QUALITY OF LIFE IN ZAMBIAN CERVICAL CANCER WOMEN POST CHEMO-RADIOThERAPY

BY

NCHEBE SINDAZA CHITASHI

A dissertation submitted in fulfilment of the requirements of the degree

MASTERS TECHNOLOGY DEGREE

RADIOGRAPHY (THERAPY)

in the

Department of Radiography

Faculty of Health Sciences

University of Johannesburg

Supervisor: Mrs Heather Lawrence

Co-supervisor: Dr Kennedy Lishimpi
ACKNOWLEDGEMENTS

This thesis could not have been completed without the support and encouragement of my family and beloved children Mable E and Choolwe Chitashi. I appreciate my children for their maturity, patience and love. I am indebted to the professional expertise and support provided by my supervisor, Mrs H. Lawrence, and co-supervisor, Dr. K Lishimpi. I also gratefully acknowledge the contributions of the following persons:

- Mr Clement Mwakamui for the statistical analysis
- Dr C. Mwaba, Dr L. Banda, Dr A. Noosery and Dr S.C. Msadabwe for the clinical advice and support during the data collection
- Sister Sofai Ntinga who assisted in the data collection
- The radiotherapy staff

I especially owe much to my director, Dr G. Syakantu. Throughout my study period, he granted me time to conduct and complete my project.
ABSTRACT

Cervical cancer is the most frequently diagnosed cancer among women in Zambia. More recently, improved cure rates have been obtained with the concomitant use of radiotherapy and chemotherapy in locally advanced cancer of the cervix. However, the side effects associated with the treatment have a major impact on the quality of life (QoL) of these women. Prior to this study, QoL in Zambian women treated for cervical cancer with chemo-radiation had not been assessed thus creating a gap in the literature and hampering an attempt to improve QoL in this cohort of patients.

The aim of this study was therefore to evaluate the impact of chemo-radiation treatment on QoL and to determine what socioeconomic and demographic factors are closely related with QoL decrements in Zambian women treated for cervical cancer at Cancer Diseases Hospital. This would then facilitate the introduction of intervention programmes aimed at improving QoL in these patients.

The study was prospective and explored the phenomenon of QoL with the use of the European Organization for Research and Treatment of Cancer (EORTC) questionnaire and a demographics questionnaire answered by 45 women treated for cervical cancer with chemo-radiotherapy at Cancer Diseases Hospital. The use of the EORTC quality of life questionnaire added validity and reliability to the
study as it is used extensively to measure health-related quality of life in cancer survivors worldwide.

Analysis of the data indicates that patients with advanced cervical cancer treated with chemo-radiotherapy generally experienced a favourable QoL, and treatment was considered worthwhile by the majority of patients. However, women described problems with sexuality and marital relationships. Low education and living without a partner were depicted as risk factors for the development of the reported problems.

To improve QoL in survivors, interventions focusing on more social support, education to improve patients’ understanding of their disease and treatment effects as well as physical rehabilitation through exercise interventions are recommended as mandatory.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>i</td>
</tr>
<tr>
<td>Abstract</td>
<td>iii</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>v</td>
</tr>
<tr>
<td>List of Tables</td>
<td>x</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xiii</td>
</tr>
<tr>
<td>List of Annexures</td>
<td>xiv</td>
</tr>
<tr>
<td>Abbreviations, Acronyms and Symbols</td>
<td>xv</td>
</tr>
</tbody>
</table>

---

# TABLE OF CONTENTS

## CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION 1

1.2 DESCRIPTION OF CERVICAL CANCER 1

1.3 CERVICAL CANCER STAGING 2

1.4 TREATMENT AND PROGNOSIS 4

1.5 TREATMENT PROTOCOL FOR LOCALLY ADVANCED CERVICAL CANCER AT CDH 5

1.5.1 RADIOTHERAPY 5

1.5.2 CHEMOTHERAPY 9

1.6 QUALITY OF LIFE 11

1.7 BACKGROUND AND RATIONALE OF THE STUDY 13

1.8 RESEARCH PROBLEM 14
1.9 RESEARCH AIM AND OBJECTIVES 15
1.9.1 AIM 15
1.9.2 OBJECTIVES 15
1.10 OUTLINE OF CHAPTERS 16
1.11 CONCLUSION 17
1.12 DEFINITION OF KEY CONCEPTS AND ABBREVIATIONS 18

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION 20

2.2 PREVALENCE OF CANCER OF THE CERVIX 20
2.3 TREATMENT AND TREATMENT OUTCOMES 24
2.4 LATE SIDE EFFECTS OF CHEMO-RADIOThERAPY 29
2.4.1 GASTROINTESTINAL (GIT) TOXICITY 29
2.4.2 SEXUAL MORBIDITY 33
2.4.3 FEMALE REPRODUCTIVE TRACT TOXICITY 36
2.4.4 GENITOURINARY TOXICITY 37
2.4.5 OTHER COMPLICATIONS 39
2.5 DEFINITION OF QUALITY OF LIFE 40
2.6 QUALITY OF LIFE AND CERVIX CANCER 42
2.6.1 PHYSICAL WELL-BEING 43
2.6.2 PSYCHOLOGICAL AND SOCIAL WELL-BEING 46
2.7 INTERVENTION PROGRAMMES 53
2.8 CONCLUSION

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

3.2 RESEARCH DESIGN

3.2.1 DESCRIPTIVE RESEARCH

3.2.2 CONTEXTUAL DESIGN

3.3 METHODS AND MATERIALS

3.3.1 DATA COLLECTION TOOL

3.3.2 THE PILOT STUDY

3.3.3 DATA COLLECTION PROCEDURE

3.3.3.1 SELECTION OF PATIENTS

3.3.3.2 PROCEDURE

3.3.3.3 THE DATA

3.4 DATA ANALYSIS

3.5 VALIDITY AND RELIABILITY OF RESEARCH PROCESS

3.6 ETHICAL CONSIDERATIONS

3.7 CONCLUSION

CHAPTER 4: RESULTS OF THE STUDY

4.1 INTRODUCTION

4.2 RESPONDENTS’ CHARACTERISTICS

4.2.1 STAGE OF DISEASE FOR RESPONDENTS
4.3 SOCIODEMOGRAPHIC DATA

4.3.1 AGE

4.3.2 MARITAL STATUS

4.3.3 LEVEL OF EDUCATION

4.3.4 OCCUPATIONAL STATUS

4.3.5 INCOME

4.4 SIDE EFFECTS OF CHEMO-RADIATION THERAPY 12 MONTHS POST TREATMENT

4.5 QUALITY OF LIFE

4.5.1 PHYSICAL WELL-BEING

4.5.2 SOCIAL WELL-BEING

4.5.3 EMOTIONAL WELL-BEING

4.5.4 FUNCTIONAL WELL-BEING

4.5.5 ADDITIONAL CONCERNS

4.6 CONCLUSION

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

5.2 QUALITY OF LIFE

5.2.1 PHYSICAL WELL-BEING

5.2.2 SOCIAL WELL-BEING

5.2.3 EMOTIONAL WELL-BEING
5.2.4 FUNCTIONAL WELL-BEING 102
5.2.5 GENERAL QoL 104
5.3 CHEMORADIOThERAPY TOXICITY 105
5.4 CONCLUSION 107

CHAPTER 6: RECOMMENDATIONS

6.1 INTRODUCTION 108
6.2 RECOMMENDATIONS FOR INTERVENTION PROGRAMMES FOR IMPROVED QUALITY OF LIFE 108
6.2.1 EDUCATION INTERVENTION PROGRAMME 108
6.2.2 EXERCISE INTERVENTION PROGRAMME 110
6.2.3 INTRODUCTION OF SPECIAL STRATEGIES AND SERVICES FOR PATIENTS AND FAMILIES 111
6.3 LIMITATIONS OF THE STUDY 112
6.4 RECOMMENDATION FOR FUTURE 113
6.5 CONCLUSION 114

LIST OF REFERENCES 115
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table Number</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLE 1.1</td>
<td>Cervical cancer FIGO staging</td>
<td>2</td>
</tr>
<tr>
<td>TABLE 1.2</td>
<td>Trials of concurrent chemotherapy with radiation in cancer of the cervix</td>
<td>10</td>
</tr>
<tr>
<td>TABLE 2.1</td>
<td>Incidence of cancer of the cervix in Zambia, Eastern Africa and the world</td>
<td>22</td>
</tr>
<tr>
<td>TABLE 2.2</td>
<td>Mortality of cancer of the cervix in Zambia, Eastern Africa and the world</td>
<td>2</td>
</tr>
<tr>
<td>TABLE 2.3</td>
<td>Trials of concurrent chemotherapy with radiation in cancer of the cervix</td>
<td>27</td>
</tr>
<tr>
<td>TABLE 2.4</td>
<td>Studies that used HRQoL instrument to measure the outcomes of women treated for gynaecologic cancer</td>
<td>41</td>
</tr>
<tr>
<td>TABLE 4.1</td>
<td>Frequency distribution of respondents by disease</td>
<td>71</td>
</tr>
<tr>
<td>TABLE 4.2</td>
<td>Late toxicity of chemo-radiotherapy 12 months post treatment</td>
<td>76</td>
</tr>
<tr>
<td>TABLE 4.3</td>
<td>Effect of age on physical well-being before and after chemo-radiation</td>
<td>78</td>
</tr>
<tr>
<td>TABLE 4.4</td>
<td>Effect of marital status on physical well-being before and</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 4.5: Effect of occupational status on physical well-being before and after chemo-radiation

TABLE 4.6: Effect of education on physical well-being before and after chemo-radiation

TABLE 4.7: Effect of age on social well-being before and after chemo-radiation

TABLE 4.8: Effect of marital status on social well-being before and after chemo-radiation

TABLE 4.9: Effect of occupational status on social well-being before and after chemo-radiation

TABLE 4.10: Effect of educational status on social well-being before and after chemo-radiation

TABLE 4.11: Effect of age on emotional well-being before and after chemo-radiation

TABLE 4.12: Effect of marital status on emotional well-being items before and after chemo-radiation

TABLE 4.13: Effect of occupational status on emotional well-being before and after chemo-radiation

TABLE 4.14: Effect of educational status on emotional well-being items before and after chemo-radiation
TABLE 4.15: Effect of age on functional well-being before and after chemo-radiation

TABLE 4.16: Effect of marital status on functional well-being before and after chemo-radiation

TABLE 4.17: Effect of occupational status on functional well-being before and after chemo-radiation

TABLE 4.18: Effect of educational status on functional well-being before and after chemo-radiation
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIGURE 1.1:</td>
<td>AP/PA simulation film</td>
<td>7</td>
</tr>
<tr>
<td>FIGURE 1.2:</td>
<td>Lateral simulation film</td>
<td>8</td>
</tr>
<tr>
<td>FIGURE 2.1:</td>
<td>Incidences of cervical cancer in sub-Saharan African countries</td>
<td>21</td>
</tr>
<tr>
<td>FIGURE 4.1:</td>
<td>Frequency distribution of respondents by age</td>
<td>72</td>
</tr>
<tr>
<td>FIGURE 4.2:</td>
<td>Frequency distribution of respondents by marital status</td>
<td>73</td>
</tr>
<tr>
<td>FIGURE 4.3:</td>
<td>Frequency distribution of respondents by education level</td>
<td>74</td>
</tr>
<tr>
<td>FIGURE 4.4:</td>
<td>Frequency distribution of respondents by occupational status</td>
<td>75</td>
</tr>
</tbody>
</table>
# LIST OF ANNEXURES

<table>
<thead>
<tr>
<th>ANNEXURE 1</th>
<th>EORTC QLQ - 30</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANNEXURE 2</td>
<td>Demographic questionnaire</td>
</tr>
<tr>
<td>ANNEXURE 3</td>
<td>Permission letter to conduct research at Cancer Diseases Hospital - Zambia</td>
</tr>
<tr>
<td>ANNEXURE 4</td>
<td>Participants information and request to participate in a research study</td>
</tr>
<tr>
<td>ANNEXURE 5</td>
<td>Informed consent</td>
</tr>
<tr>
<td>ANNEXURE 6</td>
<td>Faculty of Health Sciences: HDC</td>
</tr>
<tr>
<td>ANNEXURE 7</td>
<td>Faculty of Health Sciences: AEC</td>
</tr>
</tbody>
</table>
**ABBREVIATIONS, ACRONYMS AND SYMBOL**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>EORTC</td>
<td>European Organization for Research and Treatment of Cancer</td>
</tr>
<tr>
<td>FIGO</td>
<td>International Federation of Gynaecology and Obstetrics</td>
</tr>
<tr>
<td>EBRT</td>
<td>External Beam Radiotherapy</td>
</tr>
<tr>
<td>HDR</td>
<td>High Dose Rate</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>GOG</td>
<td>Gynecologic Oncology Group</td>
</tr>
<tr>
<td>SWOG</td>
<td>South West Oncology group</td>
</tr>
<tr>
<td>RTOG</td>
<td>Radiation therapy oncology group</td>
</tr>
<tr>
<td>CDDP</td>
<td>Cisplatinum</td>
</tr>
<tr>
<td>5FU</td>
<td>5 Fluorouracil</td>
</tr>
<tr>
<td>PA</td>
<td>Postero-Anterior</td>
</tr>
<tr>
<td>AP</td>
<td>Antero-Posterior</td>
</tr>
<tr>
<td>CDH</td>
<td>Cancer Diseases Hospital</td>
</tr>
<tr>
<td>UTH</td>
<td>University Teaching Hospital</td>
</tr>
</tbody>
</table>
CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Cervical cancer is the second most common cancer in women and the leading cause of cancer death in the developing world (Choi, Kang, Kim, Kim, Huh, Lee, Kim, & Bae, 2008:204; Thomas, 2006:140). In Zambia cervical cancer is the most common cancer affecting women and accounts for 27.7% of all histologically proven cancers (National Cancer Registry, 2006). The total number of new patients seen at Cancer Diseases Hospital since the commencement of clinical operations in 2006 to date is 2431, and 28% of these are cervical cancers (Hospital Annual Report, 2008 and 1st quarter report, 2009) most of which are locally advanced. Probably the numbers reported underestimate the true incidence of the disease.

1.2 DESCRIPTION OF CERVICAL CANCER

Cervical cancers arise commonly from the cells of the transformation zone of the uterine cervix and start to proliferate disregarding all processes of cellular growth control. The cells in this zone, as a result of predisposing factors such as infections with human papilloma virus, multiple sexual partners, multi-parity and early onset of sexual intercourse, will transform from normal to dysplastic cells then in-situ carcinoma before developing into a clinical cancer of the cervix. This process can take anything from months to years. Currently, with the advent of HIV/AIDS this process of transformation from the in-situ component to the malignant form is much shorter, sometimes less than five years. This means that all HIV-positive women should be screened for cancer of the cervix when diagnosed with HIV. A Pap smear
will usually find these abnormal cells and a biopsy will then confirm the presence of a malignant lesion. Later, cancer cells start to grow, contiguously spreading to the deep tissues of the cervix and to surrounding structures and ultimately sending cancer cells to distant organs. If not treated, carcinoma of the cervix is uniformly fatal (Ellerbrock, Chaisson, Bush, Sun, Sawo, Brudney & Wright, 2000:1031).

1.3 CERVICAL CANCER STAGING

The process of finding out how far the cancer has spread is called staging. Information is gathered from clinical examination and diagnostic tests to determine the size of the tumour, how deep the tumour has invaded tissues within and around the cervix, and the spread to lymph nodes or distant organs (metastasis). Staging ensures that the correct and optimal treatment option is selected for each patient (http://www.gyncancer.com/cervix.html).

Cervical cancer is staged using the FIGO (International Federation of Gynaecology and Obstetrics) system of staging as shown in Table 1.1 below.

Table 1.1 Cervical cancer FIGO staging

<table>
<thead>
<tr>
<th>Stage 0</th>
<th>Carcinoma in situ.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I</td>
<td>Cervical carcinoma confined to the cervix.</td>
</tr>
<tr>
<td>Stage IA</td>
<td>This is the earliest form of stage I. There is a very small amount of cancer, and it can be seen only under a microscope.</td>
</tr>
<tr>
<td>Stage IA1</td>
<td>The area of invasion is less than 3 mm deep and less</td>
</tr>
<tr>
<td>Stage</td>
<td>Description</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Stage IA2</td>
<td>The area of invasion is between 3 mm and 5 mm deep and less than 7 mm wide.</td>
</tr>
<tr>
<td>Stage IB</td>
<td>This stage includes Stage I cancers that can be seen without a microscope. This stage also includes cancers that can only be seen with a microscope if they have spread deeper than 5 mm into the connective tissue of the cervix or are wider than 7 mm.</td>
</tr>
<tr>
<td>Stage IB1</td>
<td>The cancer can be seen but it is not larger than 4 cm.</td>
</tr>
<tr>
<td>Stage IB2</td>
<td>The cancer can be seen and is larger than 4 cm.</td>
</tr>
<tr>
<td>Stage II</td>
<td>In this stage, the cancer has grown beyond the cervix and uterus, but hasn’t spread to the walls of the pelvis or the lower third of the vagina.</td>
</tr>
<tr>
<td>Stage IIA</td>
<td>The cancer has not spread into the tissues next to the cervix (called the parametria). The cancer may have grown into the upper part of the vagina.</td>
</tr>
<tr>
<td>Stage IIB</td>
<td>Tumour with parametrial invasion.</td>
</tr>
<tr>
<td>Stage III</td>
<td>The cancer has spread to the lower part of the vagina or the pelvic wall. The cancer may be blocking the ureters causing hydronephrosis.</td>
</tr>
<tr>
<td>Stage IIIA</td>
<td>The cancer has spread to the lower third of the vagina but not to the pelvic wall.</td>
</tr>
<tr>
<td>Stage IIIB</td>
<td>The cancer has grown into the pelvic wall. If the tumour has blocked the ureters (hydronephrosis) it is</td>
</tr>
</tbody>
</table>
Stage IV

This is the most advanced stage of cervical cancer. The cancer has spread to nearby organs or other parts of the body.

Stage IVA

The cancer has spread to the bladder or rectum, or extends beyond the true pelvis.

Stage IVB:

The cancer has spread to distant organs beyond the pelvic area, such as the lungs.

As can be seen from Table 1.1, this system classifies the disease in stages 0 through IV. It is based on clinical staging rather than surgical staging. It utilizes clinical examination and investigations such as chest x-ray, intravenous pyelogram, ultrasonography of the abdomen with or without cystoscopy (Rubin, 2001:465).

1.4 TREATMENT AND PROGNOSIS

In general, very high doses of radiation, which exceed the normal tissue tolerances, are needed to cure locally advanced cancer of the cervix (FIGO stage IB – IVA). Radiotherapy, when it is the sole treatment, fails to control the progression of locally advanced cervical cancer in 35% to 90% of women (Rose, Bundy, Watkins, Thigpen, Deppe, & Maiman, 1999:1144). However, the management of cancer of the cervix is greatly enhanced by the use of high dose rate intracavitary brachytherapy (Nag, Erickson, Thomadsen, Orton, Demanes, & Petereit, 2000:201).
The rationale for combining chemotherapy with radiation is to eradicate systemic micro-metastases, which are not treated by local radiation. In addition, cisplatin-based chemotherapy, used in conjunction with radiation, may inhibit the repair of radiation-induced sub-lethal damage and may sensitize hypoxic cells to radiation damage therefore improving the local control and overall survival of these patients (Rose et al. 1999:1144).

The literature today refers to large randomized clinical trials of concomitant chemoradiation using cisplatin-based regimens to define the current gold standard of care for locally advanced cervical cancer (Uno, Mitsuhshi, Isobe, Yamamoto, Kawakami, Ueno, Usui, Tate, Kawata & Ito, 2008:18). The five-year survival rates are 80%, 65%, 40%, and <20% for stages IB bulky, IIB, III, and IV respectively, after treatment with concurrent chemo-radiotherapy (Bradley et al. 2006:479).

1.5 TREATMENT PROTOCOL FOR LOCALLY ADVANCED CERVICAL CANCER AT CDH

All patients undergo staging using FIGO (International Federation of Gynecology and Obstetrics) criteria.

1.5.1 Radiotherapy

External beam radiotherapy (EBRT) is administered to a clinical target volume that includes the primary cancer, uterus, internal iliac, presacral, external iliac and lower common iliac lymph nodes. Patients with stages IB2, IIA and IIB lesions receive 46 Gy external beam therapy delivered homogeneously to the pelvis five days/week in
23 fractions at 2 Gy per fraction. High dose rate brachytherapy is given at 6.5 Gy x 4 fractions to supplement the EBRT.

Patients with stage IIB distal (outer half of parametria involved), IIIA and IIIB early, receive 50 Gy in 25 fractions at 2 Gy per fraction five days per week plus HDR brachytherapy 8 Gy x 3 fractions.

For EBRT an AP – PA or “four field box technique” is used depending on the AP separation and weight of the patient (see figures 1.1 and 1.2 below):
Figure 1.1 AP-PA simulation film
Figure 1.2 Lateral simulation film

a) Lower border for anterior and posterior fields
   - Bottom of ischial tuberosity
   - If the lower third of the vagina is involved, this is marked and the lower border of the field is placed 2 cm below the mark (Figure 1.1)

b) Upper border for anterior and posterior fields – Mid L5 (Figure 1.1)

c) Lateral borders 1.5 – 2 cm beyond pelvic rim, unless the lower ⅔ of the vagina is involved. Inguinal nodes treated to beyond acetabulum margin (Figure 1.1)

d) Posterior margin for lateral fields (Figure 1.2)
   - IB2 – IIB proximal – bottom S3
   - IIB distal (outer half of parametria involved) – IIIB entire anterior sacrum
e) Anterior margin lateral fields (Figure 1.2)

- top of pubic symphysis

The entire treatment period is completed in six to seven weeks. High dose rate brachytherapy is given concurrently during the final weeks of external beam, and not on the same day with chemotherapy.

This improved therapeutic approach has increased the number of women surviving cervical cancer. However, the side effects associated with the treatment have a major impact on the quality of life (QoL) of these women (Bergmark, Lundqvist, Dickman, Henningsohn, & Steineck, 2002:1448). Until recently, treatment for gynaecologic malignancies has focused almost exclusively on prolongation of life, and few studies have adequately addressed issues related to QoL (Pearman, 2003:2).

1.5.2 Chemotherapy

The chemotherapy protocol used at CDH is modified from the five randomized trials of treating locally advanced cancer of the cervix with cisplatinum-based chemoradiation as shown in Table 1.2 below.
Table 1.2 Trials of concurrent chemotherapy with radiation in cancer of the cervix

<table>
<thead>
<tr>
<th>Trial</th>
<th>N</th>
<th>Stage</th>
<th>Treatment</th>
<th>Overall survival (3-year) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whitney et al. GOG 85</td>
<td>368</td>
<td>IIB – IVA</td>
<td>CDDP + 5FU</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>H U</td>
<td>57</td>
</tr>
<tr>
<td>Rose et al. GOG 120</td>
<td>526</td>
<td>IIB – IVA</td>
<td>CDDP</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>CDDP+5FU+HU</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>H U</td>
<td>47</td>
</tr>
<tr>
<td>Keys et al. GOG 123</td>
<td>369</td>
<td>Stage IB (Bulky)</td>
<td>CDDP</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>74</td>
</tr>
<tr>
<td>Morris et al. RTOG 9001</td>
<td>403</td>
<td>IIB – IVA</td>
<td>CDDP + 5FU</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>63</td>
</tr>
<tr>
<td>Peters et al. SWOG 8797</td>
<td>243</td>
<td>IA₂ – IIA</td>
<td>CDDP + 5FU</td>
<td>87</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>77</td>
</tr>
</tbody>
</table>

Patients with stage IB₂ – IVA disease are given cisplatinum 80mg/m² IV on day 1 of starting radiotherapy repeated every 21 days through the course of radiotherapy. The creatinine clearance is calculated and only patients with values of 60 and above
receive the chemotherapy with 1 liter normal saline for prehydration; then 16mg of
dexamethasone IV and 100mg dalasentrone IV bolus injections are given to prevent
emesis. The cisplatinum is given with 1 liter normal saline to which one ampoule of
potassium chloride, magnesium sulphate and calcium gluconate is added and
infused over 3 – 4 hours. Post this infusion another liter of normal saline is given with
an oral antiemetic for the patient to take home. The patient is then sent for
radiotherapy after the chemotherapy protocol is complete.

As shown in the studies above, chemo-radiation leads to increased survival rate.
However, patients treated for cervical cancer with chemo-radiotherapy face physical
changes as well as functional, psychological and social effects that affect their QoL
(Hawighorst-Knapstein, Fusshoeller, Franz, Trautmann, Schmidt, Pilch,

1.6 QUALITY OF LIFE

QoL refers to the individual’s sense of well-being and ability to perform daily tasks,
potentially affected by an illness and its treatment. It is a key concept in cancer care,
encompassing several domains of health, including physical, psychological, social,
and functional well-being (Alexander, 2003:62; Pearman, 2003:2). Functional well-
being relates to whether a patient for example is able to manage a household, use
the telephone or dress independently. Social well-being includes engagement in
activities or involvement with others. Physical well-being includes symptoms of pain,
bleeding, fatigue, shortness of breath, etc, while psychological well-being may
include symptoms of depression, loss of fertility, problems related to sexual
intercourse, anxiety, etc. Toxicities arising from treatment protocols are known to
have an impact on lifestyle. According to Rubin et al. (2001:22), five broad categories are used to describe QoL: normal life, happiness/satisfaction, achievement of personal goals, social utility, and natural capacity. Normal life is the ability to function at a level similar to healthy persons of the same age; happiness implies short-term positive feelings, whereas satisfaction implies a longer cognitive experience. QoL in all refers to a state of complete physical, mental and social well-being (Maduro, Pras, Willemse & de Vries, 2003:479).

In research, QoL subsumes two distinct domains. One is health-related QoL (HRQoL); the other, nonhealth QoL. HRQoL encompasses domains of life directly affected by changes in health (Quality-life-Definition-Measurement, 2002). Measuring health-related QoL is a standardized way of describing the physical, psychological and social effects of a disease and its treatment. It is based on the patient’s own rating of simple questions and can provide an overview of how and to what extent a disease and its treatment affect the lives of the patients (Klee, Thranov & Machin, and 2000:5).

Women treated for cervical cancer face physical changes as well as functional, psychological and social effects that affect their QoL. According to Berclaz et al. (2002:1317), data on QoL or long-term toxicity associated with chemo-radiotherapy is scarce. In Zambia to date no study of this type has been conducted to assess QoL issues in women treated for locally advanced cervical cancer.
1.7 BACKGROUND AND RATIONALE OF THE STUDY

Cancer Diseases Hospital is located in Lusaka, the capital city of Zambia, and was built in 2005 on the grounds of the University Teaching Hospital (UTH). The hospital was built as a result of a National Cancer Registry report in 2004 which reported that there were 5000 cancer patients waiting to go for treatment abroad. However, only about 350 patients managed to go abroad for radiotherapy at a cost of U$D10, 000 per patient. Moreover, in Zambia cervical cancer is the most common cancer and is the leading cause of cancer-related death. The annual number of new cancer cases is about 1650 (WHO REPORT, 2007). According to the World Health Organization (WHO), the incidence of cervical cancer in Zambia is 63 out of every 100,000 women. The Cancer Diseases Hospital annual report in 2008 documented that 28% of all new cancer cases seen at the hospital were cervical cancer patients. Since its inception in 2006, the Cancer Diseases Hospital has seen 2431 new cancer patients out of which 681 are cervical cancer patients.

Currently Cancer Diseases Hospital has a dedicated chemotherapy unit and radiotherapy unit with one linear accelerator, one cobalt-60, one simulator, one orthovoltage unit, one brachytherapy unit and a dedicated planning unit. Cancer Diseases Hospital has a strong link with UTH and social workers attached to the Cancer Diseases Hospital also belong to the UTH social work support unit.

As indicated above, Cancer Diseases Hospital is a newly opened institute which has been mandated to treat cancer patients. The institute has adopted a protocol to treat
locally advanced cervical cancer with chemo-radiation therapy which, according to the international literature, can lead to increased survival rates and lower rates of local recurrence (Novetsky, Einstein, Goldberg, Hailpern, Landau, Fields, Mutyala, Kalnicki & Garg, 2007:635). However, patients treated for cervical cancer face physical changes as well as functional, psychological and social effects that affect their QoL (Sabine et al. 2004:399). The comprehensive care of cervical cancer patients thus requires not only curative efforts but also attention to physical, social, emotional and functional needs of patients and their families.

Clinical management of gynaecologic malignancies, however, has focused almost exclusively on prolongation of life, and few studies have adequately addressed the issues related to QoL (Pearman, 2003:2). Similar results have been reported by Hawighorst-Knapstein et al. (2004:399).

QoL after cancer treatment cannot be assessed accurately by monitoring physicians’ impressions of patients’ lives. Patients need to be asked directly about their experiences. In an effort to assist the clinicians in understanding and addressing QoL effects of cervical cancer in Zambia, this study intends to evaluate therapy-related problems and other variables affecting QoL after cervical cancer treatment with chemo-radiation therapy.

1.8 RESEARCH PROBLEM

Results from several studies show that chemo-radiation therapy prolongs survival in women with locally advanced cervical cancer as shown in Table 2 above (Rubin et
al. 2001:470). Because of the improved therapies, the number of women surviving cervical cancer has increased. However, this treatment and or in combination with other demographic factors is associated with QoL problems that negatively affect women treated for cervical cancer, a phenomenon which has not been addressed in a Zambian context.

The question that arises from this problem statement is “does chemo-radiation therapy affect QoL in Zambian women treated for cervical cancer and what demographic variables contribute to the decrease in QoL in these women?”

1.9 RESEARCH AIM AND OBJECTIVES

1.9.1 Aim

The aim is to evaluate the impact of chemo-radiation treatment on quality of life and to determine what socioeconomic and demographic factors are closely related with quality of life decrements in Zambian women treated at Cancer Diseases for cervical cancer.

1.9.2 Objectives

The objectives of the study are the following:

- To evaluate the impact of chemo-radiation therapy on quality of life in Zambian women treated for cervical cancer at Cancer Diseases Hospital
• To analyse the effects of socio-demographic factors on quality of life in these women
• To make recommendations to improve the QoL of Zambian women with cervical cancer treated at Cancer Diseases Hospital

1.10 Outline of chapters

This dissertation is divided into the following chapters:

Chapter 2 – consists of a literature review that underpins the theoretical framework that informed this study. This chapter reviews relevant research done internationally. It also reviews the Zambian situation under the period of study.

Chapter 3 – outlines the research design and methodology that was used. It highlights the type of data collected, the selection of participants, statistical methods used, ethical considerations.

Chapter 4 – presents the results of the study.

Chapter 5 – discusses the principal findings of the results presented in chapter 4.

Chapter 6 - presents the conclusions based on the results discussed in chapter 4 and the discussion presented in chapter 5. It also highlights the study limitations and recommendations for both future research and departmental practice. This chapter is then followed by a list of references and the appendices.
1.11. CONCLUSION

Locally advanced cervical cancer is treated with radiation therapy. Concurrent cisplatin-based chemotherapy significantly improves treatment outcome and survival, and hence chemo-radiotherapy is now standard care for locally advanced cervical cancer. However, the side effects associated with this treatment have a major impact on QoL of the patients.

Research on QoL associated with chemo-radiation therapy is limited. In Zambia no study has been conducted to assess QoL associated with chemo-radiation in cervical cancer patients. Furthermore, there have been no studies on the impact of demographic and socioeconomic factors on QoL in women in Zambia specifically. It is therefore essential that QoL be recognised as an important factor in long-term treatment, and that ways in which to improve QoL in Zambian women with cervical cancer be found and implemented.
1.12. DEFINITION OF KEY CONCEPTS AND ABBREVIATIONS

- **Quality of Life (QoL)**
  An individual’s sense of well-being and ability to perform daily tasks or contentment with everyday life; the degree of enjoyment and satisfaction experienced in everyday life as opposed to financial or material well-being.

  For the purpose of this study QoL will be defined as an individual’s sense of well-being and ability to carry out various activities such as being able to work, enjoy life, sleep well, involvement with others, etc.

- **Chemo-radiation**
  Treatment that combines chemotherapy with radiation therapy to improve disease control.

- **CCRT**
  Concurrent chemo-radiation therapy.

- **Cervical cancer**
  Uncontrolled growth of cancer cells that affects a woman’s cervix.

- **Side effects**
  Side effects are problems that can occur as a result of the treatment. They may occur with radiation therapy because the high doses of radiation used to kill cancer cells can also damage healthy cells in the treatment area. Higher doses can cause varying side effects during treatment (acute side effects) or in the months or years following treatment (chronic side effects). The nature, severity and longevity of side effects depend on the organs that receive the radiation and
the treatment itself (type of radiation, dose, fractionation and concurrent chemotherapy).

- **WHO**
  World Health Organization.

- **GOG**
  Gynecologic Oncology Group.

- **SWOG**
  South West Oncology Group.

- **RTOG**
  Radiation Therapy Oncology Group.

- **CDDP**
  Cisplatinum.

- **5FU**
  5 Fluorouracil.

- **Hyperfractionation**
  Radiation treatment in which the total dose of radiation is divided into small doses and treatments are given more than once a day.

- **HU**
  Hydroxyurea.
CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter covers the theoretical framework that has informed the study. It includes those aspects of the literature that are relevant to the research topic. The prevalence of cancer of the cervix worldwide, in developing countries and in particular Zambia, is discussed. In addition, the treatment of cancer of the cervix and its outcomes are described. The outcomes are discussed with specific reference to chemo-radiotherapy and its effects on quality of life post treatment. Intervention programmes that improve quality of life are also outlined. The chapter ends by highlighting the gaps presented in the literature and the potential benefits of addressing these gaps.

2.2 PREVALENCE OF CANCER OF THE CERVIX

Cervical cancer is the second-most common cancer to affect females worldwide (Spensley, Hunter, Livsey, Swindell & Davidson, 2009:49-55). Although the incidence and mortality have declined in the last 50 years because of increased availability of Papanicolau smear screening programmes, cervical cancer continues to be a leading cause of death for women living in developing countries (Tambaro, Scambia, Maio, Pisano, Barletta, Laffaioli & Pignata, 2004:33–44; Korfoge, Bot, Mols, Franse, Kruitwagen & Ballegooijen, 2009:1501-1509). Despite the availability of screening programmes, a number of researchers (Vistad, Cvancarova, Fossa & Kristensen, 2008:1335-1342; Parker, Evans, Hanna & Adams, 2009:140-146) report
that cervical cancer ranks high in mortality and morbidity worldwide. They also report high incidence rates particularly in developing countries.

Among the women in sub-Saharan Africa and Latin America, cancer of the cervix remains the most common cancer (Parkin 2001:533-543). According to the World Health Organization (WHO) information centre report of 2009, Zambia has the second-highest incidence of cancer of the cervix at 53.7/100 000 women, second only to Tanzania at 68.6/100 000 in sub-Sahara African countries (see Figure 2.1) (www.who.int/hpvcentre).

Figure 2.1. Incidences of cervical cancer in sub-Saharan African countries (www.who.int/hpvcentre).
Tambaro et al. (2004:33-44) also confirm the above WHO findings of higher incidence of cancer of the cervix in sub-Saharan Africa. The authors indicate that almost 80% of cases occur in less developed countries, with the highest incidence in Latin America, the Caribbean, sub-Saharan Africa, South and South-East Asia. Their study shows that the number of women diagnosed with locally advanced cervical cancer is still high in women from undeveloped areas and in a proportion of women living in Western countries because they remain unscreened.

There are 3.21 million women in Zambia aged over 15 years who are at risk of developing cervical cancer. Current estimates indicate that every year 1650 women are diagnosed with cancer of the cervix and 1340 die from the disease as shown in tables 1 and 2 below (Human papillomavirus and related cancers: WHO summary report- Zambia, 2009).

**Table 2.1. Incidence of cancer of the cervix in Zambia, Eastern Africa and the world** ([www.who.int/hpvcentre](http://www.who.int/hpvcentre))

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Zambia</th>
<th>Eastern Africa</th>
<th>World</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crude incidence rate</td>
<td>30.6</td>
<td>25.7</td>
<td>16.0</td>
</tr>
<tr>
<td>Age-standardized incidence rate</td>
<td>53.7</td>
<td>42.7</td>
<td>16.2</td>
</tr>
<tr>
<td>Cumulative risk (%) ages 0-64 years</td>
<td>3.6</td>
<td>3.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Standardized incidence ratio (SIR)</td>
<td>311.0</td>
<td>250.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Annual number of new cancer cases</td>
<td>1650</td>
<td>33903</td>
<td>493243</td>
</tr>
</tbody>
</table>
Table 2.2 Mortality of cancer of the cervix in Zambia, Eastern Africa and the world (www.who.int/hpvcentre)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Zambia</th>
<th>Eastern Africa</th>
<th>World</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crude mortality rate</td>
<td>24.8</td>
<td>20.6</td>
<td>8.9</td>
</tr>
<tr>
<td>Age-standardized mortality rate</td>
<td>44.0</td>
<td>34.6</td>
<td>9.0</td>
</tr>
<tr>
<td>Cumulative risk (%) ages 0-64 years</td>
<td>2.8</td>
<td>2.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Standardized mortality ratio (SMR)</td>
<td>489.0</td>
<td>391.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Annual number of deaths</td>
<td>1340</td>
<td>27147</td>
<td>273505</td>
</tr>
</tbody>
</table>

Cancer of the cervix is the most frequent cancer among women in Zambia, and the second-most frequent among women between 15 and 44 years of age after kaposi sarcoma (Human papillomvirus and related cancers: WHO summary report- Zambia, 2009). Cancer Diseases Hospital annually treats about 1400 new cancer patients of whom 28% are cervical cancer patients and of these 60% are locally advanced (CDH, 2009). Probably the numbers reported underestimate the true incidence of the disease because there are no country-wide screening programmes available and also no reliable collection and registration systems to collect data regarding cancer cases.

Despite the high prevalence of cancer of the cervix, the prognosis of patients globally with locally advanced cancer of the cervix has not improved for several decades in spite of technological advances (Tambaro et al. 2004:33-44). The literature reveals that since 1950, the gold standard of care for locally advanced cancer of the cervix has been primarily radiation therapy, but the unsatisfactory prognostic improvement
prompted several oncology groups worldwide to assess the efficacy of new strategies including combined treatment modalities with radiotherapy, surgery and chemotherapy. More recently, improved cure rates have been obtained with the concomitant use of radiotherapy and chemotherapy in locally advanced cancer of the cervix (Tambaro et al. 2004:33-44).

These advances in gynaecological cancer treatment have resulted in improved local control and overall survival. However, the side effects associated with the treatment have a major impact on the quality of life of these women (Bergmark et al. 2002:443-450). Until recently, treatment for gynaecologic malignancies has focused almost exclusively on prolongation of life, and few studies have adequately addressed issues related to QoL (Pearman, 2003:1-9).

Thus, relevant literature was searched on this subject and no published studies were found which looked at long-term side effects and quality of life in Zambian women treated for cancer of the cervix with chemo-radiotherapy.

2.3 TREATMENT AND TREATMENT OUTCOMES

There are two goals of cancer treatment: to cure and, where there is little or no chance of cure, to prolong and to maintain the quality of those lives as much as possible (Jones et al. 2006:26-42). The increase in survival rates of cancer of the cervix patients has meant that health-related quality of life has become an important issue for survivors (Davidson, Burns, Routlogde & Swendell, 2003:241-247).
Compared with other gynaecological cancers, cancer of the cervix regularly affects younger women, the mean age being 50 years. If cured, these women may have an additional life expectancy of 25 to 30 years after treatment, but they may have to face eventual impairment due to the cancer of the cervix and its treatment for an extended period of time (Jones et al. 2006:26-42).

Cancer of the cervix multimodal treatment programmes affect the lives of surviving women to a varying degree in terms of their physical, psychological and social functioning. Despite the trend towards more effective but toxic multimodal treatment regimes, little focus has been placed on the long-term effects of therapy that could affect quality of life negatively (Vistad et al. 2006:563-572).

Pelvic radiotherapy with external beam radiotherapy followed by intracavitary brachytherapy has been the standard definitive therapy for cancer of the cervix for many years (Berclaz et al. 2002:1313-1318). Similarly, Vistad et al. (2008:1335-1342) have found that radical radiotherapy is a recognized approach for more advanced cancer of the cervix (IIB – IVA). However, according to Chel-Hun, Jeong-Won, Tae-Joong, Woo Young, Hee Rim, Broung-Gie, Seung Jae, Je-Ho & Duk-Soo, 2007:817), conventional radiotherapy for patients with locally advanced cancer of the cervix fails both locally and distally in about 50% of cases, suggesting the need for additional therapeutic modalities.
Rose, Bundy, Watkins, Thigpen, Deppe and Maiman (1999:1144) also report that radiotherapy, when it is the sole treatment, fails to control the progression of locally advanced cervical cancer in 35% to 90% of women. These authors reported a total pelvic failure rate of 23% in stage IIB, 42% in stage III, and 74% in stage IVA after radiotherapy alone. According to Tambaro et al. (2004:36), “cure” rates decrease with advancing stage, and 5-year survival rates range from 70% for stage IIB to 40% for stage III, and 20% for stage IVA. Tambaro et al. (2004:36) have also indicated that treatment of cancer of the cervix FIGO stage IIB – IVA locally advanced disease accounts for almost 32% of all stages with an overall 5-year survival rate of approximately 40-50% when conventional treatments are used.

As a result of the reported treatment failure with radical radiotherapy, combined chemoradiation has become the standard of care for advanced cervical cancer. This follows the publication of five randomized clinical trials comparing radiotherapy with chemo-radiation and the National Cancer Institute alert in 1999, which recommended incorporation of concurrent cisplatin-based chemotherapy with radiation therapy in women who require radiation therapy for treatment of cervical cancer (Goonatillake, Khong & Hoskin 2009:567). The superiority of cisplatin-based concurrent chemotherapy and radiotherapy (CCRT) over radiotherapy (RT) alone for treating invasive cancer of the cervix has been demonstrated in these clinical trials (Table 2.3). In contrast, two randomized trials by Pearcey, Brundage, Drouin, Johnston, Lukka, Maclean, Souhami, Stuart and Tu. (2002:968) and Tseng, Chang, Lai, Soong, Tang and Hsueh SA et al. (1997:56) showed negative results for CCRT.
### TABLE 2.3. Trials of concurrent chemotherapy with radiation in cancer of the cervix

<table>
<thead>
<tr>
<th>Trial</th>
<th>N</th>
<th>Stage</th>
<th>Treatment</th>
<th>Overall survival (3-year) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whitney et al. GOG 85</td>
<td>368</td>
<td>IIB–IVA</td>
<td>CDDP + 5FU</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>H U</td>
<td>57</td>
</tr>
<tr>
<td>Rose et al. GOG 120</td>
<td>526</td>
<td>IIB–IVA</td>
<td>CDDP</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>CDDP + 5FU + HU</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>H U</td>
<td>47</td>
</tr>
<tr>
<td>Keys et al. GOG 123</td>
<td>369</td>
<td>Stage IB (Bulky)</td>
<td>CDDP</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>74</td>
</tr>
<tr>
<td>Morris et al. RTOG 9001</td>
<td>403</td>
<td>IIB–IVA</td>
<td>CDDP + 5FU</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>63</td>
</tr>
<tr>
<td>Peters et al. SWOG 8797</td>
<td>243</td>
<td>IA₂–IIA</td>
<td>CDDP + 5FU</td>
<td>87</td>
</tr>
</tbody>
</table>

CDDP= Cisplatin, 5-FU= 5-Fluorouracil, HU = Hydroxyurea.

The rationale for combining chemotherapy with radiation is to eradicate systemic micro-metastases, which are not treated by local radiation. In addition, cisplatin-based chemotherapy, used in conjunction with radiation, may inhibit the repair of radiation-induced sub-lethal damage and may sensitize hypoxic cells to radiation damage therefore improving the local control and overall survival of these patients (Rose et al. 1999:1144).

Largely based on the publication of large, randomized clinical trials in 1999 and 2000, concomitant chemo-radiation using cisplatin-based regimens is currently the standard treatment for locally advanced cervical cancer. The five-year survival rates are 80%, 65%, 40%, and less than 20% for stages IB bulky, IIB, III, and IV,
respectively, after treatment with synchronous chemoradiotherapy (Rose et al. 1999:1144-53; Novetsky, Einstein, Goldberg, Hailpern, Landau, Fields, Mutyala, Kalnicki & Garg 2007:635). According to Shang-Wen, Ji-An, Yao-Ching, Lian-Shung, Wei-Chun, Wu-Chou, Shih-Neng and Fang-Jen (2006:1371), chemoradiotherapy has become an established treatment policy for locally advanced cancer of the cervix, however, there are major concerns regarding toxicity, especially for late complications that may negatively affect quality of life.

Although the most important outcome measure in cancer research is survival, quality of life issues are relevant for women who have survived gynaecologic cancer. This is because the side effects associated with the treatment have a major impact on quality of life (Shang et al. 2006:1371). According to these authors, late toxicity information regarding concomitant chemoradiotherapy is scarce; however, they indicated that a toxicity profile is important for patients who decide to be treated with this combination as well as for physicians in order for them to offer a more appropriate informed consent. Furthermore, by determining whether these women experience quality of life decrements, an appropriate intervention programme could be developed to improve their quality of life. Such intervention would be especially important given that better quality of life has been associated with increased survival (Bradley, Rose, Lutgendorf, Costanzo & Anderson, 2006:480).

According to Korfarge et al. (2009:1501) and Bradley et al. (2006:479), cervical cancer has a relatively good five-year survival rate; however, patients treated for this disease face physical changes as well as functional, psychological and social effects
that affect their quality of life. This is as a result of the side effects of the treatment. Concerns over the risk of increased morbidity from CCRT for some patients should be considered because a small gain in local control through CCRT might be counteracted by the risk of increased complications (Korfarge et al. 2009:1502).

2.4 LATE SIDE EFFECTS OF CHEMORADIOThERAPY

As defined by Cheung, Chiu and Chung (2003:461-463) and King et al. (2006:38-45), late side effects are those treatment complications that appear from months to many years after cancer treatment. Although chemo-radiotherapy has been reported to significantly improve treatment outcome and survival, it is associated with major treatment complications that affect patients’ quality of life (Uno et al. 2008:18). According to Jones et al. (2006:26-42), late side effects of radiotherapy and chemotherapy are multiple and well documented. Foremost among such late effects are gastrointestinal (GIT) complications, urinary complications, sexual and reproductive system complications and others (Roseke, Mundt, Halpern, Sweeney, Sutton, Powers, Rotmensch, Waggoner & Weichselbaum, 1997:551-552; Perez, Grisby, Lockett, Chao & Williamson, 1999:855-866).

2.4.1 Gastrointestinal (GIT) toxicity

There are several studies that have compared cancer of the cervix treatment with chemo-radiotherapy and have reported late complications of the GIT. For instance, Shang et al. (2006:1373) reviewed the treatment outcome and complications of patients with advanced cancer of the cervix treated with CCRT and HDR. They found
toxicity of chemo-radiotherapy to be substantial. Recorded complications in this study include rectal-rectosigmoid complications such as rectal stricture and radiation proctitis. Also reported were complications of the small bowel which are consistent with the results found in the study by Ferringo, Novaes, Pellizzon et al. (2001:1123-1135).

Other studies assessing GIT complications of radiotherapy report late effects such as bowel obstruction, rectal bleeding, sigmoid perforation and fistula formation as secondary effects of radiation-induced endarteritis (Cheung et al. 2003:461-463; Grisby et al. 2001:984-985). The median time to late toxicity was reported to be 36 months. Nevertheless, Grisby et al. (2001:984-985) associated the high rate of late complications in their study to the effect of hyperfractionation and 5 Fu and probably the larger paraortic radiation fields. Vistad et al. (2008:1335-1342) also found major intestinal problems in locally advanced cancer of the cervix survivors many years after radiotherapy. Although GIT complications are reported in the literature, Vistad et al. (2008) reported a high risk of under-reporting by physicians during follow-up visits. They suggest that sufficient time be taken when examining patients so that information with regard to relevant side effects can be collected and possible interventions can then be initiated.

Thomas, Dembo, Flyes, Ackerman, Franssen and Balogh (1990:449) have shown similar results in their study of 200 patients treated for bulky cancer of the cervix with chemotherapy. Thomas et al. (1990: 449) reported bowel complications including obstruction, stricture, perforation, bleeding and fistula development at the median time of eight months. The study showed that these complications were more
pronounced in the chemo-radiotherapy arm compared to those treated with radiotherapy alone.

Other authors similarly reported bowel toxicity including rectal fistula, sigmoid stricture, persistent diarrhoea, vomiting, constipation, anal bleeding, stenosis of the small intestine, sigmoid-vaginal fistula and small bowel obstruction at three years (Spensley et al. 2009:49-55; Berclaz et al. 2002:1313; King et al. 2006:41-42). Notable in the King et al. (2006:41-42) study, however, is the fact that patients who developed late toxicity were reported as having advanced stage of disease at presentation, and advanced stage of disease is associated with increased morbidity.

Parker et al. (2009:143) compared treatment outcomes and complication rates between patients treated with chemo-radiotherapy and radiotherapy alone in a retrospective study. They reported recto-vaginal fistula, persistent diarrhoea and perforated bowel in some patients. However, there was no significant difference in side effects seen between patients treated with chemo-radiotherapy and radiotherapy alone. Though the study represents the results of treatment in the general population, the late effects of chemo-radiotherapy would have been underestimated due to its retrospective nature.

Maduro, Pras, Willemse and Veries (2003:471-488) have reported the results of a pilot study where hyperfractionated radiotherapy in combination with cisplatin and 5 Fluorouracil (5Fu) was used. The evidence that chemoradiotherapy increases the
risk of late gastrointestinal toxicity such as rectal bleeding and enterocutaneous fistula and small bowel obstruction was conclusive although their results did not suggest increased late side effects when patients were treated with radiotherapy alone. Grigsby et al. (2001:984-985) in a similar study revealed unacceptably high rates of late bowel toxicity at 36 months. Nevertheless, Maduro et al. (2003:471-488) and Grigsby et al. (2001:984-985) suspect the high rate of late toxicity to be the effect of the combination of radiotherapy hyperfraction and 5 Fu and probably of the larger paraaortic radiation fields.

According to Abayoni, Kirwan and Hackett (2009:262), 80% of all patients treated for pelvic cancers such as cervical, endometrial, prostate and bladder will experience a permanent change in bowel habit after radiotherapy. Commonly reported side effects in their study include abdominal pain, urgency, diarrhoea, faecal incontinence and bloating. According to Sause, Bundy, Malfetano, Hannigan and Fowler (1991:339-489), in stage IIB – IVA disease patients with negative common iliac and aortic lymph nodes, major late GIT complications are seen three years post chemo-radiotherapy. However, the use of belly board devices during radiotherapy treatments has been reported to reduce the incidence of these complications as a result of reduced irradiated bowel volume (Meduro et al. 2003:471-488).

In contrast, Pearcey et al. (2002:968) reported no difference in late toxicity in a phase III clinical trial when comparing radiotherapy and radiotherapy plus cisplatin at a median follow-up of 82 months. In a study by Young, Jong, Seung, Sang, Seong, Joo-Hyun, Young-Tak, Yong-Man, Jong-Hyeok and Eun (2009:1522-1528) it was
observed that chemo-radiotherapy is feasible in women with cancer of the cervix with acceptable late morbidity.

Similarly, Sood, Timmins, Gorla, Garg, Anderson, Virkram and Goldberg (2002:704) found no evidence of an increase in bowel toxicity when applying combined chemotherapy and radiotherapy modality in patients with cancer of the cervix. However, the small number of patients and different chemotherapeutic regimens described in the Young et al. (2009:1522-1528) retrospective study poses a limitation to the conclusions made in their findings. In a study conducted by Gonzalez, Cetina, Sanchez, Gomez, Rivera, Hinojosa, Graniel, Enchiso and Garza (2003:1361-1365) it was found that there were no significant chemo-radiotherapy late complications eight months post treatment, but the short follow-up time in the study makes it difficult to document the occurrence of late complications.

2.4.2 Sexual morbidity

Sexual health is known to have an impact on quality of life and it is recognized that sexual dysfunction can be high following treatment for cancer of the cervix (Davidson et al. 2003:241-247). The literature reveals that 50% of women treated for cancer of the cervix experience sexual dysfunction as they recover and become cancer survivors (Cull et al. 1993:1216-1220; Flay & Mathews, 1995:399-404; Anderson, Woods & Copeland, 1997:221-229). Cancer of the cervix and its treatment directly affect the sexual organs and may disrupt the physical and psychological phases of the female sexual response cycle (Lindau, Gavrilova & Anderson, 2007:413-418).
Studies assessing the effects of cancer of the cervix treatment with radiotherapy with or without chemotherapy have reported several late sexual complications affecting women post treatment (Bergmark et al. 1999:1383-1389; Maduro et al. 2003:477). Complications reported in these studies include reduced sexual desire, lack of arousal and orgasm, diminished lubrication and sensation, reduction in vaginal elasticity, a shortened vaginal cavity, vaginal atrophy, stenosis and retrovaginal or vesicovaginal fistula which often inhibit a patient’s ability to resume satisfactory sexual functioning.

Lindau, Gavrilova and Anderson (2007:413-418) compared sexual morbidity in long-term survivors of cancer of the cervix and vaginal cancer to national norms. In this study cancer survivors reported significantly more sexual problems than in the population-based comparison group. The prevalence of pain during sex and difficulty lubricating were reported to have been very high among cancer survivors. Other recorded late effects by these authors included post-coital bleeding, unable to climax and lack of interest in having sex. Carter, Rowland, Chi, Brown, Rustum, Castiel and Barack (2005:90-95) reported similar results. However, Lindau, Gavrilova and Anderson (2007:413-418) associated higher sexual morbidities to lack of conversation with a physician about the sexual effects of genital tract cancer and its treatment.

According to Grigsby et al. (1995:185-189), many women have difficulty with sexual adjustment following pelvic radiotherapy. Flay and Mathews (1995:399-404) also reported sexual dysfunction in patients with locally advanced cancer of the cervix at one year after radiotherapy. Women in this study reported pain during intercourse,
low back or pelvic pain, vaginal dryness, shortening, narrowing and vaginal bleeding as the main reasons for reduced sexual activity. Like Lindau, Gavrilova and Anderson (2007:413-418), Flay and Mathews (1995:399-404) also indicated that high sexual morbidity in their study was associated with inadequate counselling about the effects of treatment and ways to minimize the morbidity.

A study by Cull et al. 1993 (1216-1220) reported pain and loss of enjoyment during intercourse in women 97 weeks post radiotherapy. Some women in this study reported bleeding after intercourse. Overall sexual function was rated to be poorer in women treated with radiotherapy. However, the study indicated that these problems were not severe and there were no significant differences between women treated with radiotherapy and the control group. Similar results were reported by Berclaz et al. (2002:1313). Women in this study developed dryness and shortened vagina and proximal closure prohibiting sexual intercourse. Other late effects reported were sigmoid-vaginal fistulae. This study, however, was carried out on a small size sample and there was a short follow-up time which limits the conclusions that can be drawn when determining sexual and other reproductive system impairments in long-term survivors of cancer of the cervix.

Despite the many documented late complications experienced by cancer of the cervix survivors, almost all the authors agree and recommend that women having treatment for cancer of the cervix and other pelvic malignancies should be given adequate counselling about the effects of treatment and ways to minimize the morbidity.
2.4.3 Female reproductive tract toxicity

Cancer of the cervix treatment can negatively impact female fertility through administration of chemotherapy drugs that are toxic to the ovaries or radiotherapy which causes permanent ovarian failure (sterility) (American Cancer Society - cancer facts and figures 2004; Herzog & Wright, 2007:572-577). Carter et al. (2005:90-95) studied the experiences of women who lost their fertility one year after cancer of the cervix treatment. Approximately half of the study sample experienced trouble in accepting their infertility. Survivors also reported menopausal symptoms to be very bothersome. These symptoms included hot flushes, night sweats, weight gain and forgetfulness. However, caution is advised in generalizing the Carter et al. (2005:90-95) findings because patients sampled were not representative of the general population; almost all of the women in their study were Caucasian, highly educated and married. In addition, their sample size of 20 women is too small to generalize the findings.

To consolidate the findings by Carter et al. (2005:90-95), Wenzel et al. (2005:310-317) also assessed cognitive and affective factors associated with infertility and reproductive concerns in women diagnosed with cancer of the cervix. In this study, cancer of the cervix survivors reported a great incidence of hot flushes and vaginal dryness. Although the sample size was small in the Wenzel et al. (2005:310-317) study, the clinical significance of this data is important, given the implications for follow-up care for this population. Data in this study suggest that those with the greatest unresolved reproductive concerns may have associated long-term physical and psychosocial disruptions leading to the hypothesis that cervical cancer survivors
who experience negative effects due to compromised childbearing may be at risk for long-term diminished QoL. However, the Wenzel et al. (2005:310-317) study does not indicate the type of treatment these women received to be able to compare the incidence of late side effects with the type of treatment, e.g. chemo-radiotherapy or radiotherapy alone.

### 2.4.4 Genitourinary toxicity

Treatment of cancer of the cervix with radiotherapy or in combination with chemotherapy may result in a high rate of genitourinary system complications. Meduro et al. (2003:471-488) conducted a small study on women who were treated by means of hyperfractioned radiotherapy in combination with cisplatin and 5-fu. Six patients experienced severe bladder fibrosis, vesicovaginal fistula and ureter obstruction. However, the authors suspect this to be the effect of the combination of radiotherapy hyperfractionation and 5-fu.

To consolidate findings by Meduro et al. (2003:471-488), Thomas et al. (1990:446-451) carried out a study for patients with bulky cancer of the cervix treated with radiotherapy and chemotherapy. They found severe bladder toxicity such as bleeding and fistula that occurred in six patients at the median time of eight months. The incidence of bladder toxicity was similar to that seen in the study by Spensley et al. (2009:49-55). Severe toxicity in the Meduro et al. (2003:471-488) study is, however, associated with the inclusion of mitomycin C, which the authors believe led to serious complications.
According to Bye et al. (2000:173-180), patients treated for cancer of the cervix with radiotherapy have urinary problems years after treatment. In their study to evaluate long-term effects of diagnosis and treatment in stages I-IIb cancer of the cervix, patients reported frequent urination three to four years post treatment. Bye et al. (2000:173-180) also reported urinary urgency and incontinence to be frequent problems in cancer of the cervix survivors. However, patients in this study did not receive chemotherapy; thus it is not known whether the addition of chemotherapy would result in additional complications. The study by Klee et al. (2000:14-23) supports the study by Bye et al. (2000:173-180) by finding similar urinary problems. However, it was noted in these studies that there was a small percentage of reported complications. Thus, no matter how small the reported percentage may be, medical staff must be careful not to ignore the negative effects these complications may have on the patient’s quality of life years after treatment.

Kirwan et al. (2003:217-226) have reported findings of 19 randomised studies of chemo-radiotherapy in cancer of the cervix. Long-term toxicity was only described in eight trials but seven showed no difference in the incidence of long-term side effects between patients in chemo-radiotherapy and radiotherapy arms. At 36 months median follow-up, the authors reported late toxicities as occurring in 6-23.3%. This small toxicity figure is associated with under-reporting. It is difficult to define the urologic complications in this study because complications were not specified. To conclude that chemo-radiotherapy increases late toxicity in these patients is difficult because of the different designs of the individual studies.
2.4.5 Other complications

Other complications following treatment of cancer of the cervix radiotherapy or in combination with chemotherapy have been reported in the literature. King et al. (2006:41-42) assessed late side effects in women treated with concurrent cisplatin and radiotherapy. Other than gastrointestinal and genitourinary complications, they reported thromboembolic and musculoskeletal late complications. Pelvic bone fractures were documented as late complications that occurred at 24 months in these women. Nevertheless, the authors associated severe late toxicity with higher disease stage.

Similarly, Meduro et al. (2003:471-488) have reported studies with bone complications such as femoral neck fractures 5 to 10 years after radiotherapy in cancer of the cervix survivors. A study by Huh, Kim, Kang et al. (2000:264-268) showed fractures of the pelvis and pelvic pain in cancer of the cervix patients treated with radiotherapy. These patients experienced this complication from 7 to 19 months after treatment although the study indicated that pain resolved with conservative therapy.

Other studies have reported fatigue and difficulty in sleeping in cancer of the cervix survivors treated with radiotherapy or a combination of radiotherapy and chemotherapy (Bergmark et al. 2002:448; Bye et al. 2000:178; Cull et al. 1993:1216-1217; Berclaz et al. 2002:1316; Herzon & Wright, 2007:573). These effects were also reported to have played a role in decreased QoL in these survivors.
2.5 DEFINITION OF QUALITY OF LIFE

Quality of life refers to the individual’s sense of well-being and ability to perform daily
tasks, potentially affected by an illness and its treatment. It is a key concept in
cancer care, encompassing several domains of health, including physical,
psychological, social, and functional well-being (Alexander, Kim, Terrell, Dawson,
Ship & Eisbuch, 2003:62). Quality of life has also been defined in a similar manner
by Maduro et al. (2003:479), Pearman, (2003:2), and Jones et al. (2006:26).
Functional well-being relates to whether a patient for example is able to manage a
household, use the telephone or dress independently. Social well-being includes
engagement in activities or involvement with others. Physical well-being includes
symptoms of pain, bleeding, fatigue, shortness of breath, etc, while psychological
well-being may include symptoms of depression, loss of fertility, problems related to
sexual intercourse, anxiety, etc. Toxicities arising from treatment protocols are
known to have an impact on lifestyle. According to Fuller, Braden and Thomas
(2004:1334), lifestyle satisfaction, level of comfort, and the ability to pursue daily
activities are increasingly becoming primary concerns of radiotherapy patients.

Measuring health-related quality of life is a standard way of describing the effects of
the disease and its treatment. It is based on the patients’ own rating of simple
questions. It also provides an overview of how and to what degree the disease and
its treatment affect the lives of the patients. Beside the evaluations of treatment
toxicity by physicians, quality of life reflects the patient’s perspective (Klee, Thranov
& Machin, 2000:5).
To collect information relating to health-related quality of life, well-validated questionnaires have been designed and used in a number of studies. The table below shows various studies that have measured QoL using the EORTC QoL instruments.

Table 2.4. Studies that used health-related quality of life (HRQoL) instrument to measure the outcomes of women treated for gynaecologic cancer

<table>
<thead>
<tr>
<th>No</th>
<th>Study</th>
<th>Cancer</th>
<th>HRQoL instrument</th>
<th>Study design</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bye et al. 2000:173-180</td>
<td>endometrial and cervical</td>
<td>EORTC QLQ-C36</td>
<td>cross-sectional prospective cohort</td>
</tr>
<tr>
<td>2</td>
<td>Jensen et al. 2003:937-949</td>
<td>cervical and vaginal</td>
<td>EORTC QLQ-C30</td>
<td>prospective cohort</td>
</tr>
<tr>
<td>3</td>
<td>Klee &amp; Machin, 2001:16-24</td>
<td>Endometrial</td>
<td>EORTC QLQ-C30</td>
<td>prospective cohort</td>
</tr>
<tr>
<td>4</td>
<td>Klee et al. 2000:14-23</td>
<td>cervical and vaginal</td>
<td>EORTC QLQ-C30</td>
<td>prospective cohort</td>
</tr>
<tr>
<td>5</td>
<td>Chan et al. 2001:10-19</td>
<td>gynaecological malignancies</td>
<td>EORTC QLQ-C30</td>
<td>prospective cohort</td>
</tr>
<tr>
<td>6</td>
<td>Klee et al. 2000:5-13</td>
<td>cervical and vaginal</td>
<td>EORTC QLQ-C30</td>
<td>prospective cohort</td>
</tr>
</tbody>
</table>
2.6 QUALITY OF LIFE AND CERVIX CANCER

The efficacy of chemo-radiotherapy has yielded an increasing number of long-term cancer of the cervix survivors in whom treatment-related modifications of life style may appear (Greenlee, Harmon, Murray & Thun, 2001:15). According to Jones et al. (2006:26), gynaecological cancers are major sources of mortality and morbidity. Although many articles have reported on the impact of these diseases, few studies have reviewed the evidence, specifically with regard to the effect of treatment on health-related quality of life (Jones et al. 2006:26).

A good proportion of cervical cancer cases are diagnosed at a relatively young age, yet little is known about long-term adjustment and survivorship in this population. One reason for the importance of health-related quality of life measurement in oncology is because despite improvement in survival rates, due to the treatment there are physical, psychological and social side effects. The literature shows that adverse physical and psychological and social effects may be serious and persistent among young women diagnosed with cancer (Wenzel et al. 2005:311; Jones et al. 2006:28).

Similarly, Bradley et al. (2006:479) reported that women treated for cancer of the cervix, as they survive the disease, must frequently adjust to physical limitations, worry about the possibility of recurrence, adjust to changes in sexual function, and adjust when resuming their roles in family, work place and society. Their study confirms the findings of Wenzel et al. (2005:311) and Pearman, (2003:2) according to whom there is a gap in the literature with regard to the long-term impact of cancer of the cervix on QoL.
The literature reviewed above indicates how long-term side effects impact on the well-being of cancer of the cervix survivors. Side effects include bowel and urinary dysfunction and changes that compromise sexuality. It is important therefore to discuss the different side effects on QoL, including the physical, social and psychological aspects of the cancer of the cervix survivors’ well-being.

2.6.1 Physical well-being

The physical health domain encompasses the physical changes and disruptions of daily activity caused by the disease and its treatment. Several studies have been carried out to assess the prevalence of physical and functional effects in cancer of the cervix patients treated with chemo-radiotherapy (Bergmark et al. 2002:448; Bye et al. 2000:178; Cull et al. 1993:1216-1220; Berclaz et al. 2002:1316). The results show that patients suffer several physical and functional effects that negatively impact on their quality of life.

Bye et al. (2000:173-180) reported that about 23% of patients treated with radiotherapy suffer from diarrhoea three to four years after treatment, affecting health-related quality of life negatively. Shang et al. (2006:1373) and Abayom et al. (2009:262-267) also studied the QoL of long-term survivors of cancer of the cervix. Their results indicate that women treated with chemo-radiotherapy suffer gastrointestinal complications that impair their quality of life. Complications such as diarrhoea, faecal incontinency and bloating were reported to have limited patients’ movement forcing some to be virtually house-bound. A study by Vistad et al.
(2008:1339-1341) also showed that treatment effects of the cancer of the cervix on the GIT such as urgency for faeces and faecal leakage can greatly impact on daily life and may lead to isolation.

In addition, a study by Berclaz et al. (2002:1318) looked at 22 women treated for advanced cancer of the cervix with chemo-radiotherapy. The study revealed several side effects that affected women’s quality of life years post treatment. The late side effects that included recurrent diarrhoea, sigmoid-fistula, anal bleeding and stenosis of the small intestine were reported to have led to reduced physical activity in these women. The study reported two women who were unable to return to their jobs immediately due to these treatment effects. Bye et al. (2000:173-180) reported less diarrhoea in patients following a low-fat diet during radiotherapy in their study, and thus nutritional guidance may be of importance.

Other physical late effects of radiotherapy and chemotherapy that affect survivors’ QoL have also been reported in the literature. Vistad et al. (2008:1339-1341), reported urologic complications like urgency for urine, cystitis, stress incontinence and urinary leakage. Urologic complications were also reported by Korfage et al. (2009:1501). According to Vistad et al. (2008:1339-1341), these altered bodily functions may inhibit a patient’s ability to resume a satisfactory functional life.

Nevertheless, better QoL in cancer of the cervix survivors is reported by Greimel, Thiel, Peintinger, Cegnar and Pongratz (2002:144). Their study compared quality of
life in women with gynaecologic cancers to that of women with other cancers such as breast cancer. They found that during treatment, patients with gynaecologic cancer are significantly more physically impaired compared to breast cancer patients. However, quality of life was comparable between the two groups at one-year follow-up, suggesting that gynaecologic cancer survivors experience significant improvement in quality of life following treatment.

According to a study on the physical sexual effects of radiotherapy treatment (Jensen, Croenvold, Klee, Thranov, Petersen & Machin, 2003:937-949), women treated for cancer of the cervix experienced persistent sexual and vaginal problems that compromised their sexual activity and satisfaction. Similarly, sexual morbidity in long-term survivors of cancer of the cervix was reported by Lindau, Gavrilova and Anderson (2007:415-418). Although the study conducted by Lindau et al. (2007:415-418) showed no difference between the long-term survivors and a population-based comparison group in relation to sexual participation, survivors exhibited very high prevalence and complexity of sexual problems, including pain and lack of pleasure.

Vistad et al. (2008:1341) found that 54% of sexually active women reported vaginal dryness and 42% had pain with intercourse years after treatment for locally advanced cervical cancer. Similarly, Berclaz et al. (2002:1318) showed that survivors of advanced cervical cancers treated with radiotherapy experienced vaginal dryness and a shortened vagina and proximal closure prohibiting intercourse ten years post treatment. Interestingly, Korfage et al. (2009:1501-1509) found similar results as Vistad et al. (2008:1341) and Berclaz et al. (2002:1318) but reported no difference in
sexual functioning and QoL between cancer of the cervix survivors and the normal population group.

In contrast to Vistad et al. (2008:1335-1342), Flay and Mathews (1995:402) contest that a considerable proportion of women treated for cervical cancer with radiotherapy alone or in combination with surgery do experience some form of sexual dysfunction. The results of their study showed a reduced sexual desire and vaginal atrophy and fibrosis after radiotherapy. Similar results were shown by Cull et al. (1993:1218-1219), who reported that patients who were sexually active before treatment became sexually inactive after treatment due to severe pain caused by vaginal stenosis and fibrosis. The authors stated that sexual dysfunction in these patients was highly correlated both with physical and psychological distress scores.

Though most of the physical problems faced by cancer of the cervix women are not life threatening, persistent problems of milder morbidity might lead to a decrease in the patients' quality of life to a greater extent. Patients should therefore be encouraged not to underreport morbidity during their follow-up programmes. Vistad et al. (2008:1341) indicated in their study that patients tend to underreport disease and treatment morbidity when facing a doctor, and embarrassing problems such as leakage of faeces are less likely to be mentioned and yet these are symptoms that limit patients' daily activity and sexual functioning.
2.6.2 Psychological and social well-being

Studying psychological and social morbidity associated with cancer of the cervix is important because its treatment has been reported to threaten women’s self-concept and body image (Cull et al. 1993:1216-1220). According to Cull et al. (1993), long-term survival may be compromised not only by persistent late effects of treatment, but also by the psychological reaction to having a life threatening illness and by the challenges of recovering the premorbid lifestyle. Bergmark et al. (1993) also supports the fact that QoL can be affected in many ways in women treated for cancer of the cervix. The treatment of this disease may thus significantly impact on self-image and social well-being. The psychological and spiritual toll can be severe as survivors recognise the importance of both continued surveillance and possible recurrent cervical cancer (Bergmark et al. 1999:342).

Several authors have highlighted the need for an assessment of quality of life and psychological and social functioning. Using the EORTC QLO-30 questionnaire, a widely used and well validated quality of life instrument to describe the psychological and social reactions of women with advanced stages of cancer of the cervix during and after treatment, the authors found that patients treated for cancer of the cervix with radiotherapy experience both psychological and social effects of the disease and its treatment. Psychological effects noted in the studies include anxiety, depression, worries about risk of recurrence, stress and coping problems, and isolation. The studies indicated that patients continued to think about their illness and treatment throughout the 24-month study period and had difficulties expressing themselves to others. Quality-of-life scores in these women never reached that of the

The fear of local recurrence was found to have increased levels of worry in patients who underwent cancer of the cervix treatment with radiotherapy in the study of Cull et al. (1993:1219). At 97 weeks follow-up, the researchers found that 91% of women were worried about the risk of recurrence of the disease. This resulted in isolation and difficulties in sharing their worries with others. The fear of disease recurrence in these women also contributed to the feeling of loss of control and these women experienced difficulties in making plans for the future. Cull et al. (1993:1219) also found that the QoL levels in cancer of the cervix survivors were lower compared to the control group data obtained from women in the general population. Similar results were reported by Klee, Thranov and Machin (2000:6-12), Berclaz et al. (2002:1317), and Flay and Mathews (1995:399-404).

Worse social functioning and body image was also reported by Park, Bae, Nam, Chong, Cho, Lee, Kyung, Kim, Sang and Yun (2007:2716-25). Their study demonstrated that long-term survivors of cancer of the cervix who are treated with chemo-radiotherapy experienced significantly worse social functioning. Women in this study reported more pronounced worry and anxiety about sexual performance. Chemo-radiotherapy side effects such as nausea and fatigue were highly associated with reduced social functioning (Jansen et al. 2003:938-949; Wenzel et al. 2005:310–317).
Other researchers (Carter, Rowland, Chi, Brown, Rustum, Castiel & Barakat, 2005:92; Bergmark et al. 2002:448; Bye et al. 2000:178; Flay & Mathews, 1995:399–404) also made similar findings. Women in these studies reported emotional and relationship alterations after treatment. The women’s ratings of their difficulties in their relationships were highly correlated with both physical symptoms and psychological distress scores. Some women suffered negative thoughts and emotions and failed to resume their former social and leisure activities suggesting some persistent impairment of function. Moreover, Cull et al. (1993:1216-1220) showed that women who had difficulties with finances reported more social life problems. These studies show that oncology staff lack the time and skill to deal with psychological and social concerns although the literature suggests that giving patients opportunity to express such concerns can be preventive of problems (Caffo, Amichetti, Tomio & Galligioni, 2001:13-20).

According to Carter et al. (2005), female cancer survivors suffer changes in their emotions and relationships after treatment. The authors also indicated that women treated for gynaecologic cancers experience severe psychological distress. Feelings of depression, grief and stress were also reported in these women especially in those who lost their fertility as a result of the cancer treatment. The research of Cull et al. (1993:1216-1217) showed similar results where patients treated for cancer of the cervix scored high on anxiety and depression.

In the patients treated for locally advanced cancer of the cervix with radiotherapy alone or in combination with chemotherapy, Meduro et al. (2003:477) found that
patients suffer QoL decrements following treatment. The psychological and physical
effects experienced by these patients caused them to have feelings of being less
desirable. Other researchers have documented that there is a percentage of women
who separate from their partners due to treatment effects that caused relationship
problems (Juraskova, Butow, Robertson, Sharpe, Mcleod & Hacker, 2003:267).

In another study, Lindau, Gavrilova and Anderson (2007) found that relationship
problems were associated with little knowledge among survivors of their cancer and
its treatment effects. This study reported more complex sexual worries in women
who had not discussed the effects of cancer and cancer treatment on their sexual life
or function (Lindau, Gavrilova & Anderson, 2007:416). In a study presented at the
academy health meeting (2003), Weaver, Sun, Schover, Aday, Mueller and Bodurka
reported similar findings.

The importance of communication between the cancer of the cervix patient and her
partner is highlighted by Herzon and Wright (2007:572-575). When a patient and her
partner have unequal responses to the diagnosis and treatment, illness-induced
disruptions in their relationship and intimacy can arise. Therefore, the
comprehensive care of cancer of the cervix patients requires not only curative efforts
but also that attention be given to the psychological needs of patients and their
families.
Similarly, Miller, Pittman and Strong (2003:111-119) have highlighted the need for assessment of quality of life and emotional functioning in patients treated for gynaecological cancers. In their retrospective study, 57% of patients reported needing help dealing with emotional problems. The majority of patients wanted their physicians to ask questions dealing with spirituality, death and dying, and emotional problems. Campelli, Vincenzo, Addamo, Bartolozzi, Braggio and Scambia (2002:2500-2507) also noted that women with primary gynaecologic cancer experience more emotional problems after treatment than healthy women. Poor QoL in this study was more pronounced in young women with cancer of the cervix. This was seen to be in opposition to women with other gynaecologic cancers (ovarian and endometrial cancer) where age was negatively correlated with QoL.

On the other hand, Miller, Pitman, Case and McQuellon (2002:179-183) showed a higher emotional impact in older patients compared to younger patients. Generally, quality-of-life scores in their study were observed to be lower in patients with poor education and a lack of help at home. This finding was explained by assuming that younger patients had a better education, better support and better general health than older patients which led to them reporting good QoL indicators. Lower levels of education may be predictive of a less supportive social environment, limited knowledge of health issues and poor general health (Miller et al. 2002:179-183; Chan, Ngan, Yip, Li, Lau & Tang 2001:387-394, Pearman 2003:3 ; Korfarge et al. 2009:1501).
Compared to other cancers, the literature reveals that cancer of the cervix survivors report more mood disorders (Herzon & Wright, 2007:572-573). Cancer of the cervix survivors experience significantly more anxiety, dysphonia, anger and confusion compared with other cancer survivors. Interestingly, Lutgendorf et al (2000:1402-1411) indicated that during the first year following treatment, quality of life and mood improved in patients treated for gynaecological cancers. Coping strategies appeared to be very predictive of quality of life at one year post treatment. This study revealed that psychological interventions directed to improve coping strategies can have some effect on the well-being of cancer patients (Lutgendorf et al. 2002:1409, 1410).

Mood disorders and subsequent declining QoL scores were found to be associated with demographic variables in a study by Bradley et al. (2006:485). The study showed that unemployed and unmarried cervical cancer women reported significant decrements in quality of life and mood. Unmarried women were more likely to report decrements in quality of life, mood and mental health, leading to the hypothesis that those who do not have someone to share the cancer treatment and survivor experiences with may be at risk for the development of mood disorders.

In another study Wenzet et al. (2005:310-317) examined the QoL of women of childbearing age treated for cancer of the cervix. Their results suggest that survivors who report less social support and lower spiritual well-being are more likely to experience decrements in QoL. Also related to QoL decrements in this study were lower education levels. Chan et al. (2001:387-394) also agree that low religious belief or spiritual well-being and low education level will impact on survivors’ QoL negatively. Although the sample size in the study of Wenzel et al. (2005:310-317)
was small to support their findings, the clinical meaning of their results is important, given the implications for follow-up gynaecologic care for this population group.

The literature reviewed above thus shows conflicting reports concerning QoL in cancer of the cervix survivors. Some show deterioration in QoL and some show stability or improvement over time. Nevertheless, QoL is an especially important issue on which to focus given the challenges and changes that women must face after diagnosis and treatment of cancer of the cervix. It can therefore be safely said that any studies and interventions focusing on improvement of QoL in survivors should be encouraged. Schover (2000:3-4) indicated in his study that identifying any problems in the quality of life after treatment for cancer of the cervix is important because health care professionals may be able to design intervention programmes that can prevent or ameliorate such problems.

2.7 INTERVENTION PROGRAMMES

Intervention programmes are necessary to improve the quality of life of patients treated for cancer of the cervix because of the considerable impact that treatment has on the physical, functional and psychological states of the patients. Women should be given adequate counselling and information about the effects of treatment and ways to minimize the morbidity because patients who know what to expect will hopefully be better at coping with their situation (Klee, Thranov & Machin, 2000:12; Flay & Mathews, 1995:403). Moreover, it is important to identify any problems in quality of life after cervical cancer because this can help health professionals to
develop intervention programmes which may improve the quality of lives of patients under their care.

There are various intervention programmes mentioned in the literature that have shown to improve the quality of life of cancer patients after treatment. The challenge is how to provide and implement these programmes to improve life-style changes post treatment. Katz (2005:238-241) suggests that an educational intervention programme regarding sexuality can be helpful for improving female cancer survivors’ quality of life. Park et al. (2007: 2718-2720) also recommend that involving cancer patients in educational programmes concerning their disease and its treatment effects should be encouraged. Patients who have participated in intervention programmes have reported improved quality of life years post treatment (Klee, Thranov & Machin, 2000:12; Flay & Mathews, 1995: 403).

Katz (2005:238-241) suggests numerous ways to educate survivors especially in sexuality. Those who are able to read can be given textbooks dealing with sexual functioning, as well as dedicated journals. Workshops and conferences dealing with specific areas could also be organized for these women. Good communication and counselling skills are essential to provide patients and survivors with appropriate and timely information related to social, psychological and physical changes after treatment.
Although an educational intervention programme is seen to be effective in improving the quality of life of survivors, it should be noted that implementing these programmes requires extra financial resources, dedication and expertise in order for such a programme to be successful. Sexuality is an integral part of normal life for most individuals and is an important aspect of quality of life. Therefore health care providers must be prepared to assess problems in this area and provide guidance related to treatment and resumption of sexual activity. Health care providers must be proactive in providing information in a timely manner because the literature reveals that well-informed cancer survivors are better at coping with their situation (Klee, Thranov & Machin, 2000:12; Flay & Mathews, 1995:403).

Christopher and Marrow (2004:101, 102), have reported that an exercise intervention programme in women cancer survivors can also improve psychological and social well-being. Exercising will result in improved physical capacity, decreased fatigue and controlled weight gain, effects that have been reported to negatively affect quality of life if not addressed. Exercise intervention has also been recommended by other authors as it improves emotional well-being, self-esteem and decreases anxiety and depression, thus improving the overall quality of life in survivors (Knobf, Musanti & Dorward, 2007:285-296; Spence, Heesch & Brown, 2010:185-194; Courneya, Vallance, McNeely, Karvinen, Peddle & Mackey, 2004:249-261).
2.8. CONCLUSION

As can be seen from the literature reviewed, the treatment for cancer of the cervix poses special challenges in terms of quality of life. Given the challenges and changes that women must face after a diagnosis and treatment of gynaecologic cancers such as cancer of the cervix, quality of life is an especially pertinent issue which needs more attention. The comprehensive care of cervical cancer patients requires not only curative efforts but also attention to the physical, social, emotional and functional needs of the patients and their families. This is because of the considerable impact of the treatment on the physical, functional and psychological states of the patients. To minimize morbidity and improve the quality of life of patients treated for cervical cancer, intervention programmes are necessary. Therefore, health care professionals need to pay attention not only to life prolongation but also need to identify any problems in the quality of life after cervical cancer treatment in order to be able to design cost-effective and useful intervention programmes that could be used to improve and maintain QoL.
CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

The aim of this study was to evaluate the impact of chemo-radiation treatment on quality of life and to determine which socioeconomic and demographic factors are closely related with quality of life decrements in Zambian women treated at Cancer Diseases Hospital for cervical cancer.

In this chapter the research design is described that was employed to meet the research aim described above. The methods and materials used will be outlined below, and then the research procedure and data analysis will be presented.

3.2 RESEARCH DESIGN

Research design is the set of logical steps taken by the researcher to answer the research question. It forms a plan outlining how information is to be gathered for an assessment or evaluation that includes identifying the data gathering methods, the instruments to be used, how the instruments will be administered, and how the information will be organized and analyzed (Creswell, 2009:3; Der Walt & Rensburg, 2007:92).

In this study, a quantitative, descriptive, contextual study design was utilised. This design involved techniques that are used to gather numeric data (Cresswell, 2009:4). This design was selected because of the nature of the research problem which was
an empirical investigation into QoL. A quantitative research design was used for the purpose of generating and organizing numerical data into a meaningful theory.

3.2.1 Descriptive research

Descriptive design is a way of obtaining complete and accurate information about the phenomenon within a particular field of study through description and documentation. Descriptive design provides a picture of the phenomenon as it occurs naturally (Der Walt & Rensburg, 2007:102). In this study a descriptive approach was followed in order to obtain complete and accurate information from a representative sample of participants about their experiences after chemo-radiation therapy treatment using a questionnaire.

3.2.2 Contextual design

In a contextual research strategy, the phenomenon is studied because of its immediate contextual significance (Mouton, 1996:133). Contextual studies involve situating the phenomenon of the study within its immediate setting, therefore in this research the focus was on the experiences of CDH cancer of the cervix patients post chemo-radiation.

3.3 METHODS AND MATERIALS

3.3.1 Data collection tool

A quantitative data collection method inquiring about Zambian women’s quality of life after chemo-radiotherapy was used to prospectively collect data. This was in the
form of a structured EORTC CQL-30 questionnaire (Annexure 1), a validated questionnaire that is reproducible for this type of study. This questionnaire was identified through an extensive literature search that was conducted to obtain information on data collection tools for assessment of QoL. This tool was considered appropriate because its structure met the objectives of the current study.

The questionnaire was made available to participants in English because English is one of Zambia’s official languages and most women were able to use this instrument with minimal assistance. However, patients who had problems with understanding and writing were assisted by research assistants who were used as translators in the four most commonly used languages (Nyanja, Tonga, Bemba & Lozi). Research assistants were used in order to avoid any bias on the part of the researcher and they were trained by the researcher.

The questionnaire was based on items covering all quality of life fields which include physical, social, functional and emotional well-being. All the questions were clearly presented to the patients as being oriented towards evaluating the effects of the cancer and its treatment on their lifestyle. Information on sociodemographic issues such as educational status, marital status, employment, age, race and religion were obtained from the patients’ files (Annexure 2). This demographic data was needed because it has been shown to influence the QoL outcomes post treatment. The patients’ files also provided medical information which aided in evaluating the effects of treatment; however, patients were also interviewed to confirm any treatment effects as reported by the physician.
Late treatment-related side effects were prospectively reported by oncologists clinically and as reported by patients during follow-up visits. For the purpose of this study, the researcher used 12 months follow-up recorded side effects and respondents were asked by the researcher to confirm if they were experiencing any treatment side effects as described by the oncologists in the medical files.

The questionnaire consisted of 31 statements that participants had to respond to by using a 4-point Likert scale to rate their general feeling in terms of an A-E scale. This scale is also called a summative scale and consists of questions that are easy to understand and lead to consistent answers (Likert, 1932:1-55). The rating on the scale describes the extent each statement applies to a patient. For example, the statement “I am satisfied with my sex life” is rated according to the following:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Responses 0 and 1 (not at all and a little bit) will describe negative experiences, 2 (somewhat) will indicate fair, while 3 to 4 (quite a bit and very much) will indicate more positive experiences. Other general statements questionnaires use an alphabetical order, and statements are rated from A to E, with D to E describing negative experiences/feelings.

Only completed questionnaires were considered for data analysis. However, the questionnaire contained a section that dealt specifically with sexual issues. This section was optional, and compulsory completion of this section was not a
requirement. Therefore, questionnaires where this section was not completed were nevertheless accepted.

3.3.2 The pilot study

In an attempt to test the understanding of this questionnaire by patients in the study group, the questionnaire was first administered to ten patients in a pilot study. The pilot study was conducted before the main research took place in order to check feasibility as well as to improve the design of the research (Haralambos & Holborn, 2000:998). From the pilot study, the researcher established that the sections contained in the questionnaire fitted well within the objectives of the study.

This pilot study was conducted twice - prior to chemo-radiotherapy and at the end of chemo-radiotherapy on the relevant population. The patients that participated in the pilot study were excluded from the research.

Based on the observations from the pilot study, no modifications were made to the questionnaire. However, information concerning patients' demographics (marital status, education, employment, income, religion) as taken from patients' files was added. Although the questionnaire included instructions for its completion, the researcher nevertheless also verbally explained the instructions to those participants who needed further clarification on certain sections in the questionnaire.

3.3.3 Data collection procedure

3.3.3.1 Selection of patients

A convenient sampling method, as described by Der Walt and Rensburg (2007:132-133) was used for selecting patients for inclusion in the study. However, the limitations of convenience sampling are acknowledged by the researcher.
The selection of patients was limited to those patients treated between 2009 and 2010 for biopsy-proven and FIGO stage 1Bii – Iva cancer of the cervix at CDH. Participants aged between 20 and 70 years were recruited for the study. The patients were prescribed to receive chemotherapy and a full course of radiotherapy to a total dose of 46 – 50 Gy in 23 – 25 fractions respectively (2 Gy/fraction) with intracavitary radiation treatment (4 fractions at 6.5 Gy/fraction or 3 fractions at 8 Gy/fraction). This group of patients was selected because they were expected to be a representative sample of the population of Zambian women treated with chemoradiotherapy for cervical cancer.

Statistically, a representative sample size was considered to be 64 patients from a population of an average of 304 patients treated annually at CDH for cancer of the cervix. The first 64 patients that came for simulation and treatment for cancer of the cervix stage I-IV between February, 2009 and February, 2010 were approached to participate in the study.

The sample size was designed using a guide advocated by Welman and Kruger (1994: 63), and in consultation with a statistician. The authors suggest that the following should be well thought out when the sample size is determined:

- the size of the population (N),
- the fact that the number of units of analysis from which usable data is obtained may be much smaller than the number that was drawn originally, and;
- the variation (heterogeneity) of the variables (Welman & Kruger, 1994 : 64).

The required sample size was therefore calculated as follows:
A. Sample size

\[ SS = \frac{Z^2(P)(1-P)}{C^2} \]

Where:

\[ Z = Z \text{ value (1.96 for 95\% confidence level)} \]
\[ P = \text{percentage picking a choice, expressed as decimal (0.5 used for sample size needed)} \]
\[ C = \text{confidence interval, expressed as a decimal} \]

Using the above, \[ SS = 1.96^2 (0.5) (1-0.5) / 0.05^2 = 384 \]

B. Correction for CDH finite population

On average, cervical cancer patient population according to CDH hospital reports was 304. Approximately 63 patients were HIV –ve and were used as a number for the finite population using the following formula:

\[ \text{New ss} = \frac{SS}{((SS-1)/\text{pop}+1)} \]

Where:

New ss - actual sample size
SS- infinite sample size
Pop- finite population

Therefore, \[ \text{New ss} = \frac{384}{((384-1)/63 +1)} = 64.1 \approx 64 \]

Hence 64 were obtained as sample size for the study.

3.3.3.2 Procedure

Participants received the questionnaire at two points: before chemo-radiotherapy (during simulation) and at 12 months post treatment at the follow-up clinic. The
standard follow-up schedule at Cancer Diseases Hospital is that patients are seen at the completion of the treatment and again at, 1, 3, 6, and 12 months post treatment. Twelve months post treatment follow-up was chosen because it was assumed that participants would be able to provide sufficient information concerning incidences of late treatment complications and changes in QoL at this stage. In addition, the 12-month follow-up period was selected due to time and financial implications of the study as the student’s masters programme required submission of final dissertation results within a specified period of time. The questionnaire administered before treatment was used to determine the participants’ baseline QoL measure. Every Tuesday all patients booked for simulation and who met the inclusion criteria and consented to participate in the study were given questionnaires by the researcher or research assistant at simulation. Tuesday is the specific day when CDH attends to cancer of the cervix patients simulations. The questionnaire was explained and patients were asked to fill in the QoL questionnaire in order to obtain baseline information on their quality of life before treatment.

Patients who were unable to read and write were helped by the research assistant to complete the questionnaires. Patients were asked to complete the baseline questionnaires at simulation in order to ensure a maximum response rate. Identification of eligible patients was easily achieved through the use of the hospital data base which details type of cancer, prescribed treatment, and when patients are due for simulation. Patients answered the post-treatment questionnaire during their follow-up clinics at 12 months.
3.3.3.3 The data

The study included data of two kinds: primary and secondary data. Primary data was obtained from the responses of the patients to the questionnaires. Patients had to complete a validated quality-of-life EORTC QLQ-C30 questionnaire (Appendix 1) which was chosen as a method of data collection to provide information about physical, psychological and social function. Secondary data was in the form of review of patients' oncology files. Data retrieved from the patient's files included details about medical and sociodemographic issues. Only the responses from patients who met the inclusion criteria and returned completed questionnaires were considered.

3.4 DATA ANALYSIS

The study was designed to evaluate the impact of chemo-radiation treatment on quality of life and to determine what socioeconomic and demographic factors are closely related with quality of life decrements in Zambian women treated at Cancer Diseases for cervical cancer. Descriptive data analyses were used as the primary statistical analysis tool to report demographics and quality of life changes in women treated with chemo-radiation for cervical cancer. Care was taken to avoid manipulation of variables so as to have a meaningful outcome. According to Brink (2007:104), a descriptive study is intended to describe a phenomenon. The researcher does not manipulate any variables, and makes no effort to determine the relationship between variables. The researcher merely searches for accurate information about the characteristics or the frequency of a phenomenon's
occurrence. This approach, therefore, allowed searching for accurate information about quality of life issues experienced by study participants.

The EORTC-QLQ-C30 questionnaire was used to collect data that was then analysed by the statistician. This was accomplished by using frequency tables and cross-tabulations to correlate the data with the QoL scores of the study group. Descriptive statistics were used to describe and summarize identified variables in the form of tables, frequency distributions and pie charts. In this study the Statistical Package for the Social Sciences (SPSS) was used to analyse the data. Chi-square tests were used to indicate the strength and direction of the relationship between variables and the level of significance. A p-value of 0.05 was used to define the chosen level of statistical significance. Statistical significance was defined as a Pearson's chi-square p-value < 0.05. A p-value > 0.05 indicated that there is no difference between the variables.

3.5 VALIDITY AND RELIABILITY OF RESEARCH PROCESS

Reliability is the consistency of measurement, or the degree to which an instrument measures the same way each time it is used under the same condition. In other words, reliability is finding out the likelihood that the study reports something that is reproducible (Der Walt & Rensburg, 2007:163). There are two ways that reliability is usually estimated: test/retest and internal consistency. For the purpose of this study, internal consistency was used in order to address the extent to which all items on the instrument measured the same variable. Studies that have used the data collection tool used in the current study have shown good internal consistency. In the
questionnaire used in the study, the assessment of internal consistency using Cronbach’s alpha evaluated reliability (Fu-Min et al. 2004:1396).

Validity is an assessment of how well the data collecting instrument represents all the components of the variables to be measured (Der Walt & Rensburg, 2007:160). The instrument used for this research captured all the relevant variables that were in line with the objectives of the study. This instrument has been used by other researchers and is said to be extensively validated (Klee, Thranov & Machin, 2000:6) (see Table 2.4 above). It was thus established that relationships between variables would be measured. In addition, validity of the research process was established by adhering to specific inclusion criteria for the study sample selection. The selection was conducted by the researcher and a research assistant who was also a qualified nurse. The pilot study conducted prior to the research study was another method by means of which validity was established.

3.6 ETHICAL CONSIDERATIONS

When conducting research on human subjects, ethical considerations are critical to minimize harms and risks, respect human dignity, privacy and autonomy. Ethical considerations also help in taking special precautions with vulnerable populations and strive to distribute the benefits and burdens of research fairly (Resnik, 2009; Responsible conduct of research: 2011). This study had no effect on the treatment options of the patients and had no deleterious effects on the patient. The following ethical issues were taken into consideration. Permission to use the EORTC QLQ-C30 was obtained from the Quality of Life unit (Annexure 8). The study was approved by the Faculty of Health Sciences at the University of Johannesburg and the Academic Ethics Committee (Annexures 6 and 7). Permission for the
performance of the study was obtained from CDH because the study involved the use of patient records. Data was only collected after permission had been granted (Annexures 3 and 4).

Eligible patients received a letter of invitation that described the study and requested their participation (Annexure 4). Informed consent was obtained from all the women who agreed to participate in the study. To ensure confidentiality, no patient names appeared on the questionnaires; instead, number coding was assigned to the questionnaires for easy processing of data (Berg, 1995:213). Completed questionnaires were confidentially kept by the researcher and access to the completed questionnaires was restricted to the researcher and the research assistant only.

Patients were informed that there were no risks in participating in the study and that their medical care would not be affected regardless of whether they took part in the study or not. No patients were forced to participate in the study and participants were free to withdraw from the study at any time.
3.7 CONCLUSION

For the purpose of this study, a quantitative, descriptive, contextual study design was used. Data was captured using the EORTC QLQ-C30 questionnaire administered to patients before treatment and at 12 months post treatment. Demographic data was captured from the participants’ treatment files. The results of the study are presented in chapter 4.
CHAPTER 4

RESULTS OF THE STUDY

4.1 INTRODUCTION

In this chapter the results of the QoL questionnaires are presented. Descriptive and inferential statistics have been used in the presentation of the results based on the results from frequency distributions and cross-tabulations. Tables, graphs and charts are used in some instances to display the results.

4.2 RESPONDENTS’ CHARACTERISTICS

Pre-treatment data was obtained for all of the participants recruited into the study (n=64). As the study was prospective there was a decreasing proportion of patients who completed the questionnaires with time. At 12 months post treatment, a response rate of 70.4% was achieved (n=45). Nineteen questionnaires were excluded for the study for the following reasons. Four questionnaires were not completed because of the patients’ bad health, six participants expressed a wish to withdraw from the study, another six participants missed the designated deadline for completing the questionnaire, and three participants died for reasons unknown.

4.2.1 STAGE OF DISEASE FOR RESPONDENTS (n=45)

Twenty-five (53.3%) of the participants presented with stage II disease at the beginning of the study, 42.2% (n=19) presented with stage III disease, while 4.4% (n=2) presented with stage I disease. All the respondents were treated radically with either a Linear accelerator 6 MV or Co-60 with chemotherapy. Follow-up data was
collected at 12 months post treatment to assess any side effects that could affect the respondents’ quality of life.

Table 4.1  Frequency distribution of respondents by disease stage

<table>
<thead>
<tr>
<th>STAGE</th>
<th>FREQUENCY (n)</th>
<th>PERCENT (%)</th>
<th>CUMULATIVE PERCENT (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>2</td>
<td>4.4</td>
<td>4.4</td>
</tr>
<tr>
<td>II</td>
<td>24</td>
<td>53.3</td>
<td>57.7</td>
</tr>
<tr>
<td>III</td>
<td>19</td>
<td>42.2</td>
<td>100</td>
</tr>
</tbody>
</table>

4.3  SOCIODEMOGRAPHIC DATA

The sociodemographic data of the respondents which was relevant in this study included age, marital status, occupational status, educational status and religion. The information provided the researcher with a better understanding of how these sociodemographics may influence the QoL of cancer of the cervix women post chemo-radiotherapy.

4.3.1  Age (n=45)

The respondents were grouped into age ranges as shown in the figure below.
Figure 4.1  Frequency distribution of respondents by age

The results show that a high percentage (84%) of respondents were women in the category of over 41 years.

4.3.2 Marital status (n=45)

Participants’ marital status was obtained from their medical files. The marital status distribution is depicted in Figure 4.2 below.
As indicated in the results, the majority of the respondents with regard to marital status were married (52%) followed by the widowed category (34%).

4.3.3 Level of education (n=45)

This variable (education status) was selected to evaluate its impact on QoL measures in women treated for cancer of the cervix. The education status frequency table is shown in Table 4.3.
As shown in Figure 4.3 above, the educational background of most of the respondents was below college education (96%).

4.3.4 Occupational status (n=45)

The researcher was required to choose the category of participants’ occupational status as literature indicates in some instances that cancer of the cervix survivors who have difficulties with finances report QoL problems (Cull et al. 1993:1216-1220). Figure 4.4 below shows the results of occupational status.
With regard to employment, most of the respondents were unemployed (86.4%).

4.3.5 Income (n=45)

Almost all the respondents were unemployed as was indicted in participants’ medical record files.

4.4 SIDE EFFECTS OF CHEMO-RADIATION THERAPY 12 MONTHS POST TREATMENT (n= 45)

Information about any side effects experienced by the respondents was obtained from their medical record files. According to Berclaz et al. (2002:1313), chemo-radiation therapy has been associated with several physical and functional effects that negatively impact on quality of life. For this reason respondents were asked to confirm if they were experiencing any treatment side effects as indicated by the
oncologists in the medical files to evaluate the impact on QoL. Recorded side effects are presented in Table 4.2.

Table 4.2 Late toxicity of chemo-radiotherapy 12 months post treatment

<table>
<thead>
<tr>
<th>TOXICITY</th>
<th>PATIENTS (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GIT complications</strong></td>
<td></td>
</tr>
<tr>
<td>Radiation proctitis</td>
<td>2</td>
</tr>
<tr>
<td>Rectal bleeding (intermittent)</td>
<td>1</td>
</tr>
<tr>
<td>Rectovaginal fistula</td>
<td>2</td>
</tr>
<tr>
<td>Constipation</td>
<td>1</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>2</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>1</td>
</tr>
<tr>
<td><strong>Urological complications</strong></td>
<td></td>
</tr>
<tr>
<td>Dysuria</td>
<td>3</td>
</tr>
<tr>
<td><strong>Sexual complications</strong></td>
<td></td>
</tr>
<tr>
<td>Coital bleeding</td>
<td>2</td>
</tr>
<tr>
<td>Vaginal dryness</td>
<td>4</td>
</tr>
<tr>
<td>Vaginal shortening/narrowing</td>
<td>8</td>
</tr>
<tr>
<td><strong>Other complications</strong></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>27</strong></td>
</tr>
</tbody>
</table>

Out of 45 respondents, 20% (n=9) complained of gastrointestinal complications, 6.6% (n=3) experienced urological problems, 2.2% (n=1) reported fatigue and 31%
(n=14) sexual function problems. Although 60% of respondents reported side effects, most of the respondents reported that they were not bothered by the side effects. However, two respondents with rectovaginal fistulas reported difficulties in meeting family needs, although not statistically significant (p=0.0820).

4.5 QUALITY OF LIFE

The questionnaire included assessments on physical, social, emotional and functional well-being, including general questions to determine patients’ health status and their quality of life. Demographic variables (age, marital status, level of education, religion and occupation) potentially believed to affect the QoL outcomes were tested for their influence on the above indicated QoL subscales.

To determine whether respondents’ QoL was affected, the questionnaire was administered at two points: before and after treatment. The pre-treatment questionnaire was to check respondents’ baseline QoL which could then be compared to post-treatment QoL.

4.5.1 Physical well-being

Associations between physical well-being outcome measures (energy, pain, treatment side effects and trouble meeting family needs) and demographic variables (age, marital status, level of education, religion and occupation) were tested. P>0.05 indicated a strong association and P <0.05 indicated a weak association. Tables 4.3 – 4.6 reflect the findings.
Table 4.3 Chi-square test for effect of age on physical well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Age group</th>
<th>I have lack of energy</th>
<th>I have pain</th>
<th>I am bothered by side effects</th>
<th>Trouble meeting family needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 45 years</td>
<td>P=0.5987</td>
<td>p=0.0820</td>
<td>p=0.5987</td>
<td>p=0.0820</td>
</tr>
<tr>
<td>46-50</td>
<td>p=0.1116</td>
<td>p=0.1991</td>
<td>p=0.2203</td>
<td>p=0.3115</td>
</tr>
<tr>
<td>51-55</td>
<td>p=1.0000</td>
<td>p=0.1991</td>
<td>p=0.4795</td>
<td>P=0.1116</td>
</tr>
<tr>
<td>56-60</td>
<td>p=0.1116</td>
<td>p=0.2770</td>
<td>p=0.7530</td>
<td>p=1.1116</td>
</tr>
<tr>
<td>61-65</td>
<td>p=0.0271</td>
<td>p=0.4429</td>
<td>p=0.2318</td>
<td>p=0.4969</td>
</tr>
</tbody>
</table>

No statistical difference was noted suggesting that age is not a variable that affects QoL from a physical well-being perspective. However, eight respondents in the age group 61-65 years who had reported lack of energy at the beginning of chemo-radiotherapy had higher energy levels after treatment and were able to carry out housework (p=0.0271).

Table 4.4 Chi-square test for effect of marital status on physical well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Marital status</th>
<th>I have lack of energy</th>
<th>I have pain</th>
<th>I am bothered by side effects</th>
<th>Trouble meeting family needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>P=0.3235</td>
<td>P=0.1863</td>
<td>P=0.5218</td>
<td>P=0.4137</td>
</tr>
<tr>
<td>Widowed</td>
<td>P=0.3235</td>
<td>P=0.6524</td>
<td>P=0.4074</td>
<td>P=0.4376</td>
</tr>
<tr>
<td>Divorced</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P= 0.5000</td>
</tr>
<tr>
<td>Separated</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
</tr>
<tr>
<td>Single</td>
<td>P=1.0000</td>
<td>P= 0.2231</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
</tr>
</tbody>
</table>
When physical well-being items were measured before and after treatment and correlated with marital status, the physical well-being score was not affected by marital status at both points of completing the questionnaire. Results indicated no significant differences and associations (see Table 4.4). However, although not statistically significant, married and widowed women reported better physical well-being at 12 months post treatment.

**Table 4.5 Chi-square test for effect of occupational status on physical well-being before and after chemo-radiation**

<table>
<thead>
<tr>
<th>Occupational status</th>
<th>I have lack of energy</th>
<th>I have pain</th>
<th>I am bothered by side effects</th>
<th>Trouble meeting family needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Un-employed</td>
<td>P=0.2117</td>
<td>P=0.5120</td>
<td>P=0.5245</td>
<td>P=0.2896</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
</tr>
<tr>
<td>Full-time employment</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
</tr>
</tbody>
</table>

The findings in Table 4.5 above show no significant influence of occupational status on physical well-being. Although not statistically significant, the unemployed group in this study showed difficulties with energy and trouble meeting family needs (p=0.2117 and 0.2896 respectively).
Table 4.6 Chi-square test for effect of education on physical well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Educational status</th>
<th>I have lack of energy</th>
<th>I have pain</th>
<th>I am bothered by side effects</th>
<th>Trouble meeting family needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>P=0.1013</td>
<td>P=1.0503</td>
<td>P=0.2213</td>
<td>P=0.04225</td>
</tr>
<tr>
<td>Primary school</td>
<td>P=0.1013</td>
<td>P=0.0820</td>
<td><strong>P=0.04225</strong></td>
<td>P=0.2213</td>
</tr>
<tr>
<td>High school</td>
<td>P=1.4852</td>
<td>P=0.7755</td>
<td>P=0.9798</td>
<td>P=0.1147</td>
</tr>
<tr>
<td>College</td>
<td>P=1.0000</td>
<td>P=0.1991</td>
<td>P=0.6872</td>
<td>P=0.1116</td>
</tr>
</tbody>
</table>

When correlated with educational status, results showed that fewer educated respondents experienced problems with treatment side effects (p=0.04225).

4.5.2 Social well-being (n=45)

Factors pertaining to social well-being of respondents assessed relationships with partners, friends, emotional support and whether respondents were satisfied with the way they communicated about their illness with others. Correlations were used to assess relationships between QoL outcome measures with regard to social well-being and demographic variables (age, marital status, level of education, religion and occupation). The results are presented in Table 4.7 below.
Table 4.7 Chi-square test for effect of age on social well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Age group</th>
<th>Close to friends</th>
<th>Emotional support</th>
<th>Satisfied with family’s communication about illness</th>
<th>Feel closer to partner</th>
<th>Difficulty with sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;45 years</td>
<td>P=1.000</td>
<td>P=0.2206</td>
<td>P=0.8208</td>
<td>P=0.0455</td>
<td>P=0.0404</td>
</tr>
<tr>
<td>46-50</td>
<td>P=0.4978</td>
<td>P=0.02534</td>
<td>P=0.1572</td>
<td>P=0.1533</td>
<td>P=0.2614</td>
</tr>
<tr>
<td>51-55</td>
<td>P=1.000</td>
<td>P=0.0253</td>
<td>P=1.000</td>
<td>P=0.2691</td>
<td>P=0.0497</td>
</tr>
<tr>
<td>56-60</td>
<td>P=0.3271</td>
<td>P=0.1572</td>
<td>P=0.0253</td>
<td>P=0.1138</td>
<td>P=0.0497</td>
</tr>
<tr>
<td>61-65</td>
<td>P=0.0191</td>
<td>P=0.0507</td>
<td>P=0.6176</td>
<td>P=0.0035</td>
<td>P=0.0005</td>
</tr>
</tbody>
</table>

Relationships between age and social well-being variables are shown in Table 4.7. The respondents reported difficulties with their sexual function that was statistically significant in all the age groups except for those between 46-50 years, probably due to the smaller number of respondents in this age group. Respondents who were younger than 45 years reported a statistically significant improvement in the category “feeling closer to my partner” despite reporting sexual difficulties. Those between 45 and 50 years reported an improvement in emotional support, and those between 56 and 60 years reported satisfaction in their communication with family but significant sexual difficulties, while the elderly age group (61-65 years) reported statistically significant better relationships with family and friends but declared difficulties with sexual satisfaction (p-value=0.0005) at 12 months post treatment. Out of eight respondents who were married in this age group, seven reported that they were not satisfied with their sexual life. Five of these women reported painful sex while the
other two reported post-coital bleeding. Significant sexual dissatisfaction was also reported by respondents in the younger age group (p-values<=0.05).

Table 4.8 Chi-square test for effect of marital status on social well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Close to friends</th>
<th>Emotional support</th>
<th>Satisfied with family’s communication about illness</th>
<th>Feel closer to partner</th>
<th>Difficulties with sexual function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>P=0.0025</td>
<td>P=0.00018</td>
<td>P=0.3241</td>
<td>P=0.0041</td>
<td>P=0.0802</td>
</tr>
<tr>
<td>Widowed</td>
<td>P=0.0037</td>
<td>P=0.1789</td>
<td>P=1.0000</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Divorced</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Separated</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Single</td>
<td>P=1.0000</td>
<td>P=0.1991</td>
<td>P=1.0000</td>
<td>P=0.2231</td>
<td>P=1.0000</td>
</tr>
</tbody>
</table>

N/A = Not Applicable

The respondents who were married and widowed indicated closer relationships with friends (p=0.0025 and 0.0037 respectively). Married women also showed positive support from their partners (p=0.0041). With regard to emotional support, the married women reported better emotional support from their families (p=0.0018) than other marital status categories. The social well-being score was found to be significantly influenced by marital status, with married women showing better relational scores.
Table 4.9 Chi-square test for effect of occupational status on social well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Occupational status</th>
<th>Close to friends</th>
<th>Emotional support</th>
<th>Satisfied with family’s communication about illness</th>
<th>Feel closer to partner</th>
<th>Difficulties with sexual function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>P=0.0011</td>
<td>P=0.0000</td>
<td>P=0.0760</td>
<td>P=0.0000</td>
<td>P=0.0050</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
</tr>
<tr>
<td>Full-time employment</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=1.0000</td>
<td>P=0.2500</td>
<td>P=0.2500</td>
</tr>
</tbody>
</table>

The results presented in Table 4.9 indicate that employment have an influence on social well-being. The unemployed respondents reported a significantly better social life with closer relationships with friends, emotional support and closeness to partners but had significant sexual problems.

Table 4.10 Chi-square test for effect of educational status on social well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Educational Status</th>
<th>Close to friends</th>
<th>Emotional support</th>
<th>Satisfied with family’s communication about illness</th>
<th>Feel closer to partner</th>
<th>Difficulties with sexual function</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>P=0.0253</td>
<td>P=0.0904</td>
<td>P=0.1846</td>
<td>P=0.0122</td>
<td>P=0.0035</td>
</tr>
<tr>
<td>Primary school</td>
<td>P=0.0253</td>
<td>P=0.0904</td>
<td>P=0.3181</td>
<td>P=0.0122</td>
<td>P=0.00351</td>
</tr>
<tr>
<td>High school</td>
<td>P=0.0182</td>
<td>P=0.0000</td>
<td>P=0.2714</td>
<td>P=0.0000</td>
<td>P=0.0823</td>
</tr>
<tr>
<td>College</td>
<td>P=1.000</td>
<td>P=1.000</td>
<td>P=1.000</td>
<td>P=1.000</td>
<td>P=1.000</td>
</tr>
</tbody>
</table>
High level education status was reported only by a minority of respondents. Most of the respondents had reached an education up to high school or less. The results of this study showed no statistical significance in social well-being in the respondents with higher education although the numbers of respondents to confirm this finding was too small with only 4% (2 of 45) having had an education at college level. Social well-being was still found to be good in less educated respondents and this could also be related to strong family ties as most of the women in this group were married and reported satisfied relationships with friends, family and partner (Table 4.10). However, those in the categories of uneducated and primary level education reported significant difficulties (p=0.0035) with sexual function while no difference was observed in the educated respondents concerning sexual functioning (p=0.0035).

4.5.3 Emotional well-being (n=45)

Emotional well-being factors assessed included issues of depression, sad feeling, coping, worrying and concerns about dying. These items were rated as to how true each statement was true before and after chemo-radiotherapy from 0 (not at all) to 4 (very much). To further examine correlates of chemo-radiotherapy related emotional well-being problems, chi-square tests were conducted to assess relationships with respect to demographic variables (age, marital status, level of education, religion and occupation). The results are presented in tables 4.11 to 4.15.
Table 4.11 Chi-square test for effect of age on emotional well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Age group</th>
<th>Feeling sad</th>
<th>Coping with illness</th>
<th>Feeling nervous</th>
<th>Worrying</th>
<th>Feeling depressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 45 years</td>
<td>p=1.0000</td>
<td>p=0.04550</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
<tr>
<td>46-50</td>
<td>p=0.0619</td>
<td>p=0.1735</td>
<td>p=0.1473</td>
<td>p=0.04978</td>
<td>p=0.04978</td>
</tr>
<tr>
<td>51-55</td>
<td>p=0.0253</td>
<td>p=0.0253</td>
<td>p=0.0253</td>
<td>p=0.0253</td>
<td>p=0.0253</td>
</tr>
<tr>
<td>56-60</td>
<td>p=0.1116</td>
<td>p=0.0497</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
<tr>
<td>61-65</td>
<td>p=0.0008</td>
<td>p=0.0972</td>
<td>p=0.0617</td>
<td>p=0.0296</td>
<td>p=0.0599</td>
</tr>
</tbody>
</table>

Relationships between age and emotional well-being concerns are shown in Table 4.11. The results of the study showed a significant impact of chemo-radiotherapy on emotional well-being mostly in respondents above 50 years. Psychological problems were reported by respondents above the age of 50 years who reported a sad feeling (p=0.0296, 0.0008) and declared feeling worried (p=0.0253, 0.0296) when emotional well-being items were measured 12 months post treatment. Although younger respondents reported fewer coping problems, fewer worries and fewer depressive symptoms (p=0.04550, 0.04978, 0.04978 respectively), it was seen that little information about the treatment and its effects negatively influenced the emotional well-being subscales. In this study, it was found that chemo-radiotherapy impacted more negatively on the emotional well-being of the elderly respondents than was the case with younger women.
Table 4.12 Chi-square test for effect of marital status on emotional well-being items before and after chemo-radiation

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Feeling sad</th>
<th>Coping with illness</th>
<th>Feeling nervous</th>
<th>Worrying about dying</th>
<th>Feeling depressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>$p = 0.04117$</td>
<td>$p = 0.00305$</td>
<td>$p = 0.0000$</td>
<td>$p = 0.01184$</td>
<td>$p = 0.01448$</td>
</tr>
<tr>
<td>Widowed</td>
<td>$p = 0.00468$</td>
<td>$p = 0.03803$</td>
<td>$p = 0.07304$</td>
<td>$p = 0.03074$</td>
<td>$p = 0.00055$</td>
</tr>
<tr>
<td>Divorced</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
</tr>
<tr>
<td>Separated</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
<td>$p = 1.0000$</td>
</tr>
<tr>
<td>Single</td>
<td>$p = 0.1991$</td>
<td>$p = 0.1991$</td>
<td>$p = 1.0000$</td>
<td>$p = 0.22313$</td>
<td>$p = 1.0000$</td>
</tr>
</tbody>
</table>

Relationships between marital status and emotional well-being concerns are shown in Table 4.12. Respondents who were married reported fewer sad feelings ($p = 0.0411$), fewer coping problems ($p = 0.0030$), fewer worries ($p = 0.0118$), and less depression after treatment ($p = 0.0144$). These findings were similar to the tendency seen in the widowed group except for this group reporting more nervous symptoms ($p = 0.073$). Although the number of single women in the study group was small, there was no significant difference in their emotional well-being. The results of this study show that chemo-radiotherapy had a positive emotional impact on married and divorced women.
To determine whether there were relationships between emotional well-being changes and occupational status of respondents, further analysis was done and the results are presented in Table 4.13. As reflected in the demographics, 86% of respondents were unemployed and emotional well-being was found to have improved in these women as indicated in Table 4.13. However, the number of respondents in the employed group was too small for a comparison to be made and to conclude the findings.

Table 4.14 Chi-square test for effect of educational status on emotional well-being items before and after chemo-radiation

<table>
<thead>
<tr>
<th>Educational status</th>
<th>Feeling sad</th>
<th>Coping with illness</th>
<th>Feeling nervous</th>
<th>Worrying</th>
<th>Feeling depressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>p=0.2337</td>
<td>p=0.0503</td>
<td>p=0.0285</td>
<td>p=0.0289</td>
<td>p=0.0657</td>
</tr>
<tr>
<td>Primary school</td>
<td>p=0.23371</td>
<td>p=0.05038</td>
<td>p=0.02853</td>
<td>p=0.02890</td>
<td>p=0.06578</td>
</tr>
<tr>
<td>High school</td>
<td>p=0.02946</td>
<td>p=0.00244</td>
<td>p=0.00643</td>
<td>p=0.0001</td>
<td>p=0.00063</td>
</tr>
<tr>
<td>College</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
</tbody>
</table>
There was no statistically significant difference in the feeling of sadness in the respondents (Table 4.14). The high school respondents, however, reported fewer sad feelings than those who had primary school education and less. With regard to coping, respondents indicated better coping scores at the beginning of the study. However, the number of respondents who reported better coping skills with the illness at the end of treatment decreased significantly in the respondents with lower levels of education (p=0.0503). Less educated women experienced more problems with coping, worry, and were more nervous than those with high school education. The emotional well-being in the respondents at high school level was observed to have improved significantly after chemo-radiotherapy.

4.5.4 Functional well-being (n=45)

The impact of chemo-radiotherapy on functional well-being was assessed in 45 respondents. Items concerning functional well-being that were measured included ability to work, work fulfilment, ability to enjoy life, sleeping habits and life acceptance. To determine whether demographics (age, marital status, level of education, religion and occupation) had an impact on functional well-being problems, correlates of functional well-being items and demographics were analyzed and the findings are presented in the tables below.
Table 4.15 Chi-square test for effect of age on functional well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Able to work</th>
<th>Fulfilling work</th>
<th>Able to enjoy life</th>
<th>Have accepted illness</th>
<th>Sleeping well</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;45</td>
<td>p=0.0455</td>
<td>p=0.0455</td>
<td>p=0.2206</td>
<td>p=0.0820</td>
<td>p=0.0820</td>
</tr>
<tr>
<td>46-50</td>
<td>p=0.0619</td>
<td>p=0.0619</td>
<td>p=0.2133</td>
<td>p=0.1223</td>
<td>p=0.2381</td>
</tr>
<tr>
<td>51-55</td>
<td>p=0.0455</td>
<td>p=0.2691</td>
<td>p=1.000</td>
<td>p=0.5134</td>
<td>p=0.1728</td>
</tr>
<tr>
<td>56-60</td>
<td>p=0.0497</td>
<td>p=0.4231</td>
<td>p=0.1991</td>
<td>p=0.3011</td>
<td>p=0.2203</td>
</tr>
<tr>
<td>61-65</td>
<td>p=0.5248</td>
<td>p=0.0328</td>
<td>p=0.0642</td>
<td>p=0.1826</td>
<td>p=0.1062</td>
</tr>
</tbody>
</table>

Respondents below the age of 45 years reported fewer problems with carrying out daily activities when their work ability scores were measured after treatment (p=0.0455). Those women who reported difficulties in performing their daily life activities before treatment were able to work at home after chemo-radiotherapy and four women indicated that their work was fulfilling (p=0.0455). Respondents between the age of 51-55 years and 56-60 years also reported significant results in the ability to work (p=0.0455 and 0.0497 respectively) although they found their work not fulfilling. There was no significant difference observed in the functional well-being in elderly women before and after treatment. However, out of 19 respondents in the age group 60 - 65 years, six indicated need for help with their daily household work at 12 months post treatment.
Table 4.16 Chi-square test for effect of marital status on functional well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Able to work</th>
<th>Fulfilling work</th>
<th>Able to enjoy life</th>
<th>Have accepted illness</th>
<th>Sleeping well</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>p=0.00564</td>
<td>p=0.35404</td>
<td>p=0.4555</td>
<td>p=0.00478</td>
<td>p=0.05783</td>
</tr>
<tr>
<td>Widowed</td>
<td>p=0.29767</td>
<td>p=0.05844</td>
<td>p=0.19083</td>
<td>p=0.00757</td>
<td>p=0.26155</td>
</tr>
<tr>
<td>Divorced</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
<tr>
<td>Separated</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
<tr>
<td>Single</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=0.22313</td>
<td>p=0.22313</td>
<td>p=0.22313</td>
</tr>
</tbody>
</table>

When functional well-being was assessed before and after treatment and correlated to find out if marital status had an influence on QoL changes, results indicated fewer problems in carrying out daily duties at 12 months follow-up although respondents reported lack of fulfillment in their work. Ability to work was significant in married women (p=0.005). They reported significantly fewer problems in accepting their condition. Four women were working full-time and two were part-time workers at the beginning of the study. Three who were in full-time employment continued working after three months and one went back to work at five months post treatment. All part-time workers continued working and they all reported fewer problems with carrying out their work. These women also reported high levels of acceptance (p=0.004). Additionally, widows also reported high levels of acceptance (p=0.007), more than before treatment. Sleeping habits, work fulfilment and enjoying life was seen not to be affected by the marital status of respondents (Table 4.16).
Table 4.17 Chi-square test for effect of occupational status on functional well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Occupational status</th>
<th>Able to work</th>
<th>Fulfilling work</th>
<th>Able to enjoy life</th>
<th>Have accepted illness</th>
<th>Sleeping well</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>p=0.19300</td>
<td>p=0.12301</td>
<td>p=0.04097</td>
<td>p=0.01685</td>
<td>p=0.04734</td>
</tr>
<tr>
<td>Part-time employment</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
<tr>
<td>Full-time employment</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=0.25000</td>
<td>p=1.0000</td>
<td>p=0.25000</td>
</tr>
</tbody>
</table>

In the study, those respondents who were unemployed reported better functional well-being with regard to good sleeping habits (p=0.04734), life enjoyment (p=0.04097) and having fewer problems with accepting their life (p=0.01685). More than 50% of unemployed women were married and their better functional well-being could have been due to having better support from their partners. There was no statistical difference in the functional well-being of those who were employed (p=>0.05; however, the number of respondents in these categories was too small to conclude the findings.

Table 4.18 Chi-square test for effect of educational status on functional well-being before and after chemo-radiation

<table>
<thead>
<tr>
<th>Educational status</th>
<th>Able to work</th>
<th>Fulfilling work</th>
<th>Able to enjoy life</th>
<th>Have accepted illness</th>
<th>Sleeping well</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>p=0.3321</td>
<td>p=0.0319</td>
<td>p=0.1566</td>
<td>p=0.4416</td>
<td>p=0.2624</td>
</tr>
<tr>
<td>Primary school</td>
<td>p=0.3321</td>
<td>p=0.03195</td>
<td>p=0.15666</td>
<td>p=0.3452</td>
<td>p=0.2624</td>
</tr>
<tr>
<td>High school</td>
<td>p=0.03092</td>
<td>p=0.28126</td>
<td>p=0.06900</td>
<td>p=0.00589</td>
<td>p=0.05821</td>
</tr>
<tr>
<td>College and university</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
<td>p=1.0000</td>
</tr>
</tbody>
</table>
Out of 45 respondents, more than 50% had a primary education or less. About 33% (n=4) of respondents in the non-educated category indicated satisfaction with the kind of work they did (p=0.0319), while no significant changes were observed in other functional areas of these women. In the high school level category, a significant difference was found in the illness acceptance scale (p=0.0058). Significant results were also noted in respondents in the high school category where better sleeping habits scores were significant (p=0.0582).

4.5.5 Additional concerns

The QoL questionnaire included a section were respondents were asked to report their general concerns. There was no significant difference in the responses at all data collection times with regard to participants’ levels of worry about other members of their families developing gynaecological cancers (p=0.0664). Eighty-nine per cent (n=40) of the respondents reported significantly fewer stress problems (p=0.0118) than before treatment. Forty per cent (n=18) of the participants declared that they felt more feminine after the treatment (p=0.0025).

Of the respondents, 64% (n=29) judged their health status and quality of life as good. Twenty-two per cent (n=10) judged their health status and their QoL as fair, while 4% (n=2) considered their health status and quality of life to be poor at 12 months follow-up. Respondents were generally concerned with the amount of information they received concerning their illness and treatment side effects, which they reported could have been a reason for other women to report negative physical, social, emotional or functional well-being.
4.6 CONCLUSION

The results of the QoL questionnaires of cancer of the cervix patients were reported in this chapter. The results will be discussed in chapter 5.
CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

This chapter discusses the study findings with reference to the aim and objectives of
the study. The aim of the study was to evaluate the impact of chemo-radiation
treatment on QoL and to determine what socioeconomic and demographic factors
are closely related with QoL decrements in Zambian cancer of the cervix patients
treated at Cancer Diseases Hospital. The study findings are contextualized within
current literature so as to position the QoL findings described in this study with those
cited in the literature.

5.2 QUALITY OF LIFE

The current study assessed the physical, social, emotional and functional well-being
as well as general patients’ health status and QoL post chemo-radiotherapy.
Demographic variables (age, marital status, level of education, religion and
occupation) potentially believed to affect the QoL outcomes were tested for their
influence on the above indicated quality of life subscales. Zambian women treated
for cervical cancer in the current study demonstrated significant improvement as well
as long-term concerns resulting from the cancer and its treatment. The demographic
variables were also found to influence QoL in this study.
5.2.1 Physical well-being

When age was correlated with the QoL physical well-being dimension of the respondents 12 months post chemo-radiotherapy, the current study results found age to have no significant impact on physical well-being. The current study results are similar to the findings of Pearman (2003:1-33) who reported that age was a non-predictor of long-term quality of life in gynecologic cancer survivors. However, although not statistically significant, the present study found improved physical well-being in some respondents. Eight respondents in the 61 to 65 age group who had reported a lack of energy at the beginning of chemo-radiotherapy had higher energy levels after treatment and were able to carry out housework \( (p=0.0271) \). This, however, could have been due to a good treatment (chemo-radiotherapy) response as chemo-radiotherapy has been reported to improve treatment outcomes in cancer of the cervix patients (Tambaro et al. 2004:33-44).

In contrast to the current study results and those of Pearman (2003:1-33), Korfarge et al. (2009:1501) studied health-related QoL in cancer of the cervix survivors treated with chemo-radiotherapy and found that age significantly impacted on physical well-being scores, with survivors reporting improved physical well-being. The authors do not state the age group in which the physical well-being and QoL was mostly improved after treatment. However, it must be mentioned that their study involved a five-to-six-year-long follow-up period in which survivors could have adapted to the experienced physical problems.

The current study also shows that there was no significant influence of occupational status on physical well-being. However, there was a trend towards greater difficulties
with energy and trouble meeting family needs in the unemployed group that could have affected their quality of life negatively (p=0.2117 and 0.2896 respectively). This, however, could be related to the fact that most of the unemployed respondents were less educated and could have had problems with understanding the disease and its treatment effects thereby mystifying the disease to them. This inference may indicate that unemployed women have other challenges not related to treatment problems that may affect their physical well-being. Bradley *et al.* (2006:485) reported significant decrements in quality of life in unemployed cervical cancer women. In this regard, it is tempting to hypothesize that unemployed cancer of the cervix survivors may be at risk for decrements in quality of life and that this group could therefore benefit from interventions carried out by health care professionals.

Demographic data showed that the study population comprised mainly Christian respondents, with 2% affiliated to other religions. The findings of the current study indicated no statistically significant impact of religion on the physical well-being in the Zambian female patients treated for cancer of the cervix. This finding is probably due to the small sample size. The study by Wenzel *et al.* (2005:310-317) on the other hand reported significant decrements in QoL in women who had low religion or spiritual well-being beliefs. Although the sample size in the study by Wenzel *et al.* (2005:310-317) was also too small to support their findings, the clinical meaning of their results is important, given the implications for follow-up gynaecologic care for this population.

With regard to marital status, the majority (52%) of the respondents in this study were married followed by the widowed category (34%). When physical well-being
variables were measured and correlated to marital status, marital status did not significantly predict physical well-being at 12 months post chemo-radiotherapy. Results indicated no significant differences and associations (Table 4.4). However, although not statistically significant, married and widowed women reported improved physical well-being suggesting possible adaptation to physical limitations. This finding could be important for these two groups because they are the majority. However, it is necessary to further examine the contribution that each marital status group makes in predicting who is more likely to experience persistent problems associated with survivorship.

5.2.2 Social well-being
Social well-being was reported to have been affected positively in this current study. The study demonstrated that married cancer of the cervix women who are treated with chemo-radiotherapy experience significantly improved social well-being at 12 months follow-up. Respondents in this study reported more pronounced and improved relationships with partners, improvement in emotional support, and satisfaction in their communication with family. The social well-being score was found to be significantly influenced by marital status with married women showing better relational scores (p=0.0018). Better social life reported by these women could have been due to regular interactions with their husbands and families from sharing experiences and information with them which then improved their social life.

In contrast to the current study findings, Carter et al. (2005:92), Bergmark et al. (2002:448), Bye et al. (2000:178) and Flay and Mathews (1995:399-404) reported
relationship alterations after treatment. The women’s ratings of their difficulties in their relationships, however, were highly correlated with both physical symptoms and psychological distress scores. Some women suffered negative thoughts and emotions and failed to resume their former social and leisure activities suggesting some persistent impairment of function. Better social scores in Zambian women compared to these study results could be associated with reported improved relief from disease symptoms and strong religious beliefs.

Despite the significantly improved social well-being scores in the current study, married respondents reported difficulties with their sexual function. This was true in all the age groups except for those between 46 to 50 years, probably due to the smaller number of respondents in this age group. Respondents reported significant sexual dissatisfaction (p=<0.05) as a result of painful sex and post-coital bleeding.

The unemployed respondents in this study also reported a significantly better social life with closer relationships with friends, emotional support and closeness to partners. However, these women also reported problems with their sexual life mainly because of the physical discomfort of having intercourse or fear of recurrence due to having sex. An interesting finding of this study is that most married women reported fear of recurrence of cancer after sexual intercourse - the reason that affected their sexual life the most. It is tempting therefore to speculate that health care providers did not spend time explaining to these women about their cancer and treatment effects. In keeping with the findings of the current study on sexual problems, Park et
al. (2007:2716-25) also reported similar problems and these authors reported worse social function in long-term survivors.

Out of 25 married participants at the beginning of the current study, 23 remained married at 12 months follow-up. Two of the participants who divorced or separated after cancer diagnosis indicated that this change was related to their cancer. Although small in number, the proportion who attributed their divorce to cancer of the cervix is worthy noting, suggesting an area for further exploration given the burden that this disease and its treatment might place on relationships. Similar to the current study findings, Juraskova et al. (2003:267) also reported women who had separated from their partners due to treatment effects that caused difficulties in their relationships.

In a study by Bradley et al. (2006:485) quality of life decrements were significantly associated with relationship status. The study showed that unmarried cervical cancer women reported significant decrements in quality of life and mood. Unmarried women were more likely to report decrements in quality of life, mood and mental health, leading to the hypothesis that those who do not have someone to share the cancer treatment and survivor experience with may be at risk for these problems.

However, Lindau, Gavrilova and Anderson (2007:416) found that relationship problems were associated with little knowledge among survivors of their cancer and its treatment effects. Similarly, the present study reported more complex sexual
problems in women who had little knowledge and had not discussed the effects of cancer and cancer treatment on sexual life or function. Weaver, Sun, Schover, Aday, Mueller and Bodurka (2003) reported similar findings in their study and indicated that women who have little information about their disease and treatment effects experience more quality-of-life problems.

The findings from the present study and that of Lindau, Gavrilova and Anderson (2007:416) and Weaver et al. (2003) suggest that survivors who report less knowledge about the disease and its treatment effects are more likely to report relationship problems and decrements in quality of life. It is therefore important for health care professionals to recognize that counselling of cancer of the cervix patients is paramount to reduce QoL problems in these patients.

### 5.2.3 Emotional well-being

In the current study, age was found to significantly impact on the emotional well-being of respondents, with elderly respondents experiencing more problems than younger ones. Psychological problems were reported by respondents above the age of 50 years who reported a sad feeling (p=0.0296, 0.0008) and declared feeling worried (p=0.0253, 0.0296) when emotional well-being items were measured 12 months post treatment. Although younger respondents reported fewer coping problems, fewer worries and fewer depressive symptoms (p=0.0455, 0.0497, 0.0497 respectively), it was seen that little information about treatment and its effects negatively influenced the emotional well-being subscales.
In keeping with the current study findings, Miller et al. (2002:179-183) also showed higher emotional impact in older patients compared to younger ones. Generally, quality of life scores in their study were observed to be lower in older patients with poor education and lack of help at home. Probably, younger patients had good education, support and good general health for them to report good QoL. Miller et al. (2002:179-183) and other authors (Chan, Ngan, Yip, Li, Lau & Tang, 2001:387-394; Pearman 2003:3; Korfarge et al. 2009:1501) propose that lower levels of education may be predictive of a less supportive social environment, limited knowledge of health issues and poor general health.

Similarly, the current study reported emotional well-being problems in respondents with poor education. Although not significant, lower educated women experienced more problems with coping, worry, and were more nervous than those who had high school level education. The emotional well-being problems in these women could also be due to little knowledge about the disease and its treatment effects as a result of their lower education.

Miller et al. (2003:111-119) also highlight the need for assessment of quality of life and emotional functioning in patients treated for gynaecological cancers. In their retrospective studies, 57% of patients reported needing help dealing with emotional problems. A majority of patients also wanted their physicians to ask questions dealing with spirituality, death and dying, and emotional problems. Campelli et al. (2002:2500-2507) also noted the fact that women with primary gynaecologic cancer experience more emotional problems after treatment than healthy women.
Thus it appears that emotional well-being problems accompanying treatment of cancer of the cervix can be attributed to insufficient information from health care professionals. It is also reasonable to hypothesize that cancer of the cervix survivors who experience significant negative effects due to little knowledge about the disease and its treatment may be at risk for diminished quality of life years after treatment.

Carter et al. (2005:90-95) also reported emotional well-being problems in cancer of the cervix survivors treated with chemo-radiotherapy. The authors found that women treated for gynaecologic cancers experience severe psychological distress. Feelings of depression, grief, and stress were also reported in this study especially in those women who lost their fertility as a result of their cancer treatment. Cull et al. (1993:1216, 1217) showed similar results with their study, reporting higher anxiety and depression scores in patients treated for cancer of the cervix. It can therefore be concluded that the comprehensive care of cancer of the cervix patients requires not only curative efforts but also attention to the psychological needs of patients and their families.

5.2.4 Functional well-being

The findings in the current study reveal that married women report improved functional well-being and QoL at 12 months post treatment. These women reported fewer problems in carrying out daily duties at 12 months follow-up although lack of fulfilment in their work was a concern. Ability to work was significant in married women (p=0.005). Four women were working full-time and two were part-time workers at the beginning of the study. Three of the women who were in full-time
employment continued working after three months and one went back to work at five months post treatment. All part-time workers continued working and they all reported fewer problems with carrying out their work. These women also reported high levels of acceptance (p=0.004-0.007). High levels of illness acceptance were also observed in the respondents who had attained a high school level of education. Sleeping habits, work fulfilment and enjoying life were seen not to be affected by marital status and educational level of education of the respondents.

In contrast to the present study results, other researchers (Bergmark et al. 2002:448; Bye et al. 2000:178; Cull et al. 1993:1216-1220; Berclaz et al. 2002:1316) assessed the prevalence of functional effects in cancer of the cervix patients treated with radiotherapy and chemotherapy. Their results showed that patients suffer several functional effects that negatively impact on their quality of life. Pearman (2003:1-33) also reported functional well-being problems such as sleeping disturbances and an inability to work. Similarly, Berclaz et al. (2002:1318) reported two women who were unable to return to their jobs immediately due to treatment effects and impaired functional well-being.

Surprisingly, unemployed respondents reported better functional well-being in the current study (<p= 0.05). These women indicated that they had fewer problems with sleeping and life acceptance. The results of the study also showed statistically significant life enjoyment in this group. However, it is important to note that more than 50% of unemployed women were married with strong religious beliefs and their better functional well-being could have thus been due to having better support from their partners as well as high spiritual levels. There was no significant change in the
functional well-being of those who were working (p=0.2500–1.000). The reason for this could be because the number of respondents in this category was too small to pinpoint a general pattern.

It should be noted in this study that those women with high self-esteem had better functional well-being and reported fewer problems. This finding could mean that therapies should be aimed at improving self-esteem both during and following cancer of the cervix treatment as indicated by Pearman (2003:1-33).

5.2.5 General QoL

With regard to the general QoL of the respondents, 64% (29) judged their health status and quality of life as good. Twenty-two per cent (10) judged their health status and their QoL as fair, while 4% (2) considered their health status and QoL to be poor at 12 months follow-up. Respondents were generally concerned with the amount of information they received concerning their illness and treatment side effects which they reported could have been a reason for other women to report negative physical, social, emotional or functional well-being.

Given the literature and the present study findings, it appears that staff lack the time and skill to deal with psychological and social concerns even though the literature suggests that giving patients opportunity to express such concerns can aid in the prevention of problems (Caffo, Amichetti, Tomio & Galligioni, 2001:13-20). Although the present study results showed improved social well-being in women regardless of their financial status, the fact that medical personnel did not adequately deal with
patients’ social concerns was obvious and the sexual problems experienced by the women could be attributed to this lack of concern by medical staff. The present results therefore suggest that health care providers should be proactive in providing information and discuss social concerns of patients to help survivors cope years after treatment.

5.3 CHEMO-RADIOThERAPY TOXICITY

The current study questionnaire was not constructed to identify and record treatment complications; however, the study reported chemo-radiotherapy side effects as the participants experienced them. The study showed that patients with advanced cancer of the cervix treated with chemo-radiotherapy suffer from a number of symptoms.

Out of 45 respondents, 20% (9) complained of gastrointestinal complications (radiation proctitis, rectal bleeding, rectovaginal fistula, constipation and diarrhea), 6.6% (3) experienced dyspareunia, 2.2% (1) complained of fatigue, and 31% (14) experienced sexual function problems due vaginal stenosis and fibrosis. Similar effects have been reported in the literature. Effects such as dyspareunia, post-coital bleeding, vaginal stenosis and fibrosis, difficulty in sleeping, fatigue and cystitis have been reported by many authors (Bergmark et al. 2002:448; Bye et al. 2000:178; Cull et al. 1993:1216-1220; Berclaz et al. 2002:1316). Shang et al. (2006:1373) also reported gastrointestinal complications that significantly impaired quality of life. Since Bye et al. (2000) reported less diarrhoea in patients following a low fat diet during radiotherapy in their study, the conclusion can be drawn that nutritional guidance may be of importance in cancer of the cervix patients. However, the side effects of
chemo-radiotherapy in the current study were not seen to have a negative impact on QoL probably because the study period was not sufficient to observe the treatment effects on respondents’ quality of life beyond 12 months, whereas the study conducted by Berclaz et al. (2002:1316) included a follow-up three to four years after treatment.

Although the reported side effects were not found to be burdensome in the current study, complications have been reported in the literature that have a negative impact on quality of life (Bergmark et al. 2002:443-450). Even if in the current study side effects may be seen as side effects that are to be expected when receiving a complicated treatment, the patients should be informed about them to enable them to cope with these side effects should they arise.
5.4 CONCLUSION

Zambian women treated for cancer of the cervix with chemo-radiotherapy at CDH expressed considerable positive changes with improved social, functional and emotional well-being. However, QoL changes were seen to be dependant on demographic factors such as age, marital status, educational status, occupational status and religion. In the current study, the social, functional and emotional well-being of respondents was observed to be improved in married, educated and high spiritual respondents. Those women with relationship problems, low education and low religious beliefs experienced increased quality of life problems. Despite noted decrements in quality of life in some respondents, the majority of the study subjects indicated that their treatment had improved their well-being.

A lack of information about their disease and its treatment was found to be associated with poorer overall QoL in this study. The findings of this study suggest that there is a need for health care providers to inform patients about the disease and its treatment effects as well as to inform patients about coping strategies which is supported by Klee et al. (200:12) who have found that better informed patients show improved and better quality of life after treatment.

Based on these study findings, it is suggested that further studies and interventions focusing on improving the QoL in survivors should be encouraged. By identifying any problems in the quality of life after cancer of cervix treatment, health care professionals will be able to design intervention programmes that will help to prevent or ameliorate such problems and side effects.
CHAPTER 6
RECOMMENDATIONS

6.1 INTRODUCTION

In this chapter, the findings of the study in relation to the findings of the literature reviewed will be discussed and recommendations will be made aimed at improving the quality of life of Zambian women treated for cancer of the cervix with chemoradiotherapy.

The limitations of the current study and recommendations for future research will also be highlighted in this chapter.

6.2 RECOMMENDATIONS FOR INTERVENTION PROGRAMMES FOR IMPROVED QUALITY OF LIFE

The current study has highlighted the need for identifying problems that may impact on the QoL of cervical cancer patients so that health professionals can design intervention programmes to improve the quality of lives of the patients under their care. Various intervention programmes are mentioned in the literature that have been shown to improve the QoL of cancer patients after treatment and these could be modified and incorporated into the Zambian setting.

6.2.1 Education intervention programme

Education interventions have been reported to improve QoL in women treated for gynaecologic cancers. Katz (2005:238-241) indicated in his study that women who are educated about their disease, its treatments and side effects with the help of
health care providers report fewer social problems after treatment. Park et al. (2007:2718-2720) recommends that involving cancer patients in educational programmes concerning their disease and its treatment effects should be encouraged. Patients who undergo education intervention programmes have reported improved quality of life for many years post treatment (Klee, Thranov & Machin 2000:12; Flay & Mathews 1995:403). The first step in improving the QoL of Zambian women treated for cancer of the cervix would be to identify ways of educating and providing these women with information about cancer and its treatment effects to minimize the associated morbidity. Ways of providing information as advised by Katz (2005:238-241) would include the following:

1. Developing and implementing counselling sessions and programmes at CDH through consultations with established cancer treatment centres in Africa and beyond. The sessions could be based on group or individual sessions as both have been found to be valuable in the literature (Katz 2005:238-241).

2. Providing information through brochures and pamphlets in both English and local languages for better and effective understanding of the treatment and the associated side effects.

3. Designing and implementing programmes for women to discuss their concerns in English and all commonly spoken local languages with their health care providers either through individual or group discussions.

4. Involving non-governmental organizations in providing information about specific problems associated with different cancers and their treatment effects, through seminars, workshops and providing books and journals dealing with specific cancers.
Although educational intervention is seen to be effective in improving the QoL of survivors, it should be noted that implementing these programmes requires extra financial resources, dedication and expertise for a successful programme to be developed. For this intervention to be successful, the government of Zambia therefore needs to support health care providers by providing them with good communication and counselling skills (through training) that are essential to provide patients and survivors with appropriate and timely information related to QoL changes after treatment.

6.2.2 Exercise intervention programme

Christopher and Marrow (2004:101, 102) have reported that an exercise intervention programme in women cancer survivors improves psychological and social well-being. Exercising will result in improved physical capacity, decreased fatigue, and controlled weight gain, effects that have been reported to negatively affect quality of life if not addressed. Exercise intervention has also shown to improve emotional well-being, self-esteem and decrease anxiety and depression, thus improving the overall quality of life in cancer survivors (Knobf, Musanti & Dorward 2007:285-296; Spence, Heesch & Brown 2010:185-194; Courneya, Vallance, McNeely, Karvinen, Peddle & Mackey 2004:249-261).

This intervention could be suggested at CDH to be formally established. However, culturally speaking, exercise among Zambian women is not common. It would be interesting, however, to discuss the importance of exercise with cancer of the cervix patients to see if education about exercise and its benefits would alter the perception of exercise among this population. Therefore, clinicians should be encouraged to
integrate physical activity recommendations into practice and which are tailored to the individual's health condition and mutual goal.

6.2.3 **Introduction of special strategies and services for patients and families**

After completion of treatment, many cancer survivors face challenges as how to improve their quality of life in practical ways. This could be due to the fact that health care providers do not actively guide survivors on strategies and services which could improve their sense of well-being and promote a better quality of life. A wide variety of services are available to both patients and their families to assist them in dealing with the impact of cancer and treatment effects. Among the range of recommended services are:

1. **Individual family counselling services**.
2. **Provision of concrete services** such as assistance with meals, household chores, or nursing care with the help of a social worker who is usually the most appropriate person to evaluate the patients' supportive care needs.
3. **Informing patients of available support societies** such as the Cancer Society of Zambia for access to information and other country programmes aimed at improving QoL (Hillarie 2007).

The health care provider should develop cost-efficient and timely methods of evaluation and referral of patients and also provide the emotional support necessary to ensure that the patients and their families will follow through on the recommendations and referrals that are made. Health care providers who are more likely to come in contact with patients should make an attempt to make an
assessment of the impact that the cancer and its treatment has had on patients’ well-being. Taking the time to conduct a systematic review of the physical, emotional, functional and social consequences of cancer can be an important step in understanding the patients’ response to the cancer and treatment effects (Hillarie 2007).

While most of the patients in this study reported good treatment response, many may have specific problems and quality of life complaints as a result of the treatment. Providing these patients with a forum to discuss their concerns as well as to receive rehabilitative and supportive interventions such as mentioned above can be critical for the improvement of their quality of life.

6.3 LIMITATIONS OF THE STUDY

- A potential limitation to this study is the short period during which the patients were followed-up. The maximum study duration of 12 months of follow-up could have been too short for patients to report late treatment side effects and to evaluate the long-term effect on quality of life, although it would reflect patients’ quality of life after the treatment recovery period. However, it was not possible to have a longer than 12 months follow-up due to time constraints associated with the length of the masters degree programme.

- This study could have been designed to include qualitative data by using semi-structured interviews in order to allow a deeper exploration of the data and the feelings of respondents regarding the changes in the quality of life after treatment.
- The sample size of the study was too small to generalize the significance of the findings.

6.4 RECOMMENDATION FOR FUTURE RESEARCH

- It is recommended that a similar study with a longer than 12 months follow-up period be conducted to validate the findings of the present study.

- A study should be conducted in Zambia to implement the suggested intervention strategies and to monitor the effects of the interventions on the quality of life post treatment.

- The introduction of a cancer survivor plan is recommended. This will provide patients with a summary of their cancer care plan and will include their medical history and treatments, and will provide a set of recommendations to guide them over a long period of time with appropriate interventions to minimize and prevent further quality of life problems.

- It is also recommended that oncologists and other health care providers be trained to address the concerns of physical, emotional, functional and social well-being of patients in order to identify early problems and facilitate prompt interventions.
6.5 CONCLUSION

The objective of the present study was to evaluate the impact of chemo-radiotherapy on the quality of life of Zambian women treated for cancer of the cervix as well as to assess which demographic factors influence quality of life decrements in this population. Another objective was to make recommendations focusing on improving the quality of life of patients after treatment. The study results suggest that demographic factors such as age, educational level, religion, occupational status and marital status have a bearing on the quality of life of cancer survivors. Cancer of the cervix survivors who have lower educational levels, are unmarried and have weak religious beliefs may be at a higher risk for experiencing difficulties in their quality of life. These findings have important implications for health care professionals since they need to be attentive to the well-being of cancer survivors in order to ensure that the QoL of cancer survivors is maximized. Interventions focusing on more social support, education to improve patients’ understanding of their disease and treatment effects as well as physical rehabilitation through exercise interventions may play a crucial role in enhancing the quality of life of survivors.
REFERENCES


free survivors of cervical cancer compared with the general population. 


