UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

# LIVING WITH A STOMA: THE EXPERIENCES AND NEEDS OF COLORECTAL CANCER PATIENTS AND THEIR FAMILIES

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A research report submitted to the Faculty of Health Sciences, University of Witwatersrand in fulfilment of the requirements for the degree of Master of Science in Nursing

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# DECLARATION

I, Ndaya Mukendi Maguy, declare this research report is my own, unaided work. It is being submitted for the degree of Master of Science in Nursing at the University of the Witwatersrand, Johannesburg. It has not been previously submitted for any degree or examination at any other University.

Signature: …………………………………… Date ……22… day of…August……. 2021

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Protocol number: M190755

# DEDICATION

I dedicate this thesis to God Almighty my creator, my source of inspiration, wisdom, knowledge and understanding. He has been the source of my strength throughout this journey. To him I give all the glory.

# ACKNOWLEDGEMENTS

I thank God Almighty for being with me every step of my life, and for giving me the strength and endurance to conduct this research study.

My sincere gratitude also goes to:

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- The management and staff of an academic hospital where research was conducted for being helpful and supportive.
- All study participants in this research for their openness and cooperation.

# ABSTRACT

**Background:** Colorectal cancer, a disease characterised by a malignant growth anywhere along the colon or rectum, is the fourth most common cancer in terms of incidence and responsible for deaths throughout the world, which signifies a complex public health problem. Stoma creation remains an important treatment option for colorectal cancer, but it has a considerable impact on a patient's life afterwards. South Africa, as one of the developing countries, is affected by colorectal cancer due to lifestyle causes such as diet low in fibre and high in fat and calories, smoking and alcohol use. Despite the severe problems and consequences of living with a stoma, little is known about the experiences and needs of the colorectal cancer patients living with a stoma and their families in South Africa.

**Aim of the study:** The study is aimed at describing the experience and needs of the colorectal cancer patients living with a stoma and their families, treated at an academic hospital in Gauteng, South Africa.

**Design and methods:** A descriptive qualitative design was utilised for the conducting of this study. The accessible population comprised all colorectal cancer patients living with a stoma and their families, as identified by these patients. Purposive sampling selected the sample, and the sample size was determined by data saturation. The inclusion criteria were 18 years and older, ability to speak basic English and willingness to participate. The conducting of in-depth interviews was conducted to gather the data. The data were analysed by means of qualitative content analysis.

**Findings:** Twenty stoma patients (n=20) and twenty (n=20) family members took part in the study. Four themes arose from the data: living with the physical consequences of a stoma, living with the psychosocial consequences of a stoma, the religious/spiritual consequences of having a stoma and the unmet needs.

**Conclusion:** Living with a stoma affected patients' lives dramatically. The self-care education they received did not prevent some from soiling themselves; they therefore needed help from family members to care for their stomas; they feared the stoma would surprise them and isolated themselves from social contact. They expressed the need for home-based nursing to eliminate trial and error at home. For family members, having to care for the person with the stoma changed the lives they were used to. Some forget to take care of themselves, whilst others lost their jobs during the caring period.

**KEYWORDS**

Colorectal cancer, stoma, experiences, patients, family members

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# CHAPTER 1

# OVERVIEW FOR THE STUDY

## 1.1 INTRODUCTION

In this chapter, attention focuses on the background and rationale of the study. The problem statement, the research objective and questions are formulated, the setting, research design and methods briefly described, and the concepts defined. The chapter ends with a brief outline of the chapters that follow.

## 1.2 BACKGROUND TO THE PROBLEM

Cancer is a major healthcare problem worldwide. It is estimated that 18.1 million people would be diagnosed with cancer in 2018, whilst 9.6 million would die from the disease during the same year. Lung cancer is the most commonly diagnosed cancer in the world and responsible for most cancer deaths. Colorectal cancer is a global public health issue. In 2018, the International Agency for Research on Cancer estimated that there were 1.8 million people newly diagnosed with colorectal cancer and 881,000 deaths caused by this disease worldwide. Colorectal cancer remains the fourth most common type of cancer, with 1.8 million new cases diagnosed worldwide in 2018, in terms of incidence (6.1 %), and responsible for 9.2 % of the total number of cancer deaths (Bray et al., 2018). Colorectal cancer is no longer a disease of the Western World only. Parker et al. (2019) highlighted the increased incidence of colorectal cancer in sub-Saharan Africa, detailing the experience at an East African hospital where colorectal cancer incidence rates have increased by over 300% in two decades. These findings are consistent with several independent analyses demonstrating a rising incidence of colorectal cancer in sub-Saharan Africa. Within South Africa (SA), colorectal cancer is the fourth commonly diagnosed cancer, being the second most common among males and the sixth leading cause of cancer mortalities in South Africa (South African National Cancer Registry (2016).

Colorectal cancer requires the surgical removal of diseased portions of the colon, known as a colostomy. This will connect the colon to the abdominal wall, while an ileostomy connects the last part of the small intestine (ileum) to the abdominal wall. The colon or ileum may have to be rerouted through an artificially-created hole in the abdomen, so that feces can still leave the body. This hole is a stoma (Mota et al., 2015).

Apparently, more than 120 000 ostomy surgeries occur each year in the USA, which means that more than 700 000 Americans, ranging from infants to senior citizens, have had fecal or urinary ostomy surgery (United Ostomy Association of America, 2015).

The surgery may change the way patients perceive themselves physically, psychologically and sociologically. Additionally, they present difficulties in resuming their daily activities, difficulties related to self-care, sexuality, body image, the way of dressing and interpersonal relations (Mota and Gomes, 2013). Healthcare professionals should counsel patients prior to creating the stomas, as the patients can act and adapt themselves to the existence of a stoma better if their forthcoming problems were discussed properly before surgery (Wolters, 2020).

Studies by Pereira et al. (2012) and Di Saverio et al. (2020) stated that the level of quality of life among colorectal patients was not ideal and the presence of the stoma was an independent factor in worsening their quality of life. Patients living with a stoma must cope with stoma-related complications that develop due to the stoma. These patients need to manage sensitive issues such as changed body image, odour, loss of control over their bowel elimination of feces and gases. In addition, a stoma causes important changes in an individual's life and isolation from the society (Liu et al., 2010; Makela and Niskasaari, 2019).

Living with cancer affects both patients and their families. Families are affected by the various physical, psychological and social problems that stomas cause for the patient, which starts with the introduction of the stoma and continues after discharge from the hospital (Karabulut et al., 2014). A study conducted in the USA found that approximately one fourth of colorectal cancer patients' caregivers showed moderate to severe depressive symptoms during the initial months following the stoma surgery (Schulz et al., 2020).

In addition to these problems, stomas also result in a need for care. This care includes meeting the needs of a chronically-ill patient, such as feeding, dressing and hygiene, as well as providing emotional, physical and financial support and, again, living with a stoma causes negative impacts on the overall lifestyle of the patients (Vonk-Klaassen et al., 2016). This will affect their family members who bear the responsibility of primary caregiving

## 1.3 PROBLEM STATEMENT

Colorectal cancer is the second most common cancer among men in South Africa, affecting one in 74 men. It is the 3rd most common cancer among women, affecting one in 116 (National Cancer Registry, 2017). At the time of diagnosis, 20 – 25% of patients will have metastatic disease, the liver being the most common site. More than half of the patients who undergo curative resection may expect to have tumor recurrence, either locally or as metastatic disease (Dervenis et al., 2016).

The research problem for the study relates to colorectal cancer patients, specifically the experiences and needs of patients living with stomas and their families, as studies in the field of oncology nursing primarily focus on breast and cervical cancer. In addition, the lives of family members living with a cancer patient seem to be an under-researched field (Maree and Schmollgruber, 2014; Maree et al., 2017). With this study, the researcher hopes to gain insight into the lives of these patients and their family members and provide baseline data to address the knowledge gap and give appropriate recommendations based on the findings. If the problem is not addressed, stomas undoubtedly will dramatically change lifestyles; patients will experience physiological and psychological detriment with stoma-related problems, however minor they may seem.

## 1.4 RESEARCH QUESTIONS

The following questions guided this study:

1. What are the experiences of the patients diagnosed with colorectal cancer living with stomas and what are their needs?

2. What are the experiences of family members of these patients and what are their needs?

## 1.5 PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of this study was to gain insight into the lives of South African colorectal cancer patients living with a stoma and their families, by describing their experiences and needs after discharge from the hospital.

**The objectives of the study are to:**

1. Describe the experiences and needs of the colorectal cancer patients living with a stoma.

2. Describe the experiences and needs of the family members of these patients.

## 1.6 SIGNIFICANCE OF THE STUDY

Findings from this study will bring to light the experiences and needs of patients living with stomas, as well as those of their families. The results of this study will hopefully make the healthcare professionals who deliver care, as well as the family members who are assisting stoma patients, to appreciate and accept what their experiences are, in addition to the challenges and coping strategies. The incorporation of the findings of the study into the educational information provided to patients during the discharge period could help them adjust to living with the stomas.

Findings of this study will also be available to the research setting and other hospitals to help with the development of policies and protocols that could improve the outcomes of the colorectal cancer patients living with a stoma, and their families.

## 1.7 DEFINITION OF CONCEPTS

- **Experience:** This refers to conscious knowledge of physical, emotional, psychosocialand spiritual occurrences gained through an encounter with an event or disease process (Venes, 2017). It is the process that influences the entire life of an individual or group and usually leads to change of behaviour and way of thinking towards life (Boud et al., 2013).
- **Colorectal cancer:** Colorectal cancer is the disease in which malignant growth occurs anywhere in the colon or the rectum (Arnold et al., 2017).
- **Colostomy or ostomy**: An ostomy is a surgical procedure in which there is the externalisation of a hollow organ, such as the intestine or bladder, through a hole in the abdomen called a stoma. Colostomy refers to the actual opening from the colon to the surface of the abdomen to form a stoma (Mota et al., 2015).
- **Ileostomy:** This is a surgically-created opening in the ileum, in which the last part of the small intestine is pulled through the abdominal wall to create a stoma (Ibrahim et al., 2017).
- **Stoma creation:** This consists of bringing a segment of the colon to the abdomen wall to bypass the colorectal function of emptying waste products (Ibrahim et al., 2017).
- **Stoma:** This is a portion of the large or small intestine brought through the surface of the abdomen and folded back, like a sock cuff. A stoma provides an alternative path for urine (in case of a urostomy) or stool (in case of a colostomy or ileostomy) to leave the body (Jadav et al., 2010).
- **Family:** A family is a group of two people or more (one of whom is the householder) related by birth, marriage or adoption and residing together. All such people (including related subfamily members) are considered as members of one family (Liou and Cook, 2019).
- **Ostomate** (s): An individual who has undergone an ostomy (*Medical Dictionary,* Merriam-Webstar, https://www.merriam-webstar.com/medical/ostomate. Accessed 3 July 2021).

## 1.8 SETTING, RESEARCH DESIGN AND METHODS

The conducting of the study took place at an academic, tertiary hospital located about 30 km, north of Pretoria, Gauteng. The use of a qualitative descriptive design was to answer the research questions (Sandelowski, 2010; Majid, 2017), indicating that a research population is the study's target population that it intends to study or treat. The target population for this study consisted of all colorectal cancer patients living with stomas and discharged from the hospital, and their families, whilst the accessible population comprised all colorectal cancer patients living with a stoma treated at the study setting, and their families. The inclusion criteria were patients who had prior diagnosis of colorectal cancer living with stomas, aged 18 years and older, with the ability to speak basic English and being willing to participate. The patients identified family members. Purposive sampling, the sampling method of choice for qualitative descriptive research (Etikan et al., 2016), was employed to select the sample, (n=20) for patients and another (n=20), with the sample size determined by data saturation (Sandelowski, 2010). Unstructured face-to-face interviews (Creswell, 2014) gathered the data. A voice recorder recorded the interview with the permission of the participants. A demographic data sheet (Annexure I, J) gathered general information. Qualitative content analyses, the preferred method of analysing descriptive qualitative data (Sandelowski, 2000; Vaismoradi et al., 2013), analysed the data. The research design and methods are presented in detail in Chapter 3.

## 1.9 OUTLINE OF THE STUDY

Chapter 1: Overview for the study

Chapter 2: Literature review

Chapter 3: Research methods

Chapter 4: Findings and discussion

Chapter 5: Justification, limitations, recommendations, investigator's reflection on his/her experience and conclusion.

## 1.10 SUMMARY

Chapter 1 gave an overview of the study, and presents the introduction, the background to the problem, statement of the problem, significance of the study, purpose of the study, objectives of the study, research questions, definitions of the concepts and the outline of the study. Chapter 2 presents a review of the literature related to the study.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 INTRODUCTION

The aim of this literature review is to provide an overview of the literature focusing on the topic under study. The researcher conducted an extensive literature search on relevant concepts, which included, among others, colorectal cancer and stoma. Both the national and international perspectives of relevant published studies were reviewed.

This chapter presents two sections. Firstly, it briefly focuses on colorectal cancer, including the incidence of the disease, the structure and function of the colon and rectum, etiology and risk factors, symptomatic presentations screening tests, staging, prevention, diagnosis and treatment, complications and survival of colorectal cancer patients. Secondly, it will review issues which provide the experiences and needs of the patients who are having a stoma and their families.

A systematic search was done using the key words colorectal cancer OR colon cancer OR rectal cancer in combination with incidence, treatments, signs and symptoms, stoma, ileostomy, late-effects and experiences to search the databases PubMed, CIHAHL, Medline, Scopus and Google Scholar.

## 2.2. COLORECTAL CANCER AS A LIFE-THREATENING DISEASE

Colorectal cancer is a disease in which malignant growth occurs anywhere in the colon or the rectum (Arnold et al., 2017). Accordingly, patients with CRC must deal with many dimensions of burden during their treatment trajectory and must balance their demands and their capacity to self-manage (Ose et al., 2017). This burden of treatment can be described as the extra work that health professionals delegate to patients to live well with their chronic illness (Lippiett et al., 2019).

### 2.2.1 Incidence of colorectal cancer

Colorectal cancer incidence and mortality rates vary around the world. According to the 2018 Globocan statistics (Bray et al., 2018), globally colorectal cancer is the third most diagnosed cancer in males and the second in females, with 1.8 million new cases and almost 861,000 deaths in 2018. The incidence is increasing significantly and the rates are substantially higher in males than in females. The expectation is that these numbers will increase in the future, affecting especially low and middle-income countries (Arnold et al., 2019).

Recent studies show that the incidence of colorectal cancer in the developed world is declining, but increasing in sub-Saharan Africa (Siegel and Fedewa, 2020). An adult born in the 1990s has twice the risk of colon cancer and four times the risk of rectal cancer than an adult born in the 1950s (Siegel et al., 2016).

From 2013 to 2017, incidence rates dropped by about 1% each year. But this downward trend is mostly in older adults and masks the rising incidence among younger adults since at least the mid-1990s. From 2012 through 2016, it increased every year by 2% in people younger than 50 and 1% in people 50 to 64 (Luo et al., 2019).

In the United States, colorectal cancer is the third leading cause of cancer-related deaths in men and in women, and the second most common cause of cancer deaths when men and women are combined. It is expected to cause about 52,980 deaths during 2021 (Lawler et al., 2020).

In South Africa (SA), colorectal cancer is the fourth most common cancer among both men and women. The crude incidence is 7.17/100 000/year for men and 5.80/100 000/year for women, and colorectal cancer ranks sixth in cancer-related mortality (Bray et al., 2018).

The South African National Cancer Registry's pathology-based surveillance system (2016) confirms that South Africa has the highest incidence of colorectal cancer in sub-Saharan Africa, with marked ethnic disparities, and indicates that colorectal cancer is among the top three cancers in South African men and women. In 2018, the South African National Cancer Registry reported a lifetime risk of 1:81 for men and 1:135 for women, with an age-standardised incidence rate per 100 000 of 11.67 and 6.68, respectively. The highest rates of colorectal cancer were in White people, Asian and mixed race, and less amongst the majority Black population. Even though there is an historically low incidence of colorectal cancer among the Black South African population, there is evidence that numbers are increasing in some areas (Singh et al., 2015).

The disparities in the colorectal cancer incidence and mortality trends may reflect socioeconomic inequalities across different population groups in South Africa. There is limited data on colorectal cancer survival in South Africa (Crosbie, 2018).

### 2.2.2 Structure and function of the colon and rectum

The colon, also called the large intestine, is part of the digestive tract, which includes the mouth, esophagus, stomach, small intestine, large intestine and rectum. The large intestine is approximately five feet long, making up one-fifth of the length of the gastrointestinal tract. The rest of the colon is divided into four parts: the ascending colon travels up the right side of the abdomen, the transverse colon runs across the abdomen, the descending colon travels down the left abdomen, and the sigmoid colon is a short curving of the colon just before the rectum. The colon is responsible for processing indigestible food material (chyme) after most nutrients become absorbed in the small intestine. The large intestine performs an essential role by absorbing water, vitamins, electrolytes, salt, some nutrients and forming a stool (Ogobuiro and Tuma, 2019).

The rectum is a part of the lower gastrointestinal tract and its average length may range between 10 and 15 cm. The rectum is a continuation of the sigmoid colon and connects to the anus. The rectum follows the shape of the sacrum and ends in an expanded section called the rectal ampulla, where the storing of feces occurs before their release via the anal canal. The rectum acts as a temporary storage site for feces. As in the colon, electrolytes are absorbed (sodium, potassium, chloride) and indigestible food ingredients are decomposed by anaerobic bacteria. The stool thickens through water absorption mixed with mucus. As the rectal walls expand due to the materials filling it from within, stretch receptors from the nervous system located in the rectal walls stimulate the desire to defecate (Lee and Kim, 2020). Figure 2.1 presents a diagram of the colon and the rectum (Lee et al., 2020).

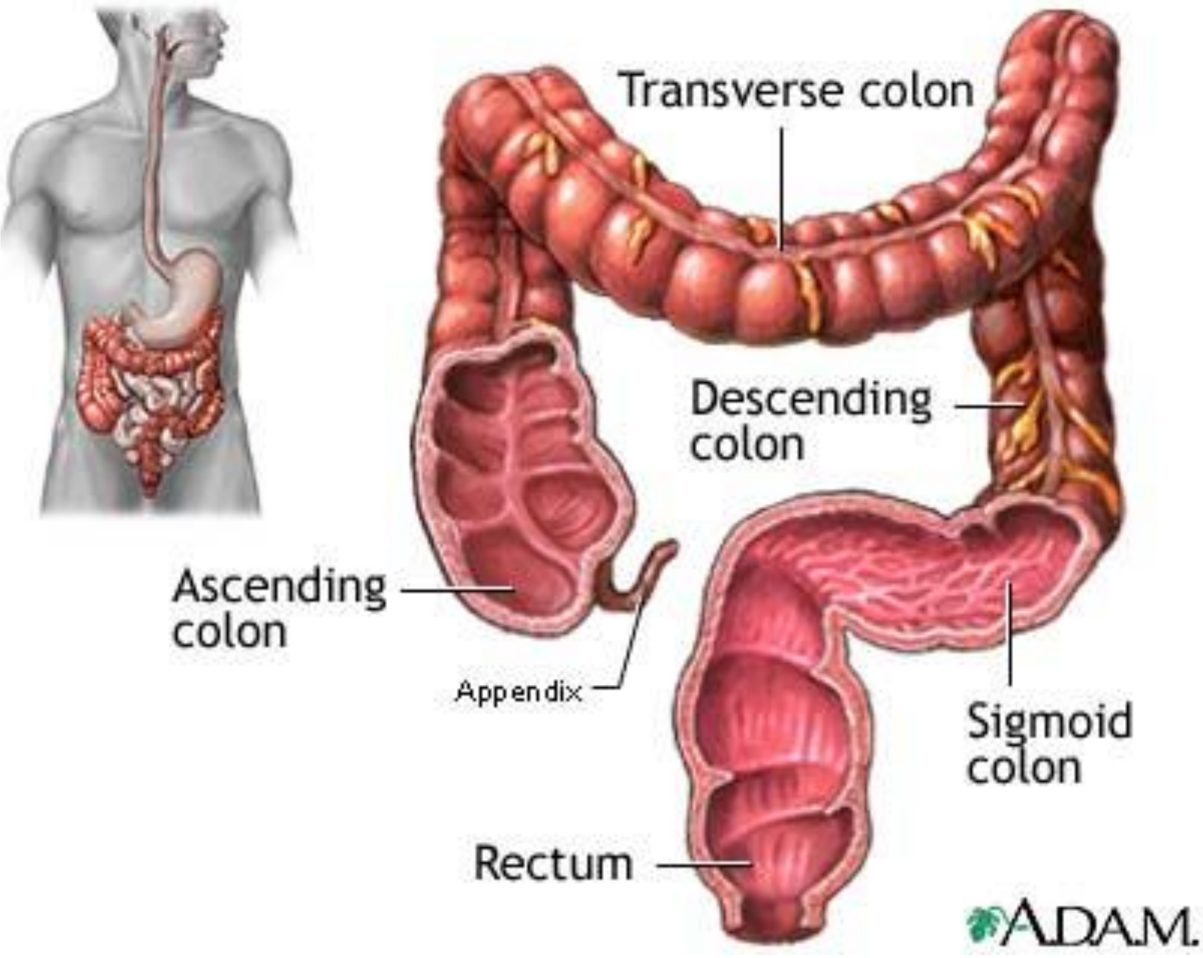

Figure 2.1 Diagram of the normal colon and the rectum. Source: MedicineNet, Inc., (www.cdc.gov).

### 2.2.3 Etiology and Risk Factors

The causes of colorectal cancer are unknown, but many researchers indicate that diet, age, genetics, environmental and other predisposing factors such as bowel disorders may play an important role in its development (Wilkes et al., 2011). According to Libutti et al. (2019), numerous lifestyle-related factors have been linked to colorectal cancer. In fact, the links between diet, weight, exercise and colorectal cancer risk are some of the strongest for any type of cancer.

Imran et al. (2016) show that factors leading to incremental risk include a sedentary lifestyle, obesity, excessive alcoholism, smoking, a low fibre diet, red and processed meat consumption, age and a family history of colorectal cancer. Other attributable factors include certain beliefs and financial barriers (Alzaidi et al., 2016).

Risk increases in individuals with a personal or family history of colon cancer or polyps, or a personal history of inflammatory bowel disease. Inherited genetic syndromes, including familial adenomatous polyposis and hereditary nonpolyposis colon cancer, are associated with significantly increased risk for development of colorectal cancer; they can affect both men and women. The children of people who carry these genes have a 50% chance of inheriting the disease-causing gene (Syngal et al., 2015). Familial colorectal cancer is a result of interactions among genetic and lifestyle factors; the amount of increased risk varies widely depending on specifics of the family history (Singh et al., 2020).

Additionally, modifiable risk factors in personal lifestyle and environmental exposure contribute to the risk for development of colorectal cancer. These include obesity, a diet high in fat, red meat, or processed foods and low in fruits and vegetables, heavy alcohol consumption, smoking and physical inactivity. In contrast, a study by Aune et al. (2011) indicates that eating fruit and a high fibre diet can reduce the risk of colorectal cancer. Fibre, red and processed meat and alcohol affect colorectal risk.

A study by Rodriguez et al. (2019) indicates that regular use of Aspirin products and non-steroidal anti-inflammatory drugs (NSAIDs) reduce the risk of colorectal cancer. Meta-analysis of Hull (2021) demonstrates that the preventability estimate for colorectal cancer is approximately 50%, highlighting the huge potential for altering modifiable lifestyle factors, including diet and body fatness, in order to reduce the risk of this common malignancy. There is strong evidence that dietary factors are important, including the intake of wholegrains. Randomised trials revealed that the use of Aspirin for approximately five years reduces incidence and mortality due to colorectal cancer. Figueiredo et al. (2021) found that Aspirin prevents blood cells called platelets from producing an enzyme that allows them to clump together. Tumor cells can attach to these clumps and spread (metastasize) throughout the body.

### 2.2.4 Clinical Presentation and screening tests

Patients with colorectal cancer suffer from different symptoms, depending on the location, size, tumor type and the individual. Generally, they present with a change in bowel habits, rectal bleeding, abdominal pain, blood in stools or melena, anemia, palpable abdominal mass, constipation or diarrhea, passing excessive amounts of gas, intestinal occlusion, narrow stools, anorexia, flatulence and indigestion and a feeling of incomplete evacuation (tenesmus). Late symptoms include loss of energy, weight loss, a decline in general health and jaundice (Friedenreich et al., 2010). According to Thompson et al. (2017), in more advanced cases, common clinical presentations include iron-deficiency anemia, rectal bleeding, abdominal pain, change in bowel habits, and intestinal obstruction or perforation.

Labianca et al. (2013) indicated that in patients presenting with a tumour in the right colon, there is an obstruction at the lowest part of the small bowel, with symptoms of vomiting, colic pain, constipation, and distension. For other patients, there was no obstruction, but they presented with anemia and weight loss. The physician confirms the palpable mass at the right iliac fossa by a physical examination, while patients who have a tumour in the left colon present as emergency condition due to obstruction or perforation of the large intestine with periodic abscesses or peritonitis. Currently, the right site location is associated with several negative prognostic factors: old age, advanced stage and mucinous histology (Wang et al., 2019). Others with left tumour come to hospital with signs of constipation, low abdominal pain, diarrhea, weight loss, blood in stools or sensation of the abdominal mass.

Richards (2014) pointed out that patients with proximal cancers rarely experience gross rectal bleeding because the blood tends to mix with the stool and degrade during colonic transit. This occult blood loss means such patients often present with iron deficiency anemia; in contrast, distal rectal tumours may present with fresh rectal bleeding, pelvic pain or tenesmus. Frostberg et al. (2020) observed in a study from Denmark dealing with older patients that patients with early-onset colorectal cancer were shown to be more likely to present with abdominal pain, although a similar trend for rectal bleeding was seen only in patients with rectal cancer.

Screening programmes reduce colorectal cancer risk by detecting and removing adenomas and increase survival and cure rates through early diagnosis (Andrew et al., 2018; Lin, 2021). The adoption of an early detection policy is imperative to prevent the progress of this disease.

For instance, the American Cancer Society (2018) guideline for colorectal cancer screening recommends that average-risk adults, aged 45 years and older, undergo regular screening with either a high stool-based test or structural (visual) exam, based on personal preferences and test availability. As part of the screening process, all positive results on non-colonoscopy screening tests need following up with a timely colonoscopy.

**• Options for screening:**

Colorectal cancer screening for average-risk adults: 2018 Guideline Update from the American Cancer Society:

Stool-based tests: Faecal immunochemical test (FIT) every year; high-sensitivity, guaiac-based faecal occult blood test (gFOBT) every year; multitarget stool DNA (mt-sDNA) test every three years.

Structural examinations: Direct visualisations, which are colonoscopy every 10 years; CT colonography every five years; Flexible sigmoidoscopy every three years; double contract barium enema every 5 - 10 years.

Colonoscopy remains an effective screening modality to provide long-term protection against colorectal cancer occurrence and death (Nishiraha et al., 2013; Issa, 2017). However, the hope is that colonoscopies will obtain survival benefits at all ages. The rationale is that colonoscopies directly alter the adenoma-carcinoma sequence by removing adenomas, which reduces cancer incidence, and by detecting cancer early it increases curability and survival (Chen et al., 2016).

### 2.2.5 Staging system of colorectal cancer

The Tumor, Node, Metastases classification (TNM), was mainly developed to reflect the patient’s prognosis and the survival. It is a fundamental step to help the multidisciplinary team plan the overall treatment modality (Tumour, Node, Metastasis). T categories describe the extent of spread through the layers of the colon wall, N categories describe the involvement of lymph nodes, and M categories the spread to distant organs (American Joint Committee, 2017). According to Pei et al. (2021), accurate cancer staging helps doctors to predict survival and provide more effective therapeutic recommendations. The TNM staging system consists of:

**• Primary tumor (T)**

TX**:** Primary tumour cannot be assessed.

TO**:** No evidence of primary tumour.

Tis: Carcinoma in situ: intraepithelial or invasion of the lamina propria.

TI**:** Tumour invades submucosa.

T2**:** Tumour invades through the muscularis propria.

T3**:** Tumour invades through the muscularis propria into the subserosa, or into the non-peritonealised pericolic or perirectal tissues.

T4**:** Tumour directly invades other organs or structures and/or perforates the visceral peritoneum.

- **Regional Lymph nodes(N)**

NX**:** Regional nodes cannot be assessed.

NO: No regional lymph node metastasis.

N1: Metastasis in one to three regional lymph nodes.

N2: Metastasis in four or more regional lymph nodes.

- **Distant metastasis (M)**

MX: Presence of distant metastasis cannot be assessed.

MO: No distant metastasis.

M1: Distant metastasis.

### 2.2.6 Treatment options

The main objective of cancer treatment is curing the disease, controlling the growth of the tumour and palliative and supportive care (Siegal et al., 2012). Ferlay et al. (2020) indicate that a correct cancer diagnosis is essential for appropriate and effective treatment, because every cancer type requires a specific treatment regimen. The primary goals of treatment are generally to cure cancer or to considerably prolong life. Improving the patient’s quality of life is also an important goal.

Treatment options and recommendations depend on several factors, including the type, stage and location of cancer, as well as the performance status of the patient. The TNM classification is considered for the choice of the treatment, and the stage can be determined (Itano et al., 2015).

According to Miller et al. (2016), patients who suffer from colorectal cancer and are not in the early stage of the disease, normally receive a combination of treatments to produce successful results.

#### 2.2.6.1 Surgical Treatment

The choice of surgical procedure for colorectal cancer is based on localisation and the expanse of the tumour. The primary treatment for patients with localised colorectal cancer is surgical resection of the concerned bowel segment and its lymphatic drainage. For tumours seated in the right colon, or the half part of the transverse colon, the surgical method is right hemicolectomy. Tumours seated in the distal transverse or in the descending colon undergo removal using left hemicolectomy with anastomosis, while removal of cancers in the sigmoideum uses a sigmoidectomy with anastomosis (Tong et al., 2017).

A major problem and frequent cause of death is the recurrence of cancer following surgery (West et al., 2010). Marino (2020) found that this complication occurs when infected fluid collects inside the abdomen. A person may experience bloating, pain, a high temperature and changes in bowel movements. Doctors typically treat abdominal collection by draining the fluid and providing the person with antibiotics.

#### 2.2.6.2 Radiation Therapy

Radiation therapy is a localised treatment that uses high-energy x-rays to shrink or destroy cancer cells, and as a palliative treatment. The external beam radiation therapy, known as brachytherapy, kills cancer cells while limiting harm to healthy cells nearby; numerous randomised trials have shown that radiation therapy given pre-operatively or post-operatively in the treatment of rectal cancer decreases the risk of local recurrence and helps prevent or relieve symptoms such as pain (Schmoll et al., (2012). In addition, radiation therapy may be an option for patients who are unable to undergo surgery and it may be given in conjunction with chemotherapy. Wasan et al. (2017) demonstrated that surgery is the main treatment for patients with colorectal cancer; in addition, other treatment including radiotherapy and chemotherapy can improve the prognosis as well.

#### 2.2.6.3 Chemotherapy

Chemotherapy is a systemic therapy to control, cure and prevent the growth of cancer in a patient; it circulates in the blood to parts of the body where the cancer may have spread and kills cancer cells at sites away from the original site (Fernando and Jones, 2015). The administering of chemotherapy drugs occurs in numerous ways, such as by injecting into a body cavity, taken orally in the form of a pill, or topically (Fisher, 2019). Shaikh et al. (2017) and Melamed et al. (2016) indicated that chemotherapy is the primary treatment, used as an adjuvant and neoadjuvant treatment for cancer.

According to Miller et al. (2016), chemotherapy may be given after surgery to eliminate any remaining cancer cells and to lower the risk of recurrence. It is recommended to start chemotherapy before the start of the symptoms, as it has been shown to prolong life. The choice of regimen depends on several factors, including any previous treatments and the overall health of the patient. Some of the common chemotherapy regimens include:

- FOLFOX: leucovorin, 5-FU, and oxaliplatin (Eloxatin).
- FOLFIRI: leucovorin, 5-FU, and irinotecan (Camptosar).
- CAPEOX or CAPOX: capecitabine (Xeloda) and oxaliplatin.

- FOLFOXIRI: leucovorin, 5-FU, oxaliplatin, or irinotecan.
- One of the above combinations, plus either a drug that targets VEGF, (bevacizumab [Avastin], ziv-aflibercept [Zaltrap], or ramucirumab [Cyramza]), or a drug that targets EGFR (cetuximab [Erbitux] or panitumumab [Vectibix]).
- 5-FU and leucovorin, with or without a targeted drug.
- Capecitabine, with or without a targeted drug.
- Irinotecan, with or without a targeted drug.
- Cetuximab alone.
- Panitumumab alone.
- Regorafenib (Stivarga) alone.
- Trifluridine and tipiracil (Lonsurf).

#### 2.2.6.4 Palliative chemotherapy

In an attempt to reduce tumour-related symptoms or prolong survival, patients with stage IV colorectal cancer can receive palliative chemotherapy. Due to recurrence or advanced tumour stage, approximately 40% of the patients with colorectal cancer receive palliative treatment; FU/Lv in combination with either oxaliplatin or irinotecan prolongs progression-free survival and overall survival (Glimelius et al., 2012). According to Henson et al. (2020), the goal of palliative care is improvement of the quality of life. Thus, good communication skills and flawless symptom control are associated with improved patient and family quality of life, greater treatment compliance, and may even offer survival advantages

#### 2.2.6.5 Immunotherapy

The study by Le et al. (2015) indicates that the design of immunotherapy, also called biologic therapy, is to boost the body’s natural defenses to fight the cancer. It uses materials made either by the body or in a laboratory and targets or restores immune system function. For people with certain gene changes in their cancer cells, another option after initial chemotherapy might be treatment with an immunotherapy drug such as pembrolizamab (Keytruda), nivolumab (Opdivo) or nivolumab and ipilimumab (Yervoy). According to Grierson et al. (2017), immunotherapy works to treat cancers like colorectal cancer by harnessing immune cells called T cells, it has also demonstrated promising efficacies and good tolerance in gastrointestinal-related cancers such as a gastro-esophageal cancer and hepatocellular carcinoma.

#### 2.2.6.6 Targeted therapy

Targeted therapy is a treatment that targets the cancer’s specific genes, proteins or the tissue environment that contributes to cancer growth and survival; it blocks the growth and spread of cancer cells while limiting damage to healthy cells. Bevacimumab, cetuximab, panitumumab, aflibercept and regorafenib are the currently approved targeted therapies in metastatic colorectal cancer. In addition, research studies continue to find out more about specific molecular targets and new treatments directed at them (Benouna et al., 2013). A study by Oh et al. (2020) indicates that the tumor microenvironment, including local blood vessels and immune cells, might also be altered by targeted drugs to impede tumor growth and enact stronger immune surveillance and attack. Small molecules, such as monoclonal antibodies, are major players in targeted therapies.

### 2.2.7 Complications of colorectal cancer

If diagnosed in early stages, colorectal cancer is curable. However, in its later stages, it can cause death. Treatment will not cure it if the cancer has spread to other parts of the body. Some of the complications of colorectal cancer include blockage of the colon leading to bowel obstruction, bowel perforation, bleeding, cancer spreading to other organs or tissues (metastasis), development of a second primary colorectal cancer, obstruction of surrounding genitourinary organs and liver failure (Garber, 2021). Eto et al. (2018) demonstrate that adhesions are the most frequently reported complication associated with laparoscopy. They affect almost 95% of the cases and are the major cause of small bowel obstruction. Other risk factors leading to small bowel obstruction are male sex emergency surgery, longer duration of surgery, open colorectal surgery and dysfunctioning ileostomy placement.

### 2.2.8 Survival of colorectal cancer

The survival or survivorship rate entirely depends on the extent of tumour progression, the degree of penetration of the tumour through the bowel wall and the nodal involvement at the time of diagnosis. Early identification of colorectal cancer is especially important as the overall five years’ survival is about 60%, for patients with advanced colorectal cancer less than 5%, whilst survival time of patients with advanced colorectal cancer without treatment is around 5-6 months (Brenner et al., 2011). In addition, the survival of patients diagnosed with colon, rectal and colorectal cancer is variable, according to the type and stage. In general, the five years’ lifespan varies from 65% in the United States, 55% in other developed countries, 14% in Africa, and 39% in developing countries (Iversen, 2012). Arnold et al. (2019) have reported that early diagnosis and improved treatments for cancer have led to higher survival rates.

The patient survival is dependent on multiple factors such as the topography, morphology, staging and treatment type. In addition, the rise in incidence rates in countries undergoing rapid developmental transition may be attributed to changes in diet, obesity and other lifestyle factors such as higher alcohol and red meat consumption (Brand, 2018).

## 2.3 STOMA OVERVIEW

### 2.3.1 Stoma creation

The literature review aimed to describe what is known about the experience and needs of colorectal cancer patients living with a stoma, and their family members.

When the evacuation of feces is physiologically impossible due to the presence of the tumour, it is necessary to put at rest the digestive segment or to protect an underlying gastrointestinal anastomosis. For this, it is necessary to create a colostomy, which consists of bringing a segment of the colon to the abdomen wall to bypass the colorectal function of emptying waste products (Ibrahim et al., 2017).

A stoma is an opening created by the surgeon in the abdomen wall that allows waste to exit the body; the surgeon will pull part of the small or large intestine onto the surface of the skin and sew it onto an opening in the abdomen. A stoma has no muscle to control defecation, but the intestine end empties waste into an ostomy appliance, which is a pouch attached to the stoma (Mota et al., 2015).

There are so many reasons for having a stoma, but in this study the researcher considers colorectal cancer. The stoma may be temporary until the restoring of normal function of the gastrointestinal tract by medical or surgical treatment, which means the stoma will be closed or reversed, in future or permanently; when the gastrointestinal tract cannot function normally again, then the stoma cannot be closed or reversed. Figure 2.2 presents the ideal stoma. (https://www.cansa.org.za).

Figure 2.2 Ideal stoma. Colostomy-patient-cancer-closeup. Source: www.ostomy.org(UOAA) United Ostomy Associations of America Inc.

### 2.3.2 Stoma-related complications

Abdominal stomas will dramatically change lifestyles. Patients will experience physiological and psychological detriment with stoma-related complications, which include stomal ischemia and necrosis, stomal retraction, peristomal infection abscess, parastomal fistula formation, parastomal hernia, prolapsed stoma, bleeding, stenosis, laparotomy wound infection, mucocutaneous separation, stoma diarrhea and peristomal skin irritation (Ondensten, 2020).

### 2.3.3 The International Association of Ostomy (IOA) recommendations

The International Association of Ostomy (IAO) has developed a charter on the rights of ostomates. According to this charter dating from June 1993, revised June 1997 and revised by the World Council in 2004 and 2007, these rights shall be realised in all countries of the World. https: www.ostomyinternational.org/about-us/charter.htm

**The ostomate shall:**

“1. Receive pre-operative counselling to ensure that they are fully aware of the benefits of the operation and the essential facts about living with a stoma.

2. Have a well-constructed stoma, placed at an appropriate site, and with full and proper consideration of the comfort of the patient.

3. Receive experienced and professional medical support and stoma nursing care in the pre-operative and post-operative period both in hospital and in their community, as well as assistance

in stoma therapy and psychological support during the pre- and post-operative period, both in the hospital and at home.

4. Receive support and information for the benefit of the family, personal caregivers and friends, to increase their understanding of the conditions and adjustments which are necessary for achieving a satisfactory standard of life with a stoma.

5. Receive complete and impartial information about all relevant supplies and products available in their country.

6. Have unrestricted access to a variety of affordable ostomy products.

7. Be given information about their National Ostomy Association and the services and support which can be provided.

8. Be protected against all forms of discrimination.

9. Receive assurance that personal information regarding their ostomy surgery will be treated with discretion and confidentiality to maintain privacy; and that no information about their medical condition will be disclosed by anyone possessing this information to any entity that engages in the manufacture, sales or distribution of ostomy or related products; nor shall it be disclosed to any person that will benefit, directly or indirectly, because of their relation to the commercial ostomy market, without the expressed consent of the ostomate."

### 2.3.4 Lifestyle experience of the patient living with a stoma

A stoma operation causes profound changes in a patient's life because of the resulting physical damage, disfigurement, loss of bodily function, change in personal hygiene and possible social isolation; in addition, the person may feel overwhelmed by having a serious disease and may find it difficult to understand the implications of a stoma. Carlsson et al. (2010) and McGrath (2017) found that the creation of a stoma often has a significant physical and psychological impact on a person. Perioperative counselling as a preventive measure is essential, but preventing complications is also important. Patients who have had a stoma experience various challenging issues, including the altered body image which begins after the surgery; when the patient sees the stoma for the first time, some have trouble acknowledging the appearance of it (Ayaz, 2019).

A study by Danielsen et al. (2013) indicated that stoma patients face a double burden: the disease, as well as the challenging sequel of a stoma. They demonstrated that stoma patients face different losses at the physical, functional, psychological, emotional and social levels. Hubbard et al. (2017) indicated that the primary areas of difficulty for people who are coping with stomas include: (1) uncontrollable bowel functioning (physical); (2) depression, distress, and anxiety due to disturbed body image (psychological); (3) occupational dysfunction (economic); (4) reduced social relations and activities (social); (5) decreased intimacy and sexual dysfunction (sexual); and (6) religious issues (spiritual).

While a stoma is a lifesaver for people who would otherwise have no way of evacuating their bowels, it also damages their dignity. For many patients, this complete lack of control is the ultimate insult, frequently causing chronic depression (Jayarajah, 2017). Swan (2010) identified the loss of dignity, particularly when experiencing flatus incontinence and leakage due to a faulty stoma bag. It is a serious issue for thousands of people around the world: the patient always wears the bag, usually with great discomfort and it often leaks waste onto the skin, causing infection and sores.

Millbury et al. in their study indicate that disease and loss of sexual appeal because the individual has a stoma may affect the way people feel about themselves as sexual beings; having a stoma, either permanent or temporary, can make the patient feel unattractive and undesirable to his/her partner (Millbury et al., 2013). According to Yilmaz et al. (2017), the shame of having the stoma interferes with intimacy and sexual activity, which can seriously affect or damage the libido and sexual satisfaction.

Thorper and McArthur (2017), in their studies, indicated that some patients experienced loss of professional identity, as they had to abandon their careers or retire early because of the illness. Again, patients experienced loss of the ability to socialise, as their digestive dysfunction affected their ability to travel, eat away from home and pursue leisure activities. Patients described feelings of anxiety about the experience of toilet training in adulthood, and the worry of leaks, escaping smells and intrusive noises. Loss of control over bowel function profoundly affected patients' sense of adult identity. In addition, having a changed body due to cancer treatment often provokes a painful identity crisis, because of the loss of body parts and changed bodily functioning (Dibley et al., 2020).

The study conducted in Romania by Ciorogar et al. (2016), with 56 patients diagnosed with colorectal cancer, concluded that the ostomy continues to have a negative impact on patients' lives, influenced by several factors such as the causes of ostomy, stoma location and depression caused by the disease and the presence of the stoma.

Another study carried out by Bulkley et al. (2018) showed that patients faced several changes in their daily life at physiological, psychological, emotional and social levels. In addition, these patients experienced difficulties related to social situations, labour, sexuality, family relations, body image and functioning of the stoma. According to Burch (2014) and Landmann (2020), persons living with a stoma experience a complex variety of challenges and concerns.

Anna Boyles (2013) found that loss of personal control, particularly in becoming dependent on family members, was one of the main challenges of the stoma just months after ostomy surgery. Patients with a stoma lived with uncertainty, not trusting their body as before. They strove to regain control of their lives (Capilla-Diaz, 2019).

### 2.3.5 Family members of the patients with a stoma

There is evidence of the importance of family involvement in the process of all levels of care, including the home environment. Both within the hospital care and in the home environment, families are a reference for professionals, to enable them to develop their plan of care (Bachelet et al., 2012). Fisher et al. (2019) indicated that family constitutes an important source of psychological stability for the patient, as well as a source of support for better recovery. In addition, family can satisfy the basic needs of the patient in the hospital to a large extent. Salles et al. (2014) demonstrated that family support and personalised professional care are crucial for the individual to adapt to the new condition and, consequently, to have a better quality of life.

After a cancer diagnosis and during cancer treatment, support by a significant other is indispensable. Langenberg et al. (2019) found that family caregivers support patients practically and emotionally, but these tasks can cause burden and distress, which may impact the family caregiver's ability to support the patient during treatment. Kim et al. (2013), in a study conducted in the USA, found that approximately one fourth of colorectal cancer patients' caregivers showed moderate to severe depressive symptoms during the initial months following the diagnosis. In addition to these problems, stomas also result in a need for care, which includes meeting the needs of a chronically-ill patient, such as feeding, dressing and hygiene, as well as providing emotional, physical and financial support. The family member who bears the responsibility of primary caregiving experiences considerable physical, emotional and social hardships during this time (Schulz, 2020).

A study involving family members of patients with advanced cancer found that demanding treatment regimens were especially challenging if providing care for long periods of time. In addition, family members often neglected their own health to provide care for patients with advanced cancer (Vivar et al., 2010). According to Bruening et al. (2019), many family caregivers put the health of the person they were caring for above their own; with the 24/7 overwhelming demands that they face, it's no wonder they neglect their own health while taking care of someone else's health.

### 2.3.6 Patients living with a stoma in South Africa

The South African situation does not differ from that described in international literature. However, some people living with a stoma have major struggles, as stated by Jonelle of Tyranny of Pink who exposed herself and allowed people to share her struggles (https://tyrannyofpink.com). Jonelle indicated that:

- *Supplies are only available through hospital pharmacies and only on order (with the exception of CANSA, where you can go and see what they have).*
- *You need to have the EXACT code to order what you need, or no one can help you.*
- *The code does not always match the one online.*
- *There is no way to ask for samples – like people can in the UK.*
- *Products are fairly expensive – medical aid does not cover it. It is not even on the chronic illness list. This is most odd to me. What do they expect me to use? A plastic bag?*
- *Options are limited – if you do not like your supplier, there are not that many more you can try!*
- *There is little to no support available in South Africa. Having said that, CANSA in Mowbray has been most helpful, except that you cannot order products, because they work on a first-come first-served basis, which means you are never guaranteed supplies!*

About lifestyle and having a stoma, Jonelle said:

*"I just miss the good old-fashioned way of life, if you know what I mean. I also have plenty of emotional moments where I struggle to deal with having a bag. The smell, for one, sometimes can be unbearable after a day and the bag needs to be changed, but sometimes I think it is all in my head. Those kinds of issues make me feel down."*

Branny Mthelebofu, a researcher from Soweto, strove to bring awareness about patients who use the colostomy bag. Following the incident that nearly killed him, this Soweto man is eager to remove the shame that patients feel when they make use of colostomy bags. In partnership with the Gauteng Department of Health in 2009, Mthelebofu researched stomas at public hospitals in Ekurhuleni, which revealed a high number of people who had stoma operations.

*"This condition seems to be a taboo subject, and many people are walking about hiding their colostomy bags out of self-pity,"* says Mthelebofu.

Besides the research, he is currently canvassing to have a special course on stoma for nurses made available in South Africa. He has also made a documentary about his own experiences as a person who has lived with a colostomy bag for six months.

After being shot in the abdomen in 2000, Mthelebofu was operated on to repair damage caused by the bullet.

"*It was something new and very complicated. I couldn't study or be around people because of the smell of the bag. I was stressed and I had no family support, because they did not understand it either. I lost friends, too,"* he said.

Gauteng Department of Health's Deputy Director in the epidemiology and research unit, Dr Mupata Libiki, the co-investigator in the research, says the government faces challenges in dealing with stoma patients.

*"It's a public health issue and the nurses aren't trained to specialise in this field. The government also does not seem to consider such training. If the colostomy is not cared for properly and the patient is not informed, it can lead to depression and infections that can cause death,"* says Libiki. sifile@sowetan.co.za

### 2.3.7 Family members of the stoma patients in South Africa

Maree and colleagues (2017), when describing the experiences of South African family caregivers caring for cancer patients, found the care responsibilities overwhelmed the participants, which was aggravated by poverty. Some felt emotionally broken and alone in this journey and experienced the rest of their family as uncaring. The lives the participants knew changed and they had to put their own lives on hold and make sacrifices involving their children, work, possible relationships and their normal activities to care for the sick person.

According to Gafner (2018), the family is the primary influence on the collective as well as the individual member's health, including health capacities and health decisions. Unfortunately, in South Africa, only a limited number of studies have examined the experience and needs of the family members of the patients living with a stoma.

### 2.3.8 The responsibilities of the healthcare team

When caring for a patient with colorectal cancer, the healthcare team must provide comprehensive information to the patient: his pathology, his physical and mental state, his living environment, his personality, his self-care of the stoma and his family member as a support. It is therefore important to be interested in the announcement of the diagnosis and its adapted treatment; the patient will receive an explanation and proposal of the treatment as a personalised care plan. According to Liao et al. (2014) and Wolters (2020), the role of nurses as healthcare providers in patients with a colostomy needs improving, owing to the low quality of life of such patients. Patient and family-centred teaching has always been a nursing responsibility. It also can be a potential area of liability, including the omission of required information about self-care, the negligent assessment of the patient's teaching needs, as well as teaching in a manner not understood by the patient or family (Dibley et al., 2019). In addition, Howard and Chady (2012) emphasise helping the family members and caregivers to deal with the situation until the bereavement stage.

Therapeutic patient education is part of the patient's care journey. It aims to make the patient more autonomous by facilitating adherence to prescribed treatments, stoma care and improving the quality of life (Townsend et al., 2010). In addition, therapeutic education is the cornerstone of interventions conducted with individuals with chronic disease, or in chronic conditions, with the goal of health-related promotion, prevention, and education. (Rojanasarot, 2018).

Kalisch, Russell and Lee (2013) suggest that developing a further understanding of the teamwork among the consistent patient care team will ultimately result in enhanced teamwork among the multidisciplinary team. Matthys (2017) indicates that patient outcomes and quality of care are enhanced and the cost reduced when health-care team members work together towards shared, patient-centred goals.

## 2.4 SUMMARY

Chapter 2 presented a literature review regarding colorectal cancer as a threatening disease. The focus on colorectal cancer included incidence of colorectal cancer, structure and function of the colon and rectum, etiology and risk factors, clinical presentations and screening tests, staging of the disease, treatment options and survival, stoma-related complications, life-style experiences of the patients living with a stoma and their families, the situation internationally and in South Africa, and the responsibilities of the healthcare team were also the focus of this chapter. Chapter 3 will discuss the research design and methods of the study.

# CHAPTER 3
# RESEARCH DESIGN AND METHODS

## 3.1 INTRODUCTION

Chapter 2 presented the literature review of the study. This chapter will describe the research design, the research setting, population and sampling, data gathering process, data analysis procedure, ethical considerations and the principles applied to ensure trustworthiness of the study.

## 3.2 RESEARCH SETTING

Research setting refers to the specific place where research data are collected (Brink, 2015; Elwood et al., 2019). According to Majid (2017), research setting is the physical, social or experimental context within which research is conducted. The research setting was an academic, tertiary hospital located about 30 km north of Pretoria, Gauteng, that serves as a training institution for both undergraduate and postgraduate students from different universities and colleges in the Gauteng Province.

According to South African Doctors (2017), the hospital has a total of 1 652 beds and serves a population of approximately 1 200 000. The hospital provides specialised services for Oncology, Nephrology, Trauma, Cardiology, Intensive Care, Surgery, Obstetrics and Gynaecology. Various departments, including the Adult and Paediatric Oncology Departments, are centres of excellence (Gauteng Provincial Government, 2014). In addition to various clinics and wards, the hospital has a stoma clinic, with qualified personnel delivering a variety of services to stoma patients. These services include pre-operative counselling, post-operative care, support and education to the patients. The rehabilitative service focuses on empowering patients and their support structures, which includes family and friends, to be able to cope with the stoma, as well as the provision of stoma appliances, according to the availability of the stock.

## 3.3 RESEARCH DESIGN

A qualitative descriptive design was chosen for the study, as according to Sandelowski (2010), it allows researchers to present a comprehensive summary of life experiences in everyday terms. In addition, qualitative description it is the method of choice when requiring straight descriptions of phenomena in situations where little is known about a phenomenon (Sandelowski, 2010), as is the case for this study.

## 3.4 POPULATION AND SAMPLING

### 3.4.1 Population

Research population is the study's target population that it intends to study or treat. Population is the totality of all participants that conform to a set of specifications, which is the entire group of people that are of interest to the researcher and to whom the research results can be generalised (Majid, 2017). The population for this study consisted of all colorectal cancer patients living with stomas, who had been discharged from the hospital, and their families.

### 3.4.2 Sampling and sample size

The process of sampling selects a portion of the population that represents the entire population to make inferences about the population (Cleary et al., 2014; Sandelowski, 2010; Crossman and Ashley, 2018). Polit (2012) describes a sample as a portion or a subset of the research population selected to participate in a study. In addition, a sample refers to a smaller, manageable version of a larger group. It is a subset containing the characteristics of a larger population (Janet, 2021).

Purposive sampling, the sampling method of choice for descriptive qualitative work (Sandelowski, 2000), was used to select the sample. In this sampling method, only participants who would be of most benefit to the study were consciously selected. Etikan et al. (2016) described purposive sampling as one of the cardinal features of descriptive qualitative studies and as the recommended sampling technique for descriptive qualitative design. Data saturation occurred after 20 interviews with patient participants, with the sample size 20 (n=20), and another 20 interviews of family members, and the sample size was 20 (n=20). Liamputton (2013), Given, (2018) and Grove et al. (2012) agree that data saturation refers to the point where new categories, themes or explanations stop emerging from the data and when enough rich, meaningful data have been obtained to achieve the study aims.

## 3.5 THE INCLUSION CRITERIA

Only patients with a prior diagnosis of colorectal cancer, and living with stomas, receiving treatment at the academic hospital in Gauteng, and their families.

## 3.6 RECRUITMENT CRITERIA

After a meeting with the unit manager, responsible for the stoma clinic of the hospital, she introduced the researcher to the patients and families. Recruited participants were 18 years and older. The patients identified the family members. Recruiting of patients was during consultations at the stoma clinic, and only of those who could speak basic English.

## 3.7 DATA COLLECTION AND PROCESS

Data collection is the procedure and instruments used to collect information from the participants for a study (Polit and Beck, 2014). In addition, data collection is the process of gathering, measuring and analysing accurate data from a variety of relevant sources to answer stated questions (Ziafati, 2021). Unstructured face-to-face interviews took place to allow participants to reflect on their experiences in a naturalistic, narrative fashion. Unstructured interviews are advantageous to this study because of the flexible approach to questioning. A face-to-face interview allows participants to narrate experiences in depth and the researcher to redirect participants' responses when out of context (Nimri et al., 2020).

Ethical clearance was obtained from Wits University (No: M190755) (Annexure M) and permission from the hospital by the Acting Director of the Clinical Services, in order to conduct the study (Annexure O). Nurses at the stoma clinic identified patients who came for stoma care and for the collection of stoma pouches and accessories, notified them of the study and introduced them to the researcher. After a meeting with the clinic's unit manager, she introduced the researcher to the patients and families. The researcher approached the participants, explained the reason for the study and handed the information leaflet (Annexure B, C) to those willing to participate. Participation was voluntary, as patients who agreed to participate to the study signed the consent before the interview (Annexure D, E).

The researcher recruited the participants according to the inclusion criteria. The recording of the interviews occurred after obtaining consent to use an audio-recorder (Annexure F, G) and signed by the participants. The conducting of the interviews was in a private room during the patient's normal scheduled appointment, with the patient and family separately. Privacy was ensured during the interviews. Interviews ranged between 30 and 45 minutes. The researcher gathered the data between October and December 2019.

The researcher, a female registered oncology nurse and a Master's student in the field of Oncology and Palliative Care nursing, had experience in the field of oncology nursing at the time of data collection.

## 3.8 DATA ANALYSIS AND MANAGEMENT

Data analysis is the process of creating meanings from data, and in qualitative research it involves building themes from ideas and making conclusions about the themes (Bazeley and Jackson, 2013; Miles et al., 2020). Qualitative content analyses, the preferred method of analysing descriptive qualitative data (Sandelowski, 2000; Vaismoradi et al., 2013; Abroms et al., 2019) was used to analyse the data. The use of an inductive approach was because of the lack of knowledge about the topic (Elo and Kyngas, 2008). According to Smith and Firth, (2011) and Lin, Lachos et al., (2018), data analysis followed the six steps below:

### Step 1: Verbatim transcription

Transcription began by listening to the recorded information repeatedly. Pausing the audio recorder allowed for transcription of the information word for word, as heard. After transcription, a repeat of the process was to capture any possible missing information during the initial process. The identification of each transcript was by using the same number as the one assigned to the recorded information, for easy detection.

### Step 2: Understanding the data

The researcher repeatedly read the transcripts until the data were clear before attempting to identify main ideas to gain familiarity with the data (Jolley, 2013; Slevin, 2020). For the transcripts needing clarity, the corresponding recorded information was listened to again and the transcript re-read, whereafter necessary changes were made to make complete sense of ideas.

### Step 3: Identifying the main idea

Highlighters of different colours highlighted the main ideas, while headings and notes were written in the margins of the transcript. This process of reading and identifying ideas occurred repeatedly, to ensure the inclusion of all headings describing all aspects of the content.

### Step 4: Grouping the ideas into sub-themes

Separate sheets of paper recorded the headings and ideas from the different transcripts. The careful studying of ideas was to identify relationships among them and those that fell under the same category formed sub-themes. The list of ideas was read repeatedly, then grouped into meaningful sub-themes.

### Step 5: Building main themes

Critical examination of the sub-themes was to identify those communicating the same sense, and similar sub-themes combined to form main themes. Unrelated sub-themes were carefully re-examined to look for a possible relationship among them for grouping into one group and represented by one theme. The process was repeated until all the sub-themes were built into the main categories.

### Step 6: Identifying main themes

The grouped sub-themes and supporting ideas were scrutinised carefully to identify higher order headings that fit each category of the sub-themes. Each category was represented by higher order headings as the main theme. The researcher used reflexivity by making any biases known or declared, to ensure that her personal beliefs and pre-conception did not affect the results of the study. Reflexivity is the process of understanding oneself as a researcher in relation to the study, in that there is an examination of the researcher’s beliefs, preconceptions and assumptions in relation to the study (Anna, 2015). According to Palaganas et al. (2017), reflexivity involves paying systematic attention to the details of knowledge construction at each stage of the research process.

## 3.9 TRUSTWORTHINESS

According to Elo et al. (2014) and Nguyen et al. (2021), trustworthiness refers to the exposition of the true value of the research results and the strong relationship between the data and the conclusions made. To enhance trustworthiness of the findings, the researcher used the strategies of Lincoln and Guba (1985), summarised by Shenton (2004), and confirmed by Thomas and Magilvy (2011). They proposed that the criteria of credibility, transferability, dependability and confirmability be the guidelines.

### 3.9.1 Credibility

Credibility relates to the true value of the research findings. Achieving credibility is when the findings from the data reflect reality (Shenton, 2004). According to Anney (2019), credibility refers to the degree to which the findings reflect the actual experiences of the participants, and a reflection of how believable the results are.

The researcher made the following steps:

- The adoption of a descriptive qualitative design was for consistency in interviewing and management of data in the field.

- The use of purposive sampling. Patients treated at the stoma clinic, and the families caring for said patients, were interviewed for this study upon consent.
- The accomplishing of member checking of interview findings followed immediately after each interview by summarising the interviewer's understanding of the participant's responses to interview questions.
- Prolonged engagement was used as the researcher familiarised herself with the field before gathering the data
- The researcher repeatedly read the transcripts until the data was clear, before attempting to identify main ideas to gain familiarity with the data.
- The research project was peer-reviewed by the supervisor of the study and the Research Committees of the Department of Nursing Education and the School of Therapeutic Sciences of the University.
- The researcher used reflective commentary when analysing data.
- The researcher completed an extensive literature review of other research findings and achieved triangulation through the literature and two sources of collected data
- The researcher reviewed the patient's history prior to the interview. Interviewing emotional cancer patients is not easy, as some might forget to give the important answers to the questions. Reviewing their history before the interview provided some the details needed. Reviewing the patient's history is the application of tactics to enhance honesty
- The researcher, trained in the field of oncology, has worked in the oncology field for years.

### 3.9.2 Transferability

Transferability is the extent to which the findings of the study can be applicable in other settings (Elo et al., 2014; Shenton, 2004). Since the findings of the qualitative study were specific to one stoma clinic, the patients and their family members, it might not be possible to demonstrate that the findings and conclusions are applicable to other situations and populations. Therefore, the researcher described the setting in detail to allow the reader to judge whether the findings could be transferred to their settings.

### 3.9.3 Dependability

Dependability refers to the consistency and repeatability of the research findings under the same conditions (Jolley, 2013; Slevin, 2020). To enhance dependability, the detailed report of the processes within the study is for the reader to have a full understanding of the research method and its effectiveness. Included in the text are the following: a description of what was planned and executed on a strategic level; operational details of data gathering; the researcher provided detailed description of research setting; methodology and the demographic presentation of the participants who were used in the study; all participants were interviewed face-to-face; each transcript was subjected to the same method of arriving at the themes and sub-themes.

### 3.9.4 Confirmability

Confirmability is concerned with proving that data and interpretations of the findings are not figments of the inquirer's imagination, but clearly derived from the data (Thomas and Magilvy, 2011; Stake, 2018). To enhance confirmability, the researcher ensured the initial responses were compared to the transcribed responses, to ensure that the transcribed are the same as the participants' original responses. In addition, the immediate transcribing of interviews was to prevent mixing of information.

## 3.10 ETHICAL CONSIDERATION

According to the World Health Organisation (2021), it is every researcher's responsibility to ensure the keeping of the ethical code at all times. The following of the Health Professional's Council of South Africa's Guideline (2017) for Health Researchers was to conduct ethical research. The inclusion of the following principles was to ensure respect for the rights of the participants:

- The principle of beneficence was maintained, as the researcher secured the wellbeing of the participants, who have the right to protection from discomfort and harm, by obtaining ethical approval from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Annexure M,) as well as the Ethics Committee of the hospital.
- The Acting Director of the clinical services of the hospital granted permission to conduct the study (Annexure O).
- The participants received an explanation of the purpose, benefits and potential risks related to the study. Only the participants who met the inclusion criteria and agreed to take part received a consent form (Annexure E, F) to sign.
- Participants were informed they could withdraw from the study at any time, to refuse to give information and to ask for clarification about the purpose of the study.
- The principle of respect of human dignity was preserved.
- The participants had the right to decide voluntarily whether to take part in the study.
- Assigning pseudonyms to participants during the recruitment ensured confidentiality and anonymity.
- Although the use of participants' names occurred in the interview, these were removed when transcribing the data, and the transcriptions numbered sequentially.
- The demographic data sheets (Annexure I, J) were numbered sequentially, and no names appeared on these sheets.

- Ensuring privacy during the interview was by taking the participant aside when others were present.
- The participants gave written informed consent for audio-recording (Annexure F, G).
- Data in the form of written records are kept in a double-locked cabinet and data in soft copy are kept in a password-protected hard drive to prevent unauthorised access to participants' information. Data are to be kept for a minimum of two years after publication of an article and no data will be taken out of the country.

## 3.11 SUMMARY

In summary, Chapter 3 presented the research design and methods, the setting of the study, the population and sampling, data gathering, data analysis, trustworthiness and ethical considerations. Chapter 4 will discuss the research findings and discussion.

# CHAPTER 4
# FINDINGS AND DISCUSSION

## 4.1 INTRODUCTION

Chapter 3 presented the study design and the methods, measures to ensure trustworthiness and the ethical considerations. This chapter will present the findings and discussion for the study. The findings will include participants' characteristics, a description of major themes, the discussion and a summary.

## 4.2 THE PATIENT PARTICIPANTS

Twenty patients (n=20), all from the Black population and mostly male (13 of 20), participated in the study. Their ages ranged from 27 to 72 years, having an average age of 52.95 and a standard deviation (SD) of ± 11.3951 years. The median age was 69.5 and the modal age classes were 48, 52, 62 (trimodal). A large number of the participants were married and unemployed (12 of 20). Some participants had permanent colostomies (15 of 20), while others had ileostomies (5 of 20). Table 4.1 presents the general characteristics of the participants; pseudonyms are used.

**Table 4.1 Patient participants' demographic information and characteristics**

| No | Pseudonym | Age | Sex | Employment | Marital status | Stoma | Permanency |
|---|---|---|---|---|---|---|---|
| 1 | Albert | 42 | M | Unemployed | Married | Ileostomy | Permanent |
| 2 | Anthony | 48 | M | Unemployed | Married | Colostomy | Permanent |
| 3 | Angela | 52 | F | Unemployed | Married | Colostomy | Temporary |
| 4 | Blandine | 54 | F | Domestic worker | Single | Colostomy | Permanent |
| 5 | Wilson | 62 | M | Unemployed | Separated | Colostomy | Permanent |
| 6 | Florence | 45 | F | Unemployed | Married | Colostomy | Permanent |
| 7 | Freddy | 58 | M | Garden worker | Single | Ileostomy | Permanent |
| 8 | Grobler | 27 | M | Unemployed | Married | Colostomy | Permanent |
| 9 | Victor | 43 | M | Unemployed | Married | Colostomy | Permanent |
| 10 | Joseph | 70 | M | Unemployed | Married | Colostomy | Permanent |
| 11 | Julian | 69 | M | Unemployed | Married | Ileostomy | Permanent |
| 12 | Kelvin | 68 | M | Garden worker | Separated | Colostomy | Permanent |
| 13 | Linda | 52 | F | Self-employed | Single | Colostomy | Temporary |
| 14 | Marco | 72 | M | Unemployed | Married | Colostomy | Temporary |
| 15 | Marcel | 41 | M | Unemployed | Married | Colostomy | Permanent |
| 16 | Nancy | 48 | M | Unemployed | Single | Colostomy | Permanent |
| 17 | Christina | 55 | F | Unemployed | Married | Colostomy | Permanent |
| 18 | Milka | 47 | F | Self-employed | Separated | Colostomy | Permanent |
| 19 | Wilma | 62 | M | Unemployed | Married | Ileostomy | Permanent |
| 20 | Shella | 44 | F | Self-employed | Single | Ileostomy | Permanent |

Table 4.1 summarises the data that arose from the patient's demographic information

## 4.2 THEMES AND SUBTHEMES ARISING FROM THE DATA FOR PATIENT PARTICIPANTS

| THEMES | SUB-THEMES |
|---|---|
| **Living with the physical consequences of a stoma** | 1. Living with the stoma and pouch |
| | 2. Living with the smell and gas |
| | 3. Experiencing sleep disruption |
| **Living with the psychosocial consequences of a stoma** | 1. Living a changed life |
| | 2. Keeping the secret |
| | 3. The fear and isolation |
| | 4. Sexual relationships |
| | 5. Experiencing financial hardship |
| **The religious/spiritual consequences of having a stoma** | 1. Disruption of religious activities |
| | 2. The importance of spirituality |
| **The unmet needs** | 1. Health education and information during hospitalisation |
| | 2. The need for home-based nursing |

Table 4.2 summarises the data that arose from the four themes and 12 sub-themes

### 4.3.1 Theme 1: Living with the physical consequences of a stoma

This theme consists of the following sub-themes: living with the stoma and pouch, living with the smell and gas, and experiencing sleep disruption.

### Sub-theme 1: Living with the stoma and pouch

Participants agreed that they experienced challenges such as skin irritation due to the use of the rubber bag, the presence of leakages and spilling of faeces, and a lack of proper information about the care of the stoma. Initially, most depended on family members to assist them, but they soon became independent.

Albert explained, *"When I came back from the hospital, I was still weak, so my wife used to change the pouch and clean the stoma site. This was like for a few months. Apart from that, everything else from personal hygiene to wound dressing to changing of the pouch I did for myself…"*

Marco *said, "The way the nurses taught me how to remove the pouch was not very good. When I went home, I was spilling feces anytime I had to empty the pouch. It's okay now. I have learnt how to do it better now…"*

Florence added, "*In the beginning, changing of the bag and care of the stoma was done by my daughter who also did not know how to do it, but now I do it myself."*

Freddy said, "*In the beginning I experienced leakages…I was just feeling it all over my bed. That is the very bad experience I will never forget."*

Julia added*, "My main struggle is when the clinic does lack the proper stock due to the huge number of patients, then I must use the plastic bag for shopping, especially when I am at home…yes, feces will spill without my knowledge."*

The participants were never sure what could happen; they feared the stoma could "surprise" them and catch them off-guard. However, some provided for the unforeseen by carrying additional stoma bags with them and making sure where toilets were should they need it.

Anthony said, *"This thing sometimes can surprise you. You are not always sure about what will happen to you next, because you could end up with loose stools spilling all over. So, you're always in this state of discomfort because you do not know what to expect*…"

Marcel *added, "I am always wondering how I will empty this bag … I worry if I get out and if I have to use the bathroom. For the house, I'm always fine; a public toilet - that is when there is big trouble; anytime I go out, I'm always looking around to see what I can do should there be trouble… I have to go out, I carry an extra stoma bag. You never know what will happen."*

Most of the patients agreed that the location of the stoma affected their clothing style and they couldn't find what clothing they could wear after the surgery; participants verbalised that some of their clothes could not sit directly on the stoma, therefore they had to discard them from their wardrobes.

Kelvin said, "*So, what I sometimes do is to select from my wardrobe some of my big jackets because they are sitting well on the stoma. When I feel the thing (feces) pouring out, then I will still be confident. Wearing the jacket that way, the odour and sound is not noticed as it would have been.*"

Angela explained, "*Since I've got stoma, I am unsure about what to wear every day of my life. My sister checks my cupboard - there is nothing that can fit me because of this thing (stoma)."*

Some of the participants were unable to prevent the pouch from leaking, especially when they used the rubber bag. In addition, having to clean the skin around the stoma numerous times led to skin irritation.

Albert explained, *"If I don't clean the area well and I place the bag, it leaks around. I had to clean again the area and replace the new bag. The more I clean the skin the more comes skin irritation…"*

Grobler said, *"Sometimes when you use the rubber and you are not lucky, it bores a hole without your knowledge and before you know, the feces would have leaked on your clothes."*

Participants often had to re-use disposable stoma pouches. Securing it led to skin damage and irritation.

Marco said, *"My mother bought some for me but they were disposable. I know it is unhealthy to be using it this way, but that is my only option. I wash it and use plaster to secure it. Sometimes when I do that, you will see that the plaster peels the skin around the stoma area, and if it stays for long, it often itches, but that is what I have to do. Getting money for this is not easy."*

### Sub-theme 2: Living with the smell and gas

Most of the participants agreed the unpleasant smell emanating from the stoma and the uncontrollable sound made by gas in the intestine made them feel embarrassed, as they could not hide the fact that they had stomas. This caused emotional distress and influenced their normal activities of daily living; some even lost their jobs as a result.

Angela explained, *"The smell of the number 2 is unbearable to me. The only odour you smell is that of the toilet..."*

Marcel added, *"The smell is unbearable to even me myself. It also comes unannounced any time and any place. My daily life was also affected, as I couldn't go to work or perform some daily activities due to smell and gas. I find it difficult to be with others and I had to stop going to my job..."*

Wilma said, *"When I pass gas from the stoma, it's usually unconsciously or involuntary, which can be smelly and embarrassing; no matter how hard you try to be discreet about this condition, the smell and sound will definitely give you away.*"

### Sub-theme 3: Experiencing sleep disruption

Most of the participants experienced sleep disruption that led to fatigue. In addition, the participants feared the soma would leak during the night and they would be embarrassed the next morning. Some experienced pain, whilst others thought about the stoma and whether they would ever have it removed.

Kelvin explained, *"I am so tired every morning because of not sleeping enough due to the pain. I wake up and sit on the chair the whole night."*

Nancy added, *"I can't sleep, especially when I think that this pouch will get full during the night and maybe burst on me. That is another extra work during the night, my sister… so eeeh!... it's difficult for me."*

Freddy said, *"…as for sleeping, my sister, anytime I lie down to sleep, I am always thinking… I think a lot about the stoma, and whether I will ever be the same again. I know I have to sleep because it is good for my health but sometimes, I find it difficult sleeping easily."*

Victor explained, *"The doctor told me I must sleep but I find it difficult sleeping, maybe it is because I think a lot about this thing (stoma)…I get up now and then in the night, and I have to go to the toilet several times to drain myself. If you don't, you will be ashamed the following morning."*

In summary, most of the participants needed help from family members to care for their stomas and change the pouch, but they became independent after a short period. Not all the participants found the education received, when admitted to hospital, sufficient to prevent them from soiling themselves. The participants feared the stoma would surprise them and some carried additional bags with them and made sure where the toilets were when they went out. The smell and gas caused emotional distress and advertised their condition. Having a stoma also interfered with sleep, as they could not sleep enough at night, so consequently felt tired the following morning.

### 4.3.2 Theme 2: Living with the psychosocial consequences of a stoma

This theme consists of the following sub-themes: living a changed life, keeping the secret, the fear and isolation, sexual relationships and experiencing financial hardship.

#### Sub-theme 1: Living a changed life

The lives the participants knew before having the stoma changed permanently and led to emotional distress. Some lost their independence and feared those who had to help them would find the task repulsive. Some participants could not continue with their normal activities of daily living. In addition, some experienced a change in body image, whilst others were acutely aware of the fact that they were different from other people.

Michael explained, *"When you look at me, I am no longer the same, I feel totally different. I feel like I am a different person."*

Linda said, *"I used to be living alone and can take care of myself. Even so, now my granddaughter has to take care of me. I know one day she will never like it…I won't be able to do as much around the house as I'd like. I probably will need to be dependent on other people to help me for a bit which isn't great. It's hard seeing stool coming out through the bag …"*

Christina said, *"Carrying this bag on my abdomen, just like that everything just changes, my lifestyle will have to change too, my body image changed too."*

Julian added, *"…I can't do my garden again, I can't lift anything, I can't do much of anything, very uncomfortable and painful this thing…"*

Some of the participants changed the way they did things, such as dressing, washing themselves and their diets.

Nancy explained, *“I sit to wash now instead of bending…. and I now wear long and loose dresses, so people won’t see what I have.”*

Joseph added, *“I forgot about swimming or showering. The only thing I can do is to wash using the small basin, paying attention to this thing not to spill in the water.”*

Marcel said, *“I miss my favorite meals, this thing …ouch, it can really inflate much. It depends on what you have been eating or drinking. With heavy meals, I know very well how badly it can affect or hurt me, so I restrict myself from taking any food.”*

Despite the hardships brought about by their changed lives, some participants accepted their stomas and displayed a positive attitude to moving forward with life.

Simon said, “*If you don’t have this done, your other alternative is you’re dead. … I gave my consent to have it or I’m gone. So, you have to get used to it because it saved your life and you’re going to be all right.”*

Kelvin added, *“Since I did accept it and carried on with life…for my wife, children to accept it, for them it was not easy to accept it but because I did.”*

Joseph said, *“I was forced to accept this condition…and obviously it’s going to have an impact on my family…”*

**Sub-theme 2: Keeping the secret**

It was not easy for the participants to disclose the stoma; some hid it from their partners for months before disclosing. One participant did not share the fact she had had a stoma with her husband and planned to keep it that way, whilst others shared with only their close family members.

Albert explained, *“I hid it from my girlfriend for about six months. It took me six months before I could explain to her.”*

Nancy said, *“My husband does not know about it. He knows I have been operated upon, but he does not know I have a stoma. I intend to keep it that way.”*

Wilma added, *“My daughter and husband are the only people who know about It.”*

Julian said, *“My wife and children are the only people who know about it. I also have my brother-in-law staying with us. He is also aware. You can’t be telling everyone your problem.”*

Some of the participants did not want their significant other to share their secret with other people, whilst one participant realised that hiding the stoma served no purpose.

Anthony explained, *"Our prayer team from church community came to the house to pray for me. I thought it was just a general kind of those prayers, but they started saying things that meant that they knew about it. When they were gone, I asked my wife and she confirmed she told them and there was no need to keep the secret. I didn't like it, but it has happened."*

Marco added, *"When I was discharged from the hospital, I didn't think it was necessary to tell some people, but my wife told some of my extended family members. She said that if it is kept a secret and anything happens, she will have trouble with the in-laws."*

Simon said, *"In the beginning I was not telling anyone except my family members who were assisting me. I had hope that they will understand the condition. But now what is the point in still hiding it. It will never go… so I tell those who are supposed to know."*

For one participant, disclosure meant possible overwhelming by people asking how you are and wanting updates on the state of the stoma.

Blandine explained, *"…I don't tell outsiders because every time they see you, they will always want to ask about the stoma. They will ask for updates on the state of the stoma and you have to keep explaining and reminding you of it. In the end, they can only pity you without helping*"

**Sub-theme 3: The fear and isolation**

The participants reported their involvement in social activity was affected negatively. Getting involved in social activities also meant having to deal with the incontinent nature of the stoma in a less controlled environment. This situation led to emotional distress, as some participants believed they should not socialise. It was not only the participants that avoided social gatherings, but their friends also sidestepped them, fearing infection with the same disease.

Angela said, *"I mostly want to go for social events like outdooring or funerals or parties, but unable to go because I am shy. I fear that when I go for such events, the bag might leak and disgrace me due to that, I don't go anywhere. I have the feeling that I am not supposed to be with others."*

Marco added, *"I know someone in my situation might be able to go for some social events but for me in particular, I don't go for any social gathering, be it wedding, funerals, etc. … I have difficulty to be among them because I feel uncomfortable doing that."*

Marcel added, *"Not that much of a social person. Not every time, like I don't go out very much but once in a while when I have some social events, I used to but once with the bag issue I couldn't.*

Linda said, *"Some friends say I will infect them with my condition. The only friend I have left is the one who every now and then calls to check on me, sends me money and encourages me."*

The fear of smelling bad and inconveniencing other passengers kept the participants house bound, which added to their isolation. Some participants feared using public transport, whilst others did not even want to be a passenger in a car.

Joseph said, *"I cannot travel anywhere. My only movement after the discharge is from the hospital to my house to stay with my family…. sitting in a public transport with this thing, people would wonder why you smell and the wind too."*

Paulina added, *"Yes, I do travel, but short distances with my own car. Using any form of public transport as public transport might inconvenient others. …No matter how hard you try to be discreet about the whole thing, the smell and sound will definitely give you away. In order to avoid this embarrassment, I always send my daughter if the situation doesn't demand my presence."*

Julian said, *"Yes, I think I travelled with it like twice. Yes. One time I went to wedding with it, one to an engagement party and the other to a funeral service…. But that was with my friend's car, but ohh, the smell."*

**Sub-theme 4: Sexual relationships**

Engaging in sexual relations was a difficult task for most of the participants as they were not comfortable with their changed bodies and feared that the pouch could leak.

Nancy explained, *"No. Ever since I got the stoma on, my boyfriend hardly comes closer less to talk about having sex with me. I do not even want to be too close because I am not comfortable with the fact that I have a sore on my body."*

Grobler said, *"I don't engage in sex again; my wife understands my situation. Sometime ago, I tried to please my wife, but the pouch was not well fixed. Some of the feces spilled on the bed and since then we have not tried anything like that anymore."*

Others did not think of sexuality as a problem, because their spouses travelled or were no longer interested in sex.

Angela said, *"Ooh, I have no problems with sexuality because my husband is far away from me for his work. He has not been around from the beginning of all this issue."*

Albert added, *"I lost all interest in sex and besides my wife is not the type of women who is demanding when it comes to sex. That part of my life has been turned down, thinking of this pouch bursting during the sexual intercourse. Who is going to clean all the linen ….and the smell?"*

Marcel said, *"With the sexual aspect, I am often tired which prevents me from having sex. Quite apart from that, the weakness I feel doesn't even make me feel like having sex.*"

For some participants, intimacy with their spouses remained as it was before the stoma creation. Kelvin explained, *"My wife feels that I will get hurt. It's still about the same, my sex life has not been affected."*

Freddy said, *"My wife understood it. Even with the bag, we have sex, so it didn't hinder the relationship between me and her. We manage our sexual life very well."*

**Sub-theme 5: Experiencing financial hardship**

Some participants lost their jobs because of the presence of the stoma, as the nature of their jobs deterred them from fulfilling their obligations. Freddy said, "*I lost my job, as I'm unable to go anywhere. When the whole problem started, it was my son who took over from me, but he has to also stop when his annual leave expires."*

Joseph said, *"Money…. Hm I really suffered financially even though my family members were giving their support randomly, but it wasn't enough. I was jobless for four years; I couldn't work again."*

Freddy added, *"I suffered financially. Even though my family members were giving their support sometimes, it wasn't enough.*"

The participants experienced challenges in obtaining, buying and managing the stoma supplies within their budgets. Participants struggled to afford and obtain the stoma bags and accessories when the hospital stock was insufficient for everybody. Blandine explained, *"My husband… he is not working at the moment, so when I am due for checkup or my stoma bags finish, my sister gives me money for all that. For now, money issues are tough for me as I don't have any work… I sweat, the bag comes off easily or gets damaged. I try as much as possible not to move about by staying at one place for long to avoid damaging the bag."*

Anthony added, "*That was the main issue. It got to a time that I couldn't afford it because I have to use two or almost three sometimes in a day. I mean it is a big challenge - no work, no money… no bags for my stoma."*

The lives the participants knew before having the stoma changed permanently and led to emotional distress. Some lost their independence and feared those who helped them would find the tasks repulsive. Some participants could not continue with their normal activities of daily living. Additionally, some experienced a change in body image, and some changed the way they did things, such as dressing, washing themselves and their diets. Despite the hardships brought about by their changed lives, some participants accepted their stomas and displayed a positive attitude to moving forward with life.

### 4.3.3 Theme 3: The religious/spiritual consequences of having a stoma

Some participants attributed their state to God, others agreed that being positive and having faith in God and prayer support helped them to cope with their new condition, whilst others had their spirituality and religiosity compromised. This was because most religious activities are performed with other people and participants feared that interacting with others, they could be seen as nuisance.

#### Sub-theme 1: Disruption of religious activities

Some participants avoided religious gatherings because they did not want to inconvenience anybody; the fear of smell and gas was the primary reason. Marcel said, *"…For me, you know prayer is compulsory. I do not go for congregational prayer. You won`t know when there will be sound. I just stay at home to pray; I no longer go to gather with others."*

Albert added, *"I was attending church often, at least until after this thing (stoma) was done. And like I said often, I hate being a nuisance or the reason why someone will be uncomfortable. I would rather stay at home and pray than to visit the church and risk smelling all over the place."*

Marcel added, *"I don't go to church regularly like I used to, but I still have faith and pray to God almost always. I only attend prayer sessions and camps every once a while to be prayed for by my church members."*

#### Sub-theme 2: The importance of spirituality

Participants' spirituality did not change; they acknowledged the importance of maintaining a connection with God. They prayed and thanked God for keeping them alive, which helped them cope with their changed lives. *Grobler said, "It has strengthened me and brought me closer to God. I had no cause to complain because I am a Christian born again, all my family were gathered around me, which made me very happy even though I was sick. Am really grateful to God almighty for my life, it is what keeps me happy." Victor added, "I thank God, when I wake up every morning to see my wife, children and family without hearing any danger in my life, all I can do is to thank God. Aside from thanking God, what else can one do? Think and think until when? With God all things are possible, he did help me cope with this stoma."*

The participants hoped they would be cured, their lives saved, and the stomas reversed one day.

Kelvin said, *"I keep praying to God to save and make me well again so that I can continue with worshipping Him. With worship, I still have faith God will do it for me."*

Christina added, *“Looking back to the past, eish…. when I saw this thing (stoma pouch) sticking on my abdomen and I had no hope of surviving. My husband, children and family were all in tears, when from nowhere I had some faith, so I told them not to cry because I have seen someone who was in a worst condition then the person survived…. It is not everybody who goes through such conditions that comes out of it alive, my only prayer to God that I must come out of this.”*

Participants avoided religious gatherings because they did not want to inconvenience anyone; the fear of smell and gas was the primary reason. Participants acknowledged the importance of maintaining a connection with God; they prayed and thanked God for keeping them alive, which helped them cope with their changed lives. In addition, they hoped for a cure and for the stomas to be reversed one day, thus saving their lives.

### 4.3.4 Theme 4: Unmet needs

Some participants did not meet their needs after discharge, lack of health education and information made them not to cope with their new life. Follow-up at home by a health care professional is ideal to ensure that the patient is coping well with their stoma.

#### Sub-theme 1: Health education and information during hospitalisation

There was division amongst the participants in terms of the pre-operative information they received from the doctors. Some found it helpful, but for some the doctors provided vague or insufficient information regarding the stoma.

Marco explained, *“I don’t have any problem with the doctors. I remember the only thing he said was that I need to have the operation and asked me to go and prepare and come. He explained that if I did not do the operation, the cancer would get worse.* Kelvin said, *“When I went to see the doctor, he asked me if I had read the information about the stoma and……that all. Then he sent me to see the nurse.”*

Sheila said, *“They didn’t tell me what specifically my problem is, but only told me I needed to be operated on. They never told me how. They just operated, that’s all. I only remember them referring to some blood tests to be done. The doctor then told me that they will take care of me immediately all labs and tests results are done.”*

Wilma added, *“Doctors only told me it was about diet, they advised my children and wife about my diet too; what to eat and what not to eat, when to eat and when not to eat and so on. They only talked so much about my diet and moving. Anyway, the advice was helpful.”*

Some of the participants found the information they received from the nurses useful and adhered to it. Some learned from the nurses, specifically on how to manage themselves. Florence explained, *“The nurses told me what I should do when I am living at home with the stoma, like* *how I should bath and changing clothes, what to do so that I don't get problems from the stoma area. They also told me things to eat and those to avoid."*

Mika added, *"They gave me a series of education about the medications, personal hygiene, what I should eat, they reminded me to respect all the appointments. Unfortunately, I don't recall the details of most of them. I receive every necessary support I believe I should have received from the team. They even taught me how to change the bag regularly and also how to keep myself clean always."*

However, some participants were of the opinion that the education the nurses gave was not adequate nor helpful. Some believed there was insufficient time spent with them to internalise what they had to do or discuss their situation. In addition, some did not understand what they were supposed to do in terms of caring for their stoma.

Blandine explained, *"The first time I saw the stoma nurse was the day prior to surgery. I don't think that gave me enough time to record all, to be honest. It's the sort of thing you need to talk about because…it has to suit your body and your lifestyle."*

Joseph said, *"There is absolutely no information at all, nurses are in hurry when telling you something. Better use your own knowledge to take care of your stoma and of yourself."*

Christina added, *"The day I was to be discharged from the hospital, a nurse came and said some confusing things about cleaning the stoma using gauze. I didn't know what that was, to clean the area, and that I should eat lots of fruits. So, in the beginning I was eating lots of fruits, but it didn't help at all; the feces were too watery and the sound was too much, with a bad smell."*

Florence said, *"The nurses in the ward didn't teach me how to use the pouch. They showed me where I could buy the bag, in case there is shortage of stock at the clinic. It was that nurse at the clinic who taught me how to use it."*

### Sub-theme 2: The need for home-based nursing

Some participants explained how life would have been much easier if they had continuous support from the nurses at home.

Linda said, *"… many people have never seen this thing before so it is somehow difficult… (if) you have a problem with the pouch or even the stoma, you can't ask anybody. If we had nurses who could visit, like the community health nurses, it would have been easier. Sometimes if you have a problem, you have to go to the hospital to complain and they will tell you it's nothing…"*

Marco added, *"If they could organise some home visits of the nurses to come and see me once a while it would be fine. Sometimes you go to the hospital and spend the whole day there but without having any problem. Once at home, here you struggle."*

Some participants agreed that the pre-operative information they received from the doctors was helpful, but for some the doctors provided vague or insufficient information regarding the stoma. However, some participants were of the opinion the education the nurses gave was not adequate nor helpful. Some opined insufficient time was allotted to them to internalise what they had to do and discuss their situation. In addition, some did not understand what they were supposed to do in terms of caring for their stoma. Some participants expressed the need for home-based nursing to eliminate trial and error. Participants opined that life would have been much easier if they had continuous support from the nurses, even once they were home.

## 4.4 The family participants

Twenty family members (n=20), all from the Black population, participated in the study. Most (12 of 20) were female, with ages ranging from 22 to 70 years; with an average age of 42.9 a standard deviation ±12.84 years, median age of 40.5 and the modal age classes of 40. Most of the family members were married and unemployed (12 of 20). Most of the family member participants had at least attended high school (16 of 20). Table 4.3 presents the general characteristics of the participants, with pseudonyms used.

**Table 4.3 Family members' demographic information and characteristics (n=20)**

| No | Pseudonym | Age | Sex | Employment | Marital Status | Level of Education |
|---|---|---|---|---|---|---|
| 1 | Amelia | 31 | F | Unemployed | Married | Grade 11 |
| 2 | Albertine | 40 | F | Unemployed | Married | Grade 12 |
| 3 | Brenda | 58 | F | Unemployed | Married | Degree |
| 4 | Celina | 29 | F | Domestic worker | Single | Grade 6 |
| 5 | Clement | 32 | M | Unemployed | Married | Grade 8 |
| 6 | Fikile | 41 | F | Self-employed | Separated | Grade 9 |
| 7 | Hall | 36 | F | Domestic worker | Single | Grade 9 |
| 8 | Gaby | 22 | F | Unemployed | Married | Grade 7 |
| 9 | Gilbert | 40 | M | Unemployed | Married | Grade 7 |
| 10 | Lisa | 25 | F | Domestic worker | Single | Grade 12 |
| 11 | Lucas | 61 | M | Unemployed | Married | Grade 10 |
| 12 | Michael | 54 | M | Self-employed | Married | Grade 12 |
| 13 | Makonde | 52 | F | Domestic worker | Married | Grade 12 |
| 14 | Nanos | 59 | F | Domestic worker | Separated | Grade 11 |
| 15 | Nicholas | 38 | M | Unemployed | Married | Grade 12 |
| 16 | Olivier | 39 | M | Unemployed | Married | Grade 6 |
| 17 | Odette | 42 | F | Unemployed | Married | Grade 10 |
| 18 | Richards | 45 | M | Unemployed | Married | Grade 11 |
| 19 | William | 70 | M | Unemployed | Married | Grade 11 |
| 20 | Zenon | 44 | F | Self-employed | Single | Grade 12 |

Table 4.3 summarises the data that arose from the family members' demographic information

## 4.5 THEMES AND SUB-THEMES ARISING FROM THE DATA FOR FAMILY PARTICIPANTS

| THEMES | SUB-THEMES |
|---|---|
| Becoming a caregiver | 1. Confronted with the cancer diagnosis and the stoma<br>2. Caring for the person with the stoma |
| Coping with the caregiving role | 1. The role of religion and spirituality<br>2. The importance of faith and hope |

Table 4.4 summarises the data that arose from the two themes and 4 sub-themes

### 4.5.1 Theme 1: Becoming a caregiver

This theme consists of the following subthemes: confronted with the cancer diagnosis and the stoma, caring for the person with the stoma.

#### Sub-theme 1: Confronted with the cancer diagnosis and the stoma

The participants agreed about the shock they received on hearing their family members had cancer and they had to live with a stoma. They were not ready for the stoma, as they had not had time to deal with the cancer diagnosis and faced an uncertain future.

Lisa said, *"I was worried and scared, and I told the surgeon not to keep the permanent stoma since he already got cancer. I broke down and cried…knowing that my husband is not going to live…"*

Amelia added, *"It was horrible. My husband and I could barely talk to each other because … we were still reeling with this cancer diagnosis. And after the surgery…here is again to live with a stoma. I couldn't talk…just put yourself in my skin…Then you will understand what I feel.* Odette added, *"… a stoma is a shocking news, my sister. I had found out that with the stoma he will never go to the toilet anymore and the feces will be sucked by the bag which must be emptied when it is full. So, I think that was probably a big defining moment for me."* Fikile said, *"My sister, you know, I don't really understand what is my tomorrow, caring for someone who is having permanent stoma but also not working anymore. The uncertainty of the future is probably the most challenging thing."*

Participants agreed they did not know what nurses expected from them after the surgery. They had no education on how to care for the stoma and change the pouch and had to use trial and error to accomplish this task. This added to the emotional distress for the already distressed family members and led to fear, despair and self-blame.

Brenda said, *"I think the most challenging was when he first came back from the hospital after the stoma operation and … the stoma device failed, and I rushed back and having to nurse him… … the pouch was failing multiple times …. There are times where I think maybe if I was a nurse, I could handle it so easy and by now his life might be far more normal."* Lucas added, *"… at first, I didn't know that I was dealing with feces and smell... I was very much afraid doing things by trial and error not knowing exactly what I was doing."* Albertina said, *"I never have knowledge of what I am doing. I just do things from nowhere… I was scared thinking if there will be any complication."*

**Sub-theme 2: Caring for the person with the stoma**

Having to care for the person with the stoma changed the normal lives of the family members. They were not prepared for the role, which physically and emotionally drained them.

Makonde said, *"The highest amount of emotion that I felt, it was when the nurse told me that I must continue the care of the stoma at home … feeling the most fear and regrets and despair. Leaving for the hospital the first time was extremely difficult where I felt like we were leaving our life behind us, I never have knowledge of what I am going to do, but I will try."*

Hall added, *"I wake up very early, bath her and prepare her breakfast and feed her before I go to work. I help her with what I can before I go to work. After work, the same continues…I have to sort out a few things before going to bed…"*

Fikile said, *"I had to go to school, cook for her, feed her, and do her laundry, which was quite challenging…"*

The participants were also responsible for providing emotional support and made various efforts to improve the patient's mood. This was an exhausting task and added to their distress.

Clement said, "*The most challenging thing is keeping her positive when she gets down … it is a challenge to try to bring her back to seeing how blessed we really are."*

Celina said, *"My husband would say things like – "I'm done" …. And I just felt like he had no hope, had given up. And that, I mean, it just took everything, I would use all energy …"*

Having to care for the person with the stoma, physically and emotionally, consumed all the time that the family members could spend caring for themselves. Their lives changed permanently due to the demanding, exhausting and stressful care burden.

Lisa explained, *"I was starting my day with a nice cup of coffee, enjoying the cool gentle wind before the heat of the day. Then I was putting my shoes on and headed out the door for a walk…. All that kind of life is over, because I am taking care of my old mother."*

Nanos said, *"Helping with toileting, feeding, lifting, positioning, transferring, massaging, changing the stoma …. No more taking care of myself."*

Sleep deprivation was a major challenge for most of the participants, whilst some also experienced pain, migraine headaches, backache, fatigue, stress-related diseases and also hopelessness.

Celina said, *"I used to have a couple of hours of sleep when he could still sleep, but now I hardly sleep, and my body has taken a lot of strain I can feel it..."*

Brenda said, *"I have been having migraines lately. I have lower back pains and my friend, who is a gym coach, told me that a lot of times caregivers carry stress on their lower back. It is very stressful…"*

Albertine added, *"I have lots of pain in my body. I can't sleep well but I am just ignoring everything so that I can focus on my son. Whatever pain I take it as nothing. Sometimes I can't sleep; I have this pain on my whole left side. There is nothing I can do about it now; I just have to concentrate on him now, he needs me. I will go to the hospital when all this is over…"*

The participants agreed they were shocked when they learnt their family member had cancer and they had to live with a stoma; they were not ready for the new role of caring for the stoma, whilst some were also responsible for providing emotional support and made various efforts to improve the patient's mood. Participants agreed they did not know what nurses expected from them after the stoma surgery. They were uneducated on how to care for the stoma and change the pouch and had to use trial and error to accomplish this task. This added to the emotional distress for the already distressed family members and led to fear and despair. In addition, having to care for the person with the stoma changed the normal lives of the family members.

### 4.5.2 Theme 2: Coping with the caregiving role

This theme consists of the following subthemes: the role of religion and spirituality, the importance of faith and hope.

### Sub-theme 1: The role of religion and spirituality

Participants emphasised that religious and spiritual activities, such as praying, meditation, joining religious groups and relying on the church for support gave the meaning of life and strength in this task of caring.

Gaby explained, *“Joining a church group…. I keep going and we had a prayer day last month… Cancer awareness. You actually got to see a whole bunch of cancer survivors sharing their experiences about what God has done for them. We have the stability of people that had it and the stories of people that didn’t make it and the people that did make it. That gave me strength to carry on.”*

Gilbert added, *“But I had so many prayers coming my way from our prayer group where we used to live and my church here and all of my friends. I could just feel it. And I have a lot of spiritual books which I never had before. And it was an experience.”*

Lisa said, *“Every morning I get up, and I have a daily meditation. And then I pray a little bit, every…. I pray for my family and everyone around me, the kids and stuff. And then I read like a little chapter in my Bible then I go to work, then I can feel that it’s bringing me closer to God.”*

### Sub-theme 2: The importance of faith and hope

Some participants agreed that maintaining faith and hope helped them to mitigate the adverse effects of caring stress on mental health.

William said, *“There is nothing that I can really do...with all the cancer going around I look at it as some guys say, why me, God? And I say, well why not me? So that is the way I felt, it is something that happens, and it happened. We are not exceptional. That is the way I accepted it and we have great faith and great strength throughout the family.”*

Hope did fortify them against hopelessness, helped them derive meaning from the caring experience, and provided them with an existential perspective on hope and suffering. Michael said, *“I pray a lot…The helplessness that you can feel from the fact there’s nothing I can do to make her better . . .. there’s no way I can make this go away unless I get some help from above or maybe that final cure will come through that we’re all hoping for, for this disease.”* Zenon said, *“Yah, it really was to me. So, I have a lot of faith and I’m a religious person and, of course, I’ve become more spiritual and have more faith since I had this experience. I will tell you that.”*

They believed there was a higher power in charge. Gaby said, *“There are things that you can control and can handle. And those that you have no control over you do what you can do and that is it. We are not in charge, God is….”*

Participants agreed that maintaining faith and hope helped them to mitigate the adverse effects of caring stress on mental health. Hope did fortify them against hopelessness, helped them derive meaning from the caring experience, and provided them with an existential perspective on hope and suffering. They believed there was a higher power in charge.

## 4.6 DISCUSSION

### 4.6.1 Patient participants

This study provided evidence that the participants experienced various problems because of the stoma, which included an unpleasant smell and gas, and pouch leakages. They perceived the uncontrolled behaviour of the stoma, smell and gas as a sanitary nuisance, which resulted in emotional distress. Experiencing these issues is not new among stoma patients. Fedden et al. (2015) and Hoeflok (2017) reported that pouch leakage caused discomfort and distress, and fear of this happening affected the daily life, activities and social life of stoma patients. Marinez et al. (2016) and Sun et al. (2013) concurred with this and reported that the uncertainty and loss of control associated with leakage of the stoma appliance caused emotional distress and disturbance in patients with a stoma. Leakages bring about unpleasant smells and make life unbearable for people.

Participants also reported leaking around the stoma area. This occurs when stoma patients do not use proper pouches specially made for stomas or reuse the same pouch after washing it. The leakages could have occurred because the reused pouch, secured with a plaster, may be loose or the rubber could have burst, causing the leakages. Studies with similar findings reported that the quality of the pouch that individuals wear has a great bearing on the quality of life of the stoma person (Liao and Qin, 2014; Galandiuk et al., 2021).

Participants were unable to sleep deeply, as they were afraid of the bag leaking and having to wake up frequently, hesitant to turn in bed and even stayed awake till morning because they did not want to wet the bed linen. Participants had disrupted sleep because of trips to the bathroom to empty the pouch. This is consistent with Dabirian et al. (2011) and Davidson (2020) who reported that most stoma patients had problems related to sleep because of fear of leakage of the bag at night.

Having to live with a stoma, and being aware of its uncontrollable nature, the fear of the smell and gas that the stoma could generate, as well as the possibility that others will be aware of the presence of the stoma or pouch, led the participants to a situation of fear and isolation. In the studies conducted by Ferreira et al. (2014), Zhang et al. (2014) and Silva et al. (2017), they identified that social relationships were conditioned by the patients' fear of the smell and noise the stoma could generate, as well as by the possibility that others would be able to see the pouch; this situation made the stoma patients stay in isolation.

Participants agreed that the presence of a stoma made them live a changed life; they had to change their clothing styles and the way they dressed. In addition, the location of the stoma affected what clothing they could wear after the surgery; participants verbalised that some of their clothes could not sit directly on the stoma, therefore they had to discard them from their wardrobes. This finding was similar to that of Repic and Ivanovic (2014), Anderson (2011) and Krone et al. (2020) who reported that permanent stoma patients said they needed to change clothing styles to avoid other people seeing the stoma through the clothing.

Findings also revealed that participants learnt how to manage their effluence through their diet. This resulted in changes to their diet; they had to stop eating certain kinds of foods whilst introducing others. Dabirian (2011) and Doty (2019) reported that most patients had to change their diet due to problems in gas control, but most of them coped with their conditions over time. Shaffy et al. (2012) mentioned that most colostomies suffer from discomfort with certain food items, which led to modification of their routine diet.

The present study highlights the psychosocial consequences in men and women living with a stoma. In the study by Cheng et al. (2013) and Bekkers et al. (2019) regarding the psychosocial consequences, the results showed that men and women had significant impairment in the psychosocial adjustment. Anderson (2011) and Everitt (2020) found that some participants, particularly women, felt the need to avoid being seen naked with either the stoma or appliance exposed, due to the loss of bodily confidence.

In this current study, some participants were hesitant about revealing the existence of the stoma to others because they were not certain about how others would react. The level of comfort of disclosure of this information varied and was determined by the relationship they had with the others and their potential reaction, the participants' circumstances and personal perspectives. Similarly, in a study by Gautam et al. (2016), the patients were fearful of the reaction of others should they know about the existence of their stomas. In addition, participants kept the stoma a secret from some people because they thought that revealing the secret would not change anything for the better, apart from people pitying them. Sarabi et al. (2015) had a similar finding, where compassionate behavior with pity caused great emotional harm in the participants. Grant et al. (2011) and Kosovan (2017) also showed that individuals are ashamed of having a stoma and tried to hide it.

Participants reported how they had profound changes in body image, physical problems and embarrassment about the stoma, which brought about disruptions in intimate relationships and sexual functioning. This is consistent with a study that reported that stoma creation could have an impact on mental health in many ways, with stoma patients reporting that the stomas have an impact on self-image as well as sexual health (Ang et al., 2013; Aktas and Gocmen, 2019).

In this current study, participants thought their body had changed compared to their pre-operative body and avoided sexual relations because they thought they were unattractive. The stoma had a negative effect on the sexuality of the person because they found themselves less attractive, a feeling not shared with their partners (Neuman et al., 2012 and Ayaz, 2018). In addition, this study also stated that the hampering of sexual relations could be because a partner may feel he/she will hurt the stoma, thus causing the spouse to avoid sexual intimacy. This finding appeared in a study where fear of damaging the stoma could cause partners to distance themselves from the person (Liao et al., 2014; Altschuler and Ramirez, 2020). In addition, they highlighted that the loss of control over bodily behaviours, such as bodily noises, embarrassed the patients due to loss of privacy and feelings of marginalisation. This finding is similar to studies that reported that physical problems of gas, smell and leakage from the stoma influenced sexual relations (Grant et al., 2011).

Participants experienced financial hardship after the stoma operation, as they had to leave their jobs, which affected their income. In addition, buying stoma accessories and supplies caused financial problems; this resulted in stoma patients who could not afford the bag using plastic bags or washing the bags for reuse, even when they were disposable. This supports the finding that stoma patients lost or changed their jobs after the operation (Dabirian et al., 2011; Francone, 2020).

Recently, stoma appliances have come with flatus filters to minimise the gas effect, and there are a variety of stoma accessories now available on prescription to secure the appliance and reduce risk of leaks (Burch, 2014); however, most stoma patients may not afford this modern apparatus due to a financial crisis (Annells, 2018).

This study provided evidence that participants had their spirituality intact. This supports the study of Bachelet et al. (2012) and Li (2017), who found that people with a strong spiritual wellbeing coped better with adjusting to their stoma than did people without spirituality. In addition, there was a compromise and reduction in religiosity, because most religious activities occurred with other people. Some participants reported they no longer joined the religious activities, fearing that leakages, smell and gas could be a nuisance. Ahmad et al. (2011) concurred with this and reported that it was difficult for a stoma patient to offer prayer in a mosque in Jamat (Muslim church) because the fellow Muslims offering prayer could react negatively on hearing the passing of flatus.

Participants had another way of expressing their spiritual implications, in the form of hope. They were hopeful that God would grant them total healing. This hope for total healing resulted from participants believing they had received a second chance, which is the creation of a stoma, since they did not die from the colorectal cancer; this experience drew them closer to God. This finding is consistent with that of Kimura et al. (2013) and Janbabaei (2019) who found that spiritual wellbeing can facilitate patients' healing and recovery by enhancing their inner strength, comfort, peace and coping abilities and by alleviating depressive symptoms, promoting mental health, increasing energy, and decreasing cancer-related distress. In addition, spirituality, including faith and meaning, acts as an important variable in predicting the ease of adjustment to life with stoma.

In this study, there did not seem to be any purposeful delivery of health education and information on the management of the stoma during hospitalisation. This left some participants using trial and error to manage their stomas. A recent study reported a similar finding, in that participants complained that after the surgery they did not receive adequate education at the hospital (Sarabi et al., 2015). Danielsen et al. (2013) and Adams, Boulton and Watson (2020) emphasised that patients want as much information as possible; it is important to know what type of information they want and need, and in a way that they understand. According to Spence et al. (2010) and Hummel (2016), access to relevant support and information could promote patient empowerment and self-management. The study conducted by Beaver et al. (2010) and Miller (2019) found that patients with a stoma described the benefit of sustained nursing support regarding stoma complications, symptoms and worries after discharge. Jayarajah and Samarsekera (2017) found that the provision of continued ostomy education after patient discharge could maintain the ostomy adjustment and life quality.

Some participants explained how life would have been much easier if they had had continuous support from the nurses, even at home; this would prevent them from trial and error when caring for their stomas. A similar study by Boyles et al. (2010) suggested that the knowledge and skills required are not always quickly learned, therefore follow-up care at home by the healthcare professional includes all elements of stoma care that facilitates independent living by the stoma patients to help them achieve a high standard of self-care and to protect their quality of life (Cengiz and Bahar, 2017). Ercolano et al. (2016) and Burch (2017) stated in their study that ostomy care by the nurse should continue following discharge. Follow-up at later time intervals for ostomy education has proved to be effective in increasing ostomy adjustment (Krouse et al., 2016; Sun et al., 2013).

### 4.6.2 Family member participants

This study provided evidence that family members were not ready to deal with the stoma and pouches, since they had not received sufficient education from the nurses. They used trial and error methods to accomplish this task. According to Gusdal et al. (2016), in a study conducted in the United Kingdom, caregivers lacked knowledge while performing their tasks and ended up doing something just to see if it would bring good results. In addition, Gautam and Poudel (2016) and Cengiz and Bahar (2017) found in their studies that individualised education for stoma patients should be available to family caregivers, in order to improve caring acceptance and decrease fear, despair and self-blame.

This study provided evidence that participants were shocked when they learnt their family members had colorectal cancer and they had to live with permanent stomas. They assumed the role of caregivers; some were not prepared for this, whilst some were also responsible for providing emotional support and made various efforts to improve the patient's mood, which added to the emotional distress for the already distressed family members and led to fear, despair and self-blame. Girgis et al. (2012) and Cotrim and Pereira (2018), in a study conducted in the United States of America, indicated that the majority of caregivers reported they took on the role because it was a family responsibility and there was little choice, or no other person to take the role, while Capello et al. (2012) and Goodhart (2020) found that family caregivers had to quit their jobs and their social lives to dedicate themselves full-time to those needing care.

Some participants did not know what nurses expected from them after the surgery. They had no education on how to care for the stoma and change the pouch and had to use trial and error to accomplish this task. Maree et al. (2017) found that the caregivers in their study lacked knowledge about how to provide care and made decisions about pain management with no, or insufficient guidance.

Having to care for the person with the stoma changed the lives of the family members; it physically and emotionally consumed all the time they could spend caring for themselves. Maree et al. (2017) found in their study that caregivers neglected themselves due the demands of caregiving responsibilities. Sleep disturbance was a major challenge for most of the participants, whilst some experienced fatigue, depression, helplessness and social isolation. The studies conducted by Kotronoulas et al. (2013) and Lee and Kim (2020) found caregivers also had a high prevalence of sleep disturbance and approximately 40% who had a family member with cancer reported sleep problems. The most common types of sleep problems in caregivers of adults with cancer are short sleep duration and nocturnal awakenings, resulting in daytime dysfunction. Sleep disturbance contributes to adverse health outcomes and poor quality of life for caregivers.

It is evident from the current study that the main support net to cope with the caring role was spirituality. Independent of religious activities, it was evident that faith was the most frequent support pursuit during this time. Hope helped participants to mitigate the adverse effects of caring stress on mental health. They believed a higher power was in charge. Asiedu et al. (2014) and Janbabaei (2019) similarly found that caregivers, regardless of the challenges, trusted in God for their strength and never stopped praying. In addition, they described that a positive relationship with and full reliance on God gave them hope.

## 4.7 CONCLUSION

Living with a stoma affected patients' lives dramatically. The self-care education they received did not prevent some from soiling themselves; they therefore needed help from family members to care for their stomas. Some feared the stoma would surprise them and isolated themselves from social contact and they had to leave their job which had affected their income. Some participants experienced disruptions in intimate relationships which the stoma brought about. Some had their spirituality intact, but religiosity was compromised because most religious activities are performed with other people. Some participants expressed the need for home-based nursing to eliminate trial and error at home. For family members, having to care for the person with the stoma changed the lives they were used to. Some forgot to take care of themselves. Others lost their jobs during the caring period. Some agreed that maintaining faith and hope helped them to cope with the new role of caring.

# CHAPTER 5

# JUSTIFICATION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

## 5.1 INTRODUCTION

Chapter 4 presented and discussed the findings of the study. This chapter will provide the justification, limitations, recommendations, researcher reflection and conclusion.

## 5.2 JUSTIFICATION OF THE STUDY

The basis for the justification of the study is its purpose, which was to describe the experiences and needs of colorectal cancer patients living with a stoma, and their families, treated at an academic hospital in Gauteng. Chapter 1 detailed the overview of the study, Chapter 2 presented an extensive literature, including both national and international perspectives of the relevant published studies, Chapter 3 described the research design and methods, and Chapter 4 presented the findings and discussion of the experiences and needs of colorectal cancer patients living with a stoma, and their families.

The study established the experiences and needs of colorectal cancer patients living with a stoma, and their families, treated at an academic hospital in Gauteng, and presented the feature in terms of four themes: living with the physical consequences of a stoma, living with the psychosocial consequences of a stoma, the religious/spiritual consequences of having a stoma and the unmet needs. Therefore, the conclusion is that the study achieved its purpose, and can be justified.

## 5.3 LIMITATION OF THE STUDY

The study only included Black people living in a specific area, which does not represent all socioeconomic and race groups. In addition, the findings of qualitative studies cannot extend to a wider population or allow for different interpretations of the raw data; however, the researcher believes the study provides a true reflection of the experiences of these patients and their families.

## 5.4 RECOMMENDATIONS

Based on the findings of this study, the recommendations are:

- The development and implementation of a nurse-led educational programme, based on the needs of the patients and their families. The educational programme for the patient should start on admission to the hospital and continue to the outpatient level. A multiprofessional team approach should be followed, and spiritual leaders should form part of the team

- The development of follow-up schedules for outpatients with stomas, and their families
- An investigation into ways of ensuring the availability of consumables required by such patients
- A psychosocial health programme should be planned to help such a group of patients and their families to cope and improve their mental health.

## 5.5 INVESTIGATOR'S REFLECTION ON HER EXPERIENCE

Reflection is an important data collection tool that enables investigators to engage in self-analysis throughout the research process. Therefore, I would like to take this opportunity to share my experience with those who will read this research study. In this session, I did not know how the patients living with a stoma experienced life with these consequences and outcomes, therefore I tried to be more patient and listen during the interview.

I had to remind myself during the interview not to give the impression that certain parts of the answers were more important than were others. I had to reassure them, and not allow them to burst into tears, but rather relax and enjoy the interview.

The interviews left me debilitated, and I reflected on the stoma patient's ordeal with a new view of the devastating consequences on everyone in a similar condition. As I interviewed the family members, it was easy to see they were more concerned than were the stoma patients; they were worried, and most of the time asked numerous questions relating to the outcomes of the patients and themselves, with many uncertain of their future. Despite all their emotions, they were always thankful and appreciated any information given to them regarding care of the patient and for themselves. They believed their hope and faith in God gave them strength to cope with the new life.

## 5.6 CONCLUSION

Living with a stoma affected patients' lives dramatically. Some participants did not receive a high standard of education to prevent them from soiling themselves; they feared the stoma would surprise them and isolated themselves from social contact. They expressed the need for home-based nursing to eliminate trial and error at home. For family members, having to care for the person with the stoma changed the lives they were used to. Some forget to take care of themselves, whilst others lost their jobs during the caring period. Some agreed that maintaining faith and hope helped them to cope with the new role of caring.

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## ANNEXURE A: PLAGIARISM DECLARATION FORM

## PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

I, Ndaya Mukendi Maguy (Student number: 2295220), am a student registered for the degree of MSC Nursing in the academic year 2021.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else’s work without their permission and/or without acknowledging the original source) is wrong.

- I confirm that the work submitted for assessment for the above degree is my own unaided work, except where I have explicitly indicated otherwise.

- I have followed the required conventions in referencing the thoughts and ideas of others.

- I understand that the University of the Witwatersrand may take disciplinary action against me if there is belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in writing.

- I have included as an appendix a report from “Turnitin” (or other approved plagiarism detection software indicating the level of plagiarism in my research document.

Signature : Date :

## ANNEXURE B : INFORMATION LEAFLET (Patient)

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

Dear Patient

Good day, my name is Ndaya Mukendi Maguy. I am a Master's student in Oncology and Palliative Care at the University of the Witwatersrand, Faculty of Health Sciences, Department of Nursing. I have been practicing in the Oncology field for a few years. I would like to invite you to take part in a study I am conducting at the stoma clinic. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to phone me at 072 335 0901. During office hours (08:00 – 17:00), after hours on 061 783 0306.

### What is the study all about?

With this study, the researcher hopes to gain a better understanding of the experiences and needs of the colorectal cancer patients living with a stoma. The study also involves the family caring for patients receiving stoma care, as they will also be asked to describe their experiences and needs.

### Length of your participation

If you are eligible and decide to participate in this study, your participation will last approximately one hour for the interview and possibly another hour for a follow-up contact.

Where the study is being done and number of people participating

The research study will take place at the stoma clinic in the academic hospital. A total of approximately 20 adults will be interviewed for the study.

### Study procedures

Your participation will involve:

- An interview with the researcher asking questions regarding your experiences and needs while living with a stoma.

- A follow-up interview may be asked of you to verify the meaning of information that you provided, to seek further information and to review the transcribed information.

- The interviews will be audio-recorded by the researcher. Your identity will be kept in confidence by using a code as the identity marker for your transcribed interview comments and will only be known to the researcher.

- All recordings will be destroyed after the analysis of the data is completed.

- You will be asked a short series of demographic questions such as age, gender, ethnic background, education level and approximate date of diagnosis.

**Possible risks or side-effects of taking part in the study**

You may feel uncomfortable discussing your experiences. If at any point you are not comfortable, you may skip a question or stop participating. The treatment of the information will be confidential. You are free to give only the information you choose.

**Costs for taking part in the study**

There is no cost for being in the study.

**Payment for taking part in this study**

There is no payment for this study.

**Possible benefits to you for taking part in the study**

You will not directly benefit from participating in this research study. However, your participation may contribute to the understanding of the issues faced by colorectal cancer patients who are living with stomas.

**About participating in this study**

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the investigator so that your information can be removed from the study.

If you have other medical problems or side-effects, the doctor and/or nurse will decide if you may continue in the research study.

**Are there any conditions that may exclude you from the study?**

You have to be a patient previously diagnosed with a colorectal cancer and living with a stoma, following your stoma care at the stoma clinic. You also need to be older than 18 years.

**How will confidentiality and anonymity be ensured for the study?**

What you say to me is confidential and only the researcher (myself) would be able to have access to your information. I will not identify you in any way on my records – your information will be given a code number which cannot be traced back to your name.

**Has the study received ethical approval?**

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee. Approval was also sought from the research site and approval was granted. Should you have any questions regarding the ethical aspects of the study, you can contact Professor Lize Maree, my supervisor, at +27 (0) 11 488 4198/4272, or the Chairperson of the Ethics Committee of the University of the Witwatersrand, Dr Clement Penny, on +27 011-7171234 or e-mail Clement.Penny@wits.ac.za

Thank you for taking the time to think of joining the study. If you have any further questions, please contact me.

Yours sincerely,

Ndaya Mukendi Maguy (Oncology Nurse)

Cell: 072 33550901

## ANNEXURE C: INFORMATION LEAFLET (Family)

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

Dear Family Member

Good day, my name is Ndaya Mukendi Maguy. I am a Master’s student in Oncology and Palliative Care at the University of the Witwatersrand, Faculty of Health Sciences, Department of Nursing. I have been practicing in the Oncology field for a few years. I would like to invite you to take part in a study I am conducting at the stoma clinic. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to phone me at 072 335 0901. During office hours (08:00 – 17:00), after hours on 061 783 0306.

### Length of your participation

If you are eligible and decide to participate in this study, your participation will last approximately one hour for the interview and possibly another hour for a follow-up contact.

### Where the study is being done and number of people participating?

The research study will take place at the stoma clinic in the academic hospital. A total of approximately 20 adults will be interviewed for the study.

### Study procedures

Your participation will involve:

- An interview with the researcher asking questions regarding your experiences and needs while caring for a patient living with a stoma.
- A follow-up interview may be asked of you to verify the meaning of information you provided, to seek further information and to review the transcribed information.

- The interviews will be recorded and transcribed by the researcher. Your identity will be kept in confidence by using a code as the identity marker for your transcribed interview comments and only known to the researchers.

- All recordings will be destroyed after the analysis of the data is completed.

- You will be asked a short series of demographic questions such as age, gender, ethnic background, education level and approximate date of diagnosis.

**Possible risks or side-effects of taking part in the study**

You may feel uncomfortable discussing your experiences. If at any point you are not comfortable, you may skip a question or stop participating. In order to minimize these risks, your information will be kept confidential. You are free to give only the information you choose.

**Costs for taking part in the study**

There is no cost for being in the study.

**Payment for taking part in this study**

There is no payment for this study.

**Possible benefits to you for taking part in the study**

You will not directly benefit from participating in this research study. However, your participation may contribute to the understanding of the issues faced by family members caring for colorectal cancer patients who are living with stomas.

**About participating in this study**

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the investigator so that your information can be removed from the study.

If you have other medical problems or side-effects, the doctor and/or nurse will decide if you may continue in the research study.

**Are there any conditions that may exclude you from the study?**

You have to be a family member of a colorectal cancer patient living with a stoma who is receiving stoma care at a stoma clinic in an academic hospital. You also need to be older than 18 years.

### Possible risks or side- effects of taking part in the study

You may feel uncomfortable discussing your experiences. If at any point you are not comfortable, you may skip a question or stop participating. In order to minimise these risks, your information will be kept confidential. You are free to give only the information you choose.

### Possible benefits to you for taking part in the study

You will not directly benefit from participating in this research study. However, your participation may contribute to the understanding of the issues faced by the family members of the colorectal cancer patients who are living with stomas.

### What are your rights as a participant in this study?

You can choose if you want to take part in the study. You can also, during the interview, say that you do not want to take part anymore. You can even tell me that I cannot use the information after you have talked to me about it.

### How will confidentiality and anonymity be ensured for the study?

What you say to me is confidential and only the researcher (myself) would be able to have access to your information. I will not identify you in any way on my records – your information will be given a code number which cannot be traced back to your name.

### Has the study received ethical approval?

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee. Approval was also sought from the research site and approval was granted. Should you have any questions regarding the ethical aspects of the study, you can contact Professor Lize Maree my supervisor at +27 (0) 11 488 4198/4272, or the Chairperson of the Ethics Committee of the University of the Witwatersrand, Dr Clement Penny, on +27 011-7171234 or e-mail Clement.Penny@wits.ac.za

Thank you for taking the time to think of joining the study. If you have any further questions, please contact me.

Yours sincerely,

Ndaya Mukendi Maguy (Oncology Nurse) Cell: 072 335 0901

UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

**ANNEXURE D: INFORMED CONSENT FOR PARTICIPATION (Patient)**

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

I hereby confirm that I have been informed by the researcher………… (name of the researcher) about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Patient Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including my personal details, will be anonymously processed into a research report. I understand that I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant ………….........… (Printed Name) Signature ……..................... Date & time ……..........

I, ……………...................................…… (name of the researcher) herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Researcher……………................ (Printed name), signature…………. Date & time.………....

Witness………………................... (Printed name), signature…………. Date & time ……….......

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JOHANNESBURG

## ANNEXUERE E: INFORMED CONSENT (Family)

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

I hereby confirm that I have been informed by the researcher………………. (Name of the researcher) about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Family/significant other Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including my personal details, will be anonymously processed into a research report. I understand that I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant…………… (Printed Name). Signature ……… Date and time………………….

I, ……………………………………………………… (name of the researcher) herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Researcher…………….. (Printed name), signature…………. Date and time…………….

Witness………………… (Printed name), signature…………. Date and time……………..

**ANNEXURE F: INFORMED CONSENT FOR AUDIO-RECORDING (patient)**

Institution: University of Witwatersrand

Telephone number(s): +27 723 350 901

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

Good day, my name is Ndaya Mukendi Maguy, I am a masters' student in Oncology and Palliative Care at University of Witwatersrand, Faculty of Health Sciences, Department of Nursing Education. Thank you for considering my invitation to participate in this research study.

I am requesting your permission to allow me to record our interview. Your name will not be on the recording or on the transcription, so the data will not be linked to your name. All data will be stored in a secure place and no one except the research team will have access to your interview.

I, ………………………. have consented to be a participant in the study being conducted by Ndaya Mukendi Maguy and have been asked to give my consent to the interview being audio-recorded to aid accurate collection and analysis of the information. I give my consent for the interview to be audio-recorded

Participant…………… (Printed Name). Signature ……… Date and time…………….

I, …………………… (name of the researcher) herewith confirm that the above participant has been fully informed about the obligation involved in recordings of the interview.

Researcher………............. (Printed name), signature……………...... Date & time……...….

Witness……………………........ (Printed name), signature……………..... Date & time…………......

## ANNEXURE G: INFORMED CONSENT FOR AUDIO-RECORDING (family)

Institution: University of Witwatersrand

Telephone number(s): +27 723 350 901

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

Good day, my name is Ndaya Mukendi maguy, I am a masters' student in Oncology and Palliative Care at University of Witwatersrand, Faculty of Health Sciences, Department of Nursing Education. Thank you for considering my invitation in participating in this research study.

I am requesting for your permission to allow me to record our interview. Your name will not be on the recording or on the transcription, so the data will not be linked to your name. All data will be stored in a secure place and no one except the research team will have access to your interview.

I, ……………………………………………. Have consented to be a participant in the study being conducted by Ndaya Mukendi Maguy and have been asked to give my consent to the interview being audio-recorded to aid accurate collection and analysis of the information. I give my consent for the interview being audio-recorded.

Participant……………….................. (Printed Name), Signature …........…… Date and time ……….

I, ……………………… (name of the researcher) herewith confirm that the above participant has been fully informed about the obligation involved in recordings of the interview.

Researcher…………….......... (Printed name), Signature…………........…. Date & time………....

Witness……………….............. (Printed name), signature……….......…. Date & time………....

UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

## ANNEXURE H: VERBAL INFORMED CONSENT

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

Verbal participant informed consent (applicable when participants cannot read or write or are unable to do so for any reason as a means of ratifying the mark given by the participant instead of a signature)

I, the undersigned, ……..............................................................…… (name of the researcher) have read and have explained fully to the participant, named ………………….................... and/or his/her relative, the participant information leaflet, which has indicated the nature and purpose of the study in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that he/ she understands that she will be free to withdraw from the study at any time for any reason and without jeopardising his/ her relationship with the health care team.

I hereby certify that the participant has agreed to participate in this study.

Participant…………................. (Printed Name). Signature …………. Date & time…………......

Researcher…………….......... (Printed name). signature………….. Date & time………......

Witness…………….................. (Printed name). signature…….……. Date & time……….......

# ANNEXURE I: PATIENT PARTICIPANTS' DEMOGRAPHIC INFORMATION AND CHARACTERISTICS

| | | | |
|---|---|---|---|
| Participant number……………. | | | |
| Population group | White | | |
| | Asian | | |
| | African | | |
| | Coloured | | |
| Language | Basic English | | |
| Age | ……………… years | | |
| Gender | Male | | |
| | Female | | |
| | Transgender | | |
| Marital status | Married | | |
| | Divorced | | |
| | Separated | | |
| | Single | | |
| | Widowed | | |
| | Co-habiting | | |
| | | | |
| Education level | Never went to school | | |
| | Up to grade 7 | | |
| | High school | | |
| | Degree | | |
| | Postgraduate | | |
| Diagnosis | Colon cancer | | |
| | Rectal cancer | | |
| Duration of living with a stoma | ……Weeks…………Months………. years | | |
| Employment | Full time | | |
| | Part time | | |
| | Unemployed | | |
| | Retired | | |

UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

## ANNEXURE J: FAMILY MEMBER PARTICIPANTS’ DEMOGRAPHIC INFORMATION AND CHARACTERISTICS

| | | | |
|---|---|---|---|
| Participant number | | | |
| Population group | White | | |
| | African | | |
| | Asian | | |
| | Coloured | | |
| Language | Basic English | | |
| Age | …………… years | | |
| Gender | Male | | |
| Age | Female | | |
| Marital status | Married | | |
| | Divorced / separated | | |
| | Widowed | | |
| | Single | | |
| Educational level | Never went to school | | |
| Educational level | Up to grade 7 | | |
| | High school | | |
| | Degree……… postgraduate ………. | | |
| Employment | Full time……. part time……………. | | |
| | Unemployed……… retired.………... | | |
| Relationship to patient | | | |

## ANNEXURE K: INTERVIEW QUESTIONS

**Study Title: Living with a stoma: The experiences and needs of the colorectal cancer patients and their families**

To gather data, the following questions were asked:

### Interview questions for patients

- Please tell me what is it like for you to live with a stoma?
- Please tell me what are your needs as a person living with a stoma?

### Interview questions for family

- Please tell me what is it for you to live and care for a person with a stoma?
- Please tell me what are your needs as a family member of a stoma patient?

## ANNEXURE L: POSTGRADUATE COMMITTEE RESEARCH TITLE APPROVAL LETTER

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076
Reference: Mrs Sandra Benn
E-mail: Sandra.benn@wits.ac.za

05 September 2019

Mrs NM Maguy
100 Hamilton Street 2295220
Flat 407 Ziervogel
Person No: 2295220
PAG
Arcadia
0083
South Africa

Dear Mrs Ndaya Maguy

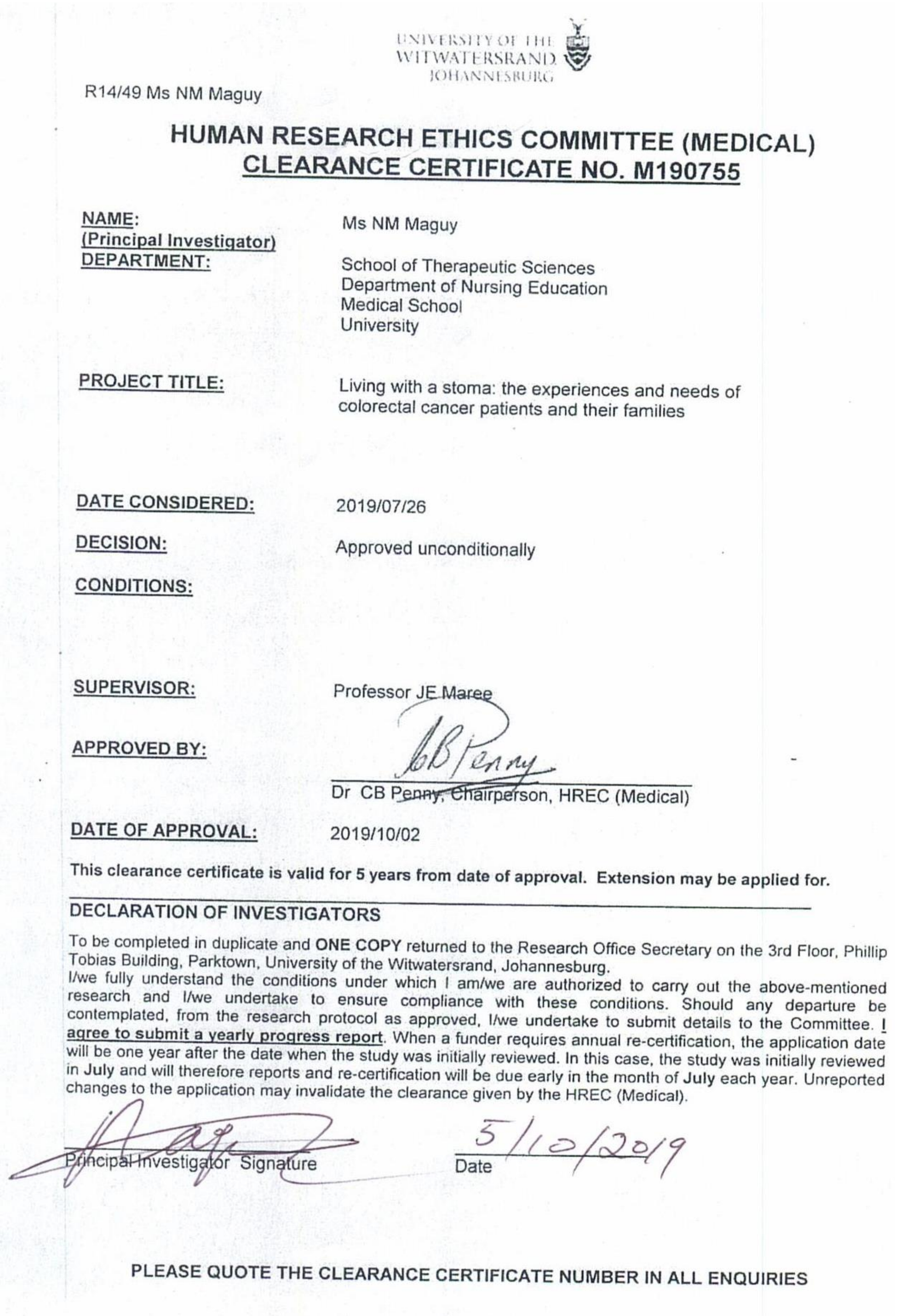
**Master of Science in Nursing: Approval of Title**

We have pleasure in advising that your proposal entitled *Living with a Stoma*: The experiences and needs of Colorectal Cancer patients and their families has been approved. Please note that any amendments to this title have to be endorsed by the faculty's higher degrees committee and formally approved.

Yours Sincerely

Mrs Sandra Benn
Registrar
Faculty of Health Sciences

## ANNEXURE M: CLEARANCE CERTIFICATE



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R14/49 Ms NM Maguy

# HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
# CLEARANCE CERTIFICATE NO. M190755

| | |
|---|---|
| **NAME:**<br>**(Principal Investigator)** | Ms NM Maguy |
| **DEPARTMENT:** | School of Therapeutic Sciences<br>Department of Nursing Education<br>Medical School<br>University |
| **PROJECT TITLE:** | Living with a stoma: the experiences and needs of colorectal cancer patients and their families |
| **DATE CONSIDERED:** | 2019/07/26 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | |
| **SUPERVISOR:** | Professor JE Maree |
| **APPROVED BY:** | CB Penny<br>Dr CB Penny, Chairperson, HREC (Medical) |
| **DATE OF APPROVAL:** | 2019/10/02 |

**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.**

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **July** and will therefore reports and re-certification will be due early in the month of **July** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

5/10/2019
Date

**PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES**

## ANNEXURE N: LETTER TO THE CEO OF THE ACADEMIC HOSPITAL

Dear Mr/Mrs

**RE: PERMISSION TO CONDUCT A RESEARCH STUDY IN THE HOSPITAL**

My Name is Ndaya Mukendi Maguy, and I am a student at the University of the Witwatersrand in Johannesburg. The research I wish to conduct for my Master's dissertation involves Living with a stoma: the experiences and needs of colorectal cancer patients and their families. This project will be conducted under the supervision of Professor Lize Maree in the Department of Nursing Education, University of the Witwatersrand in Johannesburg.

I am hereby seeking your consent to approach patients and conduct interviews for participation in this research.

I have provided you with a copy of my dissertation proposal which includes copies of the measure and consent and assent forms to be used in the research process, as well as a copy of the approval letter which I received from the Research Ethics Committee.

Upon completion of the study, I will undertake to provide the Department with a bound copy of the full research report. If you require further information, please do not hesitate to contact me on 072 335 0901 or Email address: 2295220@students.wits.ac.za. Thank you for your time and consideration in this matter.

Yours sincerely

Ndaya Mukendi Maguy

# ANNEXURE O: RESEARCH SITE APPROVAL

**GAUTENG PROVINCE REPUBLIC OF SOUTH AFRICA**

**Dr. George Mukhari Academic Hospital**

**Office of the Director Clinical Services**

Enquiries: Dr. C Holm
Tel: (012) 529 3691
Fax: (012) 560 0099
Email.Christene.Holm @gauteng.go.za
Keitumetse.mongale@gauteng.gov.za

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To Ms NM Maguy
Department of Nursing
University of the Witswatersrand
1 Jan Smuts Avenue
Braamfontein
Johannesburg
2000

**Date** 16 October2019

**PERMISSION TO CONDUCT RESEARCH**

The Dr George Mukhari Academic Hospital hereby grants you permission to conduct research on “Living with a stoma: the experiences and needs of colorectal cancer patients and their families" at Dr George Mukhari Academic Hospital".

This permission is granted subject to the following conditions:

- ✓ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University
- ✓ That the Hospital incurs no cost in the course of your research
- ✓ That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services
- ✓ That prior to conducting the research, you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.
- ✓ Formal written feedback on research outcomes must be given to the Director: Clinical Services
- ✓ Permission for publication of research must be obtained from the Chief Executive Officer

Yours sincerely

**DR. C. HOLM DATE: 17/10/2019**

____________________________

**ACTING DIRECTOR CLINICAL SERVICES**

## ANNEXURE P: WORK CERTIFICATE OF LANGUAGE EDITION

*Gill Smithies*

*Proofreading & Language Editing Services*

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: g-tech@mweb.co.za

## *Work Certificate*

| | |
|---|---|
| To | Prof L. Maree, RN DCUR (Pret) |
| Address | Wits Dept of Nursing Education |
| Date | 25/02/2021 |
| Subject | Dissertation: LIVING WITH A STOMA: THE EXPERIENCES AND NEEDS OF COLORECTAL CANCER PATIENTS AND THEIR FAMILIES |
| Ref | LM/GS/80 |

I, Gill Smithies, certify that I have proofed the following for language, grammar and style,

Living with a Stoma: the experiences and needs of colorectal cancer patients and their families, to the standard as required by Wits Dept. of Nursing Education.

*Gill Smithies*