“A Retrospective Cross-Sectional Analysis of Palliative Care Needs in Cervical Cancer patients in Gauteng”

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You matter because you are you.

You matter to the last moment of your life

And we will do all we can to help you

Not only to die peacefully

But also to live until you die!

Dame Cicely Saunders

Founder of the modern hospice movement

and world-renowned researcher into palliative care

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ABSTRACT

Introduction

Cervical cancer is the second most prevalent cancer among women in South Africa. Little published research is available on the pain syndromes associated with cervical cancer and on the specific spiritual issues in patients with cervical cancer.

Aim

The aim of this study was to describe and provide an analysis of Palliative Care and total pain needs in patients diagnosed with cervical cancer in two Gauteng hospitals.

Objectives

The objectives were to determine the physical, psycho-social, and spiritual symptom burden of cervical cancer patients and assess for any correlation between a number of these symptoms and other significant variables.

Methodology

This study was a retrospective data analysis of 138 records of confirmed cervical cancer patients enrolled at the centre for palliative care at Chris Hani Baragwanath Academic Hospital and Sebokeng Regional Hospital. The data was analysed using SPSS version 10. Categorical variables were summarised using cross tabulation and reporting using Pearson Chi-squared test to determine if there were non-random associations between two independent categorical variables. To compare groups, means, and standard deviations with t-tests for normally distributed variables, medians, and interquartile ranges were also used. All the tests were two-tailed and a p-value of less than 0.05 was considered statistically significant. The Confidence Intervals (CIs) were calculated at a 95% confidence level.

Results

The mean age was 50.53 (range 26-84), with 49% being below age 50 and 76% below age 60. A proportion of 41.7% of patients had an ECOG Performance status score of 0-1 which meant that they had no to little impact on the performance of daily activities. The majority of patients' performance was significantly impacted (58.3%) by their illness, bearing an ECOG score of 2

and above. A majority of patients (80%) reported severe to worst pain, with only 10.8% having expressed no pain at all and 2% reporting to have mild pain. The most commonly expressed distressing physical symptoms were lower abdominal pain at 75%, followed by constipation at 48%, and lower back pain at 30%. Just above two-thirds (70%) of the patients were found to be at advanced stage of the disease presenting at FIGO stage III or IV. Iron deficiency anaemia was found to be another significant clinical condition present in 80.6% of patients with a mean haemoglobin of 8.51. The most prevalent comorbid medical condition amongst this group of patients was HIV (52%) with hypertension (36%) as the second most prevalent. The data showed that 93% of the patients considered themselves spiritual, with 86% wanting a stronger connection with God or a higher being. Only 31% felt abandoned by God and 19% by their spiritual community. Further analysis revealed that 67% of patients did not feel that their illness was a punishment from a higher being and just over half of the patients (53%) felt a need to be forgiven by God for past transgressions. 81% of patients expressed a need for spiritual support as part of their clinical care. 92% of patients expressed to be worried about their illness with 87.7% being able to share how they feel with family or friends. 82.6% experienced peace despite their challenges, with only 10.9% not being at peace.93.5% still felt that life was worthwhile despite having cervical cancer. There was a positive correlation between ECOG & worry and ECOG & peace and a negative correlation between ECOG & being able to share. A negative correlation between worry and peace and a positive correlation between being able to share & peace, help for future planning & life worthwhile, information & being able to share and information and peace. Feelings of punishment seem to increase the feeling of being abandoned by a higher being, and a need for a stronger connection to a higher being emerged as a central connecting theme.

Conclusion

This research study highlighted that, indeed, cervical cancer patients have a number of significant palliative care needs that need to be paid attention to when treating them. These needs are multi-dimensional in nature, and some may be complex. Managing these patients requires an interdisciplinary approach and the involvement of multiple team members (including family) to respond to their needs adequately.

CHAPTER 1

INTRODUCTION

1.1 Background to the research

Africa was known as a hub for communicable diseases, but in the coming decades non-communicable diseases, and in particular cancer, are set to become a major cause of morbidity & mortality (1). Bray, et al went on to assess ever-changing oncological patterns in relation to human development and they predict that, with things continuing as they are currently, there will be an increase of cancer incidence from 12.7 million (2008) to 22.2 million by 2030 globally (1). They argue that this increase in cancer incidence will be associated with or largely stem from reproductive, dietary, and hormonal factors, and cervical cancer certainly falls within this narrative.

The GLOBOCAN 2018 global cancer statistics estimate that of the 8.6 million new cases, Asia has the highest percentage of 47.5% with Europe having the second highest incidence of 23.0%. It is further reported that Africa only accounts for 7% of cancer incidence and 9% cancer mortality globally (2). Though GLOBOCAN is a reputable database, the Africa statistics are not in keeping with what clinicians have been experiencing on the ground over the last couple of years, where there are dramatic increases in cancer incidences than what was seen before.

These estimates are based on the most recent data available (2) and the International Cancer Control partnership (ICCP) estimates that there are 700 cancer registries globally (3). What is of grave concern is that only 21% of the global population has well-functioning population-based cancer registries, with Africa only having an 11% cancer registry coverage (3). One would argue that this low percentage can be attributed to all the infrastructural, economical, and practical barriers to diagnosing cancers in the African healthcare and community contexts and reporting them once the diagnosis is confirmed. The argument ensues then that with only 11% cancer registration, these Globocan estimates, which largely come from these cancer registries, do not paint the real picture of how things really are on the ground in Africa. It becomes important then not to take these statistics at face value.

GLOBOCAN also estimates that breast cancer carries the highest global cancer incidence (24.2%) and mortality (15.0%) amongst females, with cervical cancer coming in 4th at 6.6% for incidence and 7.5% for mortality (2). When these statistics are broken down regionally, cervical cancer carries the highest incidence of cancer in Southern Africa at 43.1% and has a significant mortality percentage of 20% (2). This means that cervical cancer is amongst the biggest causes of morbidity and mortality amongst women in Southern Africa, and its incidence is continuing to rise. So, this is an important disease with palliative care significance. The WHO 2018 statistics estimate that there were 570 000 new cases of cervical cancer globally, with 90% of deaths from cervical cancer occurring in low and middle-income countries (4).

Low and middle-income countries carry not only a significant incidence of cervical cancer but also a very high mortality. It is well known that these countries are the hardest hit by a lack of early screening and effective oncological interventions aimed at curing cervical cancer. Effectively, patients diagnosed with cervical cancer end up having a great symptom burden, and the need for strengthening and establishing good palliative care services is of utmost importance.

The highest incidence and mortality in cervical cancer is seen in Southern Africa and is associated with a higher prevalence in alcohol consumption (5).

1.1.1 The South African perspective

The 2014 South African Cancer registry reviewed the top ten cancers among women in South Africa and cervical cancer was the second most prevalent cancer, second only to breast cancer, with an incidence of just under 25 per 100 000 (5). In terms of racial groupings in South Africa, Black women carry the highest prevalence of cervical cancer (30.46%) with a life-time risk of 1:35. The lifetime cervical cancer risk (and prevalence) in Asian, Coloured and White females are 1:91 (6.89%), 1:68 (8.36%) and 1:80 (2.49) respectively (6). What is of even more concern is that the age group that is hardest hit by cervical cancer is 30 – 59 and these are those members of society who are most economically active and have, usually, small children to raise (6).

1.1.2 A disease of inequity

There are many recent advances in cancer screening, prevention, and treatment and yet the world's poorest countries have not benefited equally, as not everyone gets the same chance at a good outcome (7). Most (90%) new cancer of the cervix cases and deaths are in low and middle-income countries (7). The cancer burden is rising and hence putting more pressure on already strained systems in these low and middle-income countries whose health systems are not, , or are least, prepared to deal with the growing numbers of cancer patients and the needs they have (7). The high burden of cervical cancer is also fuelled by gender, social and economic inequalities, and health disparities in access to HPV vaccines, screening, care and modern prevention and treatment technologies (8). Despite being one of the leading causes of death from cancer in women in low to middle-income countries, cervical cancer is also one of the most preventable and treatable cancer types, and so no woman should die of cervical cancer in this day and age, and yet it happens in big numbers in low-income countries (8).

1.1.3 Access to care

Patients with cervical cancer experience numerous barriers to accessing treatment and palliative care services in lower-income settings (9). These barriers include health system (service satisfaction, distance to the health facility and health services quality), societal and individual factors which include perceptions of adequacy of specialists, financial issues, health-related struggles (9). A number of other factors that impede timely access to care amongst these patients were identified and they are: delays in screening and diagnosis, misdiagnosis, information gaps, perceived lack of knowledge from healthcare staff, negative attitudes from healthcare staff and bad news being broken badly (10).

1.1.4 Total pain

The concept of total pain was defined and coined by Dame Cicely Saunders, the founder of the first modern hospice and responsible more than anybody else for establishing the discipline and culture of palliative care (11). Total pain was described as the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles (12). A diagnosis of a life threatening and life limiting conditions "jars open" a door of awareness about many things including about death in the background of our minds (12). This opened jar often precipitates a crisis and an acute encounter with great pain that stems from the physical,

emotional, social and spiritual domains of life and the disease (12). Poor pain relief remains a challenge in the management of patients with life-threatening and life-limiting conditions and the lack of clarity in the understanding of pain for this population contributes to the persistence of poor pain management (13). Pain relief will not be possible if all domains of total pain are not addressed. This concept of "total pain" should be the "driving force leading to the standardization of pain definition, intervention and evaluation for palliative cancer patients" (13).

1.2 The layout of the document

Chapter 1 Introduction to the study

Chapter 2 Literature Review

Chapter 3 Study Aim and Objectives

Chapter 4 Research Methodology and Design

Chapter 5 Study Results

Chapter 6 Discussion

Chapter 7 Conclusion

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CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Cervical cancer is one of the leading causes of cancer death in women worldwide and the estimated incidence of the disease per year is 500 000 of which 79% occur in developing countries (14). This cancer stands either in the top or second amongst cancers in women in developing countries while it does not even feature in the top 5 cancers in developed nations. This chapter presents the reviewed literature on the physical or biomedical challenges, psycho-social needs, and spiritual needs of cervical cancer patients.

2.2 HIV and cancer of the cervix

The Statistics South reported that the prevalence of HIV for the period of 2002 – 2018 increased from an estimated 4.25 million in 2002 to 7.52 million by 2018, with 13.1 % of the South African population being HIV positive in 2018 (15). It is further estimated that the HIV prevalence among youth (ages 15-24) slightly declined from 6.7% in 2002 to 5.5% in 2018 while on the other hand, one-fifth of South African women from the ages of 15 -49 (women in the reproductive age) are HIV positive (15). Not only are women of reproductive age at the highest risk of developing cervical cancer, but they are also more likely to be HIV positive, further increasing the burden of the disease (15).

Rohner et al published a study in 2019 that involved an analysis of collected data from various databases included clinical, demographic, laboratory, and treatment data of women from Europe, South Africa, Latin, and North America. They compared the invasive cervical cancer (ICC) incidence rates among women living with HIV and started on antiretroviral therapy (ART) between 1996 – 2014. They picked up a total of 356 incident cases of ICC and South Africa alone had 156 (44%) of these cases with Europe having 164 (46%), North America 19 (5%) and Latina America 17 (5%) (16). The ICC incidence rate per 100 000 for South African women was 447, 136 in Latin America, 76 in North America and 66 in Europe which means that South Africa had an ICC incidence rate that is 6.8 times more than in Europe, 5.9 times

more than North America and 3.3 times more than Latin America (16). They also demonstrated that ICC rates increased with age and with lower CD4 cell counts at the initiation of ARTs. An astonishing fact in this study is that they found that South African women ICC rates at 5 years post ART initiation were 11 times higher than their European counterparts (16).

It is evident that ICC is a significant burden amongst women living with HIV and so the assessment of the burden of cervical cancer cannot be done outside the contextual influences that HIV co-infection brings. In fact, Chibwesha et al did a study to estimate the burden of cervical disease among women infected with HIV in the South African public sector and this study highlights how HIV co-infection with cervical cancer carries a great illness experience burden (17).

One of the emotional burdens related to HIV infection is the challenge of disclosure. A descriptive study done in southern United States (US) consisting of 322 HIV positive women of predominantly African-America origin, found that most women disclosed to some sexual partners, close family, friends and health professionals (18). But majority of women reported that disclosure of HIV infection is an extremely difficult issue and hence needing a great need of health education, counselling and support (18). Another study done in Abidjan agrees with the US study and confirms the need to include specific psychosocial counselling and support related to disclosure, as part of women's health care programmes (19). Not a great deal of research exists on women's experiences with disclosing their cervical cancer status to their sexual partners and significant others.

The burden of HIV-attributable cervical cancer has shifted towards younger women (under 45 years) (20). Cervical cancer is caused by the Human Papilloma Virus (HPV) and HIV amplifies the cancer-causing effect of this virus (14). HIV is an important contributory challenge in cervical cancer.

2.2 Physical Pain

A number of published research articles describe the concept of cancer-related pelvic pain and this is mostly in relation to other cancers and not specifically well described in the context of cervical cancer. Reena et al, in their review of cancer and treatment related pain in carcinoma of the cervix, concur that indeed very little literature is available on the pain syndromes associated with cervical cancer (21). They have classified physical pain related to cervical cancer into 5 categories, namely (21):

Pelvic pain

This includes pain from low lumbosacral plexopathy, rectal obstruction, pyometra, sacral syndromes, burning perineal syndrome and pelvic re-occurrence.

Abdominal pain

This pain was due to nodes, lumbosacral plexopathy, L1 syndrome, bowel obstruction and malignant psoas syndrome.

Leg pain

This involves lumbosacral plexopathy and lymphoedema.

Backache

This was also due to lumbosacral plexopathy and in addition to that, hydronephrosis, para-aortic nodes and bone metastasis.

Pain at other sites

Pain at other sites included brain and bone metastasis, brachial plexopathy from supraclavicular nodes and retrosternal pain due to mediastinal nodes.

More research is needed in further defining and clarifying the nature of physical pain in cervical cancer, especially in our local context. Saphner et al published a study in 1989 which was a review of 2261 records of patients with histologically confirmed cervical cancer and they found that neurological complications and pain in cervical cancer were rare and virtually non-existent in stage 0 disease (22). They also found that neurological pain and other neurological complications were mostly due to metastatic as opposed to non-metastatic disease and that the common cause of pain was due to lumbosacral plexopathy caused by retroperitoneal lymph node metastasis (22). Kim, et al recently published a retrospective review article demonstrating that an overwhelming majority (80%) of cervical cancer patients report to have moderate to severe pain (23).

2.3 Distressing Physical Symptoms

Sari, et al did a cross sectional study involving 47 patients with cervical cancer and 58 with breast cancer and used the instrument of Quality of life – Cancer Survivors (QOL-CS) to collect data. It was found that more severe fatigue, appetite changes, pain, sleep disturbances, constipation, nausea-vomiting and menstrual changes were found in the cervical cancer group

and this difference was statistically significant with a p-value of $p<0.001$ (24). Sleep disturbances (in cervical cancer: 84.7% influence) and appetite changes (in breast cancer: 75.7% influence) were found to be the best predictors for determining physical well-being (24). In addition to the above-mentioned symptoms, cervical cancer can also lead to significant malodour and fistulae as a result of anaerobic necrosis resulting in treatment abandonment (25). Mosha et al reported per vaginal discharge was the clinical symptom mentioned by all patients with cervical cancer in their study followed by lower abdominal pain, backache and post coital bleeding (26).

2.4 Psychosocial Needs

Shyu did an analytic cohort study looking at the risk factors predisposing women diagnosed with cervical cancer in Taiwan to developing depression. They found that there was a significantly higher cumulative incidence of depression in the cervical cancer cohort than in the control group, with a significant p-value of 0,0001 (27). It was also demonstrated that patients who had comorbidities such as diabetes mellitus, ischaemic heart disease and cerebrovascular disease also had higher risks of developing depression however there was no significant differences in cervical cancer treatment modalities (27). Depression was defined by compatible ICD-9-CM Codes but it is unclear as to how they made a diagnosis of depression in patients with advanced disease who subsequently (as a result of the illness) also displayed symptoms similar to depression.

Researchers in Ethiopia conducted a qualitative study using in-depth interviews of 12 women diagnosed with cervical cancer and 3 health professionals. Content analysis of the data revealed that patients with cervical cancer experienced great psychosocial and financial problems during diagnosis and in the course of the treatment (28). A number of women reported to have sold assets such as oxen, sheep, crop products and farmlands and needed to borrow money from friends and banks to cover expenses related to their care (27). It also came out that cancer costs family time and resources as members of the family become unproductive when accompanying their loved one for treatment (28). Half of the study participants expressed that social support from their families, friends and relatives deteriorated over time (28). It is important to ascertain what the specific nature of psychosocial and financial problems and their impacts are in cervical patients in our setting.

Krakauer et al demonstrated that cervical cancer patients experience a high burden of anxiety and depression with moderate to severe financial distress (29).

2.5 Spiritual Needs

There are several studies done to explore spirituality in general oncology but there is very limited research on what the specific spiritual issues experienced by patients with cervical cancer are. Mabena et al argue that in times of health crisis such as being diagnosed with cancer, patients may need to draw on spirituality to attach some meaning to their illness (30). In the South African context, this meaning can be greatly shaped by a specific African religious context (30). In their qualitative research involving 16 women diagnosed with cervical cancer for six months or more, several spiritual meanings were attached to the diagnosis of cervical cancer and understanding these meanings in clinical care is key to providing holistic care (30).

Krakauer et al argue that women with cervical cancer (especially advanced disease) experience a great deal of spiritual suffering which included loss of faith (29). They also tend to struggle with issues around loss of meaning, anger toward a higher power and belief that the higher power is causing the illness (29).

Gutusa et al, found that culture and religion may sometimes be an impediment to early cervical cancer screening especially for rural women due to lack of knowledge, stigmatisation, cultural beliefs and values, and lack of resources (31). On the other hand, Spirituality was found to have moderated (and make less intense) the relationship between psychological challenges and quality of life and between illness perception & quality of life (32). This further emphasizes the role of spirituality as a coping strategy for patients and their family and needs to be actively included in cancer treatment (32).

2.6 Study Rationale

Overall, the literature review reveals that more research needs to be done in our South African and African contexts, focusing specifically on the total pain needs in cervical cancer patients. A great amount of the available research focuses on gynaecological cancers as one group or on cancers generally and very few on cervical cancer specifically. The aim of this research study is to contribute to the body of knowledge on palliative care needs and interventions in cervical

cancer and hence is an important contribution to highlighting what these specific needs in our context look like.

There is also a fair amount of literature looking at palliative care needs in cervical cancer patients post treatment interventions. In our setting treatment is often delayed and some patients die while waiting to start treatment. The management of their suffering is still key before treatment and there is limited literature exploring needs prior to treatment in patients in our setting. This study aims to explore this too.

CHAPTER 3

STUDY AIM AND OBJECTIVES

3.1 Study Aim

To describe and provide an analysis of Palliative Care and total pain needs in patients diagnosed with cervical cancer in two Gauteng hospitals and assess possible correlations between ECOG, psycho-social and spiritual needs.

3.2 Study Objectives

To outline:

a) The nature of the patients' physical pain experience.

b) The types of physical distressing symptoms that these individuals have

c) The comorbid conditions these patients also battle with in addition to cervical cancer

d) The clinical staging, functional status, and biochemical profile

e) The spiritual and religious needs that exist in this group of patients

f) The psycho-social challenges experienced

g) The Correlation between ECOG performance status and Psycho-social needs, the psychosocial needs and between various spiritual needs that were found.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

4.1 Study Design

This was a hospital-based, retrospective descriptive cross sectional analytical study.

4.2 Characteristics of the Study Population

4.2.1 Number of participants

Adhering to a specific and calculated sample size in a retrospective data review study such as this one was a difficult task. The sample size that was used was hence one of convenience taking all the available cervical cancer patients that were enrolled for palliative care at two Gauteng hospitals namely, Chris Hani Baragwanath Academic Hospital and Sebokeng Regional Hospital between 2012 and 2022. This included patients who met the study criteria and had enough data to be included in the study. The data collected represents a time when patients were seen for the first time (first consultation) by a palliative care practitioner and hence the information collected represents a patient's state prior to palliative care interventions. The initial step in the analytical process was to clean the data. The process involved checking if the recorded patient data had missing values. The missing values were due to information that was incompletely provided in the clinical records of the selected patients. The final sample size used for data analysis and reporting is 138. While the selected sample is deemed appropriate, data were still missing at random for some of the variables measured in the study. These missing values were reported in the findings chapter and acknowledged as part of the study's limitations.

4.2.2 Inclusion and Exclusion Criteria

Inclusion Criteria

- Confirmed histological diagnosis of cervical cancer
- Completed patient enrolment form
- 18 years and older

Exclusion Criteria

- Patients who were terminally and critically ill and unable to communicate or give reliable history
- Those who belonged to the vulnerable groups such as minors, the terminally ill, prisoners, pregnant women and the cognitively or mentally impaired because of either access challenges or inability for the patient to provide the required information.

4.2.3 Vulnerability

This study does not involve the inclusion of data from patients who belong to the vulnerable population as outlined in the exclusion criteria.

4.2.4 Location of the research

This study was carried out at the Gauteng Centre of Excellence for Palliative Care (GCEPC) which is located at Chris Hani Baragwanath Academic Hospital, a major teaching hospital in Soweto, Johannesburg and at Sebokeng regional hospital.

4.3 Recruitment and Enrolment

With the study being a retrospective data review, there was no active recruitment of participants. The enrolment into study used a convenience sampling method of suitable files of cervical cancer patients who were enrolled at both the Gauteng Centre for Palliative Care unit at Chris Hani Baragwanath Academic hospital and at Sebokeng regional hospital's gynaecology department.

4.4 Research Procedures and Data Collection Method

4.4.1 Procedures

The study did not involve any interaction with the patients themselves and hence does not expose participants to any procedures.

4.4.2 Qualifications of the Researcher

As this was a research project for degree purposes, one underwent training through course work and other seminars to prepare one for the execution of the study and have work with two supervisors to guide the research process.

4.4.3 Data Collection Tools

The current system in place for collecting and maintaining the primary study records at the GCEPC is as follows: As a routine part of clinical care for those patients referred to the GCEPC, a standardised Palliative Care Consultation form is used to record the patient's demographic, clinical assessment and management information. These first consultation and follow up forms are currently in paper format and permission was obtained to make an electronic copy of the completed form using "CamScanner", ensuring that all identifying data is blocked off when collecting the information. Hence no separate checklist was used to extract information from the patient record. The data was anonymised at the point of data collection with no identifying information such as patient file numbers, names, contact details or specimen numbers recorded. All the patients seen at Sebokeng regional hospital were also enrolled to the GCEPC.

The primary data was collected using the validated African Palliative Care Association Palliative Care Outcome Scale (APCA POS) and the spiritual data was obtained using a data collection tool that was a combination of the FICA assessment tool and the "spiritual care recommendations for people receiving palliative care in sub Saharan Africa" document put together through a collaboration between King's College London, the Cicely Saunders International, the Sir Halley Stewart Trust, APCA and the Hospice Palliative Care Association of South Africa.

4.4.4 Data Collection Process of Primary Data

The patient interviews and clerking (for the primary data) were done by trained doctors and nurses employed at the WITS Centre for Palliative Care and a palliative care trained doctor at Sebokeng regional hospital. Though the clerking tool used was in English, the interviews were conducted in the patient's preferred language, which was mostly English, IsiZulu, Sesotho, IsiXhosa or SeTswana. An acknowledgement of potential bias in the way the source data is collected is noted and appreciated.

4.4.5 Research Assistants

No research assistants were needed for this study as the data was already collected in the form of patient records.

4.5 Data Safety and Monitoring

The source data was kept in files in locked cabinets at the GCEPC with some minor statistical information kept in a password protected electronic document. All data generated throughout the course of the study was kept confidential in alignment with the University of Cape Town Institutional policies. This data was electronically stored in a database on a password protected laptop which is secured by firewall. Paper copies of the data was limited to only copies of charts or results that are not available in the source document. Even in this case an attempt to transform these into an electronic format was made, with the physical copies destroyed. Only the researcher and research supervisors had access to the stored data for the purposes of conducting the study. Should the PI leave the institution, the raw data will not be taken with nor shared with an outside colleague or institution

All patient identifying data was removed when the data was cleaned and was not included in the database and each patient file was allocated a study number as their mode of reference.

4.6 Data Analysis

4.6.1 Data Accuracy and Reliability Mechanisms

The primary data was collected, as part of routine patient assessments, by trained doctors and nurses working at the Centre for Palliative Care Unit and Sebokeng hospital gynaecology department, and regular audits of the files were done to ensure data quality controls are in place. Re-training sessions were also conducted to address any gaps found in the data that was collected by the health professional staff at the unit and opportunities were given through clinical reviews and other departmental meetings to deal with any misunderstandings of the patient assessment process.

4.6.2 Data Analysis and Monitoring

The patients' general characteristics, the biomedical issues (including pain, physical symptoms, HIV profile, other comorbidities, clinical staging, functional status and the biochemical profile), the spiritual symptoms and the psycho-social issues were all analysed with the use of descriptive statistics which included means, medians, frequencies and percentages. Differences in sociodemographic factors and associations between a number of clinical elements, psychosocial and spiritual factors were also analysed.

Data was entered electronically into an Excel database established purely for this study and all analysis was conducted using SPSS version 10 Statistics. The Excel database document was password protected to ensure protection of confidentiality of the data entered. No patient identifying data was entered into the study database. The data was anonymised in the reporting of findings with no individual patients reported on.

4.6.3 Statistical Tests

Categorical variables were summarised using cross tabulation and reported using Pearson Chi-squared test to determine if there are non-random associations between two independent categorical variables. To compare groups, means and standard deviations with t-tests for normally distributed variables, medians and interquartile ranges will be used.
All the tests were two-tailed and a p-value of less than 0.05 was considered statistically significant. The Confidence intervals (CIs) were calculated at a 95% confidence level.

4.7 Ethical Considerations

This study was approved by the UCT Faculty of Health Sciences Human Research Ethics Committee, Reference 610/2021.

4.7.1 Description of Risks and Benefits

This study carries minimal risk to the patient population being studied. The data analysed did not include any patient identifiers. There will be no immediate, direct benefits to study participants, but the knowledge obtained from the study findings will contribute towards the strengthening of staff development, patient care and service delivery at the institution. The publication and distribution of the findings will play a role in the advancement of knowledge

on the palliative care needs of patients with cervical cancer and possible benefit to future patients.

4.7.2 Informed Consent Process

Due to the retrospective nature of this study utilising an existing database, informed consent was not required for this study.

4.7.3 Distress protocol

At the time of primary data collection, patients who were found to be in great physical, spiritual or emotional distress were immediately referred to relevant health professionals to attend to their immediate needs. The interview was then completed at another opportunity.

CHAPTER 5

STUDY RESULTS

5. 1 Introduction

Chapter 5 presents the processed results of the study. In total, 138 patients who met the inclusion criteria, were enrolled in this study. Out of 146 patients records, there were 8 cases with more than 50% missing data and these were excluded from the study. Relevant primary data was taken from the patient records. The data was processed by a researcher with biostatistics experience. The results are presented in the form of frequency tables followed by a graphical representation to provide a better overview of results.

The results will be presented in four broad categories, namely: The Physical / Biomedical needs, the Spiritual needs, the Psycho-Social needs and the correlations analysis.

A. The Physical/ Biomedical needs profile will further be presented under the following sub-themes: Age, physical pain, physical symptoms, HIV related issues, other comorbidities, other distressing symptoms, clinical staging, functional performance status and the biochemical profile.

B. The Spiritual needs profile will be presented using the following sub-themes: Spiritual belief, spiritual Importance, spiritual impact, spiritual community & support system and spiritual need.

C. The Psycho-Social needs profile will be presented under the following sub-themes: Worry, sources of worry, ability to share, who able to share with, life worthwhile, peace, help & advice and Information.

D. The correlations analysis will include results looking at the correlation between the following variables: Age & clinical staging, spiritual & psycho-social issues and ECOG functional status & the psychosocial sub-themes.

5.2 The Physical / Biomedical Profiles

5.2.1 Age

Figure 1: Age Distribution

The graph below demonstrates the age distribution of study participants with the most affected age group being 40-49

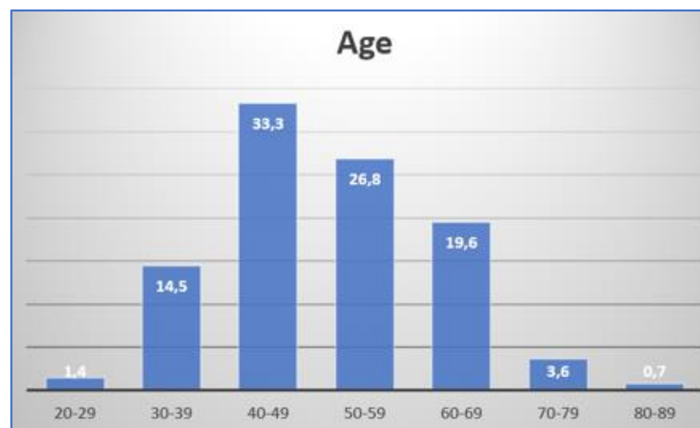


Table 1: Age Descriptive Statistics

The table below displays the age distribution of study participants

	N	Minimum	Maximum	Mean	Std. Deviation
Age	138	26	84	50.53	11.478

5.2.2 Physical Pain

i) Rating

Figure 2: Pain Presence

This figure below displays the presence of physical pain in study participants - 89% reported to have physical pain.

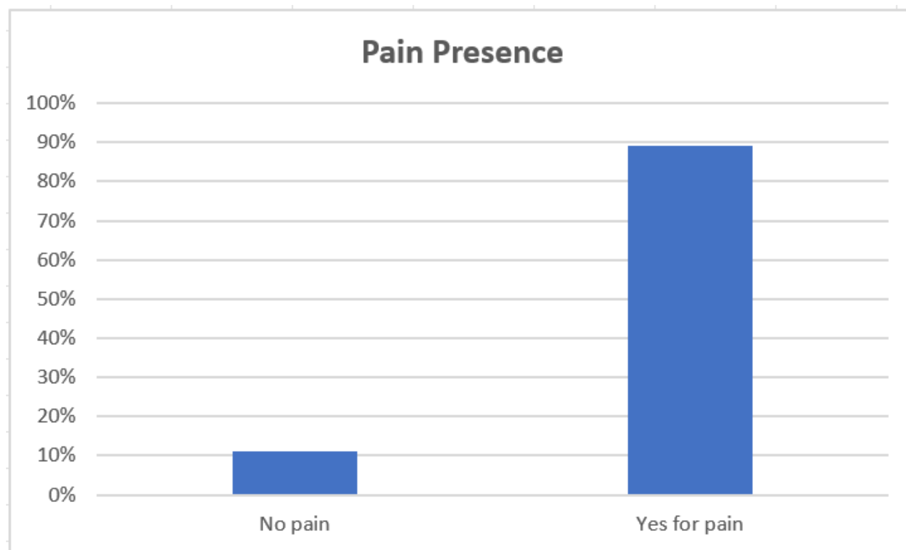
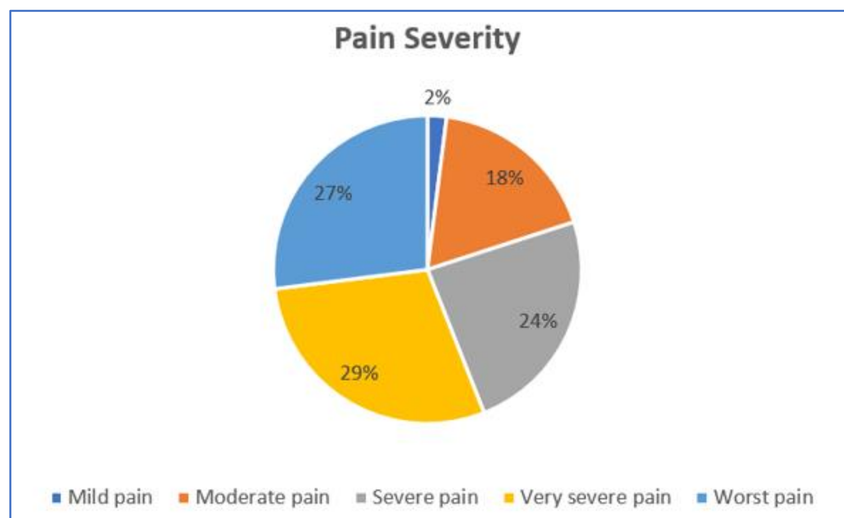


Figure 3: Pain Severity

Figure 3 illustrates the various categories of pain severity experienced. 80% of the patients reported to have severe to worst pain with only 2% reported to have mild pain.

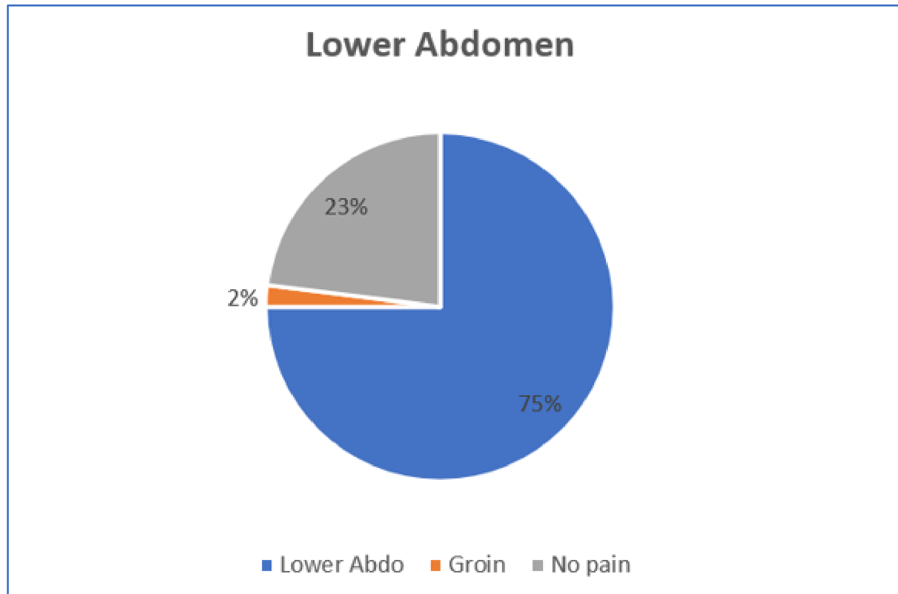


ii) Pain location

a) Lower abdomen

Figure 4: Pain Location – Lower Abdominal Pain

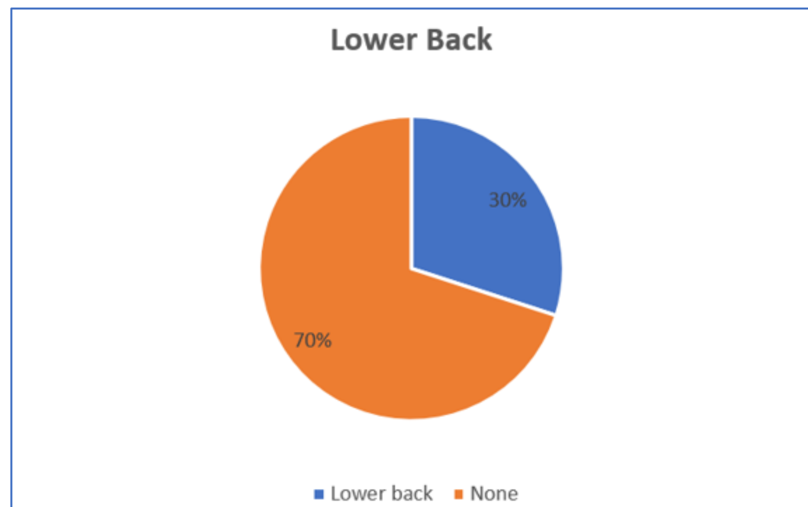
This figure demonstrates the prevalence of lower abdominal pain in this group of patients. This pain site was the most common at 75%.



b) <u>Lower back</u>

Figure 5: Pain Location – Lower Back

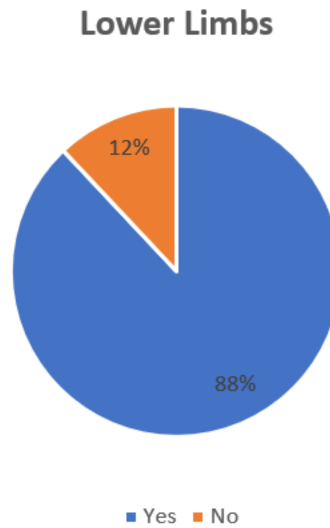
Figure 5 below displays the prevalence of lower back pain which was the second most common site of pain at 30%.



c) <u>Lower limbs</u>

Figure 6: Pain Location – Lower limbs

This figure shows how common lower limb pain was in these patients - 12% reported to have leg pain



5.2.3 Physical Symptoms

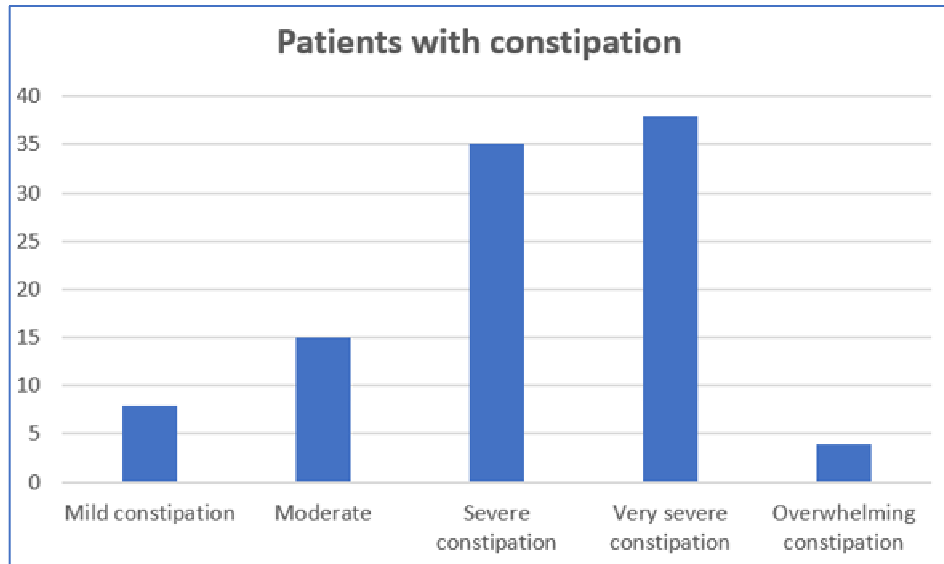
i) Constipation

Figure 7: Constipation

Figure 7 highlights the presence of constipation as a distressing symptom – 48% of patients reported to have constipation and 4%3 of patients had missing data

Figure 8: Patients with Constipation

This graph illustrates the distribution of the severity of constipation that the patients experienced - 77% of patients with constipation had severe to overwhelming constipation.



ii) Nausea and/or vomiting

Figure 9: Nausea and/or Vomiting

This graph shows the prevalence of nausea and/or vomiting in study participants - 62% did not have nausea and/or vomiting

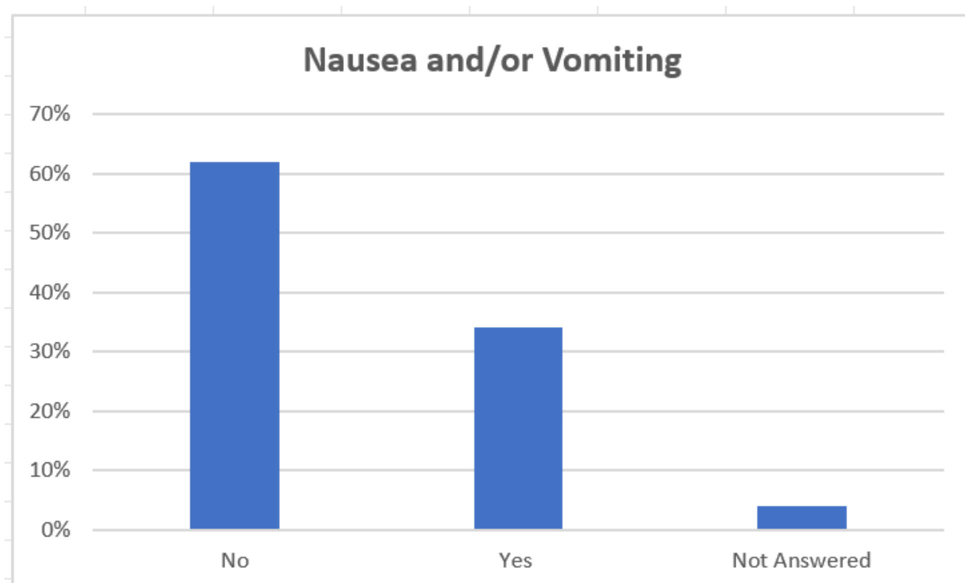
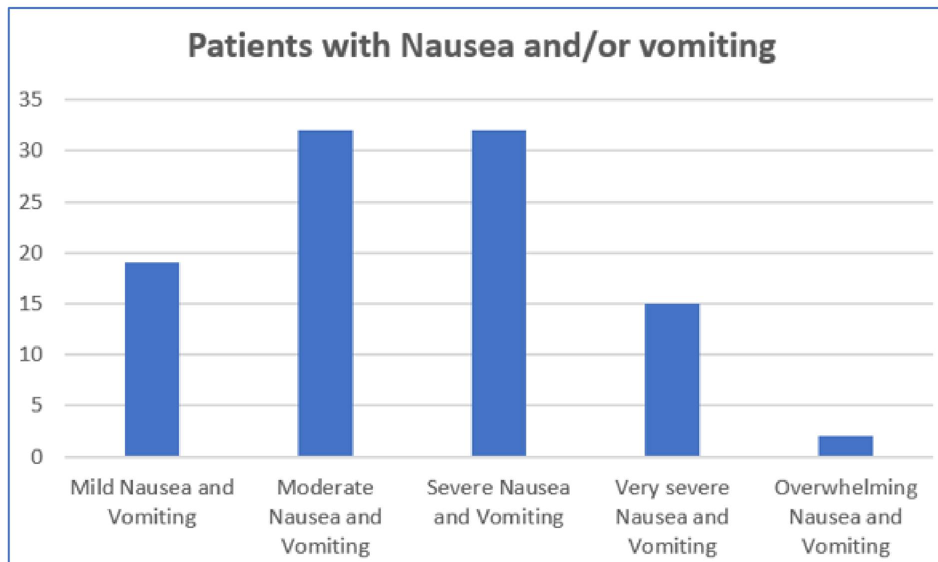


Figure 10: Severity of patients with Nausea and/or Vomiting

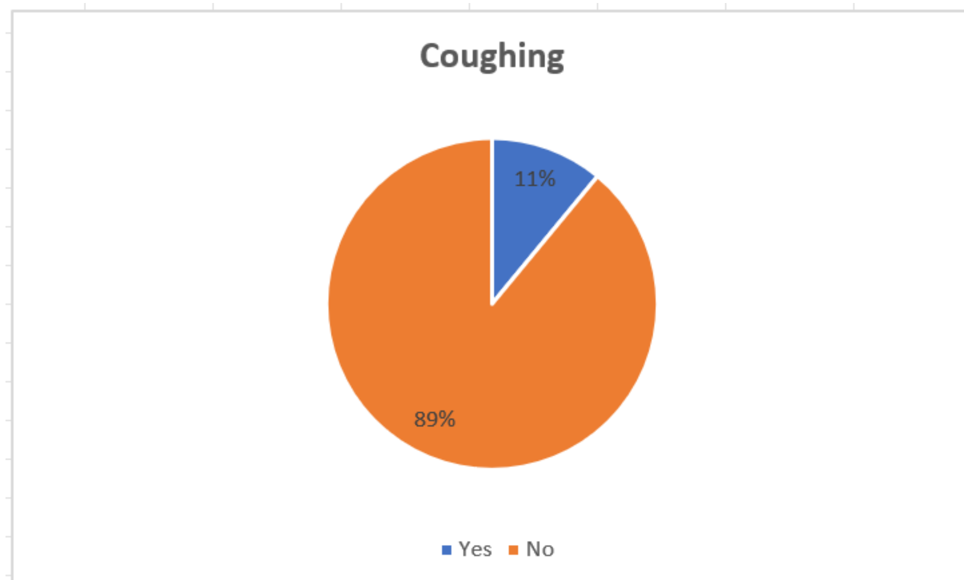
Figure 10 highlights the severity of the nausea and/or vomiting - 64% of the patients with nausea and/or vomiting experienced it as moderate to severe



iii) Coughing

Figure 11: Coughing

This graph displays the extend of the presence of a cough as one of the distressing symptoms in this group of patients - 89% did not experience the cough the symptom.

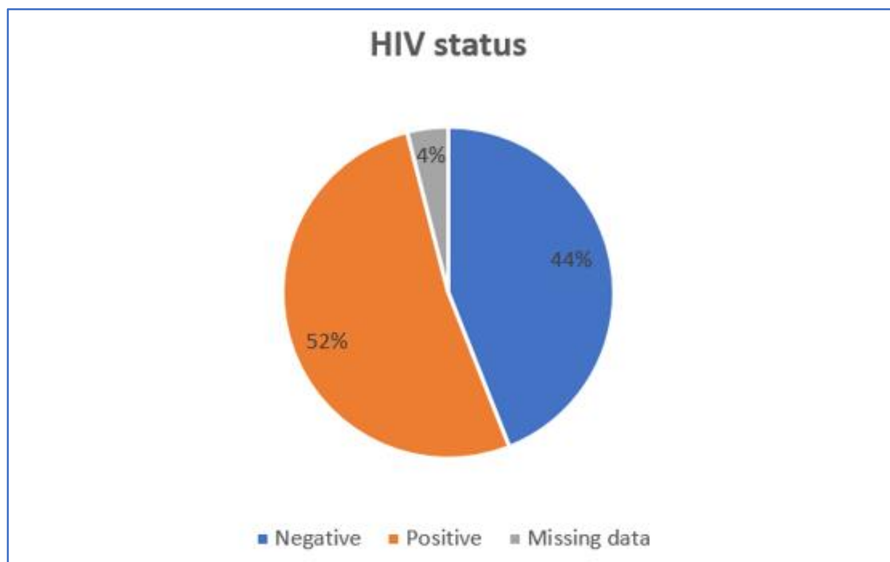


5.2.4 HIV Related

i) Status (Positivity and negativity rates):

Figure 12: HIV Status

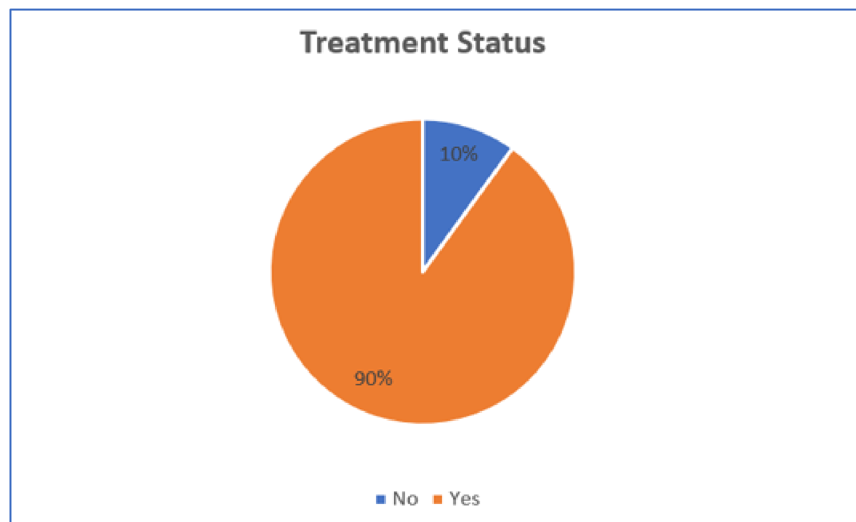
Figure 12 demonstrates the nature of the HIV status - 52% of patients were HIV positive and 4% patients had missing data in the patient records or the NHLS labtrak system.



ii) Treatment status

Figure 13: HAART Treatment Status

Figure 13 shows the proportion of HIV positive patients that were on Ante Retroviral Therapy (ART) - For the 71 HIV positive patients 64 (90%) were on ARVs



iii) CD4 count

Table 2: CD4 Count

This table below shows the distribution of the CD4 count results in the HIV positive patient group

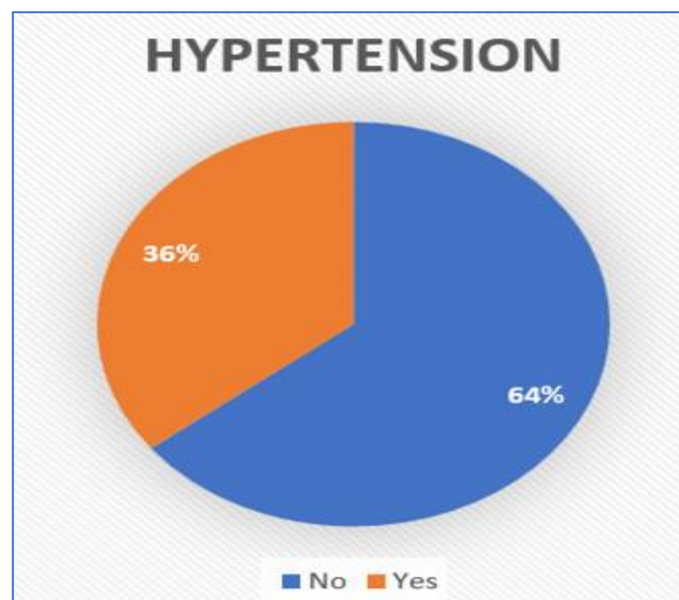
	N	Minimum	Maximum	Mean	Std. Deviation
CD 4	64	5	1565	426	298

5.2.5 Other Comorbidities

i) Hypertension

Figure 14: Hypertension

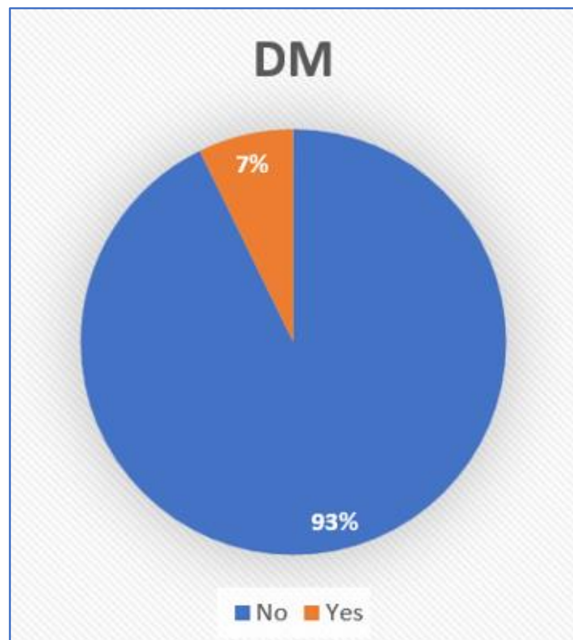
Figure 14 shows the extent of the presence of diagnosed chronic hypertension in the study population - 36% of patients had the diagnosis.



ii) Diabetes Mellitus

Figure 15: Diabetes Mellitus (DM)

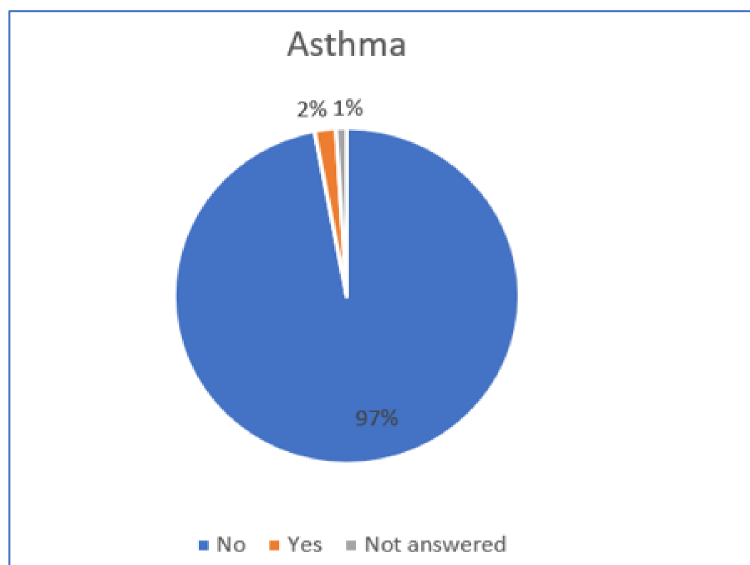
Figure 15 shows the extent of the presence of diagnosed diabetes mellitus in the study population - 7% of patients had a confirmed diagnosis of this illness.



iii) Asthma

Figure 16: Asthma

Figure 16 shows the extent of the presence of confirmed asthma in the study population - 2% reported to have a diagnosis of this illness

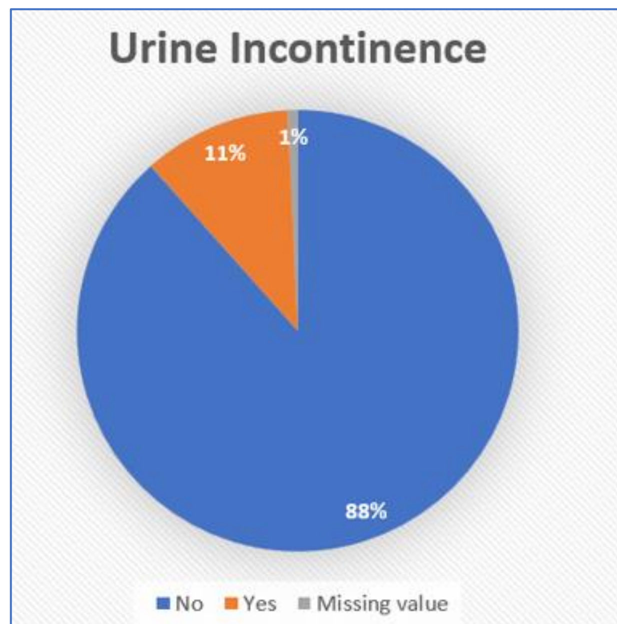


5.2.6 Other Distressing Symptoms

i) Urine incontinence

Figure 17: Urine Incontinence

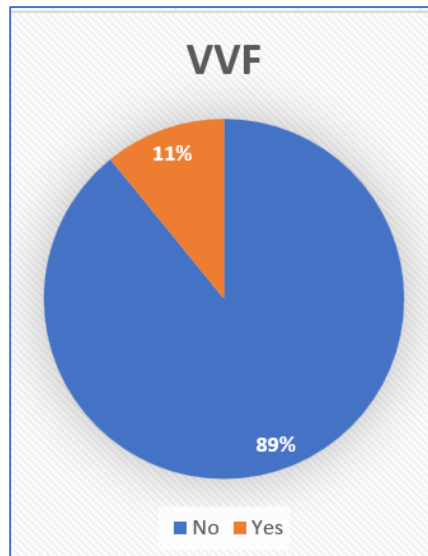
This chart displays the prevalence of urinary incontinence - 11% of patients had expressed the presence of urine incontinence with 1% of patients having missing data. 88% were not experiencing urinary incontinence.



ii) Vesico-Vaginal Fistula (VVF)

Figure 18: VVF

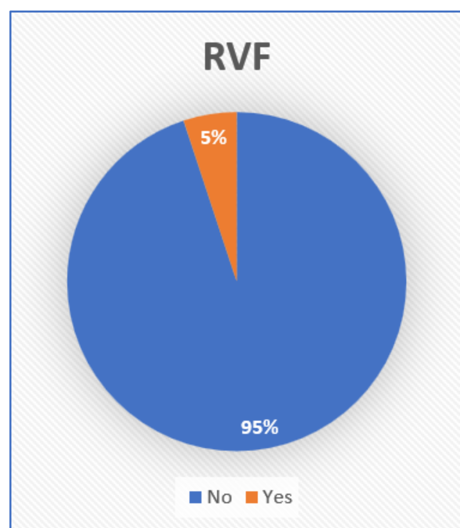
This chart below shows the prevalence of confirmed vesico-vaginal fistulae - 11% of patients had this distressing symptom



iii) Recto-vaginal Fistula (RVF)

Figure 19: RVF

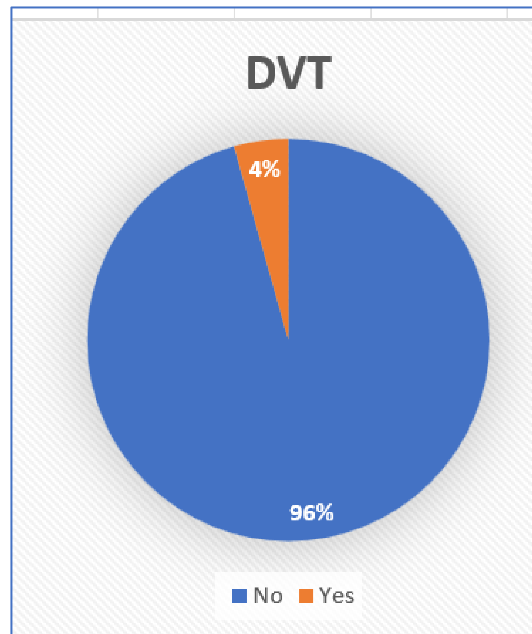
Figure 19 illustrates the presence of a confirmed recto-vaginal fistula (RVF) - 5% had a confirmed diagnosis of RVF.



iv) Confirmed Deep Vein Thrombosis (DVT)

Figure 20: DVT

Figure 20 displays the extent of the presence of a confirmed deep vein thrombosis diagnosis - Only 4% had an ultrasound doppler confirmed presence of a deep vein thrombosis.



5.2.7 Clinical Staging

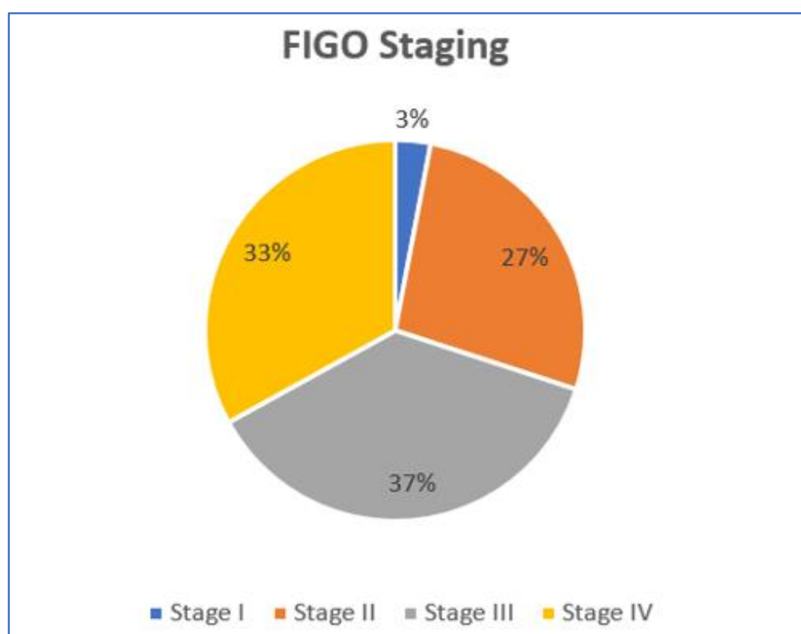
Table 3: FIGO Staging

This table provides an explanation of the various FIGO stages for cervical cancer

FIGO Staging	
Stage I	Carcinoma confined to cervix (microscopic)
Stage II	Invasive carcinoma beyond cervix but only involves upper vagina
Stage III	Carcinoma invades beyond the cervix and involves lower vagina, pelvic side wall, causes hydronephrosis or involves pelvic/para-aortic lymph nodes
Stage IV	Carcinoma extends beyond the true pelvis or involves bladder or rectum

Figure 21: FIGO Staging

This chart shows the distribution of the FIGO clinical staging of the patients in the study - A total of 70% of patients were found to be at FIGO stage III and IV at first consultation.



5.2.8 Eastern Cooperative Oncology Score (ECOG) - Functional Performance Status

Table 4: ECOG

Table 4 shows explanations of the various ECOG performance stages

ECOG Stages	
0	Fully active. Able to carry all pre-disease activities without restriction
1	Restricted in physical strenuous activity & able to carry out work of a light & sedentary nature
2	Ambulatory and capable of self-care but unable to carry out any work activities. Up and about for more than 50% of waking hours
3	Capable of only limited self-care. Confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair

Figure 22: ECOG

Figure 22 displays the distribution of the ECOG performance status of the patients in the study – 37% of patients were at an ECOG functional performance status of 1

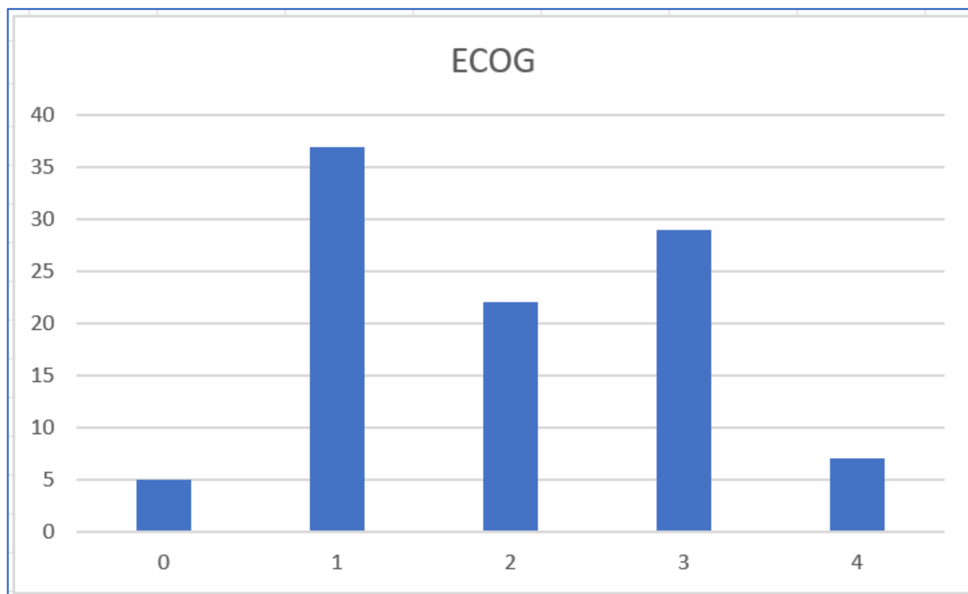
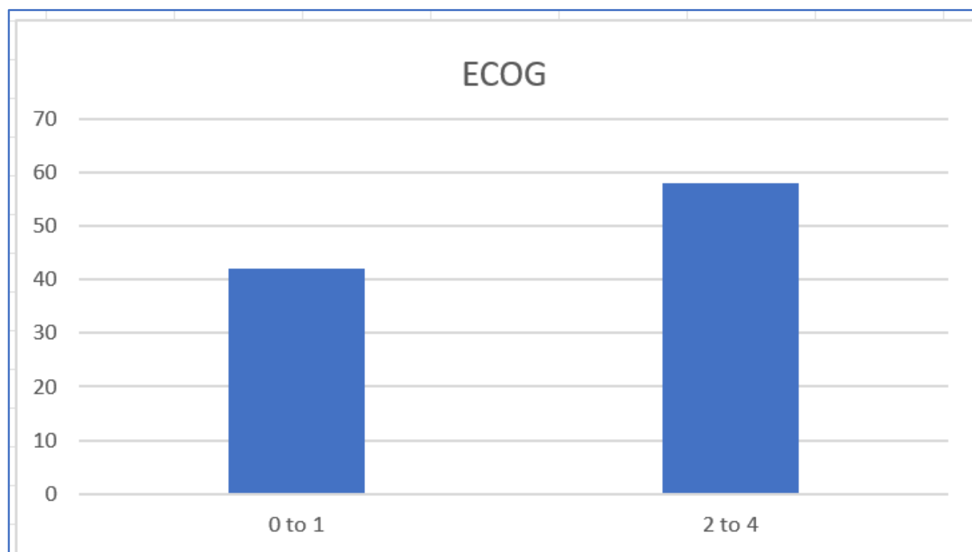


Figure 23: ECOG

Figure 23 highlights that a total of 58% of patients in the study had an ECOG of 2 and above with 42% having an ECOG of 0 to 1.



5.2.9 Biochemical Profile

Table 5: Full Blood Count and Haematology

Table 5 shows a basic summary information on the white cell count, haemoglobin, serum iron and platelet count.

Full Blood Count and Haematology	N	Minimum	Maximum	Mean	Std. Deviation
White Cell Count (WCC)	138	2.59	72.54	12.4559	8.50155
Haemoglobin (HB)	138	2.20	17.40	8.5116	2.52121
Serum Iron (Fe)	31	1.50	22.80	6.3935	4.88780
Platelet Count (PC)	138	44	1051	486.59	201.040

Figure 24: Haemoglobin (HB)

Figure 24 illustrates the haemoglobin status of study participants - 72% % were found to have anaemia (HB below 10g/dL) and 7% having severe anaemia (HB below 5).

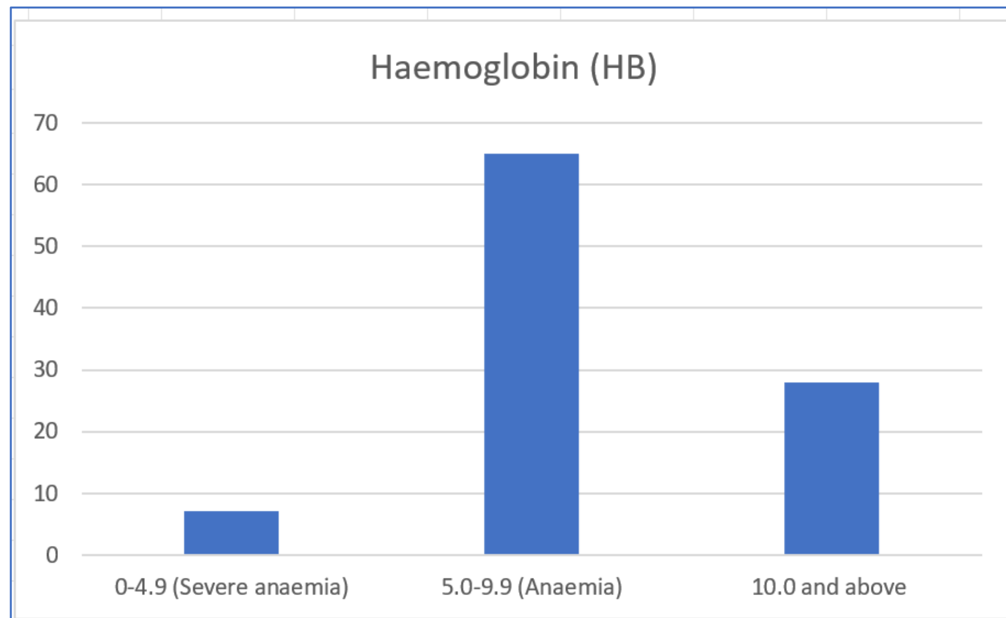


Figure 25: Iron (Fe)

Figure 25 highlights what the nature of the iron status was in the patients in the study - 78% patients had no iron (Fe) studies done on them. Of those with Fe Studies done, 81% of patients with anaemia had iron deficiency anaemia.

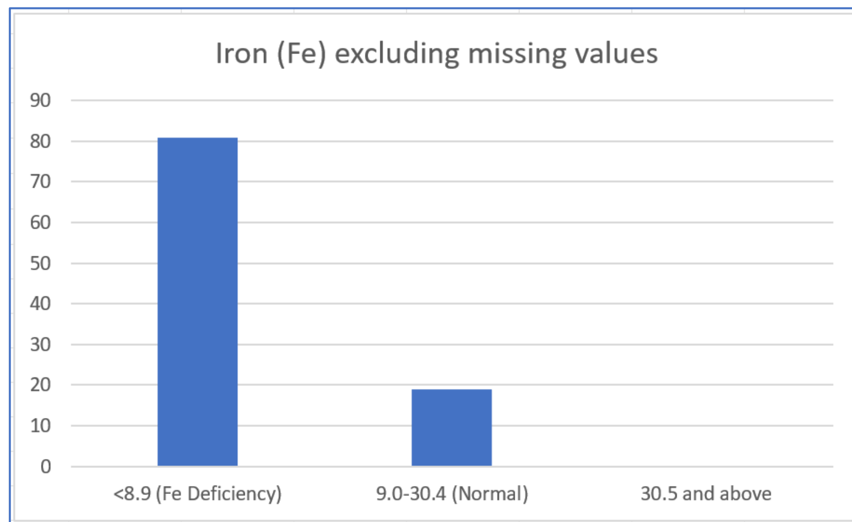


Figure 26: Platelet Count (PC)

This graph below shows the nature of the platelet count in the study population – 64% had an elevated platelet count (thrombocytosis)

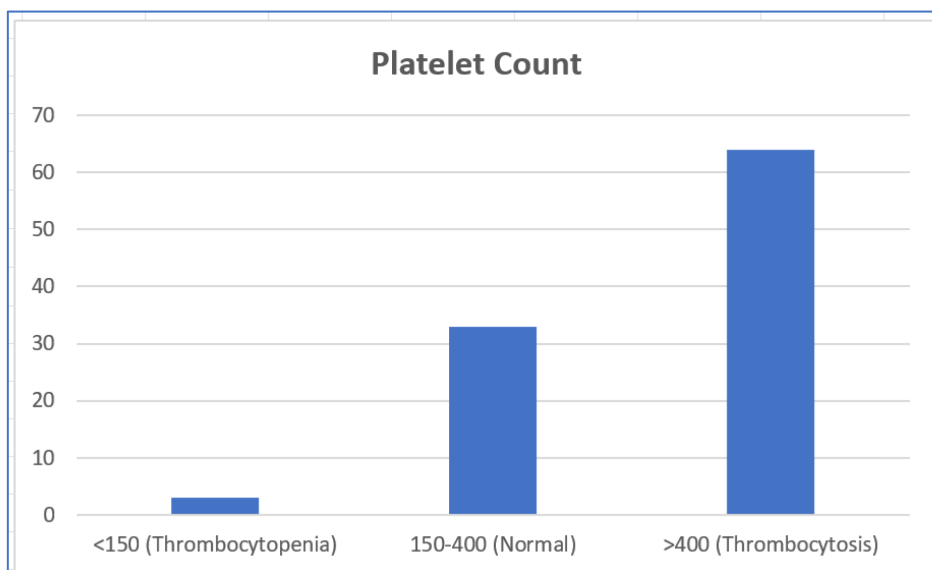


Figure 27: White Cell Count (WCC)

Figure 27 show the levels of the white cell count in the patients in the study – 56% had an elevated white cell count.

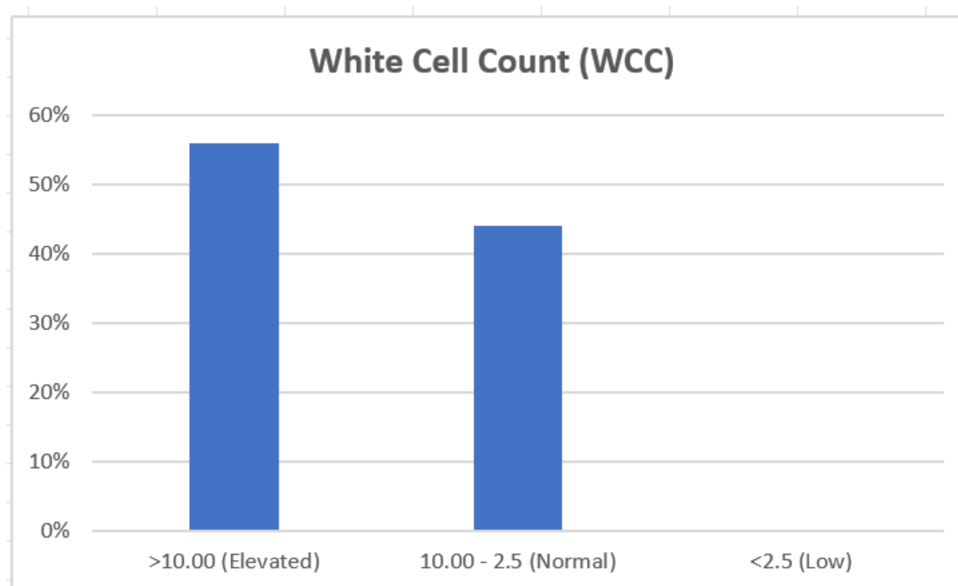


Table 6: Blood chemistry

Table 6 shows a summary of the renal function test results of the study participants.

Blood chemistry	N	Minimum	Maximum	Mean	Std. Deviation
Sodium (Na)	138	120	158	**137.14**	5.522
Potassium (K+)	136	2.40	8.70	4.4963	.94840
Chloride	138	70	114	97.90	6.872
Bicarbonate	136	2	31	17.05	4.942
Anion Gap	135	13	53	26.67	7.048
Urea	138	1.60	81.50	**11.4181**	16.14730
Creatinine	137	36	2811	273.73	512.979

Figure 28: Urea

Figure 28 highlights the blood urea levels – 30% had elevated levels.

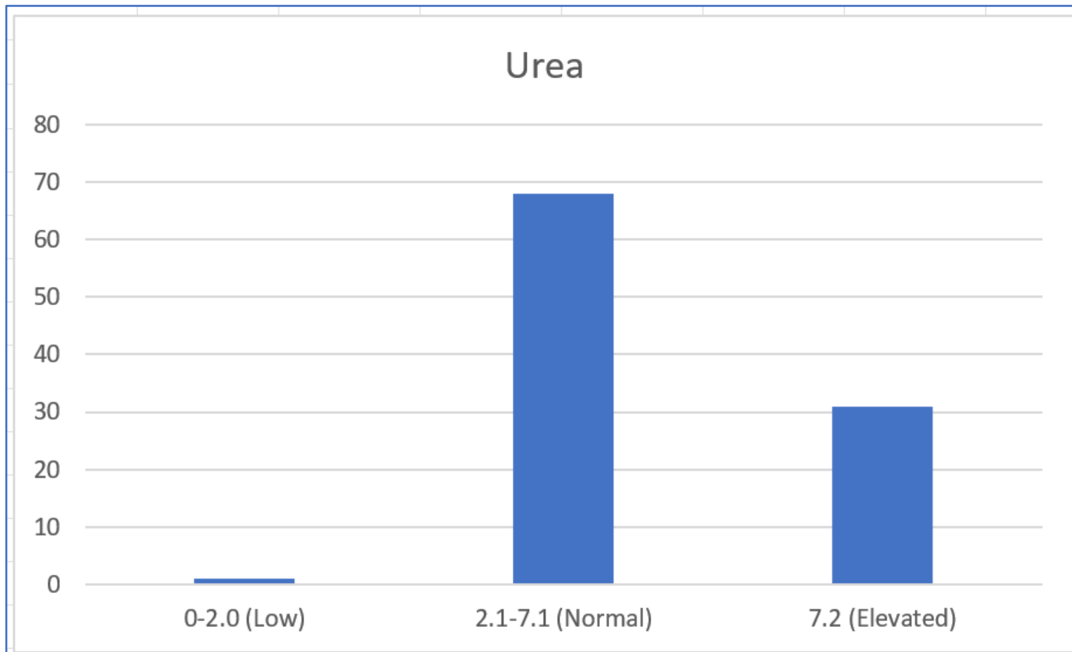


Figure 29: Creatinine

Figure 29 highlights the serum creatinine levels - 57% had normal creatinine levels with 39% having elevated levels

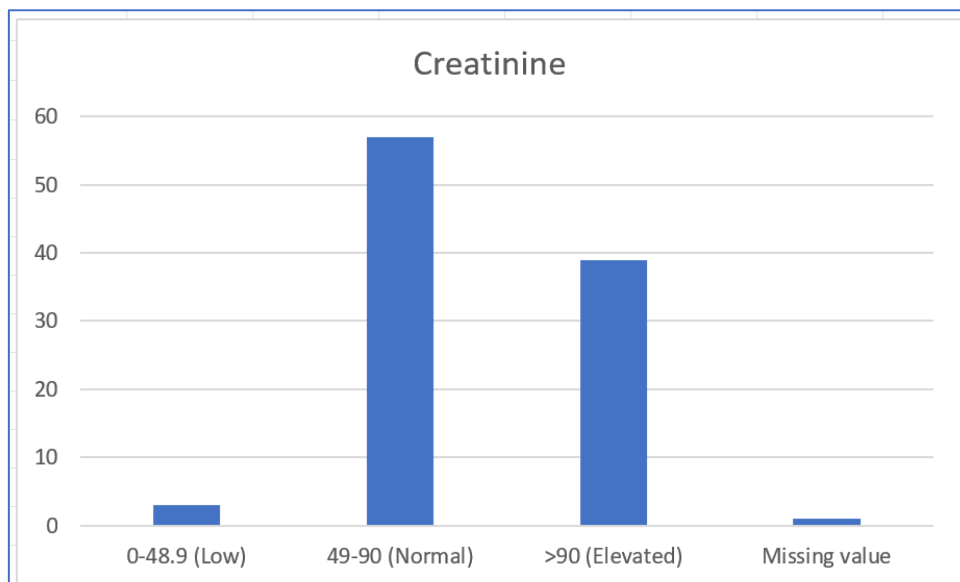


Table 7: Glomerular Filtration Rate (eGFR)

Table 7 shows a description of GFR values and what they mean in relation to renal function.

GFR
<15 (Kidney failure)
>15 and <60 (kidney disease)
>60 (Normal)

Figure 30: Glomerular Filtration Rate (eGFR)

This figure below shows a break-down of the glomerular filtration rate (GFR) of the patients – 60% showed a normal rate and 14% showed levels suggestive of kidney failure.

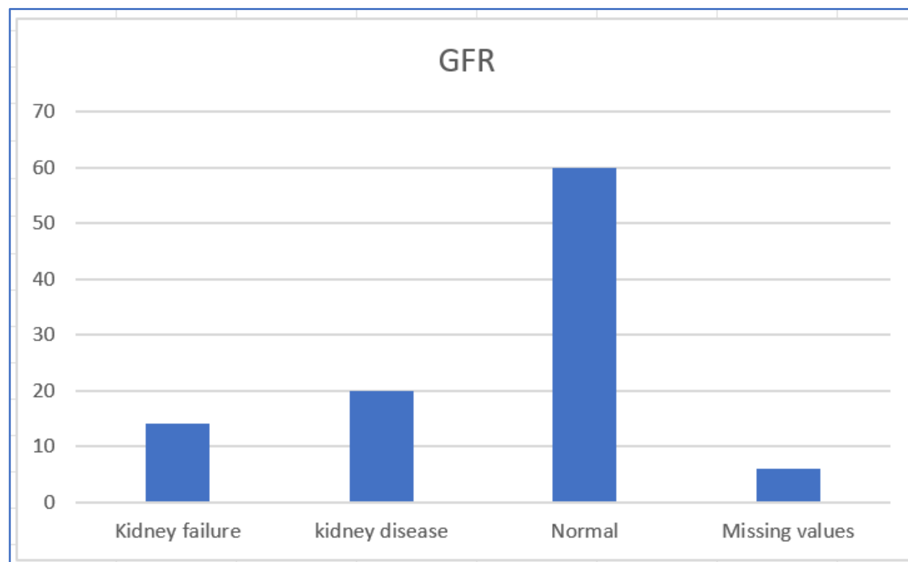


Figure 31: Serum Bicarbonate

Figure 31 highlights how 91% of patients had a low serum bicarbonate level indicating a metabolic acidotic state while 7% had normal levels.

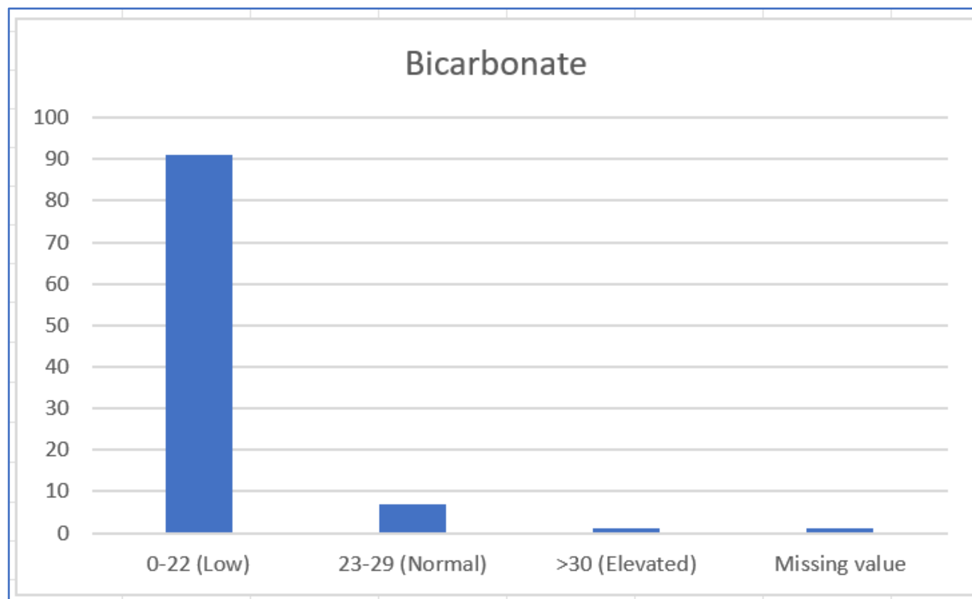


Figure 32: Anion Gap

Figure 32 illustrates the state of the anion gap which is another indicator of metabolic acidosis - 94% had an elevated level indicating metabolic acidosis and 4% of patients had a normal anion gap level.

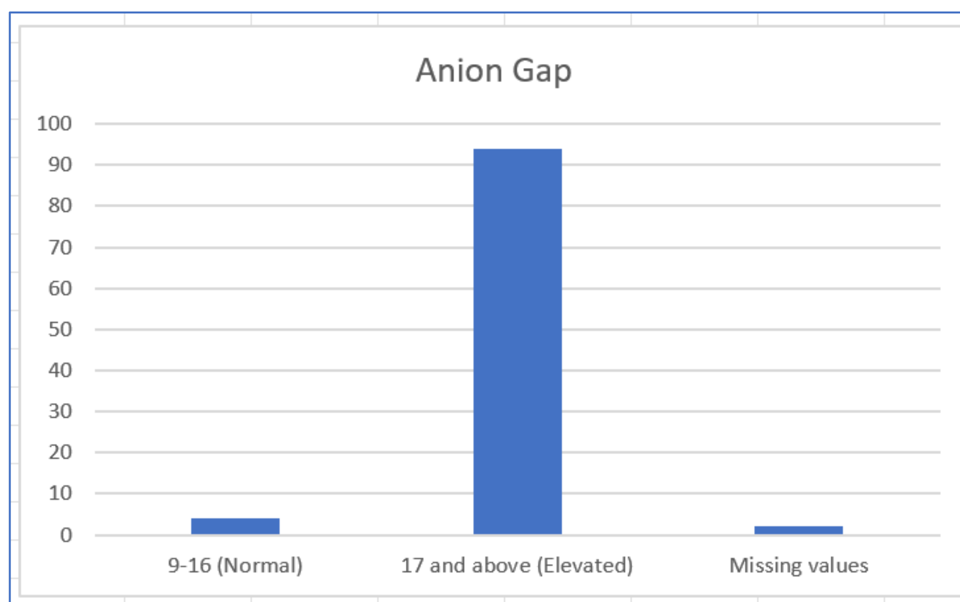


Table 8: Electrolytes

Table 8 shows a summary of electrolyte status of the study participants - 76 patients had electrolyte taken levels.

Electrolytes	N	Minimum	Maximum	Mean	Std. Deviation
Calcium (Ca2+)	76	1.60	4.04	2.2914	.34672
Magnesium (Mg)	76	.55	1.52	.8900	.16397
Phosphate (PO4)	76	.55	6.41	1.5843	.89708

Figure 33: Calcium (Ca2+)

Figure 33 shows that 45% of these patients had normal levels of serum calcium, 36% had hypocalcaemia and 20% had hypercalcaemia.

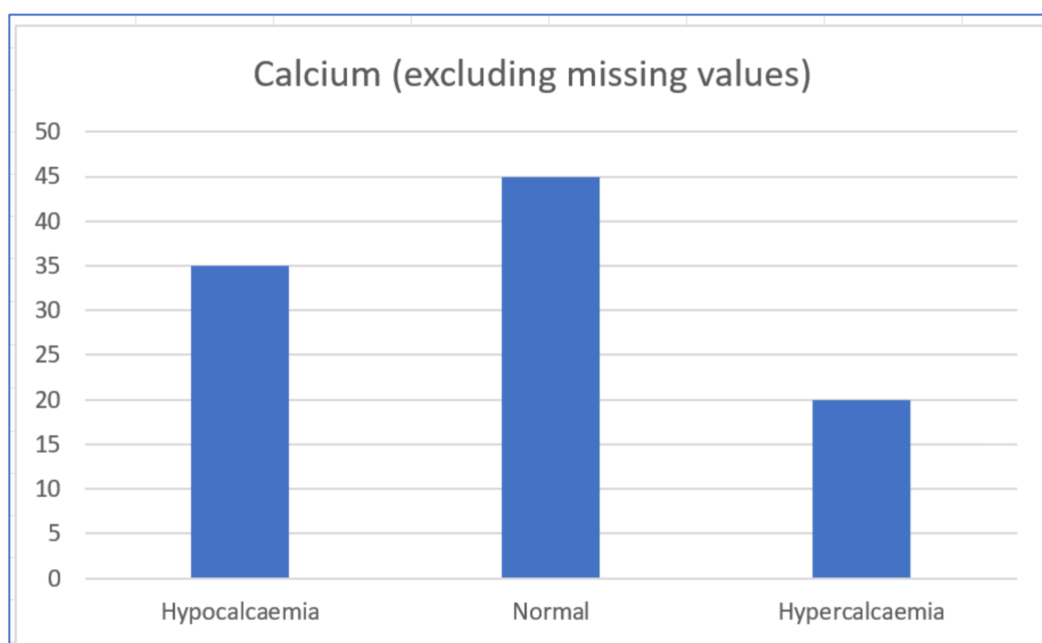


Figure 34: Magnesium (Mg)

Figure 34 shows that 84% of these patients had normal levels of serum magnesium

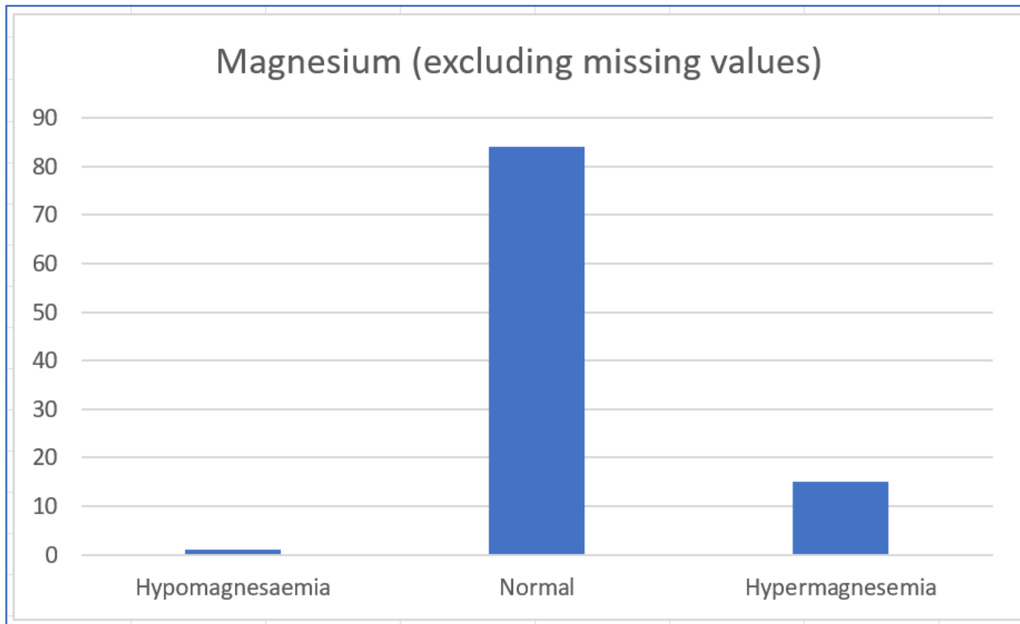


Figure 35: Serum Phosphate (PO4)

Figure 35 highlights that 42% of patients had Hyperphosphatemia and 8% had low levels of serum phosphate

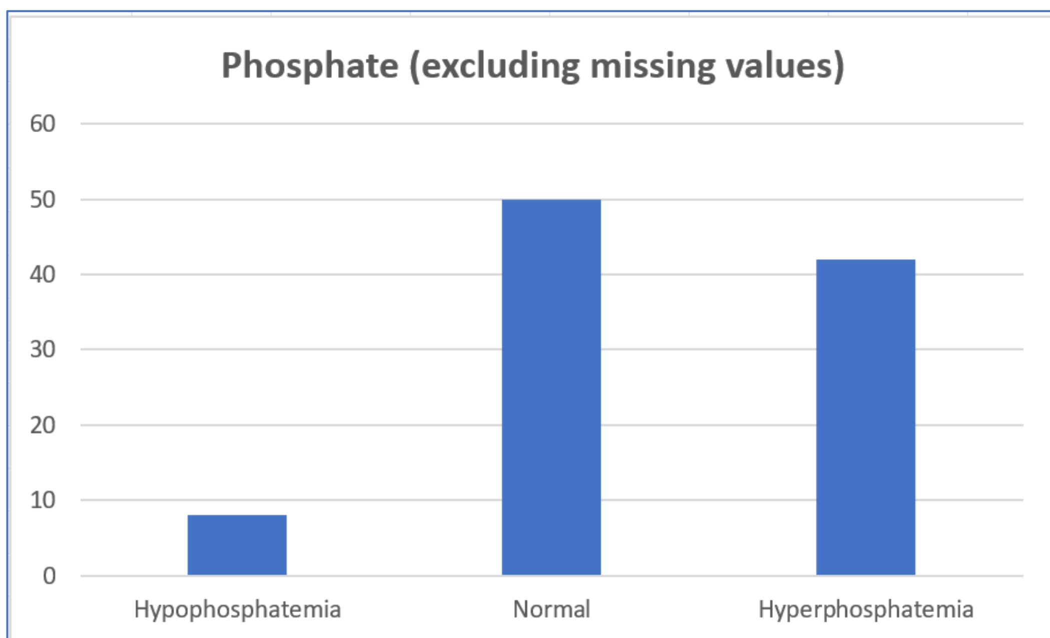


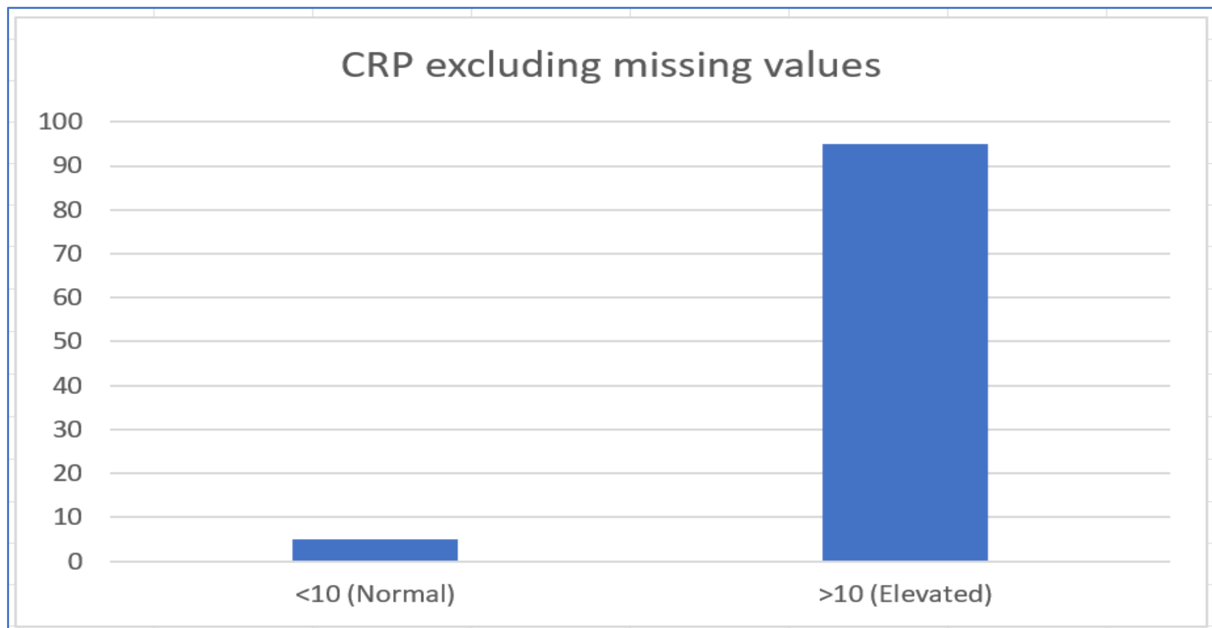
Table 9: C Reactive Protein (CRP)

Table 9 shows a review of the CRP, CRP/albumin (Alb) and CRP/ Alkaline Phosphatase (ALP) values.

CRP	N	Minimum	Maximum	Mean	Std. Deviation
CRP	75	0	479	**128.01**	119.847
CRP/Alb	64	.00	20.07	**4.3569**	4.84605
Alb/ALP	99	.01	7.04	.3978	.69944

Figure 36: C Reactive Protein (CRP)

Figure 36 demonstrates the nature of the CRP levels of study participants - 64 patients had no CRP results that could be found on the NHLS labtrak system. Of those with CRP results, 95% had elevated levels.



5.2.10 Age and Clinical Staging Analysis

Table 10: Age and Staging

Table 10 below shows the distribution of age in relation to FIGO clinical staging - 70% of patients-were at an advanced stage of cancer (stage 3 and 4) when seen at first presentation.

Of a total of 45 participants who were at stage 4 at the time of first consultation, 53% were between the ages of 20 – 49

		STAGING				
		Stage 1	**Stage 2**	**Stage 3**	**Stage 4**	**Total**
Age Categories	**20-29**	0	1	1	0	2
	30-39	1	5	4	10	20
	40-49	2	10	21	14	47
	50-59	1	15	12	9	37
	60-69	1	5	11	9	26
	70-79	0	1	1	3	5
	80-89	0	0	1	0	1
Total		**5**	**37**	**51**	**45**	**138**

5.3 The Spiritual Needs

5.3.1 Spiritual Belief and Affiliation

i) Spiritual

Do you consider yourself spiritual?

Figure 37: Spiritual

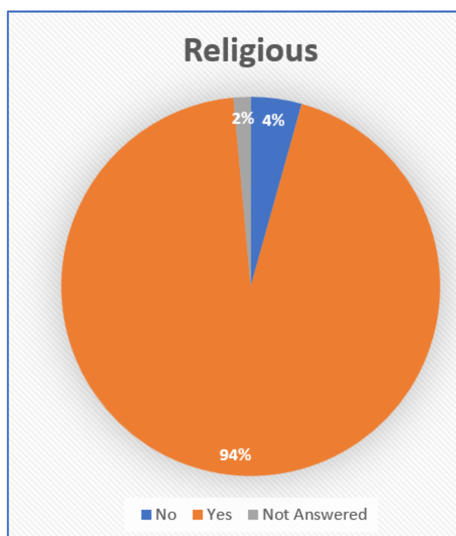
Figure 37 shows that most of the of patients (93%) considered themselves to be spiritual while only 1% did not. 6% of the patients did not answer the question.

ii) Religious

<u>Do you consider yourself religious?</u>

Figure 38: Religious

Figure 38 displays the proportion of patients who considered themselves to be religious. Majority (94%) of patients answered yes.

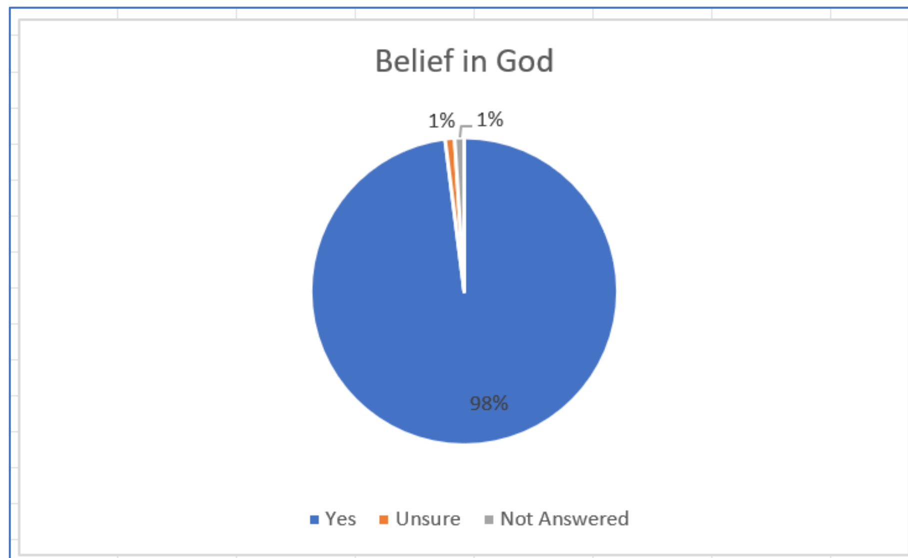


iii) Belief in God

Do you believe in God?

Figure 39: Belief in God

Figure 39 below displays the proportion of patients who believe in God. Majority of patients (98%) expressed to have a belief in God of a higher being.



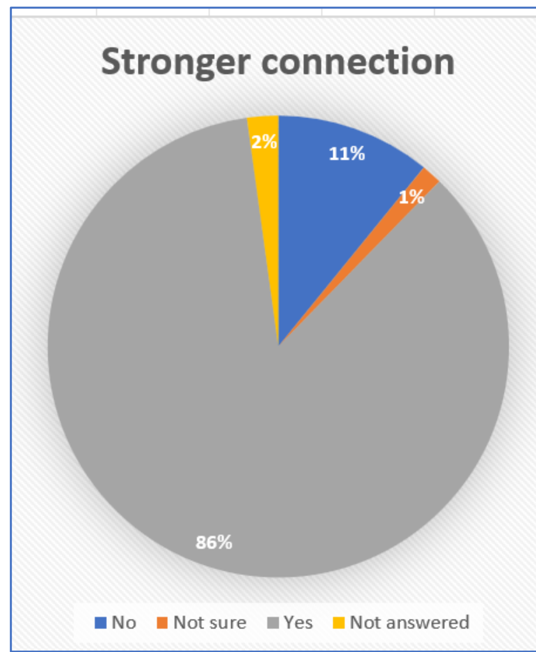
5.3.2 Spiritual Importance

i) Stronger connection

Have you been looking for a stronger connection with God?

Figure 40: Stronger Connection with God

This figure shows the extent to which patients felt a need to have a stronger connection with God - 86% of patients felt a need for a stronger connection with God now that they have a diagnosis of cervical cancer.



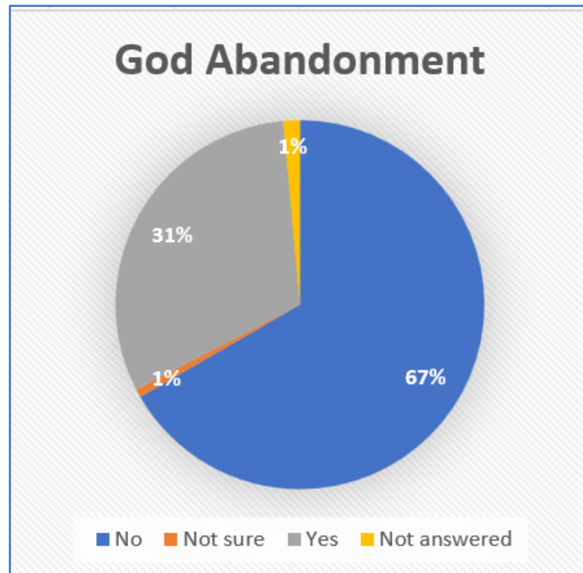
5.3.3 Spiritual Impact

i) God Abandonment

Have you been wondering whether God has abandoned you?

Figure 41: God Abandonment

Figure 41 shows that most patients (67%) did not feel abandoned by God despite the many challenges they experience because of their illness.

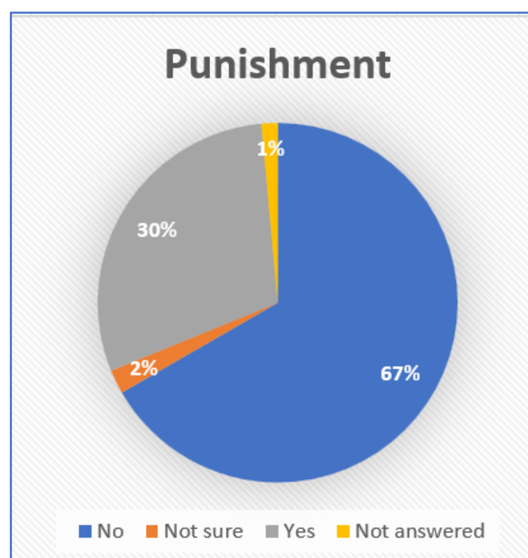


ii) Punishment

Do you feel that the disease is God's way of punishing you?

Figure 42: Punishment

Figure 42 below displays that most study participants (67%) did not feel that the diagnosis and experiences of cervical cancer are God's way of punishing them.

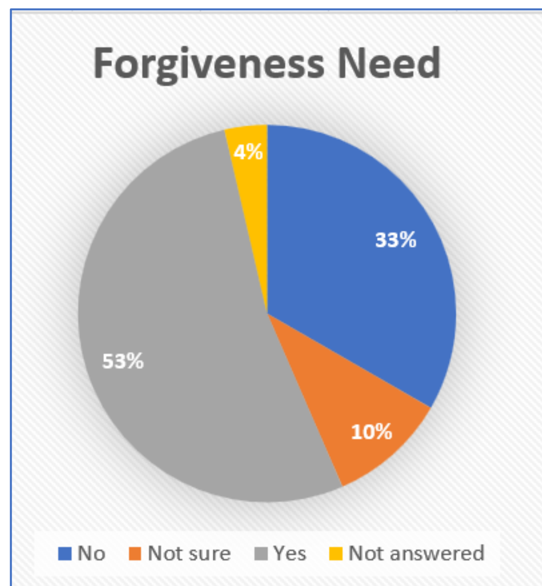


iii) Forgiveness need

Have you been asking for forgiveness for “sins”, past mistakes or any other thing?

Figure 43: Forgiveness Need

Figure 43 shows that over half of the patients (53%) have been asking for forgiveness from God for past mistakes and 33% were not.



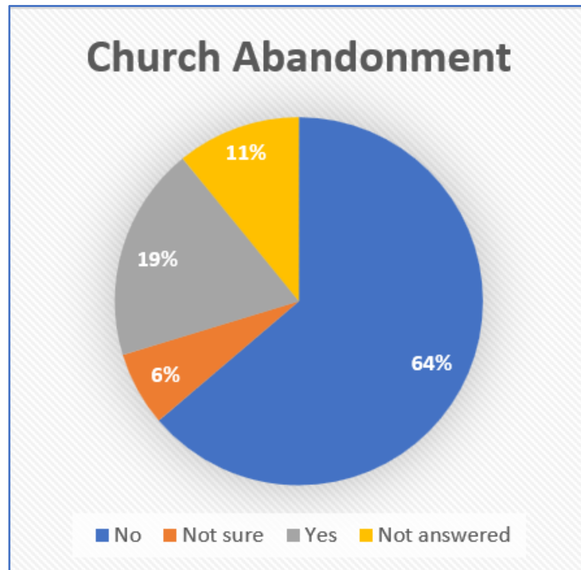
5.3.4 Spiritual Community / Support system

i) Church/Religious Group Abandonment

Do you feel abandoned by your spiritual community or religious leader?

Figure 44: Church Abandonment

Figure 44 Shows patients' views on whether they felt abandoned by their church or not - 64% of study participants did not feel a sense of spiritual community abandonment.



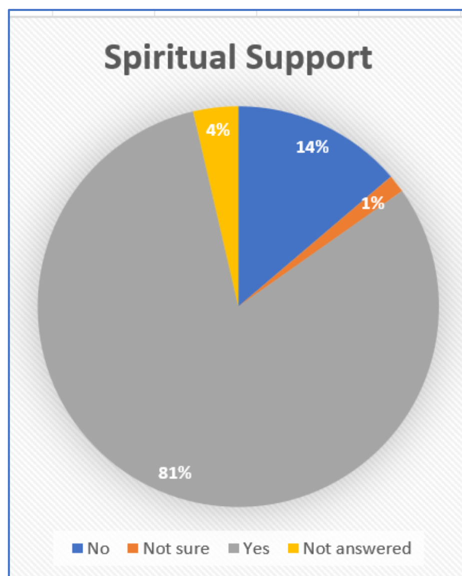
5.3.5 Spiritual Need

i) Spiritual support

Do you feel that you need spiritual support?

Figure 45: Spiritual Support

Figure 45 displays patients' views on their need for spiritual support - 81% answered that they needed spiritual support.



5.4 The Psycho-Social Needs

5.4.1 Worry

General worry

Have you been feeling worried about your illness?

Figure 46: Worry

Figure 46 displays whether patients had worry or not in their illness journey. Majority of patients (92%) expressed being worried about their illness.

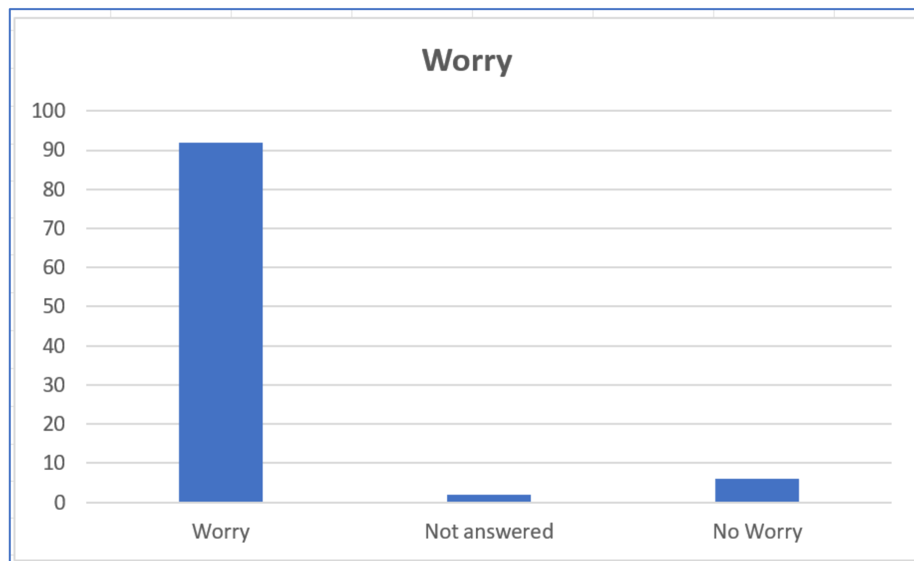
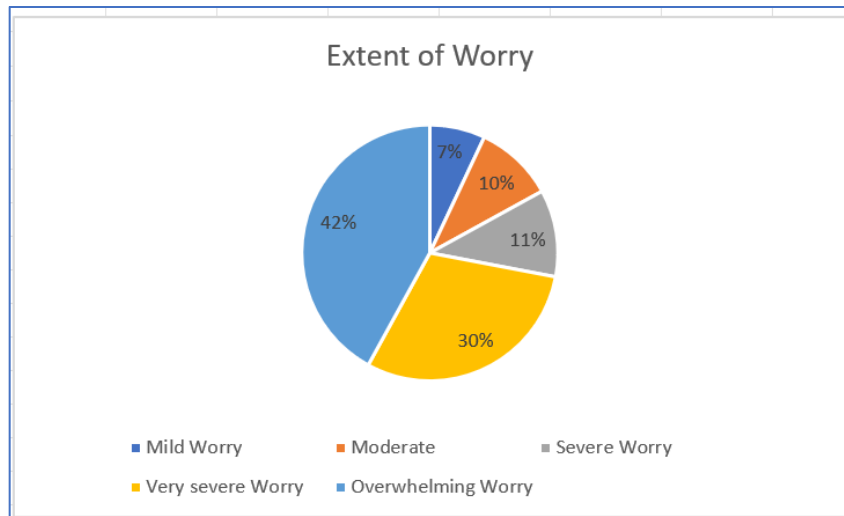


Figure 47: Extent of Worry

Figure 47 displays the extent of worry in the study participants - 72% had overwhelming to very severe worry.

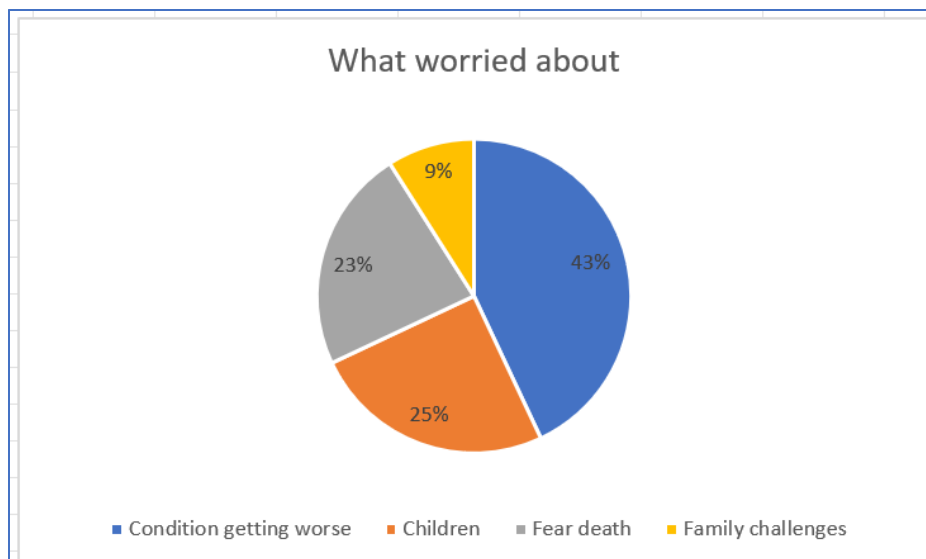


ii) What worried about.

What are the things that you are worried about?

Figure 48: Worried About

This figure shows sources of worry. Majority (43%) were worried about their condition getting worse while a quarter of patients were worried about their children and 23% expressed fear of death.



5.4.2 Able to Share

i) Sharing with others overview

Over the past 3 days, have you been able to share how you are feeling with your family or friends?

Figure 49: Sharing

Figure 49 shows the extent to which patients were able to share, with others, things that concern them - 88% expressed that they were able to share their struggles and feelings with another person.

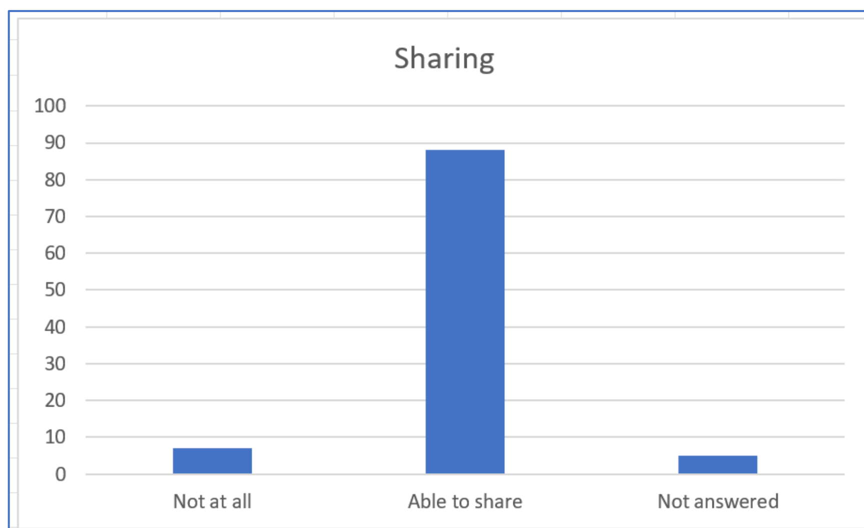
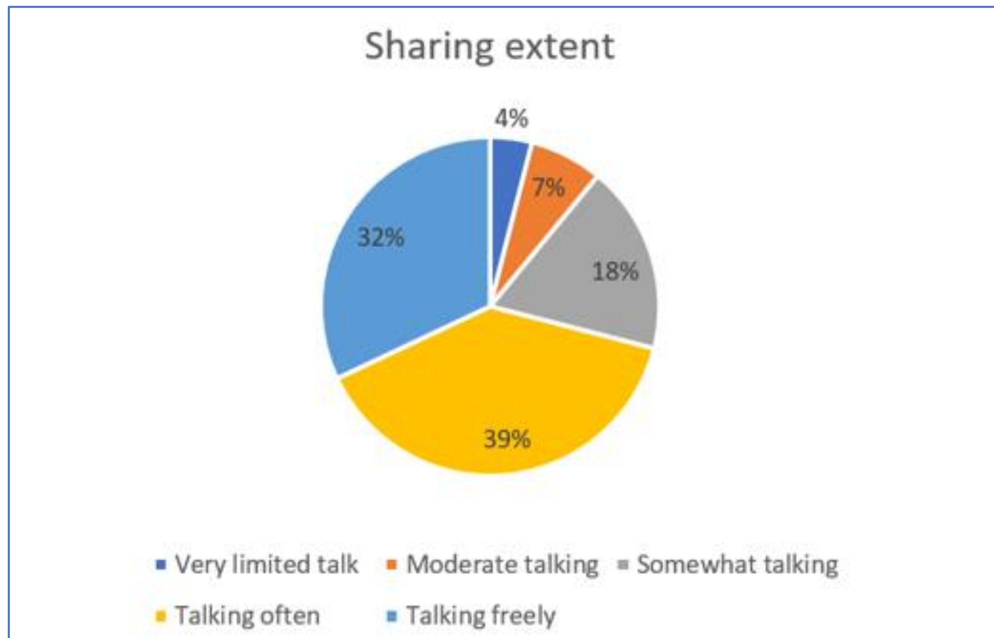


Figure 50: Sharing Extent

This figure shows majority (71%) of patients could share either often or freely to others with 25% being able to share moderately or somewhat and only 4% being very limited in their sharing.

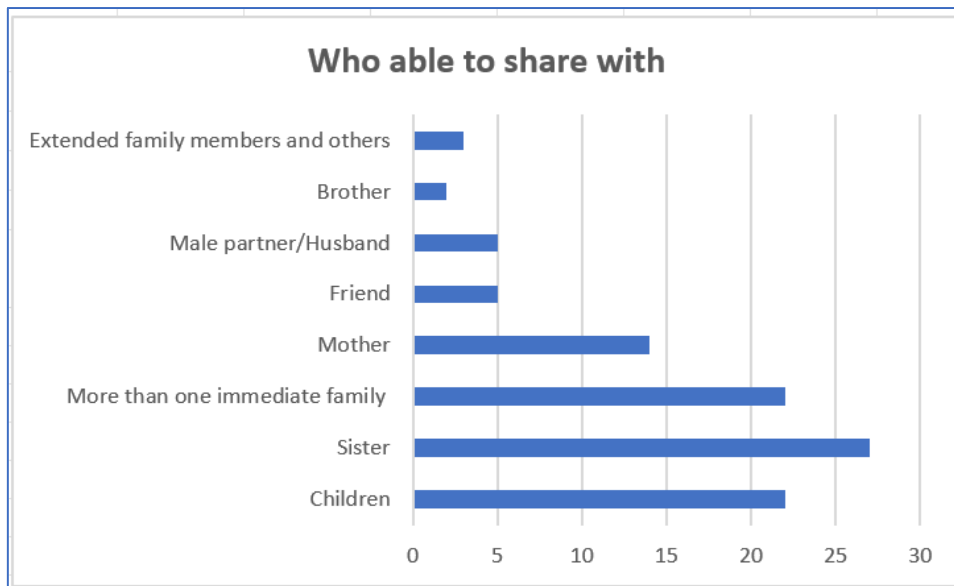


ii) Who able to share with.

Who are these people that you have been able to open up to and share with?

Figure 51: Sharing with

Figure 51 shows that most of the patients in the study seem to be able to share with a sister (27%), children (22%) or more than one immediate family member (22%) such as both a sister and mother or mother and children. Mothers also seem to feature as a source of support system at 14%.



5.4.3 Life worthwhile

Over the past 3 days have you felt that life was worthwhile?

Figure 52: Life Worthwhile

Figure 52 below demonstrates the patients' view on whether they felt life was worthwhile or not despite their clinical condition. Majority (94%) have expressed that life was worthwhile.

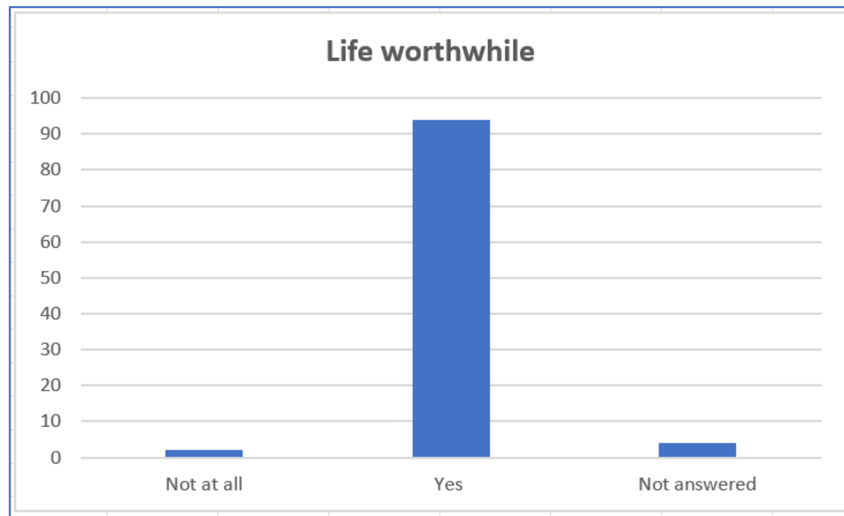
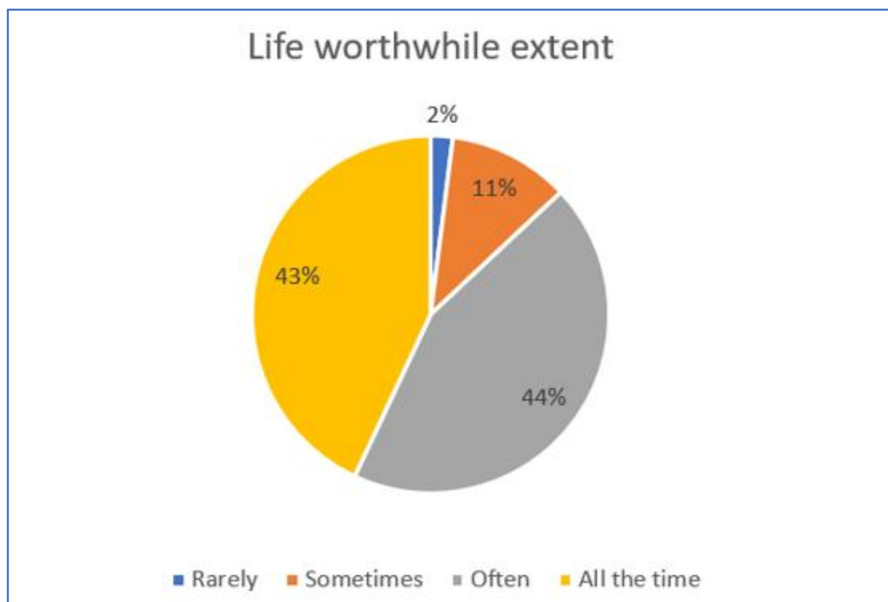


Figure 53: Extent of Life Worthwhile

Figure 53 below displays the extent of life worthwhile. Majority of patients that saw life as worthwhile (87%) felt that life was worthwhile either often or all the time.



5.4.4 Peace

Over the past 3 days have you felt at peace?

Figure 54: Peace

This figure shows the proportion of patients who felt a sense of peace despite illness challenges.

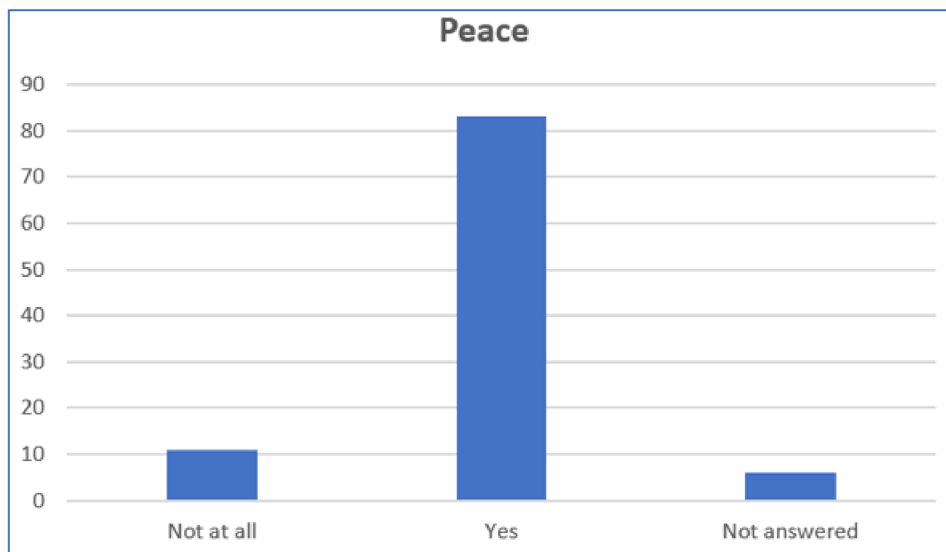
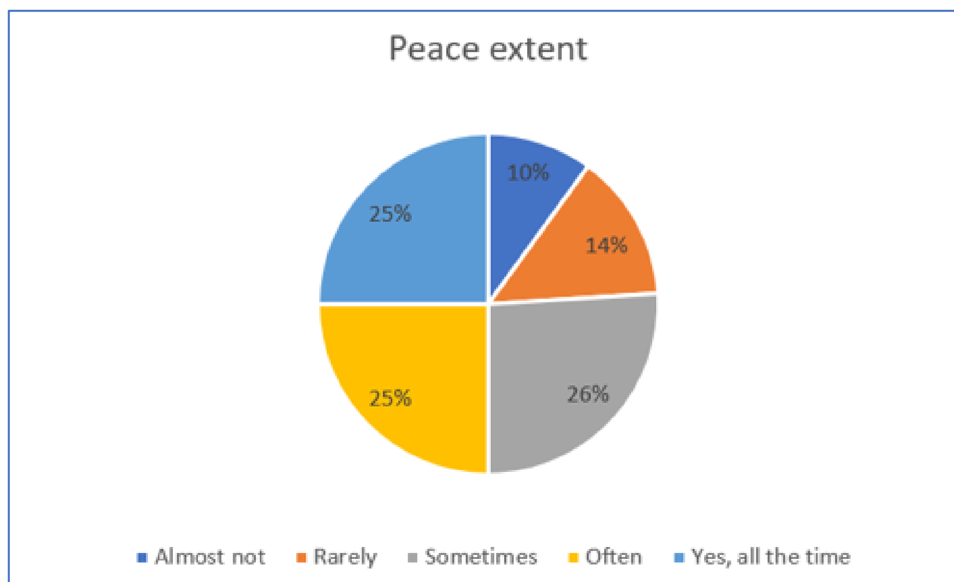


Figure 55: Extent of Peace

Figure 55 shows how often patients felt that they were able to have peace during their illness journey.

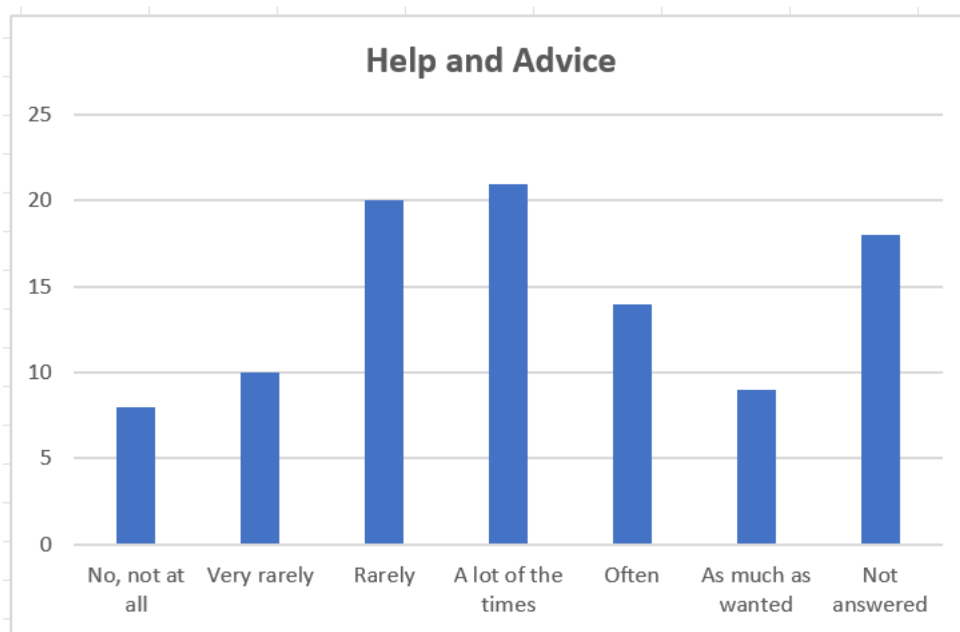


5.4.5 Help and Advice

Have you had enough help and advice for your family to plan for the future?

Figure 56: Help and Advice

Figure 56 shows the extent to which study participants felt that they received needed help and advice to plan for their future. A proportion of 44% expressed that they received help and advice often, a lot of the times and as much as they wanted.

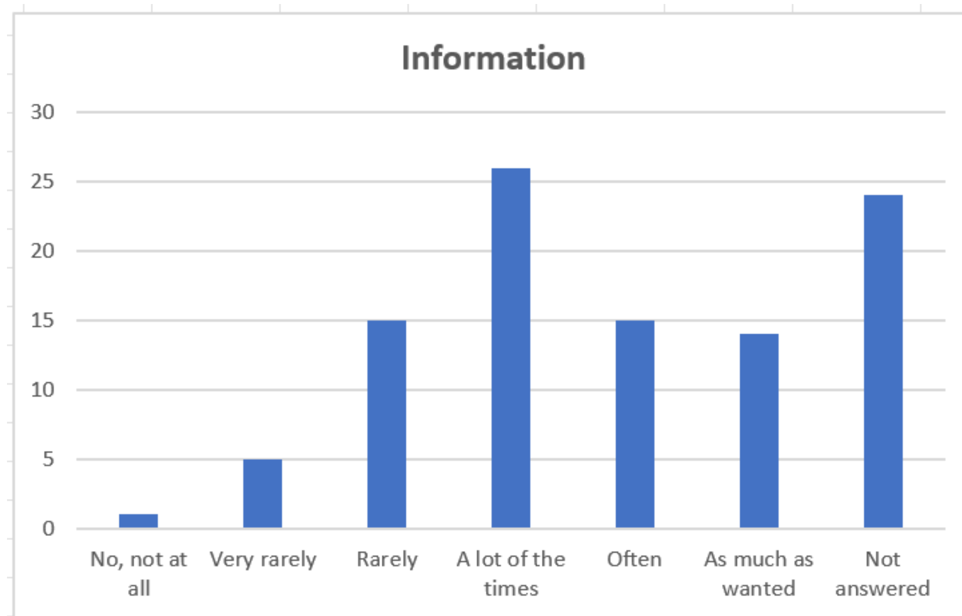


5.4.6 Information

Have you been given the amount of information you and your family need?

Figure 57: Information

Figure 57 categorises the amount of information that patients and their families felt they were given as part of their care.



5.5 The Correlations Analysis

The Pearson correlation analysis (r) results will show either a positive value which demonstrates a directly proportional relation (an increased need in one variable correlates with an increased need in another and vice versa) or a negative value which demonstrates an indirectly proportional relationship between two variables (an increased need in one variable correlates with a decreased need in another and vice versa). The sample sizes for various variables differ due to missing data.

Three correlation analyses that will be reported upon are as follows:

I. ECOG and Psycho-Social Needs correlation analysis

II. Psycho-Social Needs correlation analysis

III. Spiritual Needs correlation analysis

5.5.1 ECOG and Psycho-Social Needs Correlation Analysis

Table 11: ECOG and Psychosocial Needs

		ECOG	**Worry**	**Able to share**	**Life Worthwhile**	**At peace**	**Help & Advice**	**Information**
ECOG	Pearson Correlation	1	.205*	-.187*	-.031	-.314**	-.090	.042
	Sig. (2-tailed)		.017	.032	.727	<,001	.342	.670
	N	138	135	131	132	129	113	105

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

A Pearson correlation was run to determine a relationship between ECOG functional performance status and a number of psychosocial needs variables namely, worry, able to share, life worthwhile, at peace, help and advice and information. The following results were found:

- *ECOG and worry:* There was a positive correlation which was statistically significant (r =0.205, n = 135, p = 0.017).
- *ECOG and able to share:* There was a negative correlation which was statistically significant (r = -1.87, n = 131, p = 0.032).
- *ECOG and at peace:* This shows the strongest, negative correlation which was statistically significant (r = -0.314, n = 129, p = <0,001)

A Pearson correlation between ECOG and life worthwhile, Help & advice and information, though not statistically significant for all three, the results demonstrate interesting relationships. This will be further discussed in the discussion chapter.

- *ECOG and life Worthwhile:* There was a negative correlation which was not statistically significant (r = -0.031, n = 132, p = 0.727).
- *ECOG and Help & advice*: There was a negative correlation which was not statistically significant (r = -0.090, n = 113, p = 0.342).
- *ECOG and Information:* There was a positive correlation which was statistically significant (r =0.042, n = 105, p = 0.670).

5.5.2 Psycho-Social Needs Correlation Analysis

Table 12: Psycho-social Needs Correlation

		Worry	Able to share	Life Worthwhile	At peace	Help & Advice	Information
Worry	Pearson Correlation	1	.010	.122	-.249**	.003	-.049
	Sig. (2-tailed)		.912	.164	.005	.977	.624
	N	135	131	131	128	112	104
Able to share	Pearson Correlation	.010	1	.169	.283**	.056	.238*
	Sig. (2-tailed)	.912		.056	.001	.562	.016
	N	131	131	129	127	110	103
Life Worthwhile	Pearson Correlation	.122	.169	1	.078	.186*	.119
	Sig. (2-tailed)	.164	.056		.379	.048	.226
	N	131	129	132	128	113	105
At peace	Pearson Correlation	-.249**	.283**	.078	1	.118	.323**
	Sig. (2-tailed)	.005	.001	.379		.214	<,001
	N	128	127	128	129	112	104
Help and Advice	Pearson Correlation	.003	.056	.186*	.118	1	.435**
	Sig. (2-tailed)	.977	.562	.048	.214		<,001
	N	112	110	113	112	113	99
Information	Pearson Correlation	-.049	.238*	.119	.323**	.435**	1
	Sig. (2-tailed)	.624	.016	.226	<,001	<,001	
	N	104	103	105	104	99	105

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

A Pearson correlation coefficient was computed to assess the relationship between various psychosocial needs variables. Once again, the total sample size varied due to information that was missing in the patient records which was a limitation in the study.

Worry:

- ❖ Worry and at peace: There was a negative correlation between these two variables (r = -0.249, n = 128, p = 0.005) which was also statically significant.

Able to share:

- ❖ Share and at peace: There was a positive, statistically significant correlation between these two variables (r = 0.283, n = 127, p = 0.001).

Help and advice for future planning:

- Help & advice and life worthwhile: There was a positive, statistically significant correlation between these two variables (r = 0.186, n = 113, p = 0.048).

Information:

- Info and able to share: There was a positive, statistically significant correlation between these two variables (r = 0.238, n = 103, p = 0.016).
- Info and peace: There was a strong positive, statistically significant correlation between these two variables (r = 0.323, n = 104, p = <0.001).
- Info and help & advice: An even stronger positive, statistically significant correlation between these two variables was found (r = 0.435, n = 99, p = <0.001).

5.5.3 Spiritual Needs Correlation Analysis

Table 13: Spiritual Needs Correlation

		Stronger Connection	**God Abandonment**	**Punishment**	**Forgiveness**	**Spiritual Support Need**
N		138	138	138	138	138
Stronger Connection	Pearson Correlation	1	.282**	.281**	.364**	.282**
	Sig. (2-tailed)		<,001	<,001	<,001	<,001
God Abandonment	Pearson Correlation	.282**	1	.724**	.156	.027
	Sig. (2-tailed)	<,001		<,001	.068	.757
Punishment	Pearson Correlation	.281**	.724**	1	.123	.125
	Sig. (2-tailed)	<,001	<,001		.151	.142
Forgiveness	Pearson Correlation	.364**	.156	.123	1	.065
	Sig. (2-tailed)	<,001	.068	.151		.447
Spiritual Support Need	Pearson Correlation	.282**	.027	.125	.065	1
	Sig. (2-tailed)	<,001	.757	.142	.447	
**. Correlation is significant at the 0.01 level (2-tailed).						

With the spiritual needs analysis, the most important emerging central theme was the need for stronger connection to God or a higher being. A Pearson correlation analysis was performed between the need for stronger connection with God or higher being and 4 other variables, namely: God abandonment, feeling of punishment, need for forgiveness and spiritual support need. These relationships will be further discussed in the discussion chapter.

- *God abandonment and stronger connection need:* There was a positive correlation between the two variables which was statistically significant (r = 0.282, n = 138, p = <0.001).

- *Punishment and stronger connection need:* There was a positive correlation between the two variables which was statistically significant (r = 0.281, n = 138, p = <0.001).

- *Forgiveness and stronger connection need:* There was also a positive correlation between these two variables which was statistically significant (r = 0.364, n = 138, p = <0.001).

- *Spiritual support and stronger connection need:* There was a positive correlation between the two variables which was also statistically significant (r = 0.282, n = 138, p = <0.001).

- *God abandonment and Punishment:* In addition to the above correlation, there was also a very strong positive correlation between God abandonment and feeling of punishment (r = 0.724, n = 138, p = <0.001) which was statistically significant. This was the strongest correlation of all these variables.

5.6 Conclusion

Cervical cancer is a disease that significantly affects women between the ages of 30 and 69 with those who are 40 to 59 being the most affected. Cervical cancer patients experience very severe pain as an unmet need, with lower abdominal and lower back pain as the two most common pain locations. In addition, these patients also experience distressing symptoms that impact on their quality of life. HIV and hypertension are the two most common comorbidities that these patients have.

Majority of cervical cancer patients present late with advanced disease that also has a very significant impact on the functional performance status. The 30 - 49 age group was the highest group, in proportion, that presented at stage 4. Cervical cancer is also associated with iron deficiency anaemia, thrombocytosis, leukocytosis, possible metabolic acidosis and electrolyte disturbances, particularly hyperphosphatemia, hypocalcaemia and, to a lesser extent, hypercalcaemia and hypermagnesemia. Renal dysfunction, though not dominant, is also an important clinical condition brought on by this disease.

Most of these patients are spiritual and religious in nature and believe in a higher being and also, have been looking for a stronger connection with this being. Most patients do not see their illness as being abandoned nor punished by God and the illness has presented an increased need for forgiveness from God. An overwhelming majority of patients have a great need for spiritual support alongside their clinical care.

Patients also have enormous psycho-social needs. The illness seems to lead to great worry, particularly around fear of the condition getting worse & fear of death and concern for their children. Most patient could share struggles with others, see life as worthwhile and have peace despite their struggles.

In the next chapter, we will now further discuss these findings and the significant correlations that exist between a number of these variables, and we will do so in light of the available literature.

CHAPTER 6

DISCUSSION

6.1 Introduction

The aim of this study was to describe and provide an analysis of Palliative Care and total pain needs in patients diagnosed with cervical cancer in two Gauteng hospitals. The objectives were to determine the physical, psycho-social and spiritual symptom burden of cervical cancer patients and assess for any correlation between a number of these symptoms and other significant variables. The researcher showed that there are a number of physical, spiritual and psycho-social needs that cervical cancer patients have and these will now be further discussed in this chapter.

6.2 The Physical / Biomedical Profiles

6.2.1 Age

In this study it was found that the mean age was 50.53 with the youngest patient being at 26 years old. 48% of the patients were below the age of 50 and 75% below the age 60 with only 25% of patients being above the age of 60. The most affected age group is 40-49 at 33% followed by the 50-59 age group at 27%. Cervical cancer is not only a disease of the elderly but one that impacts younger individuals who are also economically active. HIV also contributes to this picture of younger patients being affected by cervical cancer as HIV positivity makes patients more likely to develop cervical cancer at a younger age than those without HIV (8).

Unlike other conditions, which are largely cancers of older patients, this study seems to suggest that cervical cancer seems to favour mostly 30 - 69 year old persons (95%). Huang et al, also found that there was an increasing incidence observed in younger populations (5). With only 1% of patients in this study found to be between the ages of 20 and 29 with no one below the age of 20 and 1% of patients in the age group of 80-89, the least are the affected age groups. Indeed literature does seem to agree that cervical cancer rarely develops in women younger than 20 years (33).

6.2.2 Physical Pain

Pain is one of the most common and distressing symptoms mentioned by palliative care patients (13). Cervical cancer is a common cause of pain among women (34). This pain is multidimensional, and many patients do not receive adequate management of this pain for many reasons including not being able to differentiate between different types of pain and not doing a proper assessment of this pain (35). The results of this study confirm that pain is a very significant need amongst these patients as evidenced by 89% of them indicating to have pain and only 11% reporting not to have any pain at al. Of the patients with pain, 29% reported to have very severe pain, then followed by those with worst pain (27%), severe pain (24%) and moderate pain (18%). This means that 80% of the patients reported to have severe to worst pain which highlights that only are these patients in pain but their pain is also severe in nature. This further shows how inadequate pain management is in the clinical environment and remains a significant unmet need in these patients.

Majority of patients (75%) reported to have lower abdominal pain. This was the most common pain location in the patients in the study. Lumbosacral plexopathy is one of the causes of physical pain in these patients and one of its presentations is lower back pain (35). 30% of patients in the study were found to have lower back pain. This was the second most common pain location in the study. The presence of pain in the lower back may be possibly supporting this theory of lumbo-sacral plexus damage or involvement in cervical cancer. Lumbo-sacral plexopathy is not an uncommon condition but it can be difficult to diagnose and subsequently manage. The presence of persistent lower back pain may aid in the diagnosis of this important condition (36). The third most common site of pain was leg pain at 12%. It appears that limb pain is less common in this group of patients but remains an important symptom to assess for and manage adequately. Leg pain can have vascular, neurological or musculoskeletal origins and may manifest as a combination of a number of these (37) including lumbosacral plexopathy (35).

6.2.3 Distressing Symptoms

Cervical cancer patients may experience a number distressing symptoms as part of their illness journey and the results of this study highlighted a number of them with 48% of patients reporting to have been experiencing constipation, which was the most common GIT symptom

in this group of patients. 77% of patients with constipation had severe to overwhelming constipation.

This suggests that when these patients have constipation it is most likely to be severe or worse. Constipation is an important symptom to actively assess for and adequately manage as, if unmanaged, can result in increased symptom burden and negatively impact the quality of life. The second most common GIT symptom in the study was nausea and/or vomiting at 34%. Majority of patients at 64% had moderate to severe nausea and/or vomiting. GIT symptoms are an important symptom accompaniment of cervical cancer. Information around the type of medication that the patients were taking was either not fully recorded in the patient files and only a few patients had their medication history indicated which was not enough to make an assessment. It is, therefore, unclear if the constipation, nausea and/or vomiting is purely because of the illness and its effects or if the medication history has also had an added impact. Nonetheless, these GIT symptoms impose a substantial humanistic burden in patients with cancer and are often overlooked due to the focus on cancer treatment and their impact on these patients may be underestimated (38). Coughing, at 11%, was found to be a much less common distressing symptom in these patients which is to be expected.

There were four other distressing symptoms that were found to be present in the participants, though not as dominant as other symptoms they remain important nonetheless due to their great impact on quality of care. These are, in descending order: Urine incontinence (11%), VVF (11%), RVF (5%) and confirmed DVT (4%). Of the two fistulae it looks like bladder invasion (VVF) is more common than rectal invasion RVF. This is further supported by Biewenga et al in a study looking at the prevalence of fistulae in stage IV cervical cancer patients which also found bladder invasion to be more common than rectal involvement (39). The five-year overall survival was 14.9% in patients with fistula (39) and so the presence of a fistula is an important finding. Urine incontinence and VVF were similar in number in this study which could be suggestive of urine incontinence being as a result of the VVF as opposed to it being an independent entity. More research needs to be done to differentiate between primary incontinence and incontinence secondary to VVF.

Cervical cancer patients also experience other distressing physical symptoms which include vaginal discharge, malodour, vaginal bleeding and sexual dysfunction (29). These were not assessed for in this study.

6.2.4 Comorbidities

HIV

There is a high burden of cervical disease in the HIV positive female population and cervical cancer if projected to increase in lower middle-income countries in the future particularly in countries with a high HIV disease burden (40). The incidence of invasive cervical cancer is notably high among women with HIV in South Africa and carries a significant burden in this group of patients (41). HIV positive patients have a greater risk for cervical cancer at least 5 times more common in HIV-infected women (42). UNAIDS also confirms that over 50% of cervical cancer cases are in women living with HIV as they are six times more likely to develop cervical cancer than their HIV negative counterparts (8).

In this study, 52% of patients were found to HIV positive with 4% of missing data. Of the HIV positive patients, an overwhelming majority of 90% were on anti-retroviral therapy. Only 64 patients' CD4 count results could be retrieved from the patient records and/or NHLS labtrak system. The minimum CD4 count was 5 and the highest was 1565 with a mean CD4 count of 426.22. A reduced CD4 cell count and older age at ART initiation are associated with increased invasive cervical cancer risk (42). It was encouraging to find that majority of HIV positive patients were actually on treatment though it could not be ascertained from the data whether they were virally suppressed or not.

HIV is an important comorbid condition in these patients. It is known to suppress the body's already low immune recognition ability for HPV infection which is a known carcinogen and important in causing high grade intraepithelial lesion that may later lead to cervical cancer if not treated and this allows for the HPV to cause more damage than it would in immunocompetent patients. (42).

Other comorbidities

Hypertension at 36% was found to be the second most common comorbid condition (after HIV), followed by Diabetes at 7% and Asthma at 2%. Hypertension is a known side effect of the angiogenesis inhibitors given as part of chemotherapy in cervical cancer (43). From this study it is unclear whether the slightly increased incidence of hypertension in comparison to diabetes and asthma is due to the added effects of chemotherapy, psychosocial stress, untreated

pain & other symptoms, life style or a combination of any of these. It is therefore important to pay greater attention to blood pressure monitoring and better control when these patients are undergoing therapy for cervical cancer.

6.2.5 Clinical Staging

Majority of patients were found to be at stage III (37.0%), followed by stage IV (33%) and then stage II (27%) A total of 70% of patients were found to be at FIGO stage III and IV at first consultation while only 3% presenting at stage I which may indicate poor screening strategies for this important and completely preventable cancer and suggestive of other possible reasons for late presentation. It appears that by the time patients present, they are already at an advanced stage of their disease when the diagnosis of cervical cancer is made. This is further supported by literature which also highlights that cervical cancer patients are mostly diagnosed at advanced stages among the majority of women in lower income environments (44). This highlights the need for more research to be done to further explore factors that lead to patients presenting late or having delayed treatment.

Only patients with stage I and early stage II can be offered surgery (Hysterectomy) as the mainstay of therapy with or without other oncological interventions depending on the advancement of the cancer (45). Once a patient reaches late stage II and above, then surgery is no longer the mainstay of treatment. The major treatment options now shift to radiation, chemotherapy or just palliative care with or without palliative chemo/radiation for symptom management. This means that majority of patients in this study would not qualify for surgery and would be offered either chemo/radiation or no active oncological therapy if found to be in stage IV and/or clinically not fit. Chemo/radiation comes with a great deal of symptom burden and challenges which would further add to the already existing burdens that these patients are experiencing.

The 5-year Survival rate for patients with cervical cancer depends on the clinical stage they are in: For stage I it would be greater than 90%, stage II 60-80%, stage III approximately 50%; and for stage IV it drops to less than 30% (42). This means that the 5-year survival rate for 70% of patients in this study (those with stage III and IV) is 50% or less.

Cervical cancer is amongst the biggest cause of morbidity and mortality amongst women in Southern Africa (2). The greater the stage, the more advanced the cancer is, the greater the disease burden and the more the palliative care needs a patient will most likely have which subsequently means a greater need for palliative care interventions. If majority of patients in this study present at advanced stage this means that as clinicians we should anticipate this great need, do an impeccable assessment and actively manage their multifaceted needs appropriately. The advanced stage at presentation also has implications in terms of the urgency to engage in serious illness conversations already at the point of seeing them and also appropriately engaging in thinking around advanced directives as an active part of the care of these patients. Also, advanced staging is associated with higher scores of depression and anxiety (46).

Disease staging is more than just a clinical observation, its level comes with a whole host of physical, emotional, social and spiritual implications that must constantly be assessed for as an active part of the clinical management of these patients.

6.2.6 Eastern Cooperative Oncology Score (ECOG) – Functional Performance Status

Of the individual ECOG grades, the biggest proportion (37%) of patients in this study were assessed as being at an ECOG score of 1 which means that they only experienced restriction in strenuous physical activity while they were able to perform light and sedentary activities with mild, if any, limitations. 5% of patients were found to have an ECOG of 0 and hence fully active and able to carry all pre-disease activities without restriction. This means that 42% of patients in this study were reasonably and largely functional (having an ECOG of 0 to 17).

This is significant as it indicates that despite having a diagnosis of cervical cancer, a significant percentage of these patients are still reasonably active. It hence becomes crucially important to impeccably manage any symptoms and issues (physical, spiritual and psycho-social) they may have in order to maintain their performance status and quality of life.

On the other hand, what is also significant in this study is that just above half of the patients (58%) had an ECOG score of 2 and above which means that either were unable to carry out any work activities (ECOG 2), were confined to a chair or bed for more than 50% of waking

hours (ECOG 3) or were completely disabled or bedridden (ECOG 4). This further highlights the significant impact of cervical cancer in limiting functional performance status and the subsequent challenges that come as a result of the decreased functional status. The implication of this is a limitation in self-care and possibly a subsequent need for additional assistance in the form of a carer which would then need to be paid for (increased financial burden). In other cases, one of the family members may end up needing to assume the role of carer which often has implications on that family member and their ability to either seek employment, continue working or live their own lives as now their lives would need to be centred around their ill family member and helping them with their various needs. Needing to care for a patient that has limited self-care capabilities due to their illness can also have a huge impact on family relations and the individual psychological health of the patient, their carer and the entire family. The decreased functional performance may also lead to the patients losing their employment and earning capacity. The impact of a lower level of functioning cannot be underestimated as this is also associated with increased pain over time and higher scores of depressive symptoms (47).

The impact of cervical cancer on the ECOG performance functional status is significant and it is important to keep this important issue in mind when treating these patients and attempting to manage them holistically and effectively.

6.2.7 Biochemical profile

Anaemia

With the mean haemoglobin of 8.5g/dL and 72% of patients in the study having a haemoglobin of less than 10, anaemia was a very significant condition in this group of patients. Part of the challenge with anaemia is that it may bring symptoms that may greatly & negatively impact performance of activities of daily living and quality of life.

Iron study results could not be found for 78% of the patients. It became clear that this investigation was not commonly done especially for patients with anaemia. Of those patients who had iron studies done (22%), most (81%) were found to have iron deficiency anaemia. Though the sample size of the number of patients who had iron studies done was very small,

the information that these results allude to remains significant and further studies with a bigger study population would need to be done to confirm this phenomenon.

Iron deficiency is a common nutritional disorder and often found in patients with chronic diseases such as cancer and is associated with poor clinical outcome which includes poor functional performance, decreased quality of life, increased hospitalisation and mortality (48). Iron deficiency may be severe despite the patient having a normal haemoglobin level and a full blood count and these patients may have symptoms which may be prolonged and debilitating (49). Ludwig et al also confirm that iron deficiency is frequent in cancer and is associated with advanced disease, close proximity to cancer therapy and poor performance status in patients with solid tumours (50). This therefore has implications for how we approach anaemia in cancer patients in that a mere full blood count (which is done for all patients) may not be sufficient and an effort to assess for iron deficiency (despite normal haemoglobin level) should be made. We could not assess for the prevalence of iron deficiency anaemia in patients with a normal full blood count in this study as iron studies were not done routinely but it would be helpful for future studies to look into this. Anaemia prevalence in patients with cancer is remarkably high and only limited data on iron deficiency in cancer patients is available (50). More randomised controlled trials around this issue need to be done.

Anaemia may come with a number of physical, cognitive and social impacts which vary considerably among individuals (51). Some of these include tiredness, headache, weakness, dizziness, impaired physical fitness & wellbeing and greatly impacted quality of life. Emerging data show that treating iron deficiency anaemia in cancer patients has a beneficial effect (50). Treatment with Erythropoietin (EPO) has been found to be effective in preventing anaemia and in reducing the need for blood transfusions which are expensive and not without its fair share of possible hazards (51). The challenge of EPO is its cost factor but very high-risk patient sub-groups who would benefit from this treatment could be identified and treatment with EPO depending on available financial resources. With iron deficiency being a common form of anaemia in these patients, there may be grounds to also explore the inclusion of long-term iron supplementation as a prevention and management strategy in these patients (as is the case with pregnant women). Iron fortification and supplementation are also very cost-effective interventions to reduce iron deficiency (52). This be an indication of a possible place for routine iron supplementation in these patients. Ludwig et al agrees and makes recommendations for iron supplementation for cancer patients (50). Iron deficiency alone was also found to increase

thrombotic tendency and iron replacement therapy reverses these changes (53). This is another argument for the promotion of iron replacement therapy in these patients.

Platelet disturbances

Cancer is a pathological condition that is often associated with thrombocytosis (54). With 64% of patients having elevated platelets, the study findings seem to agree with the notion that thrombocytosis is a common clinical condition in cancer patients. Its presence has a number of clinical implications. The presence of cancer leads to the production of inflammatory cytokines which, in turn, stimulate the process of platelet production in the bone marrow (54).

Thrombocytosis appears, in literature, to be a universal marker of adverse outcomes in cancer and its association with worse oncological outcomes has been reported in a number of cancers whether early or advanced (54). The association between pre-treatment thrombocytopenia and poor overall survival is widely reported in literature (55) and is an independent prognostic factor for prognosis of cervical cancer (56). Thrombocytosis is also found to be associated with iron deficiency anaemia, a very common phenomenon in patients with cervical cancer (57) and on the other hand, not predictive of thrombosis (58). Thrombocytopenia featured much less in this study with only 3% of patients found to have it.

Inflammatory state

C-Reactive Protein (CRP) and White Cell Count (WCC)

With the overwhelming numbers of patients (95%) having elevated CRP levels and 56% having an elevated white cell count, this is suggesting that cancer of the cervix patients develop inflammation as part of their disease process. Some of the signs of inflammation are swelling and pain (59). The presence of inflammation contributes to the patients’ pain experience and hence may be beneficial, as part of managing pain in this group of patients, to include drugs with anti-inflammatory properties such as NSAIDs and where appropriate corticosteroids. Inflammation seems to also be an important clinical phenomenon that forms part of the cervical cancer disease profile.

Leukocytosis, like thrombocytosis, is also associated with decreased overall survival (60). It is further reported in literature that women with both leukocytosis and thrombocytopenia (as was the case in this study) have the worst overall survival (60). This clinical phenomenon is also found to drive the development of venous thrombosis (58).

Leukocytosis, particularly neutrophilia, is usually associated with acute infection and inflammation however it can also occur as part of the para-neoplastic syndrome due to various cytokines secretion from the tumour (61). Excessively increased levels of white blood cells typically guide the diagnosis of infection, inflammation and myeloproliferative neoplasm (61). In the case of cervical cancer patients, where tumour necrosis may be present and hence attracting bacterial colonisation which would lead to an infective process, it is not surprising for these patients to have an elevated CRP and WCC.

Renal function

Majority of patients had normal urea (68%), creatinine (57%) and glomerular filtration rate (60%). These are important markers of renal dysfunction. Despite the fact that majority had normal renal function, 30% of patients had elevated urea, 39% had elevated creatinine and 34% had a glomerular filtration rate that was suggestive of renal dysfunction. Renal dysfunction is another clinical condition that needs to be paid attention to in these patients. It is surprising that the number of those with renal impairment is not higher given the nature of cervical cancer disease progression in causing hydronephrosis which may lead to renal dysfunction. Hydronephrosis is often a common feature in advanced cervical cancer and may not initially lead to abnormal renal function which may explain the lower proportion of patients with renal impairment.

There is a potential increase in risk of renal dysfunction in patients with invasive cancer of the cervix who are HIV positive and treated with cisplatin-based concurrent chemotherapy (62). This is due to the overlapping nephrotoxicity of the drugs and the nephropathy from the diseases themselves (62). There is limited literature available on the short-term renal outcomes for HIV positive patients with invasive cervical cancer (62).

It is important to also note that factors such as severe malnourishment, being underweight, muscle wasting, chemotherapy, high meat consumption and hypertension may also affect the GFR. Also, dehydration can lead to serum creatinine rising and the estimated glomerular

filtration rate (eGFR) to fall. All these factors need to be taken into account when making an analysis of these results.

Metabolic acidosis

An overwhelming proportion of patients (91%) had a low serum bicarbonate level and an elevated anion gap (94%). This may be suggestive of a widespread presence metabolic acidosis in these patients and none of the patients had a blood gas taken and analysed and hence it is difficult to make a definitive confirmation of its presence.

Metabolic acidosis may lead to a number of symptoms such as fatigue, loss of appetite, headache, nausea and vomiting and feeling week. This is an important clinical condition as it may greatly impact on the patients' illness experience by adding to the symptom burden. It may be good in future studies to explore this phenomenon further, including the analysis of patient blood gas results, to further analyse the existence of a metabolic acidotic state in cervical cancer. The presence of metabolic acidosis would be a significant finding because if indeed these patients are in a (chronic or prolonged) metabolic acidotic state, perhaps managing the acidosis may be an important part of improving the symptoms the patients experience as a result and subsequently their quality of life. Heneberg argues that the presence of cancer may lead to lactic acidosis which is associated with an extremely poor prognosis (63). Although this acidosis is worth treating, targeting systemic lactic acidosis in patients with solid cancer is usually ineffective (63). With this in mind, the goal of treating acidosis in these patients is hence more focused on improving symptoms and quality of life rather than affecting the disease process.

Electrolyte disturbances

It was found that bloods to assess for electrolyte disturbances in these patients was not routinely done with only 55% of patients results found. Of the patients who had electrolyte bloods taken, the two most affected electrolyte disturbance were serum phosphate and calcium. 42% of patients were found to have hyperphosphatemia, with hypocalcaemia found in 35% and hypercalcaemia in 20% of patients. Disturbances in magnesium levels was less common with 15% of patients displaying hypermagnesemia

Disturbances in electrolytes are important as this may also result in the patient developing a number of symptoms as a result. Failure to diagnose an electrolyte abnormality and subsequently correct it may significantly add to the patient's symptom burden.

Tumor lysis syndrome

Tumour lysis syndrome is a condition that occurs when a large number of cancer cells die within a short period and release their contents into the bloodstream (64) either spontaneously or in response to therapy (65). This syndrome is associated with four metabolic or electrolyte derangements and these are: Hyperkalaemia, hypocalcaemia, hyperphosphatemia and hyperuricemia (66). These electrolytes must be monitored daily before and after initiation of therapy and elevated levels may indicate the beginning of tumor lysis syndrome (66). With 40% of patients who had bloods taken for electrolytes, experiencing hyperphosphatemia and 35% experiencing hypocalcaemia, this may be early signs suggestive of the presence of this syndrome in these patients. The assessment for hyperkalaemia and hyperuricemia was not included in this study and the sample size was too small to make any definitive conclusions.

Cervical cancer leads to severe symptoms that negatively impact the quality of life of patients (67). Bercow et al have demonstrated that palliative care referral was associated with fewer emergency department visits, inpatient stays and intensive care unit admissions (67). This is mostly the case due to well managed biomedical and other challenges. All the patients enrolled in the study, we interviewed at first consultation and hence before palliative care intervention. With the many biomedical challenges highlighted above, this places more emphasis on the importance of palliative care referral of these patients early on in the disease process.

6.7 Spiritual Needs

6.7.1 Connection

Majority of patients considered themselves as spiritual (93%), religious (94%) and believed in God (98%). This is a significant finding as it may suggest that when these patients go through tough times their view of their suffering would most likely be influenced by their being spiritual and religious beliefs and by their belief in the existence of a God or higher being.

The spiritual needs in this group of patients were found to be multi-faceted and multi-dimensional. The most dominant need was a need for a stronger connection with God or a

higher being. This will be further discussed in the spiritual need correlation analysis section further down. The general areas of spiritual need were feelings of being abandoned by God, feelings of seeing the illness as punishment by God, needing to be forgiven by God for past mistakes and needing spiritual support as part of clinical care.

6.7.2 Abandonment

Though only 31% of patients reported to feeling abandoned by God, this is still a significant need that requires to be met amongst these patients. What was interesting was the fact that majority of patients (67%) did not feel abandoned by God and also did not feel that the disease was God's way of punishing them (67%), despite experiencing a great of pain. This may be suggestive of how patients being spiritual, religious and believing in God impacts how they make sense and digest their challenges. It appears that, largely, patients in this study do not attribute their pain to God rejecting them as evidenced by 81% of them wanting a stronger relationship with God. Feelings of abandonment and being punished instead of negatively impacting the relationship with God, they seem to lead to a desire for greater connection. This could be suggesting that our patients look towards a higher being and their spirituality or religion as source and strategy to cope with spiritual needs and challenges experienced.

With regards to social abandonment, 64% of patients did not feel abandoned by their spiritual community or religious leader with only 19% feeling that their spiritual community is not supportive. Which suggests that spiritual community may be another important and valuable source of support for patients that must not be forgotten and needs to be actively explored, protected and strengthened as part of spiritual care in these patients.

6.7.3 Need for Forgiveness

One of the sources of spiritual pain is unresolved past issues. Just over half of the patients (53%) expressed a need to be forgiven by God for their "sins" or past mistakes. This could be a significant contributing factor to spiritual pain and needs to be actively and routinely explored when a spiritual history is taken and subsequently and appropriately managed.

What was not assessed for in this study was the presence of the patients' need to be forgiven by others. Challenges with interpersonal relationships and the subsequent unresolved pain that may arise from these relationships, may also contribute to spiritual pain. More research needs to be done around this issue.

6.7.4 Spiritual Support

Another significant finding is that majority of patients (81%) desire and have a need for spiritual support alongside their clinical care. This is not surprising as majority of patients regard themselves as spiritual and religious with a belief in a God or higher being. As part of patient centred care, if patients are saying that they have a need and desire for spiritual support alongside their care, it then becomes part of our duty as health professionals to facilitate for that need to be met as part of inter-disciplinary care. One of the aims of spiritual support is to improve spiritual well-being and patients with high scores of spiritual well-being become more optimistic about life, struggles and the disease process (68). This highlights the importance and value of adequately and intentionally responding to this need for spiritual support and aiming to strengthen spiritual well-being. Patients with higher spiritual well-being also experience less anxiety about death (69).

6.8 Psycho-Social Needs

Psycho-social issues form an important part of total pain. There are a number of themes that emerged from the psycho-social needs analysis. These themes are: being worried about the illness, ability share with others, the feeling of life being worthwhile, feeling of peace, help and advice to plan for future and information needs.

6.8.1 Worry

An overwhelming majority of patients (92%) expressed that their illness has ushered in a great deal of worry. It was also found that of those who expressed worry, 83% had severe to overwhelming worry. It appears that not only is worry present in majority of patients, but it is also intense. This perhaps highlights an unmet need in the management of these patients.

Most of the patients (43%) are worried about their condition getting worse, while a quarter (25%) were concerned about what will happen to their children if they die or become sicker. Fear of death was also expressed as another source of worry in 23% of patients. A smaller

proportion of patients (9%) attributed their source of worry to family challenges. It appears that the greatest source of worry in these patients stems from issues relating to the disease itself (worsening condition and that dying is imminent) and children.

6.8.2 Ability to Share

Being able to have people to talk and share with when experiencing challenging circumstances is an important part of the therapeutic process. It was encouraging to note that majority of patients (88%) were able to share their struggles with someone. Another encouraging issue was that 86% of patients were actually able to talk often or freely to others, a valuable source of support.

The study did not assess how helpful the sharing was and what the reasons that enabled, encouraged and made it easy for them to share were. A further study looking into this would assist in further facilitating and dealing with obstacles preventing the patients' ability to share with others.

The biggest percentage of patients who were able to share with others expressed that they were able to share more with a sister (27%), their children (22%) and a combination of more than one immediate family member (a sister and mother or mother an children) (22%). Mothers also seem to feature as a source of support system though at a lesser proportion (14%). It would be interesting to find out, in future studies, what the possible reasons why mothers feature so low are. Could this be, not necessarily that mothers are not emotionally available but rather that patients do not want to further burden their elderly mothers and instead feel more comfortable to opening up to their female siblings and children.

Friends, male partners, brothers and extended family members seem to be less involved in the process. It is also a significant finding that male figures such as partners or brothers play a much less supportive role in listening. Literature suggests that a significant proportion of these patients (as high as 40%) are abandoned by their intimate partners (29) which brings another possible reason for their less involvement. Could this also be because patients feel that the male members of their family circle will not understand what they are going through even if they share or that male family members are just not emotionally available and not patient enough to just listen? More qualitative research needs to be done to ascertain why this is the case.

On the other hand, with sister siblings and children being a more common source of support, this is valuable information in re-iterating the value of including these individuals as part of the multi-disciplinary team managing these patients. The other implication is that those who care for these patients have to also pay more attention in ensuring that these individuals, who are a great source of emotional support to these patients are in turn also supported so they can continue to offer the much-needed support to their affected family member.

6.8.3 Life Worthwhile

One of the common reasons given by individuals with life threatening, life limiting, and incurable illnesses for euthanasia is that they no longer see life as worthwhile. The results in this study certainly show that these patients are experiencing a great deal of suffering and challenges. The analysis shows that 94% of patients continue to see life as being worthwhile. In addition to this, 87% of patients who felt that life was worthwhile felt it often if not all the time. It is valuable to note that despite these enormous challenges, the patients feel that life is still worthwhile. The study did not go into exploring what gives patients meaning and hence helps them continue to see life as being worth living. This would be an interesting theme to explore in future studies.

6.8.4 Peace

Similar to life worthwhile, a significant proportion of patients (83%) also experienced peace despite the challenges encountered. The majority of those with peace (76%) experienced it a lot of the times, often and/or all the time. Patients seem to have a strong sense of peace despite having a diagnosis of cervical cancer and being worried about it. These results further highlight that there are probably other factors at play that lead to patients responding to their challenges in this manner and these need to be explored further in future studies.

6.8.5 Help and advice and Information needs

Information refers to basic and generic information that patients would receive during their care and help and advice refers to more specific information and assistance aimed at helping patients plan for their future now that they have cervical cancer.

Only 1% of patients felt that they did not receive any information regarding their illness while 20% felt that they received minimal information. Majority of patients (55%) felt that they received a good amount of information. With regards to receiving help and advice for future planning,8% felt that they received none of it while 44% felt that they received a good amount. From these findings it is clear that patients still have a significant unmet need for healthcare professionals to assist them in giving appropriate help and advice for them to plan for their future as well as being given enough information regarding their illness as they navigate through the diagnosis of cervical cancer.

6.8.6 Depressions and anxiety

Depression and anxiety are important comorbid psychiatric condition in cervical and co-exist with the diagnosis of cervical cancer more commonly than one would think. Krakauer et al found a high prevalence of clinically significant anxiety and depressed mood in patients diagnosed with cervical cancer (29). It was also demonstrated that patients who had comorbidities such as diabetes mellitus, ischaemic heart disease and cerebrovascular disease also had higher risks of developing depression (27).

It was determined that cancer patients receiving outpatient treatment had anxiety and depression scores of a significant proportion which were clinically significant (70). The female sex was found, in a study by Yuce et al, to be an important factor for both anxiety and depression while advanced age was found to be an important factor for depression (70). This suggests that these patients, by virtue of their sex, are at an increased risk of anxiety and the more older patients are more like to also have depression alongside their cancer diagnosis.
A significant correlation was found, in a study by Golubovic et al, between the stage of cervical cancer and scores of depression and anxiety (46). More severe depressive symptoms correlated to a more advanced stage of disease (46). This further highlights that cervical cancer patients are vulnerable to the development of psychiatric conditions such as depression and anxiety and hence need to have active screening for these conditions especially because anxiety and depression are associated with significant disease burden and unfavourable survival rates (46). Makimbetov et al also confirms that anxiety and depression are important comorbid psychiatric conditions in cervical cancer patients. They found that 90.4% of patients with advanced stages of cancer in their study had symptoms of depression in sub-clinically and clinically expressed forms (71).

This study could not explore the issue of depression and anxiety and this important issue needs to be further explored in future studies, especially in the South Africa and African context.

6.9 The Correlation Analysis

6.9.1 ECOG and Psycho-Social Needs Correlation Analysis

The ECOG performance functional status was found to have correlations with a number of psycho-social needs in this group of patients.

The higher the ECOG functional performance score, the less mobile the patient is and the more dependent on others they are. A statistically significant positive correlation between ECOG and worry was found. These results indicated that the higher the ECOG (poorer functional status) the greater the patients' worry, indicating that a poorer functional capacity is associated with patients being more worried perhaps about this being an indication of the progression of the illness. Further studies with more comprehensive measure of anxiety or worry are needed to clarify the relationship between anxiety and functional status (72).

On the other hand, an increase in the ECOG was also associated with a decreased ability of the patients to share their struggles and emotional difficulties with others as evidenced by a statistically significant, negative Pearson correlation. In addition, an increased ECOG was also associated with decrease in other words as the patience functional status declined, they become more distressed and become less at peace.

A Pearson correlation between ECOG and life worthwhile, Help & advice and information was not statistically significant for all three but sheds some valuable light on a number of issues. There was a negative correlation between ECOG and Life worthwhile which suggests that the less functional the patients got (that is a higher ECOG score) the less they felt that life was worthwhile. Also, it was found that the less functional the patients got the less help and advice to plan for the future they were given. On the other hand, it was also shown that when a patients' ECOG score increased (poorer function), the patients received more general information. This seems suggest that as patients' function decreases, the healthcare professional(s) managing the patients' illness focus more on giving more generic information around the patients' condition

and less information around assisting the patients and their families to plan for the future in light of their new emerging needs.

6.9.2 Psycho-Social Needs Correlation Analysis

Patients with cervical cancer have a number of psycho-social needs. A computed Pearson correlation between a number of these psycho-social needs demonstrated a number of significant findings.

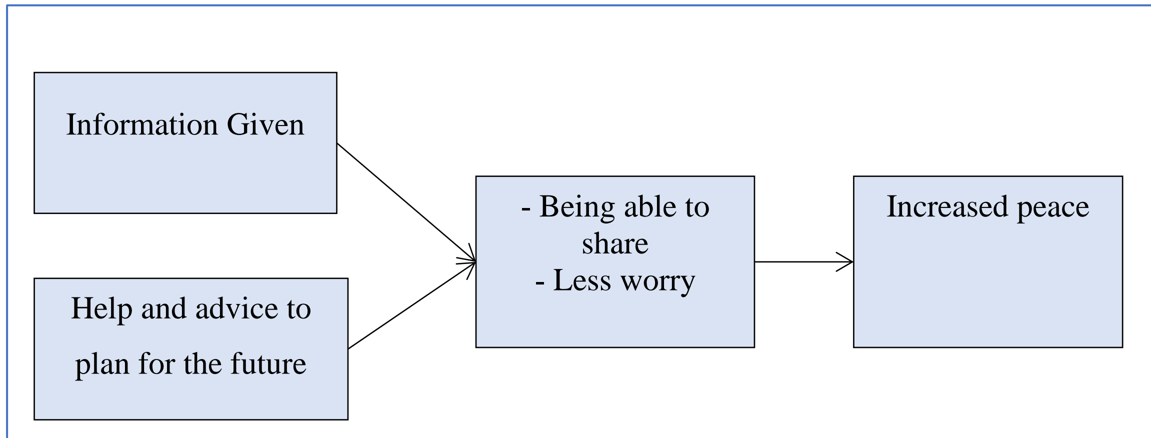
The results indicate a statistically significant negative correlation between worry and being at peace. This demonstrated that the more worried patients became over their illness, the less peace they experienced. Also, an analysis between being able to share and being at peace showed a positive correlation, indicating that the more patients were able to share their struggles with others close to them, the more at peace they became. There was also a positive correlation between being given help and advice to plan for the future and life being worthwhile. This demonstrated that the more specific assistance patients received to plan for their changing needs the more they viewed life as being worthwhile.

In the clinical context, information is provided to patients and their families on a continuous basis. Results in this study demonstrated that when patients were given more information around their illness, they were consequently able to share more with others. The giving of needed information was also associated with increased peace which suggests that the more patients know about their illness and what is happening the more they are at peace. In addition, an even stronger correlation was found between information transfer and help and advice to plan for the future. This may be suggesting that the more access to as much general information as the patients' need, the more this opens up further discussion around getting advice and planning for the future. This is echoed by Noh et al, who found that for patients who felt a need for information, their information-seeking behaviour increased (73). A healthcare worker's openness and willingness to share information to the quantity and quality needed is key in assisting to improve psycho-social needs of these patients.

This study has revealed the relationships between psycho-social needs and the antecedents of peace among cancer patients. The diagram below summarises the study's key findings. It shows that access to information contributes to planning for the future. The generic information given

by medical practitioners and help and advice to plan for the future enable the patients to share and worry less, which ultimately improves their peace.

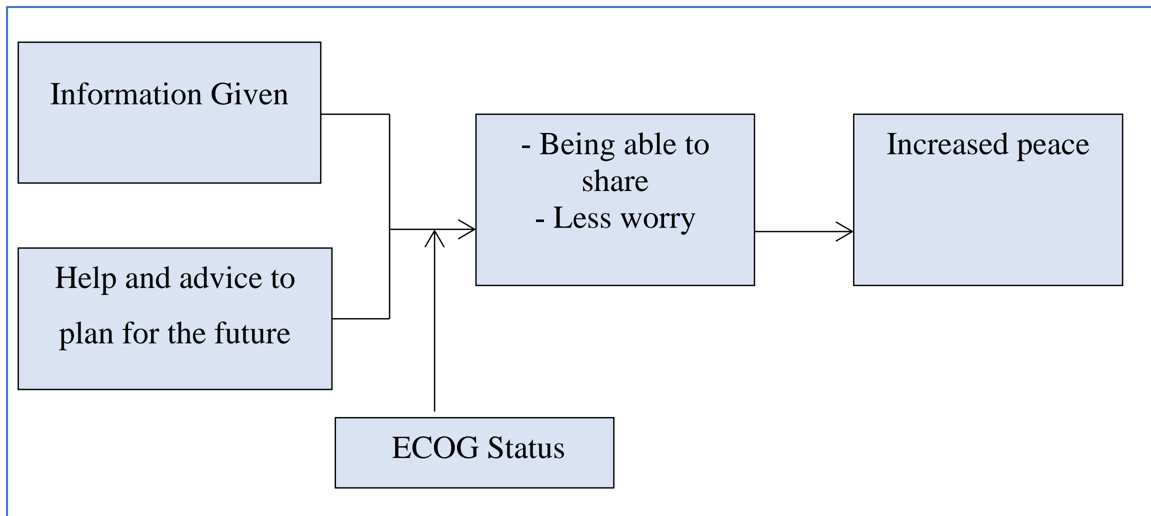
Figure 58: Relationships between Psycho-social Needs



Source: Author's own

Building on the previous section discussions, 6.9.2, it was shown that the increasing ECOG status reduce the patient's ability to share, they worry more and tend to not be a peace. The findings suggest that the status of ECOG may serve a moderator of the relationship between being able to share and worry, and peace. Thus, the reduced functionality weakens the relationship between being able to share and peace. The limitation of the study is that the full moderation analysis was not computed due to data challenges. Future research as suggested below, could focus more on unpacking the moderation effect of ECOG status. The model then becomes:

Figure 59: Relationships between ECOG and Psycho-social Needs



Source: Author's own

These suggested models based on the results can be explored in future research to unpack the interaction between ECOG and psycho-social needs. Such studies could develop hypotheses based on the model, which can be tested quantitatively.

6.9.3 Spiritual Needs Correlation Analysis

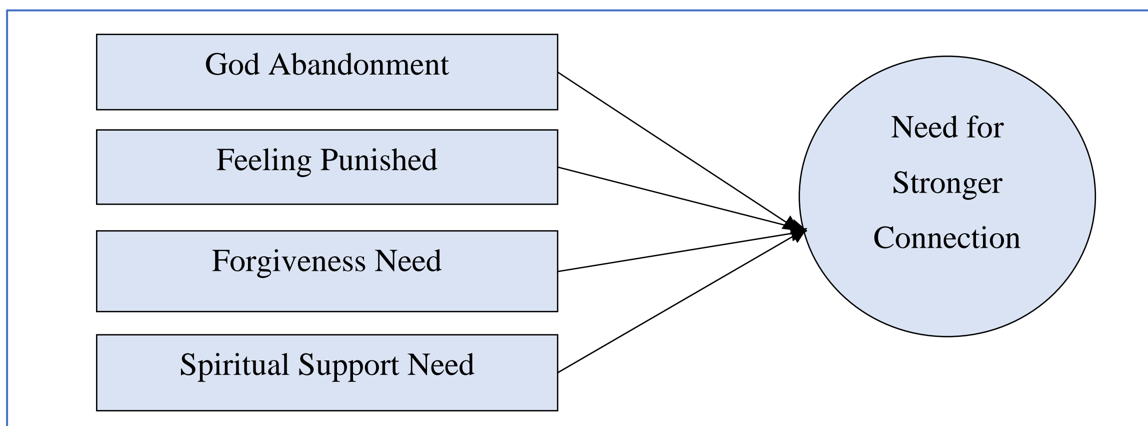
With the spiritual needs analysis, a common theme that emerged was that of connection and the need to strengthen it. It became evident, because of the statistically significant correlations, that the feeling of seeing the illness as a form of punishment from a higher being, the feeling of being abandoned by God, the need for forgiveness and the need for spiritual support all are associated with an increased desire for a stronger connection with God or a higher being perhaps as a remedy for these spiritual needs.

The results showed that the more the patients felt abandoned by God, the greater their need for a stronger connection with the same God. Also, the greater the feeling of punishment patients experienced the more they felt wanting to connect deeper with God. Similar results showed that the greater the need for forgiveness patients experienced, the greater their need was for a stronger connection with God. Another positive correlation was found between a need for increased spiritual support and a stronger connection to a higher being. These results seem to suggest that suffering and spiritual challenges in the form of feeling abandoned and punished by God and having an increased need to be forgiven for past mistakes all seem to increasing a desire to connect even deeper with God or a higher being than being pushed push from God.

Another significant spiritual correlation analysis finding was a very strong, statistically significant, positive correlation between feeling abandoned by God and seeing that as a way of being punished by God. This was the strongest correlation and further highlights the great need for connection to a higher being that these patients have when diagnosed with cervical cancer. This feeling of abandonment and subsequent view that it is because one is being punished, creates an existential void and crisis that may lead to depressive symptoms, irrespective of religious background (74). The need to manage these issues, as part of the patient's clinical care, is critical and should be paid attention to because of their impact on the patient's connection to their higher being and source of strength.

The diagram below presents the summary of the spiritual needs. Another contribution emanating from the study is that it revealed the factors that predicts connection with God among cancer patients. These factors can be tested in future quantitative studies using regression.

Figure 60: Antecedents of Need for Connection



Source: Author's own

6.10 The Attribution Theory

Fritz proposed the attribution theory which a social psychology theory that deals with how people relate and make sense of their social world and involves how individuals interpret events in their lives and how these interpretations affect their thinking and behaviour (75). In this case, the patients would partially externally attribute the causality of their suffering and illness experience to an outside factor such a higher being. The perception is that one has no choice and no control. A number of patients in the study have expressed that they view their past mistakes as contributory factors to them having cancer as evidenced by the increased need for

forgiveness for these past transgressions. This is defined as internal attribution (75). How a patient attributes causality in the midst of their illness becomes an important factor to further explore in the management of their spiritual needs and struggles.

6.11 Conclusion

Severe pain was the most common and significant distressing symptom that the patients experienced and cervical cancer is known to be a common cause of pain amongst women.
HIV is also a contributory factor towards patients being more likely to develop cervical cancer and also have it at a younger age than those who are HIV Negative. There is a high burden of cervical disease and added symptom burden in the HIV positive female population. The presence of the tumour leads to an increased inflammatory state, significant electrolyte disturbances and possible metabolic acidosis which can all lead usher in a number of symptoms that consequently add to the symptom burden.

In addition to physical struggles, cervical cancer patients also experience spiritual distress that seem to increase a desire for connection to a higher being rather than pushing them away. Feelings of being abandoned and punished by God together with an increased need for forgiveness for past mistakes seem to correlated positively with an increased need to connect deeper with God. Those who felt abandoned by a higher being, also saw this as a form of punishment by God for past "sins".

It is also clear that the more worried patients became over their illness, the less peace they experienced and the more these patients were able to share their struggles with others close to them, the more at peace they became. There is also positive correlation between being given help and advice to specifically plan for the future and patients subsequently seeing life as being worthwhile. The more patients knew about their illness and what is happening the more they became at peace and an increased access to as much general information as the patients' need, was a driver that seems to open up further discussion around getting specific advice and planning for the future.

CHAPTER 7

CONCLUSION

7.1 Introduction

The aim of this study was to describe and provide an analysis of palliative care needs that exist in patients diagnosed with cervical cancer in two hospitals in Gauteng. These patients have a number of multi-dimensional needs which contribute to their total pain. The concept of total pain acknowledges that patients who have serious illnesses suffer because of physical, psycho-social and spiritual sources of pain and suffering. This study was able to outline the needs that cervical cancer patients have in all these different components of total pain.

This cross sectional, retrospective analysis included 138 patients all histologically confirmed to have a diagnosis of cervical cancer. Their needs were extensively documented in the results chapter (Chapter 4) and further discussed in the discussion chapter (Chapter 5). The study objectives were all met.

7.2 Physical / Biomedical Profiles

It .was demonstrated that cervical cancer patients experience a number of physical issues ranging from significant pain, distressing symptoms concomitant comorbid medical conditions and biochemical derangements. It was also shown that patients mostly present already having advance disease which has implication not only for treatment but also for their illness experience and burden. The patients' level of function was also greatly affected by the illness and that too, comes with its own share of struggles and suffering.

7.3 Spiritual Needs

One cannot separate spirituality from a patient's illness experience as this is the lens through which they interpret, analyse and cope with their disease. This study has shown how cervical cancer patients experience a lot of spiritual struggles which impact their quality of life. These patients have a great need for reconnection with God or a higher being. Issues of abandonment, punishment, forgiveness, spiritual community and spiritual support have an important influence on the patients' spiritual experience and pain.

7.4 Psycho-Social Needs

Cervical cancer is not only a physical disease but it's presence also ushers in a great of psychological and social needs. These patients experience enormous worry as a result of their illness. This worry and other psycho-social sufferings don't seem to negatively impact the patients' sense of peace and their feeling of life being worthwhile. They are also in need of social and emotional support from close family members and have significant information needs around their illness and around helping them plan for their future.

A number of these issues have a significant impact on each other that needs to explored with each individual patient in order to properly and holistically manage them.

7.5 Limitations of the Study

The fact that the study was a retrospective analysis of primary data was a great limitation. A number of different healthcare professionals were also involved in the collection of the primary data and this could have had a great influence on the way the data was collected. As the researcher of a retrospective data analysis, one is very limited only to the information that is already available and cannot raised issues further in the current study.

A cross sectional, retrospective analysis study is an observational study that analyses data from a specific population at a single point in time only (76). It is therefore difficult to make a causal inference as both exposure and outcome are examined at the same time, some associations were difficult to interpret and the study was susceptible to a number of biases such as non-response and recall bias. Some of the study findings may hence not be generalizable beyond the study settings but provide valuable data nonetheless.

7.6 Implications

Palliative care is a fairly young discipline in South Africa and certainly Africa. Most of the available research is primarily from the west and high-income countries. Though the body of research from lower income countries is increasing, we are still very behind from the rest of the world. This research will add to the body of knowledge in this field and has highlighted a number of issues to stimulate further research. This study also highlighted various issues that health professionals should explore for and be aware of when managing these patients. It is another aim of this study to attempt to influence the practice of caring for patients diagnosed with cervical cancer, especially in the context of main stream medicine and healthcare and

hopefully impact policy and total pain management recommendations for patients with cervical cancer.

7.7 Recommendations for Further Studies

This study, because of its retrospective nature, was limited and a number of issues could not be explored further. A number of specific recommendations were discussed in chapter 5. More work needs to be done to explore much further these physical, spiritual, psychological and social unmet needs that these patients have.

Firstly, anaemia and pain have come up as very significant clinical issues in these patients. It appears that the type of anaemia experienced is iron deficiency. In light of very few patients having iron studies done, one cannot draw definitive conclusions. More research needs to be done to ascertain the type of anaemia experienced by this group of patients and also the extent of iron deficiency in the presence of a normal haemoglobin level. It is hypothesised that the nature of pain in cervical cancer is not just nociceptive in nature but also includes a strong neuropathic component too but little research exists on this issue and recommend for more research around this important topic. It is also recommended for more research to be done exploring the extent of metabolic acidosis and tumour lysis syndrome in cervical cancer and these conditions may be significant additions to the patient symptom burden.

Secondly, these patients have expressed a great deal of spiritual suffering. It is interesting that despite this level of distress, majority of them did not feel abandoned by God nor did they see the disease as God’s way of punishing them. Instead, they had a desire to connect deeper with God rather than losing their faith as some literature suggests is what happens. More qualitative research needs to be in our context to explore further what are the things that make our patients feel and respond this so we can understand better how they find meaning and make spiritual sense of their suffering.

Lastly, patients in the study have shown enormous worry in addition to their suffering. Of interest, is that despite this level of distress, 93.5% still view life as being worthwhile and 82.6% continued to feel peace. One would have expected the opposite and these results suggest that there are probably other factors at play that lead to patients responding to their challenges in this manner. It would be useful to explore these underlying factors further in future studies.

7.8 Plan for Dissemination of Findings

The research findings will be reported back to the Centre of excellence for palliative care at Chris Hani Baragwanath Academic hospital and to the department of Obstetrics and Gynaecology at Sebokeng Regional hospital. The findings will also be presented at relevant conferences and published in the form of peer review articles.

7.9 Conclusion

This research study highlighted that indeed cervical cancer patients have a number of significant palliative care needs that need to be paid attention when treating them. These needs are multi-dimensional in nature and some may be complex. The management of these patients requires an interdisciplinary approach and an involvement of multiple team members (including family) to adequately respond to their needs.

Dame Cicely Saunders said: "Suffering is only intolerable when nobody cares". May this research and its finding stimulate more conversations on how we, as custodians of care for the most vulnerable people, can care even better for our patients and their families.

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APPENDICES

Appendix A: Data Collection Tool

The Gauteng Centre for Palliative Care Consultation Form

Palliative Care Initial Consultation Form

Start Time: ____________________

Sex: **Race:**

☐ Male ☐ Black ☐ Coloured ☐ Other: Specify ________________

☐ Female ☐ White ☐ Indian

Age: _____

Date of referral: _________________ Referred by: _______________

Date of Hospital admission: _________________ Date of the initial visit: ___________

Patient not enrolled Died ☐ Date of Death: _____________ Place: ____________

Discharged ☐ Date of Discharge: ___________________ Declined the servi... ☐

Referred from:

○ Medical ward ○ Medical OPD ○ Clinic

○ Surgical ward ○ Surgical OPD ○ NGO

○ Paeds ○ Paeds OPD ○ Self/friend/family

○ Psychiatry ○ ARV clinic ○ other

○ O&G ○ Gynae OPD ○ OPD Palliative care

○ Oncology Meeting ○ Community health care worker

DIAGNOSIS (List, if necessary, with dates)

Diagnosis 1: ____ **ICD 10** ______

Diagnosis 2:____________________HIV Status Positive ☐ Negative ☐ Unknown ☐

Is the patient on HAART Yes ☐ No ☐

Latest CD4 count results __________________

Diagnosis 3:______________________ TB Diagnosis Yes ☐ No ☐ Unknown ☐

If No or Unknown have you screened the patient Yes ☐ No ☐

If Yes is the patient a TB suspect Yes ☐ No ☐

History obtained from: ☐ Relative ☐ Health Professional ☐ Patient's file ☐ Friend ☐ Self

Relevant History:	**Allergies:**
	Current: Medication

Place of Consultation: Team Member: ___________________

Hospital	Palliative Clinic	Home	Telephonic	Other

Outcome:

Consultation Done	Patient Unavailable	Patient Demised	Patient Declined	Bereavement	Family Consultation

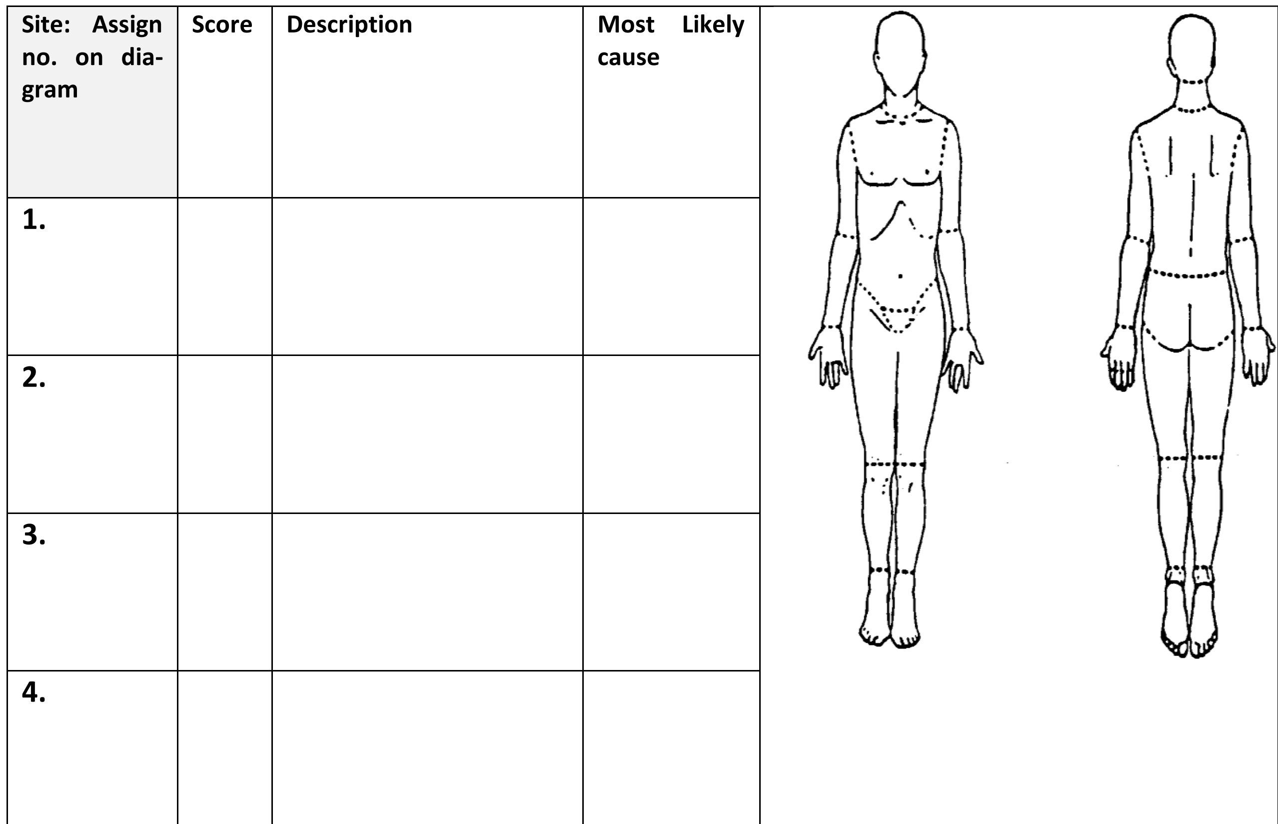
ECOG Scale

1	2	3	4	5

Examination (Relevant Signs)

Pain

Site: Assign no. on diagram	Score	Description	Most Likely cause
1.			
2.			
3.			
4.			



Psychosocial: Family tree and social circumstances

THE PALLIATIVE CARE OUTCOME SCALE (POS)

ASK THE PATIENT	POSSIBLE RESPONSES	Response
Q1. Please rate your pain (from 0 = no pain to 5 = worst/ overwhelming pain) during the last 3 days	0 (no pain) -5(worst/overwhelming pain	
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days)	0 (not at all) -5 over whelming)	
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) -5(overwhelming worry)	
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) -5 (Yes, I've talked freely)	
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) -5(Yes, all the time)	
Q6. Over the past 3 days have you felt at peace?	0 (no, not at all) -5 (Yes , all the time)	
Q7. Have you had enough help and advice for your family to plan for the future?	0 (no, not at all) -5 (as much as wanted)	
Q8. How much information have you and your family been given?	0 (none) -5 (as much as wanted) N/A	
Q9. How confident does the family feel caring for _____?	0 (not at all) -5 (very confident) N/A	
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) -5 (severe worry) N/A	

Patient: Main Expectation	Family: Main Expectation

Spiritual:

Spiritual Beliefs:

Do you consider yourself spiritual ☐ Yes ☐ NO

Do you consider yourself religious ☐ Yes ☐ NO

Do you believe in God ☐ Yes ☐ NO

What is your religion ________________________

Spiritual Importance and Impact:

Have you been looking for a stronger connection with God ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Do you consider yourself spiritual ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Have you been wondering whether God has abandoned you ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Do you feel that the disease is God's way of punishing you ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Spiritual support:

Do you feel abandoned by your church/religious leader ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Have you been asking for forgiveness for "sins" ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Do you need s spiritual support ☐ Yes ☐ No ☐ Not sure Score 0 to 5 ☐

Management / Care Plan

1. Physical
2. Psychosocial/Emotional
3. Spiritual

Problem: List	Management	Review (Date)

End Time: __________

Appendix B: The Motivation for Expedited Review of A Retrospective Data Analysis

Motivation for Expedited Review

July 27, 2021

The Human Research Ethics Committee

E 53, Room 46

Old Main Building

Groote Schuur Hospital, Observatory

Dear Sirs / Madams

Covid 19 has presented enormous challenges to the research process. With the current restrictions and subsequent anticipated challenges with meeting the required sample size for the study, a decision was made to reconsider my research study design from a prospective study to a retrospective data analysis to allow for the completion of the degree. There was also a great challenge experienced with the online academic registration process for 2021 which was only eventually processed on 23rd June 2021. This led to a great loss of research time. A request is hereby made for an expedited review to allow for the opportunity to start with the data collection at the earliest possible time so one has the adequate time needed to submit the completed thesis by the end of the current academic year.

My research study is entitled "A Retrospective Cross-Sectional Analysis of Palliative Care Needs and Interventions in patients with Cervical Cancer in a Palliative Care unit in Soweto, Johannesburg". This project involves the collection and study of existing patient records and this information will be recorded in such a way that the patients' confidentiality is protected as all identifying data will not be recorded thus ensuring that subjects cannot be identified, directly or through identifiers linked to the data. The collection, analysis and reporting of this data will not be damaging to the patients in terms of financial standing, employability, insurability, reputation or stigmatisation. The research project carries minimal risk and appropriate protections (outlined in the protocol) will be implemented so the risks related to invasion of privacy and breach of confidentiality are no greater than minimal.

Should you have any questions or concerns, kindly contact me at msobekwa@gmail.com or +27 82 773 4003.

Yours Sincerely,

Mfanelo A. Sobekwa, Study Investigator

SBKMFA001

Appendix C: The Motivation for the waiver of Consent

Motivation for a waiver of consent for conducting a retrospective record review

a) The research involves no more than minimal risk to the subject.

All the patients that will form part of this retrospective review of medical records have undergone specific treatment and management and I will, in no way, have any interaction with them nor will I have any impact on their continual access to care. This study, in its entire process, carries no greater than minimal risk to the study population.

b) The rights and welfare of subjects will not be adversely affected.

As stated in the data collection process and analysis, in order to protect confidentiality the data will be recorded in REDCap on a password protected database on an encrypted file. In this database no identifying data will included and the patient's name and file number will be replaced with a unique study number. The data will also be analysed and reported on in a de-identified way. The records of this study will be stored on the investigator's identity authenticated, secure firewall protected persona computer. Only the investigator and research study supervisors will have access to this data at any given time.

c) The research could not practicably be carried out without the waiver or alteration.

Should consent be required in order to perform this study, it will not be practically possible to perform this research given the number of records needed to ensure valid data and to meet protocol objectives. It will also not be possible to get consent from many patients as most live outside Johannesburg as the Gauteng Centre for Palliative Care is a tertiary level referral centre of patients from all over Gauteng and neighbouring provinces. A significant number of patients would have either passed on or moved back to their rural homes or provinces. Following all these patients up to obtain consent (in addition to the covid restrictions that are in place) would not be practically possible. The investigator does not have contact nor any interaction with the patients whose records will be eligible for inclusion in the review, therefore there will be no opportunity to obtain written or verbal consent.

d) Whenever possible, the subject will be provided with additional pertinent information after they have participated in the study.

This will not be applicable for this research study as there is no interaction between study personnel and subjects but every effort will be every effort made to distribute study findings to the institution to aid in further policy development and improved patient care.

Appendix D: Letter of Authorisation to Conduct Research (Chris Hani Baragwanath Academic)

CHRIS HANI BARAGWANETH ACADEMIC HOSPITAL

Department of Internal Medicine

Gauteng Centre For Palliative Care

PO Bertsham

Tel number: (011) 933 0260/0264

January 15, 2020

Dr MA Sobekwa

PO Box 24040

Three Rivers East Vereeniging

1934

Dear Dr MA Sobekwa

Re: Permission to Conduct Research

This letter serves to inform you that the Gauteng Centre for Palliative Care Unit at Chris Hani Baragwanath Academic Hospital has reviewed, and supports, your research study titled "A Retrospective Cross-Sectional Analysis of Palliative Care Needs and Interventions in patients with Cervical Cancer in a Palliative Care unit in Soweto, Johannesburg". We are very interested in your efforts that may help improve our understanding and clinical care to our cervical cancer patients and are happy to provide a platform for you to conduct your research using our database and records of cervical cancer patients

If you have any questions or need further assistance, please contact me at 011 930 0049.

Warmest Regards

Dr MJA. Ratshikana-Moloko

Director of Gauteng Centre for Palliative Care

Appendix E: Letter of Authorisation to Conduct Research (Sebokeng Regional Hospital)

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Sebokeng Regional Hospital

Moshoeshoe street

Vanderbijlpark

1984

14 February 2020

Att: Dr MA Sobekwa

Re: "A Retrospective Cross-Sectional Analysis of Palliative Care Needs in Cervical Cancer patients in two hospitals in Gauteng"

Thank you for submitting your request to conduct the above titled study in our hospital. We have the pleasure to inform you that permission has been granted to proceed with your research. We trust that the research will benefit the hospital and contribute positively to patient care.

Should you need any assistance, please do not hesitate to contact us.

Regards

Signed by candidate

N Msibi

Snr Clinical Manager

Appendix F: Human Research Ethics Committee Approval Letter

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45, E-52- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

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16 November 2021

HREC REF: 610/2021

Dr E de Vries
Division of Family Medicine
Falmouth Building
Email: Elma.devries@westerncape.gov.za
Student: msobekwa@gmail.com

Dear Dr de Vries

PROJECT TITLE: A RETROSPECTIVE CROSS-SECTIONAL ANALYSIS OF PALLIATIVE CARE NEEDS AND INTERVENTIONS IN PATIENTS WITH CERVICAL CANCER IN A PALLIATIVE CARE UNIT IN SOWETO, JOHANNESBURG-MPIL CANDIDATE-DR MFANELO SOBEKWA

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020; 06 July 2020 & 01 July 2021.

Approval is granted for one year until the 30 November 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Dr Mfanelo Sobekwa will also be involved in this study.

Please quote the HREC REF 610/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

HREC/REF 610/2021sa

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC/REF 610/2021sa