seamless. For those who will require daily radiotherapy in addition to chemotherapy, the social worker will assist in exploring what options there are for assistance with parking, transportation or accommodations if patients are coming from remote areas (Szynkarsky, 2011).

In essence, the social worker is there to assist and see where things can be made easier for the patient in a very difficult time. Care and concern should be given to patients expressing their emotions, but also those who are in denial, depressed or have resentment due to not being prepared for a possible skin cancer diagnosis as was learned through this study.

2.14 Summary

Chapter 2 focused on explaining what skin cancer is and the variety of skin cancers that can be diagnosed as well as exploring the various treatment options and how each option would work. From the discussion within this chapter, it is evident that cancer, from being diagnosed and through treatment, can affect patients' and their families. Cancer is the uncontrolled growth of cells that could be attributed to a variety of factors, including genetic factors, lifestyle and could affect everyone from all races, walks of life, etc.

The treatment for skin cancer includes a variety of surgical options and chemotherapy. Patients and family members are affected by skin cancer and they need to cope with the diagnosis, treatment etc. The diagnosis and treatment of cancer could affect people in their personal, family and work life, which all have various stressors to it. Therefore, the role of the social worker in this regard is also explored in this chapter.

The following chapter will focus on the research methodology and research findings.

3. CHAPTER 3: EMPIRICAL FINDINGS

3.1 Introduction

The purpose of this chapter is to discuss the emotional experience of a skin cancer diagnosis. Prior to the discussion of findings the research methodology will be set out as well as reviewing the aim and objectives of the study.

The aim of this study was: to explore and describe the psychosocial experiences of the patient and family of skin cancer diagnosis and treatment.

In order to achieve this aim, certain steps need to be adhered to (Fouché and De Vos, 2005:105). The objectives for this study were as follows:

Objective 1 - To describe the phenomenon of skin cancer, including the various types of skin cancer, causes, symptoms, diagnosis, disease progression, treatment options, as well as the psychosocial aspects.

Objective 2 - To explore the psychosocial experience of a skin cancer diagnosis by patients and significant others.

Objective 3 - To explore the psychosocial experiences of skin cancer treatment by patients and significant others.

Objective 4 – To formulate guidelines for social workers in terms of intervention with skin cancer patients and their families.

Following the objectives of the study and within the framework of qualitative research, the research question was as follows: 'What are the psychosocial experiences of patients and their family of a skin cancer diagnosis and treatment.'

3.2 Research approach

The researcher followed a qualitative approach in this study. The researcher attempted to understand the subjective life experience of the respondents who suffer from skin cancer and have been diagnosed and undergone treatment, in order to add to the development of insight and a better understanding of the experiences skin cancer patients have in the current South African context. This

approach is therefore suitable, as also confirmed by Du Plooy (2005:82-83), who states that the objectives of qualitative research are to explore areas in which little to no information exists, and/or to describe themes, trends or attitudes that exist. Qualitative research is therefore aimed at constructing detailed descriptions of social reality.

According to Rosnow and Rosenthal (1999:438) and Durrheim (2002:42) qualitative research is done in an observatory method and is collected in the form of written or spoken language, or in the form of observations that are recorded in language, therefore the data is described as raw and in a non-numeric form. This data is then analysed by identifying and categorising themes, rather than collecting data in the form of numbers.

This study therefore focussed on the psychosocial experiences of skin cancer patients with the anticipation of some patients sharing similar experiences. Therefore the study used a deductive, logical reasoning in order to establish specific concepts and patterns in the data collected from very broad and general information gathered from participants.

3.3 Type of research

Durrheim (2002:40-41) describes applied research as having a practical application and is aimed at contributing towards understanding and solving practical problems. According to Fouché and De Vos (2005:105) applied research is focused on solving problems in practice. Within this study, therefore, applied research was used, since it falls into this category in that it is aimed at describing and understanding the subjective and very personal experiences of having skin cancer.

According to Fouché and De Vos (2005:105), this suggests that applied research is focused on addressing the immediate problems facing professionals in practice and is aimed at helping practitioners accomplish specific tasks. Neuman (2003:22) adds to this in stating that applied research is usually through a quick, small-scale study that provides practical results that practitioners can use in the short term.

The researcher aimed to utilise existing knowledge in order to obtain new knowledge regarding skin cancer and the psychosocial experiences thereof. An attempt was made to investigate the experiences of the skin cancer on the patient. With the broadening of the knowledge base of the experience of the patient, challenges and problems in practice could be resolved and optimal support could be given to patients. As a social worker, the researcher will apply the associated skills in order to achieve this.

Social workers are skilful in interviewing, in participant observation, in case recording and analysis, according to Lauria *et al.* (2001:197). Therefore it will be valuable if these specific skills are utilised to explore the psychosocial experiences of skin cancer and by that, increasing knowledge, improving service provision and support to patients and family.

3.4 Research design

Mouton (in De Vos 2005:132) defines a research design as a plan or blueprint of how you intend conducting the research. According to his explanation, a research design focuses on the end product, formulates a research problem as a point of departure, and focuses on the logic of research. Durrheim (2002:132) adds to this by stating that a research design is a plan or protocol for a particular piece of research.

Fouché (2005:270) explains that the design that aims to understand and interpret the meaning that subjects give to their everyday lives, is called phenomenology. In order to explore the psychosocial experiences of skin cancer patients, this design will be the most appropriate to use. Fouché (2005:270) further explains that ultimately the researcher will be able to extract a central meaning of the experience and formulate a description of the essence of the experience being studied. Multiple individuals who have experienced the particular phenomenon must be identified and data will be systematically collected and meanings, themes and general descriptions of the experience analysed within a specific context.

From the above, it seems that the phenomenological design aims to study a topic of which very little or no research is available on. Phenomenology is seen by the researcher as a design used to attempt to gain new in-depth knowledge in a

certain field. Through this research, the researcher attempted to establish what the psychosocial experiences of a skin cancer diagnosis and treatment would be and to make recommendations for social work intervention.

The proposed study was consistent with the aims of a phenomenological study in that it aimed to provide an in depth description of the psychosocial experiences of a skin cancer diagnosis and treatment on the patient and the family.

The researcher aimed to collect rich data from participants' of their psychosocial experiences of skin care diagnosis and treatment.

3.5 Research methods

3.5.1 Research population, sample and sampling method

3.5.1.1 Research population

According to Gravetter and Frozano (2005:193) the term sample always implies the simultaneous existence of a population or universe of which the sample is a smaller section or a set of individuals selected from a population. Arkava and Lane (in Strydom, 2005:193) draws a distinction between the terms universe and population. Universe refers to all potential subjects who possess the attributes in which the researcher is interested. Population, on the other hand, is a term that sets boundaries on the study units. It refers to individuals in the universe who possess specific characteristics (De Vos, 2005:193).

Bless and Higson-Smith (1995:85) indicate that the entire set of objects and events, or the group of people which is the object of research about which the researcher wants to determine some characteristics, is called the population.

For the purpose of this study, the population included all adult patients who had been diagnosed with skin cancer two years prior to the study and were having on-going screenings and or treatment in the Western Cape Province at two medical specialist practitioners in private practice, as well as family members of these patients.

3.5.1.2 Sampling and sampling method

Strydom (2005b:194) explains a sample as elements of the study to be considered for actual inclusion in the study. Thus, a sample represents a group of individuals from a population being studied.

The sampling method that was selected for this study was non-probability sampling, specifically purposive sampling. Siverman in De Vos et al. (2005:328) is of the view that in purposive sampling, a particular case is chosen because it illustrates some feature or process that is of interest for a particular study. In purposive sampling, the qualitative inquirer must first think critically about the parameters of the population and then choose the sample case accordingly. The reason for this is that this type of sample is based entirely on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristics, representative or typical attributes of the population, according to Singleton (in Strydom, 2005:202). Purposive sampling is appropriate as not all possible skin cancer patients and family members can be identified, nor interviewed for the purpose of this study.

Thirteen participants were targeted from two dermatology private practices in Cape Town. The criteria for the sample included persons:

- From all races
- aged 18 years and above
- of both genders
- who had skin cancer,
- who were diagnosed two years prior to the study,
- who had undergone treatment for the skin cancer or were still undergoing treatment,
- who are patients from two identified medical specialists' in private practice, in Cape Town and were willing to participate voluntarily who are family members of patients diagnosed with skin cancer

Two specialist medical practitioners, who consented to researcher using their skin cancer patients for the study, determined the demarcation of the study in Cape

Town, Western Cape Province. These medical specialists approached their patients who met the selection criteria and informed these patients of the study. An information letter explaining the purpose of the research was given to those patients who showed interest, to explain the research project to them as potential participants. Their contact details were provided to the practitioner. Researcher later fetched these contact details at the two practices. Thereafter researcher contacted the potential participants. Appointments were made with the first 13 persons who met the sampling criteria, in order to discuss the letter of informed consent with each participant. Once they signed the letter and agreed to partake in the study, an appointment for the interview was arranged with them at a place agreed upon by the participant and the researcher. A total of 13 participants were included in this study, of which 7 were skin cancer patients and 6 were family members.

3.5.2 Data collection

For the purposes of this study, the researcher utilised an unstructured one-to-one interviews in order to gather rich information from participants on the psychosocial experiences of skin cancer by the patient and the family. Unstructured interviews are also known as in-depth interviews. This however does not mean that there is no structure or fixed structure as in the case of structured interviews. Collins (2005:292) explains that unstructured interviews are structured in a number of ways. The researcher, in the very act of initiating the interview, necessarily determines the nature of the event. As the interview progresses, an internal dynamic develops and a storyline emerges which becomes increasingly complex. Unstructured interviews are conducted without utilising any of the researcher's prior information, experience or opinions in a particular area. The researcher brackets her experiences or opinions.

The unstructured one-to-one interview, also referred to as an in-depth interview, merely extends and formalises conversation (Greeff, 2005:292). It is referred to as a conversation with a purpose. The purpose is not to get answers to questions, nor to test hypotheses, and not to evaluate in the usual sense of the term. At the root of unstructured interviewing is an interest in understanding the experience of

other people and the meaning they make of that experience. It is focused and discursive and allows the researcher and participant to explore an issue.

Neuman (2003:391) further states that it is essential to the success of this kind of interview that respondents are active participants whose insights, feelings and cooperation are central to the discussion process. An unstructured, one-to-one interview will be conducted in order to gain a detailed picture of the participant's experience, or perceptions or accounts of, a particular topic – in this instance the psychosocial experience of skin cancer diagnosis and treatment by the patient and family (Greef, 2005:297). Greef (2005:287) describes interviewing as the predominant mode of data or information collection in qualitative research and emphasises that qualitative interviews are seen as attempts to understand the world from the participant's point of view, to unfold the meaning of people's experiences and to uncover their lived world prior to scientific explanations.

Lindegger (2002:259) refers to this method of information collection as “narrative analysis” and is aimed at discovering personal and cultural narratives in order to understand the subjective meaning attached to experiences. Since interviewing is fundamental to social work practice and social workers are trained in interviewing, this method of information collection is frequently used in social work research (Gochros, 1988:267).

The specific interviewing method used in the study was an unstructured one-to-one interview. This is described by De Vos (2005:292) as “a conversation with a purpose.” Unstructured interviews are aimed at understanding people's experiences and the meaning attached to them according to De Vos (2005:293), and are therefore consistent with the purpose of phenomenological studies. This method of information collection would therefore be suitable to the proposed study which aims at developing an in depth understanding of the subjective experience of persons diagnosed with skin cancer.

Despite being called ‘unstructured,’ such interviews require a format and follow a process (De Vos, 2005:293). Rubin and Babbie (2005:293) distinguish between three separate types of questions: main questions; probing questions used to

obtain more depth, detail or clarity; and follow up questions used to pursue the implications of respondents' answers to the main questions.

Information was collected through unstructured interviews and were recorded with the consent of the participants. The researcher obtained informed consent from participants to do these recordings of interviews before the interviews were conducted. Strydom (2005:298) advises that a tape recorder should not unnerve the respondent and that it should therefore be placed inconspicuously. Using a tape recorder was the most appropriate method of data collection. De Vos (2005:334) explains that tape recorders are preferable to note taking as they are less likely to inhibit the respondent and interrupt the natural flow of the conversation. The researcher tested the tape recorder beforehand, during the pilot study with two persons who had skin cancer, to ensure it works efficiently and was placed in the best place to record effectively. The primary and secondary questions were also tested. De Vos (2005:337) suggests that duplicate copies of the recorded interviews, transcripts, process notes and field notes be made in order that there should be one master copy of the raw information for safekeeping. The researcher made sure of all these provisions.

The primary research question for the interview was as follows:

- Tell me about your experience of skin cancer?
- Tell me about the diagnosis?
- Tell me about the treatment you had?
- Tell me about the effect the treatment had on you?
- Tell me about the effect the experience had on your family?

The secondary questions will be:

- What was the most challenging experience and who was your support system during this process?
- How has living with skin cancer influenced and/or changed your life in any way – with regard to life-style, hobbies, activities, work, relationships, and self-image?

All interviews were conducted at the homes of the participants as it was the most convenient setting for them.

3.5.3 Data analysis

It is difficult or impossible to explain raw data; one must first describe and analyse the data and then interpret the results of the analysis, according to Kruger in De Vos (2005:218). Analysis means the categorizing, ordering, manipulating and summarizing of data to obtain answers to research questions. The purpose of analysis is to reduce data to an intelligible and interpretable form so that the relations of research problems can be studied, tested and conclusions drawn (De Vos, 2005:218). The tape recorded interviews were transcribed after the interview. Transcription of an interview, according to Terre'Blanche and Kelly (2002:131-132) enables the researcher to access information easier than on a cassette and facilitates the moving around of information later on in the study. Non-verbal responses should also be noted in the transcripts. Researcher noted the non-verbal responses from the field notes that were made after the interview and noted it on the transcripts.

The process of analysing the data starts here and is followed by the formal process of analysis when the data is organised, patterns, categories and themes are identified and these are coded in the written text (De Vos, 2005:337-338).

De Vos (2005:335) states that the analysis and interpretation of information, in the qualitative approach to research, is linked to the collection of information since the researcher begins interpreting information, together with the participant during the interview.

As mentioned before, the process of data analysis starts in the interview. The process of managing this data happens away from the site and after completion of the interview (De Vos, 2005:336). This data was transcribed into written documents and then filed electronically and in hard copy. The researcher ensured that the data collected in the interview was sufficient and when it becomes exhausted, that is when similar themes are repeated by various participants and that no information is lacking by doing the transcriptions and thereby immersing

herself in the data. This, according to De Vos (2005:336-337) usually generates emergent insights.

Once a holistic picture is gained through immersing in the data, the researcher will start looking for commonalities and subtle ideas and beliefs that are common across transcripts. Themes and patterns will be categorised into sub-themes, interpreted and integrated with existing literature (De Vos, 2005:338). This is all part of the process of making sense of all the data collected. In order to organise these various themes and sub-themes, different colours were used to mark them in the various texts. Terre'Blanche and Kelly (2002:143) describe coding as the breaking up of information into labelled and meaningful pieces.

According to Creswell (1998) in Delport and Fouché (2005:334) the process of data analysis and interpretation can best be represented by a spiral image – a data analysis spiral. The researcher moves in analytic circles rather than using a fixed linear approach. One enters with data made up of text or images (e.g. photographs, videotapes) and exits with an account or a narrative.

Marshall and Rossman (2005:339) state that the researcher should consider other explanations and their plausibility through challenging the themes or patterns in information previously identified. Therefore, once themes in the information are identified and coded, it will be tested by considering other reasons or explanations, through examining the information critically with available literature, for findings and then the researcher will decide on the most plausible one. The researcher conducted a literature study, as is stated by Delport and Fouché (2005:264) as part of the theory around a phenomenological study, which aims to understand and interpret the meaning that subjects give to their everyday lives (Delport and Fouché, 2005:270). Creswell (2005:264) furthermore highlights that the purpose of the literature review in a phenomenological study is to control or validate the research findings and relevant literature is thus incorporated into the analysis of the information and findings made.

The final phase of the analysis of the information is the presentation of the information in the research report, according to De Vos (2005:339). The research report is the mini-dissertation where the data is presented in written format, in

which the researcher included quotes from the participant interviews and used literature to substantiate the findings.

3.5.4 Trustworthiness

Morse and Richards in Strandberg (2009:283) and Lincoln and Guba (in De Vos, 2005:346) propose the following assumptions of the qualitative paradigm:

- **Credibility** - which is the investigation of the study. “An in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid.” The researcher ensured that she was well prepared for interviewing in order for the richest data to be derived from it.
- **Applicable** - entails the transferability of the results. According to De Vos (2005:346) transferability is sometimes seen as a weakness of the qualitative approach. The researcher used data from various, unrelated cases. The participants in the study were all diagnosed with skin cancer over a period of time, and did not receive treatment at the same time or know each other at all. The researcher believes that this strengthened the transferability, because the experience will have been different due to variables such as different doctors, different treatment - and support staff. The researcher further tried to constantly refer back to the theoretical framework and spiral of data analysis (as was shown above) to guide the study. Having firm roots in the theory, the researcher believes that she was able to honour transferability.
- **Consistent** - entails the dependability of the results. The researcher interviewed all the participants at their homes, which was their choice and not in public spaces. They were all comfortable and familiar in their own home environments, and although different environments, the researcher believes this contributed to consistency.

Lincoln and Guba (in De Vos, 2005:346) go further to explain each assumption and adds a fourth:

- **Conformability:** This captures the traditional concept of objectivity. The researcher completed a detailed literature review in order not to evaluate

herself, but to rely solely on the data and then to substantiate it with the literature.

The strategies used to ensure trustworthiness, included the following:

Each participant was debriefed after the interview to ensure that they felt comfortable with what had been discussed during the interview, to determine whether they had experienced any emotional harm and to ensure that researcher had understood what they conveyed correctly. This was seen as a form of member checking. Researcher shared her experiences of the interviews and her thoughts regarding the interpretation of the data in themes with a colleague, for peer debriefing throughout the study. Furthermore, the researcher tried to remain as objective as possible and prepared herself emotionally before each interview and kept notes of her feelings, thoughts and experiences throughout the data gathering process, to be in touch with her own feelings as a means of reflexivity.

3.6 Pilot study

Two participants were used in the pilot study for the pre-test. These two participants met the same sampling criteria as the participants of the main study and did not form part of the main study. They were, however interviewed in the same manner as which the participants in the main study were. Strydom (2005a:205) explains that testing the measuring instrument involves testing out the interview schedule on a small number of respondents with similar characteristics to those in the target group. The necessary changes were then to be made to the formulation of the primary and secondary questions, before conducting interviews for the main study, which, however, was not necessary. The data gathered from the pilot study for the pre-test of the measuring instrument were not included in this research report. The time allowed for the interview, the recording equipment, privacy in the home of the participant as a venue during the interview was tested. After the pilot study, however, the researcher did not find it necessary to make any adjustments.

3.7 Ethical considerations

In the social sciences it is more likely that respondents could be emotionally harmed. This is also likely to be harder to predict and longer lasting in nature

(Strydom, 2005c:58). Furthermore, Neuman (2000:90) states that ethical issues can be seen as concerns, dilemmas or conflicts. Furthermore it is stated that it originates from the correct way in which to conduct research. Ethical refers to what is legitimately correct or what is honourably the correct way of operating.

3.7.1 Avoidance of harm

It is possible for respondents to be harmed in either a physical or emotional way through the process of engaging in research (Strydom, 2005c:58).

The researcher attempted to orientate participants on the possible impact of the study in the letter of informed consent, before starting the interview. Upon finishing of the interviews, the researcher ensured that all the parties were fine by asking them how they'd felt during the debriefing and to ascertain whether any further emotional support and a referral was needed, which was not necessary in any of the cases.

3.7.2 Informed consent

Informed consent implies that all possible and proper information regarding the purpose of the study, the procedures to be followed, possible pro's, cons and dangers has been communicated to all possible participants of the study. The author focuses on the accuracy of the information provided in order for the potential participants to make a voluntary, well thought through decision regarding participation in the study (Strydom, 2002:65). Neuman (2000:96) states that this process can be made easier by drawing up a written permission document. For this study the researcher compiled a letter of informed consent that explained the aim and process of the study, as well as assuring confidentiality and informing them that the interview will be recorded. This was done to assist participants in making an informed decision. The letter of informed consent was read to the participants, although a few requested to read it themselves. It was signed by participants voluntarily and by the researcher prior to commencing with the interviews. Participants were also given the opportunity to withdraw from the study at any point, without any negative consequences. The written document prepared the participants that the interviews would be recorded and their consent was required. They were also informed that the data would be stored for 15 years, as

required by the university for archival purposes. The researcher kept the original signed letters of informed consent and provided participants with a copy.

3.7.3 Deception of participants

According to Strydom, deception of respondents involves withholding information or offering incorrect information in order to ensure the participation of respondents when they would otherwise have possibly refused (Strydom, 2005c:60). Participants were not deceived in any way. All information needed to understand the process and the aims of the research were communicated in the letter of informed consent as well as an opportunity for questions was given.

3.7.4 Action and competence of the researcher

The researcher was guided by a supervisor from the University of Pretoria. The researcher also had experience with research methodology in both Social Work Honours, through course work and completion of a research report as part of completion of a B.A. (Social Work) degree from the University of Stellenbosch. A research module on masters' level, namely Research Methodology (MWT 864), was also completed successfully. Great sensitivity was applied when asking the questions. The researcher agrees with Strydom (2005d:63) that it is an ethical obligation for the researcher to ensure that he is sufficiently competent to undertake the study. Finally, the researcher is a registered social worker with the South African Council for Social Service Professions and also has experience in counselling and working in the field of oncology as a social worker.

3.7.5 Confidentiality and anonymity

Strydom (2005c:61-62) states that confidentiality indicates the handling of information in a confidential manner and that a strong obligation is placed on the researcher to guard the information confided to him jealously. The researcher prioritised and committed to confidentiality, since the participants were sharing very personal feelings and emotions around their suffering from skin cancer. The researcher assigned pseudonyms to the participants after the interview, before transcribing the interviews, so as to maintain confidentiality by not being able to link their identity with the findings in any way.

3.7.6 Release of findings

In order for the research to be of value it needs to be accessible to other professionals working in the field. With this aim in mind the mini-dissertation will be available in the University of Pretoria's library. In addition an article co-authored by the research supervisor will be published in an accredited journal. Every effort made to ensure that findings were presented as accurately as possible so that other professionals are not misled by the information presented (Strydom, 2005c:65).

The participants involved in the study also have the right to access the findings of the research project. As such it is the responsibility of the researcher to ensure that these findings are presented accurately and objectively so as to avoid confusion for participants, which will be done by providing them with a shorter version of this report, on the summary of the findings.

3.8 Presentation of research findings

The research findings will be presented according to themes and sub-themes generated from transcribed interviews, it will be strengthened with direct verbatim quotes from the interviews and will then be substantiated with literature. Firstly a biographic profile of the participant will be provided:

3.8.1 Biographic profile of participants

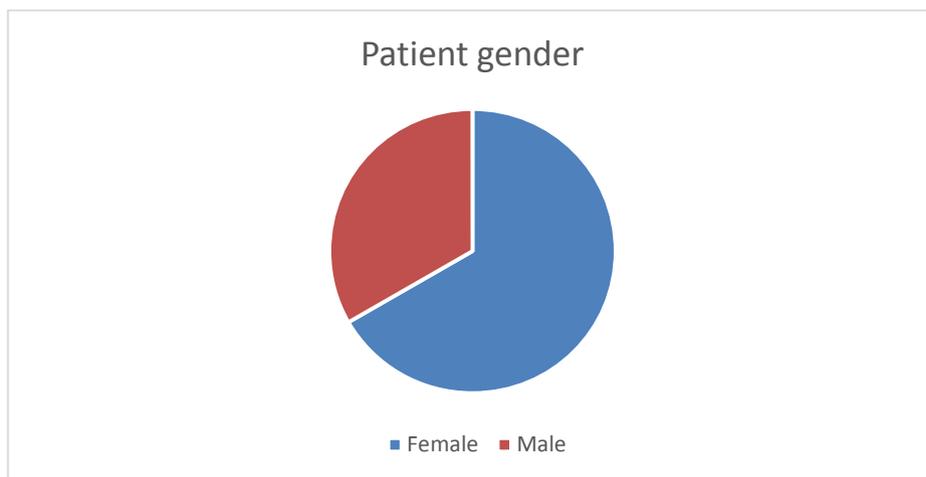
Table 3.1: Profile of research participants

Participant	Age	Gender	Patient	Relation to patient	Marital status	Melanoma	Basal cell cancer	Squamous cell cancer
A	70+	F	Yes	Wife	Married		✓	
B	70+	M	Yes	Husband	Married		✓	
C	70	M	Yes		Widowed		✓	
D	50	F	Yes		Single		✓	
E	30	F	Yes		Married	✓	✓	✓
F	60	M	No	Father	Married	✓	✓	✓
G	40	M	No	Husband	Married	✓	✓	✓
H	60	M	Yes		Married		✓	
I	60	M	No	Daughter	Married			✓
J	30	F	No	Niece	Married	✓		

K	60	F	No	Wife	Widowed	✓		
L	50	F	No	Daughter	Married		✓	
M	80	F	Yes		Widowed		✓	

The participants were between the ages of 30 and 84. Nine participants are married, three are widowed and one is single. None of the participants over the age of 60 were still working. Seven of the participants have been skin cancer patients who have had a diagnosis and treatment for skin cancer. Six participants were family members of skin cancer patients. Two participants, were both skin cancer patients, but married to each other, therefor also family members of a skin cancer patient.

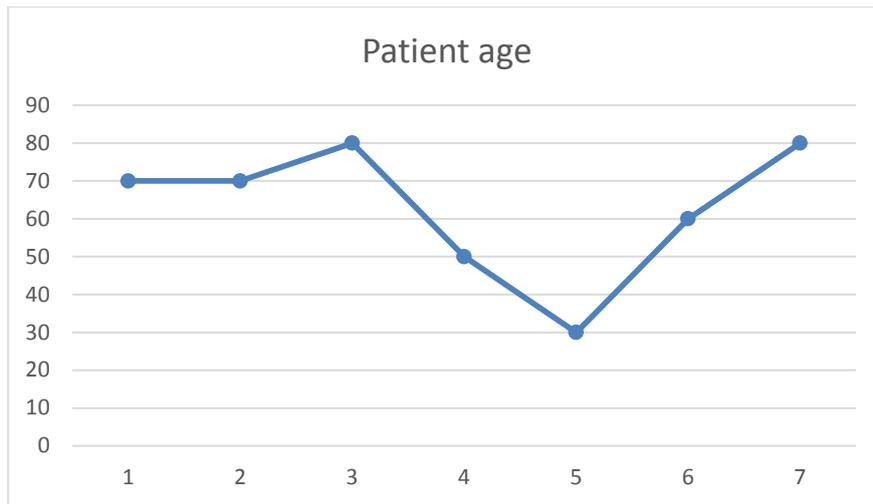
The biographic profile in tabular form shows the information very clearly and is also portrayed in graph form in the following figures:



n=13

Figure 3.1: Patient gender

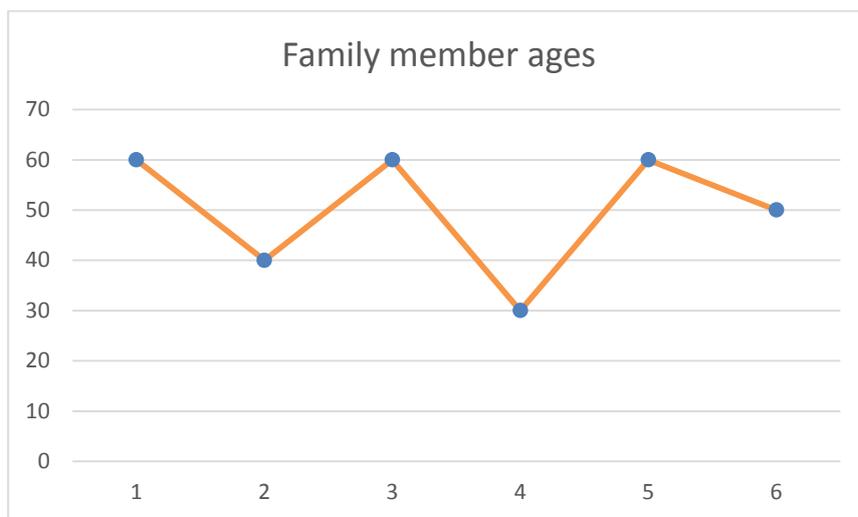
From figure 3.1, it is clear that there were more female than male patient participants in this study.



n=13

Figure 3.2: Patient age

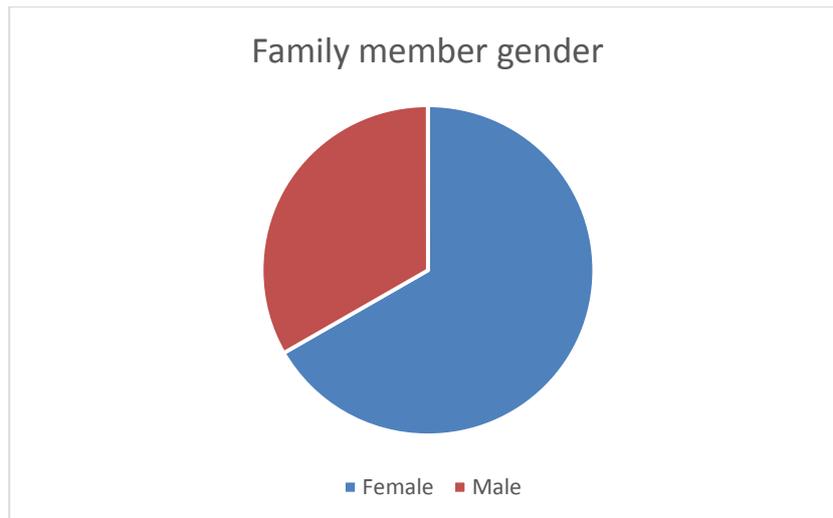
From figure 3.2, it is clear that most of the patient participants were older than 50 years of age.



N=13

Figure 3.3: Family member ages

From figure 3.3, it is clear that the family members who participated are from various ages between 30 years and over 60 years.



n=13

Figure 3.4: Family member gender

From figure 3.4, it is clear that there were more female family participants than male. Subsequently, the thematic analysis of the findings will be presented.

3.8.2 Themes and sub themes

The themes and sub themes generated from the study, which will be discussed are summarised in this table.

Table 3.2: Summary of themes and sub-themes

Themes	Sub-themes
Theme one Lack of knowledge around skin cancer	<ul style="list-style-type: none"> ✓ Nature of skin cancer ✓ Knowledge resulting in behaviour change
Theme two Reaction to diagnosis	<p>Sub themes:</p> <ul style="list-style-type: none"> ✓ Cognitive and Emotive
Theme three Treatment	<p>Sub themes</p> <ul style="list-style-type: none"> ✓ Types of treatment ✓ Experience of the treatment ✓ Scarring ✓ Prognosis
Theme four Post-diagnosis mindfulness and behaviour change	<p>Sub themes</p> <ul style="list-style-type: none"> ✓ Preventative Behaviour ✓ Thought Processes
Theme five: Support structures	<p>Sub themes</p> <ul style="list-style-type: none"> ✓ Awareness in families ✓ Honest and truthful information ✓ Faith/religion

Themes	Sub-themes
	<ul style="list-style-type: none"> ✓ Counselling and support ✓ Medical and other expenses

Subsequently these themes and sub-themes will be discussed by means of a thematic analysis, which will be supported with quotes from the interview and substantiated with the literature.

3.8.2.1 Theme 1: Knowledge of skin cancer

The following quotes reflect the participants' knowledge of skin cancer.

- **Sub-theme 1.1: Nature of skin cancer**

This theme concentrates on the aspects around noticing the skin cancer including the participants' understanding of skin cancer as well as their feelings at the time of diagnosis.

Participant D

I had skin cancer for the first time in the early 1990's. It was a cancer on my head, my scalp. It started out as a sensitive spot I felt when I combed my hair. I became aware that it was getting bigger and finally went to consult a doctor. He advised it be cut out as soon as possible, which we then did and the result came back after tests that it was skin cancer.

Those days, people couldn't say the word 'cancer' even – as though you're casting a bad omen on yourself!

Participant E

I had a patch of broken skin above my ear since 1997 when I was 17, but though it was a little sore that wouldn't heal because I wash my hair daily and it doesn't get a chance to dry out and heal. It started off very small and very gradually got bigger. I was always aware of it but really didn't think it was anything bad, so it didn't bother me.

Two years later I have a flat dark mole type of patch on my back. Dr. at first said it seems fine, but I didn't like the look of it and he agreed to remove it. He removed it in his rooms and sent it off for testing. Two days later he phoned to say it was melanoma and I had to go to theatre for a further excision to ensure they got all of it out.

Participant I

My dad had squamous cell cancer that started on his ear lobe. At first it was all fine and we thought the cancer was gone. But, later it returned.

Participant J

My uncle had gone for a knee replacement, when the anaesthetist saw a mole on his back.

Discussion of sub-theme 1.1

The above lived experiences of the participants indicate that they were not aware of the possibility of skin cancer. They all consulted a doctor due to some inconsistency with regards to a patch of skin, but none indicated that they had any idea that it might be cancer. It seems that their awareness of what skin cancer look like was very limited, despite the theory informing us that skin cancer is the most common form of cancer.

Any new growth on the skin, a spot or lump that is getting larger, or a sore that does not heal in three months, might be skin cancer and should be examined by a doctor (Gillie, 2005:28). According to Morra and Potts (2003:657), it is unlikely that you would be able to diagnose skin cancer and that you should bring any skin change to the attention of your doctor as only a trained physician can determine the nature of an abnormal skin growth, whether it is benign, precancerous or malignant. To seek the opinion of a qualified dermatologist who has had experience dealing with skin cancers is of essence. Thus the “bio” of the biopsychosocial model is important, as the patient and family needs to understand this information, which must be explained to them by the dermatologist.

It was quite evident that all the participants and their family members were rather oblivious of what skin cancer looks like and how to diagnose it as most of the participants had the cancer visible for quite some time before having it medically examined. Most of them were also rather blasé of the potential of skin cancer from sun tanning as many of them had done a lot of over the years.

- **Sub-theme 1.2: Knowledge resulting in behaviour change**

This theme focuses on how skin cancer patients and their family have change their behaviour with increased knowledge around skin cancer.

Participant A

Those years you would do anything for a tan. Sunbathing was very important to everyone. **We would rub baby oil, even cooking oil on**

our skins to improve our tans! I think maybe then I was a little oblivious to what it really was, as it was never really explained to me. Later years, I've realized the danger of exposure to sun and, maybe too late, started to protect myself against sunburn. My husband and I also played bowl for a long time and that **may also have been too much sun exposure**, now that I think of it...

Participant D

Well, I certainly do not leave the house without a day cream containing some sunblock. Also, when I do gardening or spend longer periods outside I always wear a hat since then. Times have changed, you see – when I was younger, in the 60's and 70's tanning was very important. You'd do anything to get as tanned as you possibly can! I know always 'preach' to my children and grandchildren to put on sunblock and wear hats and protective clothing as far as possible to prevent them from getting skin cancer. I know for some tanning is still very important, but I promote 'safe tanning' – they must put sunblock on, always!

Participant G

I didn't know much about skin cancer like what the symptoms really was or is, I was just afraid that she might die and that made me very protective over her and I am sort of paranoid about her and very over protective about her skin and the sun. Everything we now do I do the preparations for, for example hiking or camping, which we love doing. I will always have it in mind to protect her skin and think of things like, are there trees or shade and take the season and everything into consideration. My first priority is to block the sun away from her because all we can really do to prevent this is to stay out of the sun and not get burnt.

In fact also now with our kids, we make sure they never burn and try to protect them as much as possible from the sun.

Participant M

Well I always, always use sunblock now and a hat if I must and I try to keep out of direct sunlight. Back in the day when we were young, tanning was fashion and we did really silly things to ensure a great tan. You know, we would put cooking oil on our legs and sit in the sun for hours on end. We didn't know of the dangers, and knowing what I know now, I always try to encourage people not to burn or spend too much time in the sun. But young people don't think of the long term consequences, they live for the moment and just enjoy life. But, if you can prevent something, you should - especially now a days with all the information that we have to our disposal – we really didn't have that back in the day.

Discussion of sub-theme 1.2:

A majority of participants changed their behaviour after their diagnosis. The only participant who didn't report a change in behaviour is an older man who

mentioned that the cancer “wasn’t anything serious or had real effect on my life” as “an old man who has lived my life.” He did however mention that his family now makes an effort to keep him away from the sun. The findings also show that the family members modified their behaviour, but it seems that some patients are less focussed or committed to the changed behaviour despite the increased awareness.

From the information obtained from various resources it seems that once an individual has been diagnosed with skin cancer, they are at risk of developing another skin cancer. Limited time in the sun and avoiding sunlamps and tanning booths are advised as tanning may increase the risk of developing another skin cancer. The best way to prevent skin cancer is to stay protected from the sun (CANSAs, 2014, Types of skin cancer, 2008 and Skin Cancer Foundation, 2014). Thus the interconnectedness of the bio, the psycho and the social components of the biopsychosocial approach are reflected here.

3.8.2.2 Theme 2: Reaction to diagnosis

This theme focuses on the reaction the various patients and family members had upon the diagnosis of skin cancer.

- **Sub-theme 2.1: Cognitive and Emotive**

The following quotes reflect the cognitive and emotive reactions towards a skin cancer diagnosis.

Participant D

Oh, the word ‘cancer’ did scare me, especially since I didn’t at all anticipate it.

I must also ad, that if I hadn’t been diagnosed with breast cancer in the late 1980’s which I by this stage had survived, it probably would’ve been more of a shock and caused more panic than it actually did eventually.

I think it still had a big impact. One of fear and of ‘is it all out cut out’, ‘has it spread’, etc.

Participant E

The word ‘cancer’ was such a shock. I thought I was going to die! I did not at all expect this. I felt like saying good-bye to everyone. Some of my family members had little skin cancers that they had burnt off by their doctor’s and I felt that if I got now, at age 24 what they got in their 70’s,

I'm surely not going to grow old! I wanted to break off my relationship not to 'fail' my partner in not being there for him for a lifetime ... I was very shocked and very distressed. Also, knowing I now have to go for regular check-ups for the rest of my life really depressed me. I felt almost sentenced to suffer and worry for the rest of my life because neither my skin, nor the sun is going to go away.

Even more so, after I had a melanoma I felt like this is never ending drama and surely a life sentence.

I've really been cautious and mindful. I felt, how much more can I do?

Participant F

She got skin cancer in her face when she was around 20 years old, which was a great shock to me. I was very taken back as it's not something one never expects. And not just that – it's the last thing you want your child to have to go through! She is my only daughter and I struggled with fears of her being disfigured and having scars in her face, which devastated me.

My only consolation was that we had good medical care and medical aid, so I knew we are able to do the best under the circumstances and having a plastic surgeon operate to minimize scarring.

I do think for someone to hear the word cancer must be very traumatic – because it certainly was for me and it wasn't even my own diagnosis. I think perhaps people should have support at hand and know that they don't have to go through all of these emotions alone.

Participant H

It was initially a great shock. My doctor however assured me that it is at least a curable skin cancer, which comforted me somewhat. I don't think of it constantly now, but before my yearly check-up I am a little bit worried that something might have again popped up.

Participant K

I was devastated and angry. I could not comprehend why he got this disease. He didn't deserve it. He was such a kind man and always working hard and loved life, his family and just recently became a grandfather. I felt it was just so unfair. I just couldn't comprehend it.

It felt so surreal and it was really so hard to believe what was happening. He was initially diagnosed in Dec 2011 as a mole on his back had discoloured and he went into hospital then for a half knee replacement and they took a skin graph and it came back malignant, it was taken out and they the doctors said it was large but they had removed the cancer but little did we know it would surface again at end of June 2012 by a lump under his right arm. It was such a hard time.

Participant M

I got quite a fright, because I thought it must be an age spot or something, but when he confirmed it was cancer I was very shocked. I

was very worried about how it will be treated and if it could be treated etc.

Discussion of sub-theme 2.2

From the above statements, it is evident that not all participants experienced the same intensity of anxiety or shock when they found out that they had skin cancer. The emotional reactions of participants ranged from shock and devastation to total complacency.

When a person is diagnosed as having cancer he or she will often experience anxiety which can be very severe. Anxiety is a normal response to stressful events and is part of the process of coming to terms with an illness. Fear of the unknown is often a significant cause of anxiety.

Individuals with the same diagnosis or treatment may experience very different levels of distress. A high level of distress could result from an individual's perceptions that either the demands of a situation are very high or his or her resources are very low (or both). Conversely, low distress is the result of a perception that the demands of a situation are very low or the individual's resources are high to lower distress, therefore, either the perceived demands of the situation should be lowered, or the perceived resources should be increased (National Cancer institute, 2010). Patients may feel less anxious when they are given more information about their illness and their treatment (Gillie, 2005:42).

The youngest of the participants expressed the highest levels of anxiety, shock and fear of death. There is evidence that younger patients are more vulnerable to psychosocial distress in the context of cancer, and in a setting where health professionals avoid discussion of emotionally charged issues, there is the risk that this distress in younger patients is not detected, or is responded to inadequately (National Breast Cancer Centre, 2003:118).

Not only did most of the patient participants express anxiety and shock. Most family members responded with shock and a feeling of sympathy for the patients.

A diagnosis of cancer is a very stressful event for the patients and their families. Patients, partners and other family members can suffer from clinical levels of

depression and severe levels of anxiety and stress reactions. The similarity in levels of distress between patients and partners and patients and offspring suggests that there are common factors that impact on families' distress levels. Results from multilevel models indicated that family functioning was important. Families that were able to act openly, express feelings directly, and solve problems effectively had lower levels of depression. Direct communication of information within the family was associated with lower levels of anxiety. Aside from differences anxiety due to cancer type, patients' illness characteristics appear to be risk factors in patients' but not relatives' depression and anxiety. This suggests that researchers and clinicians need to be family-focused as cancer affects the whole family, not just the patient (Edward & Clarke, 2004:562). Thus the appropriateness of the biopsychosocial approach when intervening with patients and family is supported.

The diagnosis certainly had a big impact on most of the participants, whether they were patients themselves or family members of a patient. Because the sun is a major contributor in skin cancer and in South Africa we have a lot of sunshine and often embrace it in our social time, a lot of changes were made to ensure patients and now very often family members, too are protective from the sun. This raised concern with time spent in the sun, being sensible with regards to tanning, using sunblock and hats and an increase general awareness of prevention.

3.8.2.3 Theme 3: Treatment

The following quotes will reflect the participant's treatment of their skin cancer.

- **Sub-theme 3.1: Types of treatment**

This theme explores what types of treatments the various participants had undergone.

Participant E

- ... Operated on me in theatre.
- ... Surgically in his rooms ... to go to theatre for a further excision.
- ... Had to use a certain cream on cancerous spots in my face.

Participant F

- ... Plastic surgeon operate to minimize scarring

Participant G

... Operated on
... also had smaller cancer spots burnt off ... and two cut out on her neck line ...

Participant J

... do a biopsy and draw blood ... sent it away for testing.
... Operation to remove the tumour ... the wound wouldn't heal or dry up and he also had to go for another operation to remove more tumours or tissue and then after that they started with radiation and chemotherapy.

Participant K

... They took a skin graph and it came back malignant, it was taken out
...
... He had 25 sessions of radiation and I think 2 treatments of chemo ...
... Admitted to hospital twice. Where he was given blood ...
... Pain specialist ... five injections to assist with pain.
... Given Zobone chemo drug to assist ...

Participant L

... Was excised ... a big operation as he had to create a skin flap ...

Discussion of sub-theme 3.1

According to the interviews most patients had received treatment in the form of freezing or burning with others having surgical intervention for melanoma or larger affected areas. Some participants mention using creams to use on smaller facial spots. There is mention of radiation and chemotherapy only by the family of one patient. It is also clear from the laymen's terms used that perhaps the participant are perhaps not really well informed of the procedures and treatment, for example the cream the patient used may well have been chemotherapy in the form of a cream, but that is not ascertained. This potentially causes a great down play of potentially serious intervention. From the above it is evident that some of the procedures do have some discomfort as well as severe pain as result, depending on the type of treatment.

• Sub-theme 3.2: Experience of the treatment

The quotes below describe the participant's reflection of how they experienced their skin cancer treatment.

Participant A

I can't say that it's nice ... was sore ... annoying ...

Participant C

Irritating, stinging feeling ... sensitive afterwards ... a little bit painful when the feeling returned and the anaesthetic had worked out and my skin was stiff. Healed fairly quickly

Participant D

... Fear and of 'is it all out cut out', 'has it spread' ...

Participant E

... Skin was pulled so tight to close the hole, my left eye even pulled so I could hardly open it when I got out of the theatre.

... Very stressful and painful in healing. The one in my face was particularly bad, because they used local anaesthetics and I had to lay there hearing how they cut away skin almost right in my ear. The sounds freaked me out. Also when the doctor spoke to the sister and wondered how he would get the skin together to stitch it up as it was a big spot and the skin was under a lot of stress. It was very overwhelming and upset me quite a lot.

Participant G

... Very painful, especially the second time when they had to go deep to take out all the bad cells. She had quite a few stitches.

I think she experiences it as quite emotional every time. Me too, but then I'm also concerned about paying the bills and that the medical aid is a priority because of this because she has had skin cancer so many times and it seems to be something that doesn't really stop. And not just the bills, sunscreen is also very expensive and it's a priority and I think should be covered by medical aids when a patient is diagnosed with skin cancer – it's a chronic illness because in South Africa we all spend a lot of time in the sun because of the climate.

Participant I

... But it returned and had spread to other glands in and around his face, which was also removed in a big operation and really scarred him badly, I think that did cause a lot of stress for both of them.

... Also nurses to care for the wounds ...

Participant L

... Severely scarred and disfigured by skin cancer excisions and treatments ...

... She did not look too well to be honest and the bandaging made it look like her face was almost cut in half, but as the wound healed it really looked much better. She was very depressed right after the procedure ... As it healed her mood also lifted.

Participant M

... Worrisome ... afraid ... concerned ...

... Huge bandage and could feel stitches all the way from my forehead over the length of my nose, but the pain was under control and it was covered neatly, albeit largely.

... I must say the operation was sore and uncomfortable, but the pain was never unbearable.

Discussion of sub-theme 3.2

Reported experiences ranged from mild discomfort to very painful and uncomfortable experiences. The level of discomfort and pain was higher in those with more serious variations or with larger affected areas.

Treatment for skin cancer depends on the type and stage of the disease, the size and place of the tumour, and general health and medical history. In most cases, the aim of treatment is to remove or destroy the cancer completely (Department of Health and Human Services, 2010 and Morra and Potts, 2003:665; National Cancer Institute, 2010).

Anxiety may make the pain experienced by cancer sufferers feel worse (Gillie, 2005:42). Anxiety seems to be a variable that may well influence how much pain or discomfort patients had and also emphasises that patients and their families need support especially around their anxieties and concerns. It was evident from the interviews that the more invasive the treatment was, and the more concerns patients had, the higher their levels of anxiety was, as expressed. The three components of the biopsychosocial approach were again evident in the experiences of the participants.

The participants all had some form of treatment, some more extensive than others and in that, also their reactions and experiences around that were very different.

- **Sub-theme 3.3: Scarring**

These quotes focus on how the participants express their thought and feelings around the issue of scarring as a result of skin cancer treatment.

Participant A

... Which left a very big lesion.

Participant F

... Fears of her being disfigured and having scars in her face, which devastated me.

Participant I

... Really scarred him badly, I think that did cause a lot of stress for both of them.

Participant L

... The scar now runs from her forehead down to the tip of her nose.

Participant M

... Will the skin close again, and how I would look afterwards. I was concerned about the long scar.

I must say I'm relieved that the scar is very minimal and neat and I'm very relieved that all of it was removed successfully.

Discussion sub-theme 3.3

The diagnosis of a skin cancer can produce emotional scars of two kinds, the first the initial weight of the diagnosis of a cancer and its implications, the second having to deal with the psychosocial burden of disfigurement and change in body image which - despite recent advances – may last a lifetime. The term “scar” encompasses a spectrum of marks left on the skin as a result of healing and can lead to disfigurement, functional impairment and pain. Excision treatment is the treatment that the majority of patients suffering from basal cell carcinoma, squamous cell carcinoma or melanoma receive, with inevitable scar formation (Todkill 2006:10-12).

The interviews showed that the biopsychosocial approach was appropriate in this study, as the majority of patients were more relieved that the cancer (the bio) had been removed than the actual scarring. The family members definitely showed more concern over the appearance of the patients than the patients themselves (social). One could speculate that the patients are more aware of the possible

outcome than the family members or that the family members are in a state of denial over the possible outcome (psycho).

- **Sub-theme 3.4: Prognosis**

The following statements show the participant's version of the prognosis of their own skin cancer diagnosis.

Participant A

The first time I had skin cancer was 32 years ago.

Participant D

I had skin cancer for the first time in the early 1990's.
... it was squamous cell cancer, which doesn't spread as I understand it like melanoma does. In a way that was a relief, but the reality that one is not immune to cancer if one had had one form of it!

Participant I

My mom and dad weren't too distressed after it was first removed, but it returned and had spread to other glands in and around his face ...

They could also provide more information on what to expect and how serious it is. It was never really spoken about and he eventually died of it after it spread and it could not be contained any longer. Other treatments were not advised because of his age and his bad prognosis.

Participant J

He went down very fast after his operation and died months from being diagnosed with skin cancer.

Discussion of sub-theme 3.4

The majority of patients had basal and squamous cell cancers that were removed with no serious consequence. One participant had melanoma which had been removed before it had spread and one patient of which the family was interviewed had melanoma which had spread and one with squamous cell carcinoma which had spread. In both cases where the cancer had spread, the patients had deceased of skin cancer. Some of the participants illustrated relief at the confirmation of basal and squamous cancers rather than the more dangerous melanoma. This indicates that the cure rate for cancer that is detected earlier is very good.

Schofield et. al. (2002:3) states that “most in the medical community now agree that patients have a moral and legal right to know the truth about their illness”. Patient satisfaction is a popular outcome measure and has been positively related to information provision, uninterrupted time spent with the patient in an appropriate environment. Patients being offered a choice in treatment have been significantly related to patients’ subsequent psychological adjustment. Lower levels of anxiety were observed amongst patients who reported having their need for life expectancy discussions satisfied and being able to discuss their questions the same day as the diagnosis. Patients reporting that the doctor talked about their life expectancy were more likely to express lower levels of depression than other patients. Whether the doctor talked about the severity of the cancer was not significantly related to over time; however, there was a significant interaction effect between this factor and time (Schofield et. al., 2002:3). Thus the connectedness between the bio and the psycho in the biopsychosocial approach was illustrated here.

3.8.2.4 Theme 4: Post diagnosis mindfulness and behaviour change

This focuses on how participants became more mindful and how their behaviour changed after a skin cancer diagnosis.

- **Sub-theme 4.1: Check-ups, self-awareness, prevention**

This theme describes how participants described their responsiveness of check-ups, self-awareness and prevention of skin cancer.

Participant C

I do go for check-ups once a year as he has suggested, but there really is nothing I am concerned about.

Well, they’re very concerned with sun protection and hats and suntan lotion is part of any outdoor activity – sports or braai, which ever.

Participant D

Well, I certainly do not leave the house without a day cream containing some sunblock. Also, when I do gardening or spend longer periods outside I always wear a hat since then. Times have changed, you see – when I was younger, in the 60’s and 70’s tanning was very important. You’d do anything to get as tanned as you possibly can! I now always ‘preach’ to my children and grandchildren to put on sunblock and wear hats and protective clothing as far as possible to prevent them from

getting skin cancer. I know for some tanning is still very important, but I promote 'safe tanning' – they must put sunblock on, always!

Participant E

Also, knowing I now have to go for regular check-ups for the rest of my life really depressed me.

Participant G

I will always have it in mind to protect her skin and think of things like, are there trees or shade and take the season and everything into consideration. My first priority is to block the sun away from her because all we can really do to prevent this is to stay out of the sun and not get burnt.

And not just the bills, sunscreen is also very expensive and it's a priority and I think should be covered by medical aids when a patient is diagnosed with skin cancer – it's a chronic illness because in South Africa we all spend a lot of time in the sun because of the climate. There should also be more information on the effects of the sun in general, I think.

Participant H

I am now very responsible when in the sun. I wear protective clothing and regularly put on sunblock. I also raise awareness for other regarding sun safety. I also encourage youngsters to take good care of their skin.

Participant L

And of course after care is of vital importance – people should be encouraged to go for their regular check-ups to ensure that any possible re-occurrence are attended to a.s.a.p. to prevent the spread of melanoma for example, which I've seen many people cost their life.

Participant M

I can just say that if anyone asked my advice is that one should not wait to have anything suspicious checked out. Also, if like in my case your GP burned or froze off something and it returns, rather see a dermatologist and make sure it's not something sinister.

Well I always, always use sunblock now and a hat if I must and I try to keep out of direct sunlight.

But young people don't think of the long term consequences, they live for the moment and just enjoy life. But, if you can prevent something, you should.

Discussion of sub-theme 4.1

Causes of skin cancer, according to Daniel, 2005:408 include: Excessive sunlight (90% of cases), genetic inheritance (2% of cases), compromised immune function (with co-existing leukaemia or lymphoma or when using immune suppressant drugs e.g. after transplants), radiation, multiple skin moles, use of sunbeds, chronic leg ulcers, occupational exposure to tar, asphalt, pitch, waxes, heavy oils (including shale oil) and arsenic, a diet which is low in vitamin A, beta-carotene and vitamin C and a high fat intake.

From the information gathered by the participants, it supports the theory that in 90% of the cases, skin cancer is caused by sunlight. All the participants enjoy the outdoors, sports and nature, which usually exposes them to sunlight regularly. Most of the interviewed patients report that they take precautions and have regular check-ups. The participants that are family members reported that they are very aware and supportive of regular check-ups and prevention, in general, but especially for the patients. There is a clear level of self-awareness in patients in that they analyse past behaviours and have modified these.

3.8.2.5 Theme 5: The needs of skin cancer patients and their families

The following extracts focus on what the participants felt the needs of skin cancer patients and their family members are.

- **Sub-theme 5.1: Awareness in families**

This sub-theme focuses on extracts on awareness of skin cancer within families of skin cancer patients.

Participant B

No, not what I can recall of. Only, as my wife mentioned, my daughter has had some small spots, similar to mine burnt and she goes for check-ups regularly now.

Participant D

I now always 'preach' to my children and grandchildren to put on sunblock and wear hats and protective clothing as far as possible to prevent them from getting skin cancer. I

I'm not too sure, not that I really know of – maybe it didn't have a name? Those days' people couldn't say the word 'cancer' even – as though you're casting a bad omen on yourself!

Participant E

Some of my family members had little skin cancers that they had burnt off by their doctor's ...

Yes, my grandmother and two of her brothers.

Participant H

Yes, both my parents had skin cancer, but none of my 5 brothers except for me.

Participant L

My mother had basal cell carcinoma ...

Discussion of sub-theme 5.1

Melanoma sometimes runs in families. Having two or more close relatives (mother, father, sister, brother, or child) who have had this disease is a risk factor for developing melanoma. Other types of skin cancer also sometimes run in families. Rarely, members of a family will have an inherited disorder, such as *xeroderma pigmentosum* or *nevroid basal cell carcinoma syndrome*, that makes the skin more sensitive to the sun and increases the risk of skin cancer (National Cancer Institute, 2010).

The interviews clearly show a familial predisposition to skin cancer as most of the participants indicated that there has been skin cancer in the family.

It became evident that there is now, since being diagnosed or having a family member diagnosed with skin cancer, a definite awareness of it, the causes, how to prevent it, and how to identify it.

- **Sub-theme 5.2: Honest and truthful information**

Participant E

That was bad – I know basal cell and squamous cell carcinoma was sort of okay to deal with and not fatal, but melanoma was the evil one that spread where you don't see it. I was back in theatre a few days later and a bigger incision was made.

But I also knew then that I can and have had melanoma, which was very sad for me.

Also, knowing I now have to go for regular check-ups for the rest of my life really depressed me. I felt almost sentenced to suffer and worry for the rest of my life because neither my skin, nor the sun is going to go away.

Even more so, after I had a melanoma I felt like this is never ending drama and surely a life sentence.

Participant G

... How long will she live and will she die because of the cancer.
... Pray that they can remove all of it and we stress until we hear from the doctor that all is clear.
... Also concerned about paying the bills

Participant H

... Doctor however assured me that it is at least a curable skin cancer, which comforted me somewhat.

Participant K

... The doctors and skin specialist said the Melanoma skin cancer would eventually kill him.

Participant L

I am a nursing sister and have seen people being severely scarred and disfigured by skin cancer excisions and treatments, so when I learnt that it will have to really be operated on and they were talking of grafts and flaps, I was very concerned. I tried to be honest with my mother about it all and that it really is necessary and must be done. She is 84 and a very smart, proud lady, who always takes good care of herself and enjoys dressing up and wearing makeup and looks after herself really well.

Yes, I had the support of the doctors, who are colleagues of mine and it was good to have open conversations with them and also them making the time to really sit with my mother and discuss all the options and giving her opportunity to express her fear. I think I also gave her comfort in knowing I won't hide anything from her and she knew exactly what was going on.

Discussion of sub-theme 5.2

The responses from the interviews show that clear and truthful information from medical professionals reassures both patients and family members. It is mentioned more than once that just the word 'cancer' instils fear and shock and that upon receiving more comprehensive information from doctors on the type of cancer and prognosis patients and family report being comforted by this

confirmation. Thus the use of the biopsychosocial approach when intervening is again of essence.

Research findings by the National Breast Cancer Centre suggest that patients desire to know both positive and negative aspects of their prognosis, but that specific information preferences are diverse. One approach consistent with the data is to tell patients what type of prognostic information is available, then ask how much of this information they want to hear. It appears best to discuss prognosis in relation to the outcomes for each different treatment option, and to emphasise the hope-giving aspects of each option. Focusing on what can be achieved, rather than what cannot be achieved, is a useful strategy (National Breast Cancer Centre, 2003:247).

It seems that the severity of the condition and stages of cancer of the two deceased patients was not initially explained to them in a more comprehensive way, which makes one wonder whether the patient was informed of the situation and prognosis or whether perhaps the family would protect them from the truth.

According to Schofield et al., (2002:3): “..most in the medical community now agree that patients have a moral and legal right to know the truth about their illness”. However, the medical principle of *primum non nocere* may be threatened if a blanket policy of full disclosure is adopted, since not all patients wish to be given all the details of their illness. In an area dominated by expert opinion, the pertinent issue is to determine which communication practices make a measurable difference to patient outcome.

- **Sub-theme 5.3 Faith/Religion/Beliefs**

This sub-theme focuses on comments made by participants relating to faith, religion and beliefs when exploring their experiences of skin cancer.

Participant C

They came with age, you see – I am almost 80, you know? So for me as an old man who has lived my life, it really wasn't anything serious or had real effect.

Yes, my dear, I think if you're over 70 and these things happen, then it's not too bad. There is still a lot to be thankful for.

Participant D

In a way that was a relief, but the reality that one is not immune to cancer if one had had one form of it!

Participant E

But I continue living life now, knowing that I can only do what I can do in preventing it and if I go for regular check-ups, I should be fine. But, I cannot stop living until I stop living, so I choose to live life and still enjoy nature. I think being a believer helps as well.

Participant G

Every time there is something we stress a bit and pray ...

Participant H

I know I have to go because the sooner something is found, the better your outcome, but I'm always nervous for what he may find. I also keep an eye out myself and regularly check my skin.

Discussion of sub-theme 5.3

Distress has been defined as “an unpleasant experience” of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis (National Cancer Institute, 2010).

Some participants indicated comfort gained from their faith and prayer as part of the process of dealing with cancer. Responses from some of the older patients indicate a kind of complacency with age and the nature of life. The interviews also show that a good support structure, whether it is family or friends also brings much comfort for patients.

In general it is important to encourage all individuals to talk about the illness and its impact and to offer appropriate support. Directly confronting the reality of the illness and openly expressing emotions appears to be associated with enhanced adjustment whereas avoidance of issues is associated with higher levels of distress. Therefore it is important to encourage the individual to talk about the

illness and its impact and to offer appropriate support whilst recognising individual preferences (Schofield et. al, 2003:44).

It is therefore of great importance that skin cancer and their patients are supported, as this need was clearly identified from most participants, thus emphasising the biopsychosocial approach be implemented.

- **Sub-theme 5.4: Counselling and support**

Sub-theme 4 refers to patients' comments around counselling and support they received and/or needed during their skin cancer experience.

Participant E

... Shock. I thought I was going to die! I did not at all expect this. I felt like saying good-bye to everyone.

Also, knowing I now have to go for regular check-ups for the rest of my life really depressed me. I felt almost sentenced to suffer and worry for the rest of my life because neither my skin, nor the sun is going to go away.

... Never ending drama and surely a life sentence.

... Sounds freaked me out. Also when the doctor spoke to the sister and wondered how he would get the skin together to stitch it up as it was a big spot and the skin was under a lot of stress. It was very overwhelming and upset me quite a lot.

Participant F

I'm not too sure if she went on to seeing someone. I did not, but we talked about it a lot. I do think for someone to hear the word cancer must be very traumatic – because it certainly was for me and it wasn't even my own diagnosis. I think perhaps people should have support at hand and know that they don't have to go through all of these emotions alone. Especially people who do not have such close family relations, love and support.

Participant G

There should also be more information on the effects of the sun in general, I think.

I think someone who has skin cancer should get immediate support or counselling. Even for me it was the biggest shock every hearing that word. People don't know that it's okay to stress until they're told it is, so someone should be there since the beginning of the process at the diagnosis for the patient and any other people close to them. It should also not be a secret and people should all help in raising awareness so that people can take more precaution in general.

Participant I

I would say regular visits from a social worker or counsellor or a Pastor, and also nurses to care for the wounds, especially in older, less mobile patients. They could also provide more information on what to expect and how serious it is. It was never really spoken about and he eventually died of it after it spread and it could not be contained any longer. Other treatments were not advised because of his age and his bad prognosis.

Discussion of sub-theme 5.4

Many of the participants indicated that a greater level of education on the dangers of skin cancer and especially the effect of the sun would have prepared them. Some also indicated that support from social workers or pastors could provide the correct counselling through the entire process and not just in the worst case scenario. As mentioned previously, a number of the participants found comfort in truthful information.

Cancer care today often provides great biomedical treatment, but fails to address the psychological and social (psychosocial) problems associated with the illness. This failure can compromise the effectiveness of health care and thereby adversely affect the health of cancer patients. Psychological and social problems created or exacerbated by cancer – including depression and other emotional problems; lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family life – cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health (National Academy of Sciences, 2008).

With all the emotion participants expressed, the support they had, the support they needed and the perceived supported needed provided by them, it is evident that the multi-disciplinary team has to also consist of spiritual, emotional and counselling professionals as part of the care plan patients are offered and that a holistic approach, such as the biopsychosocial approach is implemented.

From the information gathered there was also a lot of information on how much and what type of support the patients and their family members needed. How they would want it and what they perhaps needed and did not get through their experience with skin cancer.

- **Sub-theme 5.5: Medical and other expenses**

This sub-theme refers to mention made by skin cancer patients and/or their family members around the medical and other expenses they incurred during their skin cancer ordeal.

Participant E

The tests came back and it was indeed basal cell carcinoma and I now had to go every three months for check-ups.

Participant F

My only consolation was that we had good medical care and medical aid, so I knew we are able to do the best under the circumstances and having a plastic surgeon operate to minimize scarring.

She is also very responsible and knows that a good medical aid is vital for her problem skin.

Participant G

I support and encourage her the whole time to keep out of the sun and to check her moles and to see her doctor every six months as she is expected to.

Me too, but then I'm also concerned about paying the bills and that the medical aid is a priority because of this because she has had skin cancer so many times and it seems to be something that doesn't really stop. And not just the bills, sunscreen is also very expensive and it's a priority and I think should be covered by medical aids when a patient is diagnosed with skin cancer – it's a chronic illness because in South Africa we all spend a lot of time in the sun because of the climate. There should also be more information on the effects of the sun in general, I think.

Participant I

I would say regular visits from a social worker or counsellor or a Pastor, and also nurses to care for the wounds, especially in older, less mobile patients.

Participant K

We had to do a lot of driving around and since I don't drive ...
... To the end when he went to hospital just before he died.
He was admitted to hospital twice ...
He also went to a pain specialist ...
... Walked with crutches. He had to sleep in the lazy boy and could no longer sleep in our bed, as it was easier for him.
... From the oncology people and the Hospice

Participant M

The doctor then referred me to a plastic surgeon to do the surgery.

When I got out of theatre, I had a huge bandage and could feel stitches all the way from my forehead over the length of my nose, but the pain was under control and it was covered neatly, albeit largely. Fortunately my medical aid paid for it all as I do have a good medical aid.

Discussion of sub-theme 5.5

Financial needs can arise from the high costs of medical treatment, drugs, and other health support needs, such as medical supplies that are not covered by insurance and/or are beyond an individual's income level. This financial stress is compounded when a patient suffers a job loss, is not working during periods of treatment, or lacks health insurance (National Academy of Sciences, 2008).

Various responses indicate that patients had extensive medical aid which assisted them in finding the correct help and not being hampered by finances. This could also be because the participants were found by using patients from private practices. One could also assume that some of the older participants who did not mention medical aid or financial issues were also supported by their families financially. It remains a reality that goes along with treatment and could lead to concern for patients as treatment can result in absence from leave, even during annual or more frequent check-ups. It is important that this concern is assessed and addressed where necessary.

3.9 Summary

From the interviews held and the information gathered, five themes were identified and discussed. The psychosocial experiences of a skin cancer diagnosis and treatment were explored from a biopsychosocial approach and the themes and sub-themes discussed, made it clear that participants did have a variety of psychosocial experiences of skin cancer diagnosis and treatment, albeit seen as curable, less lethal cancer and very common.

The themes and their sub-themes from this study were:

Theme one Lack of knowledge around skin cancer	✓ Nature of skin cancer ✓ Knowledge resulting in behaviour change
Theme two Reaction to diagnosis	Sub themes: ✓ Cognitive and Emotive

Theme three Treatment	Sub themes <ul style="list-style-type: none"> ✓ Types of treatment ✓ Experience of the treatment ✓ Scarring ✓ Prognosis
Theme four Post-diagnosis mindfulness and behaviour change	Sub themes <ul style="list-style-type: none"> ✓ Preventative Behaviour ✓ Thought Processes
Theme five: Support structures	Sub themes <ul style="list-style-type: none"> ✓ Awareness in families ✓ Honest and truthful information ✓ Faith/religion ✓ Counselling and support ✓ Medical and other expenses

The next chapter will include the conclusions and recommendations from this study.

4. CHAPTER FOUR: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

In this final chapter the summary of the research will be discussed. The focus will be on how the aim and objectives of the study were met, as well as whether the research question was answered. Conclusions from this study will be made from the literature review and according to the key findings from the five themes and their sub-themes that were obtained from this research. This will be followed by recommendations for practice and for future research.

4.2 Summary

The objectives, aim and research question will subsequently be addressed and how they were met.

4.2.1 The objectives of the study

To achieve the aim of the research study, the following objectives were pursued:

- To describe the phenomenon of skin cancer, including the various types of skin cancer, causes, symptoms, diagnosis, disease progression, treatment options, as well as the psychosocial aspects.
- To explore the psychosocial experience of a skin cancer diagnosis by patients and their families.
- To explore the psychosocial experiences of skin cancer treatment by patients and their families.
- To formulate guidelines for social workers in terms of intervention with skin cancer patients and their families.

Objective 1 - To describe the phenomenon of skin cancer, including the various types of skin cancer, causes, symptoms, diagnosis, disease progression, treatment options, as well as the psychosocial aspects

This objective was achieved through the conducting of a literature study of skin cancer, the causes, symptoms, diagnosis, disease progression, treatment options,

as well as the psychosocial aspects thereof. Medical terminology and key concepts were also defined.

Objective 2 - To explore the psychosocial experience of a skin cancer diagnosis by patients and significant others

This objective was achieved by conducting a literature study which also focused on the experience of the diagnosis of skin cancer as well as through the literature review and the empirical research conducted. The literature review in chapter 2 described the theoretical framework, namely the biopsychosocial approach underpinning this study. It then focussed on cancer, the skin and skin cancer, the various forms, treatment options, the causes and prevention. Lastly it described the psychosocial experience it has on patients and their families. The research showed that both patients and their families are affected by skin cancer, the diagnosis, as it was described as unexpected and a shock by most and they were affected on the bio, the psycho and the social spheres, supporting the biopsychosocial approach.

Objective 3 - To explore the psychosocial experiences of skin cancer treatment by patients and significant others

This objective was achieved by means of the literature review in chapter 2, as well as the empirical research. Family members and patients shared their experiences as participants, indicating that the type of treatment and the stage of the cancer has an immense impact on variables such as pain, trauma and scarring for example. The treatment affected them on the bio, the psycho and the social spheres, supporting the biopsychosocial approach. It became evident that a lot of support is needed by skin cancer patients and their families during this time.

Objective 4 – To formulate guidelines for social workers in terms of intervention with skin cancer patients and their families

This objective was achieved and is provided in the recommendations: guidelines for practice made later in this chapter. These recommendations are grounded on

the research findings and conclusions drawn from the exploration of the psychosocial experiences of a skin cancer diagnosis and treatment on a patient and their family.

4.2.2 Aim of the research

The aim of the study was: to explore and describe the psychosocial experiences of the patient and family of skin cancer diagnosis and treatment.

Chapter 2, the literature review, explored the types of skin cancer, the treatment options, causes and prevention of skin cancer as well as focussing on the psychosocial impact of a skin cancer diagnosis and treatment, as well as the role of the social worker within this.

From the empirical research the following themes were generated, reflecting the experiences of patients and family of skin cancer diagnosis and treatment from a biopsychosocial perspective: lack of knowledge around skin cancer, reaction to diagnosis, treatment, post-diagnosis mindfulness and behaviour change and support. Sub-themes identified and discussed were the nature of skin cancer, knowledge resulting in behaviour change, cognitive and emotive reactions, types of treatment, experience of the treatment, scarring, prognosis, preventative behaviour, thought processes, awareness in families, honest and truthful information, faith/religion, counselling and support and medical aid.

This aim was achieved by achieving all the objectives

4.2.3 Research Question

The research question in the context of this study was:

What are the psychosocial experiences of patients and their family of a skin cancer diagnosis and treatment?

From the data collected during the in-depth interviews with participants themes and sub-themes were generated relating to their psychosocial experiences of patients and family of a skin cancer diagnosis and treatment. These themes and sub-themes were discussed in chapter 3 of this study.

Table 4.1: Themes and sub-themes of this research

Themes	Sub-themes
Theme one: Lack of knowledge around skin cancer	✓ Nature of skin cancer ✓ Knowledge resulting in behaviour change
Theme two: Reaction to diagnosis	Sub themes: ✓ Cognitive and Emotive
Theme three: Treatment	Sub themes: ✓ Types of treatment ✓ Experience of the treatment ✓ Scarring ✓ Prognosis
Theme four: Post-diagnosis mindfulness and behaviour change	Sub themes: ✓ Preventative Behaviour ✓ Thought Processes
Theme five: The needs of skin cancer patients and their families	Sub themes: ✓ Awareness in families ✓ Honest and truthful information ✓ Faith/religion/beliefs ✓ Counselling and support ✓ Medical and other expenses

4.3 Key findings and Conclusions

The following key findings and conclusions are made based on the research methodology, literature study and empirical findings of this study. The researcher is of the opinion that the findings of this study cannot be generalised, but could be transferable to similar populations.

A qualitative approach was appropriate for this applied study, using the phenomenological research design and unstructured interviews to gather the data. The researcher was able to obtain first-hand rich information, as it allowed the participants to share their deepest thoughts, feelings and experiences freely with the researcher. The information gathered was in the form of words and concepts, which gave meaning to the participants' experiences of a skin cancer diagnosis and treatment. The qualitative data analysis process, with the transcription of the interviews, the generating of themes and sub-themes, and the subsequent

analysis and interpretation proved to be an enriching experience for the researcher.

The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery (Cohen and Brown Clark, 2010). In using the biopsychosocial approach, skin cancer and the experience of patients and their families guided an adoption of a very holistic approach to the research.

From the literature study in Chapter 2 it was concluded that cancer, from the moment of being diagnosed and through the treatment process, can affect patients and their families. Cancer is the uncontrolled growth of cells that could be attributed to a variety of factors, including genetic factors, lifestyle and could affect everyone from all races and walks of life. The treatment for skin cancer includes a variety of surgical options and chemotherapy. Patients and family members need to be thoroughly prepared for these options, so as to reduce their anxiety and uncertainty. Patients and family members are affected by skin cancer on a bio, psycho and social sphere, which supports the use of the biopsychosocial approach. They need support to cope with the diagnosis and treatment, as this could affect people in their personal, family and work life. The role of the social worker in the team, with regard to the skin cancer patient and family is important and was also explored, with the emphasis on the biopsychosocial approach, in holistically looking at the experiences of the skin cancer patients and family and thereby determining their need for intervention. As this approach encompasses biological, social and psychological factors as considerations, when looking at social work in health care intervention, this approach serves to be the most suitable in assessing the experiences of skin cancer patients and their families, but also in emphasising the role of the social worker in this field of oncology. Subsequently, the conclusions regarding the themes generated from the study are discussed.

4.3.1 Theme One: Lack of knowledge around skin cancer

The research showed that the participants had very little to no knowledge of skin cancer. This includes awareness, knowledge of what it looks like, how to prevent or identify it, nor the knowledge that the sun is the biggest contributing risk factor.

Although the participants had knowledge that they were diagnosed with skin cancer, some of them would not even call it that. They would refer to ‘*spots*’ or ‘*rodent ulcers*’ or even ‘*sun spots*’. Most were unsure of what type of skin cancer they actually had and of the staging thereof.

Sub-theme 1.1: Nature of skin cancer

Most of the participants mentioned that they had a ‘*spot*’ that would not heal or a ‘*sore*’ that would not heal. Despite that being a clear warning of skin cancer, the participants did not have the knowledge to identify it as a potential skin cancer. All of them had eventually gone to a doctor, who then diagnosed it as skin cancer. None of the participants expected a diagnosis of skin cancer.

Sub-theme 1.2: Knowledge resulting in behaviour change

After being diagnosed with skin cancer, most participants had changed their ways, especially around unprotected sun exposure. Most of the participants had been exposed to the sun a lot and enjoyed the outdoors in ways like tanning, doing sports like bowling, running, and tennis, hiking and cycling. Most of them and their families had since the skin cancer diagnosis changed their lifestyles in being more aware of sun protection and skin cancer prevention. Some of the participants shared that they had gone to extreme measures to obtain a tan in the past and if they’d known what they were doing to their skin, they would have done things differently.

4.3.2 Theme Two: Reaction to diagnosis

Sub-theme 2.1: Cognitive and Emotive

None of the participants expected a skin cancer diagnosis. Most of them were very shocked and one or two mentioned that it was not really very traumatic for them. Mostly the female participants expressed shock and disbelief or elaborated on their emotions around the diagnosis. The oldest participant was very complacent

about it and mentioned that at his age it's not that big of a shock, whereas the youngest patient participant expressed that she feared dying. It is evident that the unexpected nature of skin cancer contributes to the shock people have when being diagnosed without an expectation of being diagnosed with skin cancer. Within these findings, the biopsychosocial approach was found to be appropriate, as it rendered the opportunity to understand each participant's experiences, as the approach allowed for the biological, psychological and social factors to be considered.

4.3.3 Theme Three: Treatment

Sub-theme 3.1: Types of treatment

Interestingly the participants mentioned most of the treatment options. Two patients who had passed away of skin cancer had more invasive treatment as they both had extensive multiple surgeries and one had chemotherapy as well as radiation. Some mentioned having been given ointment to apply, which may well have been a form of chemotherapy. Patients referred to 'burning' and 'freezing' or having had cancer 'removed' or 'cut out' and interestingly not to cryosurgery or surgery. The participants' treatment experiences, could holistically be explored and analysed by applying the biopsychosocial approach on three levels – biologically, psychologically and socially.

Sub-theme 3.2: Experience of the treatment

Some participants expressed discomfort and some expressed severe discomfort and or pain. It was evident that the extensive nature of the treatment did imply a variation in how patients experienced the treatment. One participant who had surgery in her face, near her ear, mentioned the trauma of having been operated on and hearing everything so intensively. The family members of both deceased skin cancer patients mentioned how extreme the surgeries were and how much support the patients needed after having had extensive treatment. One of these family members mentioned that they had to request pain medication and that the patient's pain was not under control, thus it was a painful agonising experience. The biopsychosocial approach to this research, assisted in not only exploring the biological experiences of skin cancer patients and their families of the treatment,

but also the psychological (emotional) and social (relationship) experiences and effects, ranging from discomfort to trauma as they expressed it.

Sub-theme 3.3: Scarring

The issue of scarring came up and again, interestingly the family members of patients mentioned that more than the patients themselves. Family members mentioned that they would motivate or try to console the patient with words and encouragement and mention that the scars are not too bad, or one could hardly see them. It seems however that for the patients, that their concerns lie more with being cured than with the aesthetics of their healing or scarring. Again, it must be noted that the surgical procedures were done mostly by a dermatologist and a plastic surgeon that are both specialists had a keen interest in skin cancer. Participants did perhaps not expect the same standard of work from a GP or general surgeon.

Sub-theme 3.4: Prognosis

Two of the participants were family members of patients that had died of their skin cancer. In both cases extreme measures were taken to treat them, but evidently the stages they were in decreased their prognosis. Initially it also seemed that all the family involved did not expect death upon first learning of the skin cancer diagnosis. Only later when begin informed of the stages and metastasis, were they aware of the potentially lethal consequences of skin cancer. All the other participants had fairly superficial skin cancers and mostly basal cell and squamous cell carcinomas. Interestingly, although the theory mentioned that melanoma is the most likely skin cancer to be incurable to metastasise fast and potentially fatally, the one incident was in fact squamous cell carcinoma that started on a patients' ear. One patient participant also had melanoma, which was fortunately in stage 2 or 3, as it was contained after a second surgery. It seems from the information gathered that patients do need education on skin cancer in general, but also on the stages and prognosis involved as there is a lot of ignorance around it.

4.3.4 Theme Four: Post diagnosis mindfulness and behaviour change

From the findings it is clear that skin cancer patients and family members of skin cancer patients are far more mindful after a skin cancer diagnosis and treatment.

This was ascertained by the underpinning of the biopsychosocial approach to health care within this study, as the participant's reactions and behaviour could be explored on a biological, psychological and social level. Specifically on the psychological and social spheres, it was found that the participants indeed had made great changes in their thoughts and behaviour around protecting their skin in the future from further skin cancer.

Sub-theme 4.1: Preventative behaviour

Almost all participants confirmed that they take better care of themselves now not to get sun burnt and also not to allow their family members or loved ones get burnt as they are aware of the consequences of that now. Hats and sunblock seemed to now be at the order of the day and a norm when doing sports and outdoor activities and shade and avoidance of direct sunlight as well.

Sub-theme 4.2: Thought processes

Most participants mentioned that they still enjoy their active, outdoor lifestyles, but that they do ensure they wear hats, sunblock and avoid the harsh sunny hours of the day to be outdoors. Some patient participants now keep their children and grandchildren safe and some family participants expressed great motivation to ensure that their loved ones do not get exposed to the sun unnecessarily. They are thereby ensuring that the next generation has the information they perhaps did not have that early in their lives.

4.3.5 Theme Five: The needs of skin cancer patients and their families

This theme proved to be an important need expressed by participants.

Sub-theme 5.1: Awareness in families

It seems from the findings that there is awareness in families of skin cancer as well as the awareness that other family members of some participants have also had skin cancer. Whether they were aware of that before their own skin cancer diagnosis, or only after, remained uncertain and could be an interesting exploration for future research.

Sub-theme 5.2: Honest and truthful information

From the comments participants made, it was clear that not everyone felt that they had understood the implications of a skin cancer diagnosis and treatment fully. It was mentioned by more than one participant that they had not expected the invasive nature of the treatment and also in the two cases where death had occurred; it was not initially anticipated by the family members. One participant had consciously explained the processes and procedures to her mother who was diagnosed with skin cancer before surgery in order to ensure she had no misconceptions of what is happening and what the consequences would be. It is never a pleasant task to have to communicate bad news, but from the findings, skin cancer patients and their family members expressed the need to have honest and truthful information given to them by both the professionals and the family members.

Sub-theme 5.3: Faith/religion/beliefs

Faith, religion or beliefs were identified as playing a role in the lives of most participants. One family member mentioned that the patient really benefited from her Pastor visiting her in hospital. One family member mentioned that there was no Pastor involved, as if she would have expected it or they potentially would have appreciated that. One participant referred to God's will and plan, which indicates some form of religion or belief system. One participant mentioned that being only diagnosed with skin cancer at his (older) age is nothing to complain about, which also indicated some sort of belief that being older implies getting ill or suffering. A younger participant expressed shock and fear of death when she was diagnosed, which implies a belief system that it was not acceptable to die so young perhaps. Many participants mentioned enjoying the outdoor and spending time in nature. Another participant believed that going to his check-ups are vital as he believes the sooner another skin cancer is diagnosed potentially the better his prognosis would be. Tapping into this type of information is of vital importance in establishing a patient's or family's belief systems, potential resources and needs as their faith, religion and/or beliefs contribute to their understanding of their circumstances, as well as could be a major support or coping system for them, when it is acknowledged and applied correctly and suitably.

Sub-theme 5.4: Counselling and support

Many of the participants mentioned that they would have benefitted from counselling and support. There was also mention of their ignorance around skin cancer and that information would have been very important to them in understanding their situation and the way forward. Participants also expressed feelings of shock and anxiety at the time of diagnosis. The treatment was also expressed by some participants as daunting and it was not mentioned that any participants had had counselling or debriefing at any time during their processes of being diagnosed and treated. It is important that counselling or debriefing is not neglected for skin cancer patients, and perhaps close family members, to address and support their concerns and fears around the shock, the treatment challenges and possibly also accepting and working through scarring and a lifestyle of consciousness to prevent skin cancer and frequent check-ups.

Sub-theme 5.5: Medical and other expenses

There was mention amongst some of the participants that skin cancer and treatment and death, in one instance, had posed unexpected financial expenses. Regular check-ups were mentioned. Since all of the participants were patients of private doctors who are specialists, it must also be taken into account that specialist fees were relevant. Not only did they mention doctor's fees, but also that of hospital stays, theatre time, anaesthetists, travelling for patients and family member who visit and support them. Counseling was mentioned, which will probably also imply extra costs if not provided by the specialist or hospital in other circumstances. One participant also mentioned that a plastic surgeon operated on his family member, which gave him comfort for minimum scarring for the patient's sake. There was not mention of any patient that they could not afford the costs, but that there was many expenses. This may not be the case for all patients and families that are affected by skin cancer. It is important to be aware of this concern, as well as the practicalities around it in order to offer effective support to skin cancer patients and their families.

4.4 Recommendations

The recommendations from the research findings will firstly be discussed, followed by the recommendation and guidelines for practice and lastly the recommendations for future research will be provided.

4.4.1 Recommendations from the research findings

From this research, it was evident that skin cancer patients and their families had little knowledge and awareness around skin cancer. This is an important observation in that this oblivion has a direct influence on the reaction to diagnosis, treatment, post-diagnosis mindfulness and behaviour change, as well as the support structures – therefore on all the themes identified in this research. It is therefore of utmost important that any member of the health care team be made aware of this and that a thorough assessment is done of the patient and family members' knowledge of skin cancer, as this could be indicative of the experience and support they may need.

4.4.2 Recommendations: guidelines for practice

It became apparent that skin cancer patients and family members of skin cancer patients, go through a lot of emotional tumult and therefore it is of vital importance that the medical personnel or the multi-disciplinary team be aware of this when working with skin cancer patients.

It was clear that at the point of diagnosis patients and their families have a lot of shock and disbelief to work through. Some even have immediate fears of death whereas others are oblivious of the severity of the condition. The whole team should benefit and in that, also the patient and their families if they are well educated not only in their scope of practice, but also in exceptional communication skills in order to ensure that information is given, clarified and repeated to ensure all involved really understand their diagnosis, staging, treatment options, effects of treatment and support structures are identified.

It was mentioned as a need from participants, but also noted in theory, that knowledge or a good understanding of a condition and of the treatment lowers anxiety levels. All members of the multi-disciplinary team should ideally be aware and motivated to ensure patients' emotional needs are identified and addressed. Social workers have a vital role to play, as their skills to identify needs and deal with emotions are highly developed and have a good understanding of the family

as a support system, as well as connecting patients and families with support systems within their environment and community.

In applying the biopsychosocial approach, relationships were recognised as central to providing health care. Self-awareness should be used as a diagnostic and therapeutic tool. The patient's history should be elicited in the context of their life circumstances and it must be decided which aspects of biological, psychological, and social domains are more important to understanding and promoting the patient's health. Lastly, multidimensional treatment must be provided.

Social workers as part of the multi-disciplinary team should have the opportunity to be at hand and available, even from the initial diagnosis and thereby supporting the patient and their families even from the onset. They can give patients information and set time for patients to talk through their thoughts and experiences, something clinicians are not always trained, motivated or able to do due to various reasons, time being one constraint.

Social workers could also play a vital role in educating other members of the multidisciplinary team in skills, such as communication skills, listening and observing and thereby ensuring patient and their families levels of distress or anxiety are noted and addressed and the necessary referrals then made for patients, to ensure they get all the care they need, not just the medical interventions.

The social worker will be able to work on various levels as they are all trained to do. On individual level, counselling can be done and awareness and education. Counselling and awareness and education could also be done in a group setting – whether it is a support group for patients, family members, the team, or training or information sessions. All will benefit and support patients and their families. On a larger scale and on community level, social workers can be of great value as educator and advocates within a health care setting or even the wider community in raising awareness of skin cancer and prevention thereof.

4.4.2 Recommendations for future research

Research in future can be done where there is perhaps more focus on the gender differences, or perhaps the age differences of the experiences of skin cancer patients. Larger samples would also contribute to the research and information obtained.

Possible intervention strategies for skin cancer patients and their families could also be a field for future research.

A study converging on a certain type of skin cancer only, would also be more focussed and interesting for future research.

The issue of scarring specifically could also be an interesting study.

Support or care for the family of skin cancer patients is also a potential topic for study, as it became evident that the diagnosis and treatment of skin cancer has severe effects on them too.

It would have been very interesting to see more young participants, to see if a correlation exists between age and experience of skin cancer. The responses are not divided by gender either.

Furthermore, studies which are more representative of the population and represent different racial groups would also be recommended to see if there are differences in the experiences of patients from different racial groups.

4.5 Closing statement

Skin cancer is seen as a preventable, curable and manageable illness given it is diagnosed early and by ensuring prevention and sun safety. Despite this, there are still evidently many people that are oblivious to what causes skin cancer, what it looks like, it's various stages and how it's treated. The shock, disbelief and sometimes denial of a skin care diagnosis were very evident in this study. This implies that people need support. Family members expressed the exact same

needs and perhaps even less denial. The changes, challenges and distress skin cancer patients and their families go through cannot be ignored. They need support on various levels and through various phases of the disease as the emotions around it are dynamic.

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5. Appendices

5.1 Appendix 1: Ethical Approval Letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

10 October 2012

Dear Prof Lombard

Project: The psychosocial experiences of a skin cancer diagnosis and treatment by the patient and family
Researcher: C Human
Supervisor: Dr CL Carbonatto
Department: Social Work and Criminology
Reference number: 25366531

Thank you for your response to the Committee's letter of 1 June 2012.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 9 October 2012. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

A handwritten signature in black ink, appearing to read 'John Sharp'.

Prof. John Sharp
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof A Mlambo, Dr C Panebianco-Warrens; Prof J Sharp (Chair); Prof GM Spies; Prof E Taljard ; Dr FG Wolmarans, Dr P Wood

5.2 Appendix 2: Title Change Registration



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Our Ref: 25366531

25 November 2014

Ms C Human
PO Box 136
TABLE VIEW
7439

Dear Ms Human

TITLE REGISTRATION: FIELD OF STUDY – MSW HEALTH CARE

I have pleasure in informing you that the following has been approved:

TITLE: The psychosocial experiences of the patient and family of skin cancer diagnosis and treatment

SUPERVISOR: Dr CL Carbonatto

I would like to draw your attention to the following:

- 1. ENROLMENT PERIOD**
 - (a) You must be enrolled as a student for at least one academic year before submission of your dissertation/essay.
 - (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be able to have supervision if you provide a proof of registration to your supervisor.
- 2. APPROVAL FOR SUBMISSION**

On completion of your dissertation/essay enough copies for each examiner must be submitted to Student Administration, together with the prescribed examination enrolment form signed by you, which includes a statement by your director of studies that he/she approves of the submission of your dissertation/essay.
- 3. NOTIFICATION BEFORE SUBMISSION**

You are required to notify me at least three months in advance of your intention to submit your dissertation/essay for examination.
- 4. INSTRUCTIONS REGARDING THE PREPARATION OF THE DISSERTATION/ESSAY AND THE SUMMARY APPEAR ON THE REVERSE SIDE OF THIS LETTER.**

Yours sincerely

for DEAN: FACULTY OF HUMANITIES

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5.3 Appendix 3: Permission letter from Doctor de Goede

Dr. Francois H. de Goede Inc.

M.B. CH.B. (Stell.) M.Med. (Derm.) (Stell.)
DERMATOLOOG / DERMATOLOGIST
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19-03-2012

WIE DIT MAG AANGAAN

IS: CARINE HUMAN (STUDENT NO: 25366531)

Hiermee gee ek die ondergetekende, Dr FH de Goede, van bogenoemde adres, skriftelik toestemming dat Carine Human haar navorsing in my praktyk mag doen.

Die uwe



DR FH DE GOEDE
fdg/cvv

5.4 Appendix 4: Permission letter from Doctor Smit

Dr. Christie Smit Ing./Inc.

MB ChB (Stell) M Med (Plast & Rekons)

Plastiese Chirurg • Plastic Surgeon

PR 3601277

Reg No 97/03107/21

209 Panorama Medi-Clinic, Panorama 7500 • christie.smit@xsinet.co.za
Tel 021 930 3982 Fax 021 930 3984 Cell 082 452 4448

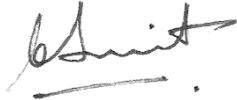
13 Februarie 2008

AANDAG: CARINE HUMAN

WIE DIT AANGAAN

Hiermee verleen ek toestemming aan Carine Human om navorsing aangaande
velkanker en die psigososiale effek daarvan asook die effek van letsels weens
behandeling, deur my praktyk te doen.

Die uwe



DR C S F SMIT

5.5 Appendix 5: Informed consent letter



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Department of Social Work & Criminology

Informed consent letter

Section A: Research information

Researcher: Carine Human (MSW): Health Care

Student nr: 25366531

Address:

PO Box 136

Table View

7441

Dear Participant,

Research Title:

The psychosocial experiences of the patient and family of a skin cancer diagnosis and treatment.

Purpose of the study:

The main purpose of this study is to explore the psychosocial experiences of skin cancer diagnosis and treatment by the patient and family. This study is for the completion of a Master's degree in Social Work in Health Care. The study will take place between September and October 2014. The participants will be selected by means of purposive sampling. Due to the exploratory nature of the study, an unstructured interview will be conducted with each participant.

Process

As a selected participant, a questionnaire will be sent to you to complete via e-mail for you to complete as thoroughly as possible in reflecting your own personal experience.

Confidentiality

Information obtained during this study will be treated with the utmost confidentiality and anonymity will be ensured in the research report. The recorded data will be transcribed by the researcher and pseudonyms (false names) will be given to each participant to ensure anonymity. This data will be used for the purposes of research only.

Risks and benefits

Department of Social Work & Criminology Tel: Number 00 27 12 420 2325/2030 www.up.ac.za
University of Pretoria Fax: Number 00 27 12 420 2093
PRETORIA 0002
Republic of South Africa

There is no direct benefit to you as the participant, although information gathered during the study may provide a better understanding of the psychosocial experiences of skin cancer by patients and family. The data will be stored at the University of Pretoria's Department of Social Work and Criminology for a period of 15 years for research purposes.

Participants' rights during the study

You have the right to withdraw from participating in this study at any time and without any negative consequences.

Financial compensation

As a participant, no form of remuneration or compensation will be provided or offered to you.

Should you have any further queries, please contact the researcher on 0845280598 or carine.human@gmail.com.

Kind regards,

Carine Human (Researcher)

Dr. CL Carbonatto (Research Supervisor)

Section B: Participant Informed Consent

In signing this form, I agree that I am voluntarily participating in this research. I acknowledge that I have read the participant information (Section A). I am aware of what is required of me as a participant and I understand that my identity will be kept anonymous and that all the information will be kept confidential. I may withdraw from this study if and when I wish.

Please complete the following:

Participant permission:

Name & Surname: _____

Signed at: _____

Date: _____

Signature: _____

Researcher:

Name & Surname: _____

Signed at: _____

Date: _____

Signature: _____

Should you have any questions, please contact the researcher at any time.

Carine Human

0845820598