DEVELOPMENT AND PILOT TESTING A SUPPORT PROGRAMME FOR WOMEN TREATED FOR CERVICAL CANCER

Annah Mosalo

A thesis submitted to the Department of Nursing Education, Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree of Doctor of Philosophy

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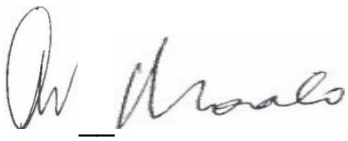
DECLARATION

I, Annah Mosalo, declare that this Thesis reported is my own, unaided work. It is being submitted for the degree Doctor of philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



Signature

10 May 2021
Date

DEDICATION

I dedicate the study to
all women treated for cervical cancer (past and current),
who contributed immensely of their time despite the hardships of the treatment to pour their emotions to bring this study to life.

ABSTRACT

Background: Cervical cancer is the fourth most common cancer among women worldwide and the most common cause of cancer related deaths. Whilst developed countries have reduced morbidity and mortality from the disease, the situation is experienced differently from the developing countries due to lack of resources including support from the health care as patients navigate the health care system. Women in Sub-Sahara are affected by this disease resulting in increased mortality. Even though South Africa has a screening policy in place, Black South African women are mostly affected, even so at the prime of their lives when they contribute to the economy of their families. Women present late when the cancer has advanced.

Curative treatment for stages IIB- IVA disease includes external beam radiation and brachytherapy with or without concomitant chemotherapy. However, facilities that offer treatment for cervical cancer are limited. Women may need to be treated away from home, family and friends whom they rely on during the disease trajectory to help them adjust and cope with the illness. Women may need to be offered time off from work to afford them an opportunity to attend the treatment. It is crucial that women are supported during this period, as it has been reported that support buffers the effects of cancer and its treatment.

Aim of the study:
The study explored the needs of women receiving curative treatment for cervical cancer at an Academic hospital and developed a support programme based on the needs identified. The programme was evaluated at the end.

METHOD
An exploratory sequential mixed method approach was utilised to explore the support needs of women receiving curative treatment for cervical cancer and to develop a support programme. The study consisted of two phases. Phase 1 utilised a qualitative approach to explore the support of women receiving curative treatment for cervical cancer including radiation and developed a support programme. Phase 2 utilised a quantitative approach using pre-and post-test to implement and evaluate the programme.

RESULTS

Six themes emerged which were: symptoms experienced leading to accessing the healthcare facility; information pertaining to the disease and treatment; need for counselling during the cancer trajectory; emotional support; need for instrumental support; network, peer and media support. The needs highlighted guided the development of a support programme which was implemented and evaluated on the last day with participants who attended all the sessions. The study provided evidence that the programme was effective in providing the perception of improved support based on the opinions of the participants who attended the programme.

CONCLUSION

Participants in the program felt empowered regarding the information about the disease and its treatment. They felt confident that they could inform others (women) about their illness without experience of shame and could encourage them to go for screening. The program provided an environment where one could talk freely about their situation without being stigmatised.

Although the programme was a pilot study it provided evidence of being effective based on the participants evaluation. However, quality of life could not be evaluated as the programme was completed on the last day of the participants receiving treatment when it could have been appropriate to asses. The researcher suggest that the programme be offered according to the different phases of the cancer trajectory, as it was noted that lots of information were shared with the participants within a short time which may not have been easy to understand considering their situation. It is further suggested that the participants in such programmes be followed up over longer period to evaluate their perception of quality of life.

Key words: cervical cancer; pilot-test; intervention; programme

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ACRONYMS AND ABBREVIATIONS

AAT	- Acetic Acid Testing
AICP	- Advisory Committee on Immunisation Practices
AIDS	- Auto Immune Disease Syndrome
ASCUS	- Atypical Squamous Cell of Undetermined Significance
BSSS	- Berlin Social Support Scale
CIN	- Cervical Intraepithelial Neoplasia
C-MUIS	- Chinese Version of Mishel's Uncertainty Scale in Illness Scale
EORTC QOL-CX 24	- European Organisation for Research and Treatment of Cancer Quality of life questionnaire
EU	- European Union
EBRT	- External Beam Radiation Therapy
FSFI	- Female Sexual Function Index
FACT-Cx	- Functional Assessment of Cancer Therapy for Cervical Cancer
FACES-II	- Adaptability and Cohesion Scale, Second Edition
FSFI	- Female Sexual Function Index
HSIL	- High-Grade Squamous Epithelial Lesion
HADS	- Hospital Anxiety and Depression Scale
HIV	- Human immunodeficiency virus
HPV	- Human Papillomavirus
FIGO	- International Federation of Gynaecology Obstetrics
IAEA	- International Atomic Energy Agency
LEEP	- Loop Electrosurgical Excision Procedure
LSIL	- Low-Grade Squamous Intraepithelial
LVSI	- Lymphovascular Space Involvement
MLBC	- Manual Liquid Based Cytology
MOS-SSS-C	- Medical Outcomes Study Social Support Survey
PLND	- Pelvic Lymph Node Dissection
PET	- Position Emission Tomography
PRISMA	- Preferred reporting Items for Systemic Reviews and Meta – Analysis

POMS	- Profile of Mood State
SPSS	- Statistical Package for the Social Sciences
SLN	- Sentinel Lymph Node
SVQ	- Sexual Function- Vaginal changes Questionnaire
SCJ	- Squamocolumnar Junction
TAH	- Total Abdominal Hysterectomy
TCHI FACT-G	- Traditional Chinese version of Functional Assessment of Cancer Therapy-General
UK	- United Kingdom
QOL	- Quality of Life
WHO	- World Health Organization

CHAPTER 1

1. INTRODUCTION AND BACKGROUND TO THE STUDY

According to the 2012 Globocan statistics (International Agency for Research on Cancer and World Health Organization, 2014), there was an estimated 14.1 million people newly diagnosed and 8.2 million cancer-related deaths, as well as 32.6 million people living with cancer within 5 years of diagnosis. Cervical cancer is the fourth most common cancer-affecting women globally and the fourth highest cause of cancer deaths (Small et al., 2017; IAEA, 2012; Camilleri & Blundell, 2009). Furthermore, it is reported that most of the global burden of the disease occurs in low- to middle-income countries (Small et al., 2017; Colombo et al., 2009). According to reports from the World Health Organization (2006), cervical cancer is the most common cancer of women living in sub-Saharan Africa. It is further asserted that Black South African women are mostly affected by the disease (Moodley, 2009), which is further compounded by presenting late when the disease is advanced (Snyman & Herbst, 2013; Moodley, 2009).

Women infected with the human immunodeficiency virus (HIV) have also been reported to be at higher risk of developing cervical cancer than those not infected (Finocchario-Kessler et al., 2016; Denny, 2010), resulting from the suppressed immune response due to the disease process (Dunleavey, 2009; WHO, 2006). According to Anorlu (2008), cervical cancer affects relatively young women who are in their most productive years and contribute to the economic stability and wellbeing of their families. However, this is of great concern as cervical cancer has been reported to have a longer pre-invasive period, which makes it feasible for treatment (Rwamugira et al., 2019; Snyman & Herbst, 2013; Moodley, 2009). Further, to confirm the severity of the disease Snyman and Herbst, (2013) in their study conducted in Tshwane, South Africa to investigate the circumstances of women presenting with cervical cancer, found that one in 41 women was diagnosed with advanced disease.

Receiving a cancer diagnosis can be devastating. Herzog and Wright (2007) found that women experience fear, self-blame, distress and anxiety, which could have a negative influence on their body image, self-esteem, relationships with partners and sexuality.

Maree et al. (2013), in a study conducted in Tshwane, found that women subjected themselves to some form of isolation due to symptoms experienced, such as offensive vaginal discharge and/or bleeding. Women also experienced sadness and embarrassment, which left them feeling flawed and undesirable (Ashing-Giwa et al., 2004). Being treated for cancer can have its impact on individuals as they face the plight of being subjected to extensive treatments.

Treatment for cervical cancer entails complex treatment consisting of surgery, radiotherapy and chemotherapy based on stages of disease, location of the tumour and patients' general health (Small et al., 2019; IAEA, 2012). The International Atomic Energy Agency (2012) recommends that women with stages IIB to IVA cervical cancer receive curative treatment consisting of external beam radiation and brachytherapy with or without concurrent chemotherapy. Those with lesser disease should be treated with surgery, if surgically fit, whilst palliative radiotherapy is used to palliate specific symptoms in women with metastatic disease. Being treated for cervical cancer may involve significant amounts of time away from home and can deplete reserves of energy resulting in a need for practical assistance with activities of daily living (Hinds & Moyer, 1997). Patients who experience support during the trajectory of cancer are found to adjust and cope better with treatment (Ussher et al., 2006). This is confirmed by Shiozaki et al. (2011), who state that support plays a protective role. McDowell et al. (2010) concur with this statement by indicating that patients who receive emotional, instrumental or informational support from health professionals, family members and friends report a better adjustment to their illness.

Support is a complex phenomenon with various dimensions and components, such as natural and formal support (Hogan, Linden & Najarian, 2002), and social support consisting of material, emotional, instrumental and affirmative support (Chan et al., 2001; Taylor et al.,1986). Unfortunately, being supported during the trajectory of cervical cancer is not a given. Mosalo (2011), in a study Conducted in Tshwane, South Africa, found that women were left with the task of informing partners and family about their "illness," even though they did not know much about it. Although women did not know what was wrong, they made efforts to navigate different care facilities in search for help

(Schalkwyk et al., 2008), before being informed of a cancer diagnosis. For some it meant being sent to the treatment facility without being informed about the disease. Women had to attend treatment at specialised care facilities, which involved travelling each day for five days over six weeks in order to complete intended treatment. It is crucial therefore, that women receive support during the cancer trajectory. The researcher is not sure whether developing a support programme based on needs of the woman might improve their perception of being supported and improve their quality of life.

1.1 RESEARCH PROBLEM AND QUESTION

Cervical cancer has been reported as disease of the poor as it commonly affects women of low socioeconomic status due to lack of finances to access treatment and poor knowledge of the disease (Denny et al., 2006; Anorlu, 2008). Most women treated for cancer at public cancer care settings in various provinces, suffer from cervical cancer. Mosalo (2011) highlighted the fact that, even when hospitalised for treatment, women were not necessarily supported; some were supported whilst others received partial support, and some were abandoned. Giving and receiving support was also a challenge because of the distance between women's homes and the hospital and the cost of visiting. It is not clear how women would like to be supported during the time they are hospitalised for cervical cancer treatment. It is also not known whether a support programme would improve their experience of being supported and their quality of life, as no studies investigating this topic could be found.

The three-part research question for this study was therefore *"What are the support needs of women treated for cervical cancer at a public hospital in Gauteng, how would they prefer to be supported and would a support programme developed according to their needs improve their perception of being supported and improve their quality of life?"*

1.2 PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of the study was to develop; and pilot test an intervention (support programme) tailored to meet the support needs of women receiving curative treatment for cervical cancer treatment at a public hospital in Gauteng Province in two phases.

The objectives of Phase 1 were to:

- explore the support needs of women receiving curative treatment for cervical cancer including radiation therapy and how they preferred to be supported;
- develop and validate a support programme

The objectives of Phase 2 were to:

- pilot-test and evaluate the effectiveness of the support programme in terms of one primary outcome, perceived support and a secondary outcome, quality of life by pre-testing participant's perceptions, implementing the support programme and post - testing perceptions of these outcomes.
- Obtain the opinions of a selected number of participants regarding the effectiveness of the programme.

1.3 SETTING

The study was conducted at an academic hospital in Gauteng, South Africa, which renders highly specialised services to all categories of patients, including those diagnosed with cancer. Cancer patients have access to surgery, cancer chemotherapy and radiotherapy as primary treatment modalities. Patients with cervical cancer are treated in the department of radiation oncology. The majority of these patients receive treatment on an outpatient basis. Most patients are admitted to satellite hospitals in the Gauteng region/district and transported in a hospital bus to the radiation oncology department of the specific hospital. Such referrals were made because these healthcare settings (primary health clinics and satellite hospitals) lack appropriate resources to provide specialised services. Although the tertiary healthcare hospital operates daily on a 24-hour basis, specialised care services are offered from 7 am until 4pm on Mondays to Fridays. Whilst the majority of the patients are treated as outpatients, some of them were admitted with other oncology patients to a 25-bedded ward of the hospital. Patients were admitted to the ward because of difficulty of accessing treatment due to their disease process, physical disability, old age, and distance to the radiation oncology department. Approximately 70 patients with cervical cancer are treated with radiotherapy per day. As patients receive daily treatment for six consecutive weeks, the same number of patients are treated per week and per month; this number however varies.

1.4 THE STUDY DESIGN AND METHODS

This study utilised a sequential exploratory mixed method approach to develop a support intervention for women admitted and treated for cervical cancer. Mixed methods approach involves the use of both quantitative and qualitative methodologies in a single study (Creswell & Plano-Clark, 2014; Ivankova, Creswell & Stick, 2006). Phase 1 utilised an exploratory design to explore the support needs of women receiving curative treatment for cervical cancer, whilst phase 2 utilised a pre-and post-test design to implement and evaluate the programme. The intention was to collect, analyse and integrate data from both methodologies at some stage during the research process (Polit & Beck, 2012), which in the case of the current study was done at the completion of phase 2 when the outcomes of the intervention were evaluated.

The research methods are summarised in Table 1.1.

Table 1.1: Summary of the Research Methods of the Study

PHASE 1: DEVELOPMENT AND VALIDATION OF THE SUPPORT PROGRAMME			
Approach	**Population and Sampling**	**Data Collection**	**Data Analyses**
Objective 1: Explore the support needs of women treated for cervical cancer and how they would prefer to be supported			
Exploratory qualitative	All women treated for cervical cancer at the academic hospital Purposive sampling (n=22)	Qualitative interviews as per interview guide	Content analyses
Objective 2: Validate the support programme			
Qualitative	Group of experts in the field of cancer treatment and care as well as patients treated for cervical cancer (n=11) Purposive sampling	Individual discussions	Content analysis
PHASE 2: PILOT TESTING OF THE SUPPORT PROGRAMME			
Quantitative pre- and post-intervention	All women participating in the support programme (n=56) Census sampling	Structured interviews The Berlin Social Support Scale QLQ-CX 24 (Cervical cancer module) (structured –self report)	Descriptive and inferential statistics
Qualitative post intervention	Group of women who participated in the support programme Purposive sampling (n=8)	group discussion	Content analyses

1.4.1 Research Design Phase 1 - Exploration of the Needs of Women Receiving Curative Treatment for Cervical Cancer

An exploratory qualitative design was used to explore the women's support needs and how they would prefer to be supported during the period they are treated for cervical cancer. Exploratory studies are conducted when a problem or a complex issue needs to be explored or to gain new perspectives on issues where much is already known (Creswell, 2013; Gray, 2009). Qualitative research consists of a set of interpretive material practices that makes the world visible (Creswell, 2013; Burns & Grove, 2009). An example of such practices relates to the use of open and deep interviews to reveal participants' meanings or understanding of phenomena. Qualitative approaches or designs consider the existence of multiple realities or truths and participant's subjective view of those realities, as well the context where the experience took place (Creswell, 2009; Streubert & Carpenter, 2011). Qualitative studies are useful approaches for providing guidance to researchers for intervention development (Sullivan-Bolyai, Bova & Harper, 2000). A qualitative design was utilised in this phase of the study to address one of its aims, exploring the support needs of women and development of a support programme.

1.4.2 Population and Sampling

The target population for this phase of the study were all women treated for cervical cancer at an academic hospital in Gauteng Province, South Africa. Purposive sampling, which is a selective sampling method where the researcher consciously selects certain participants for a study (Burns & Grove, 2009; LoBiondo-Wood & Harber, 2010) was used to select participants. Purposeful sampling was applicable to the study as the researcher chose women who experienced the phenomenon being studied. Purposeful sampling was relevant for this qualitative phase of the study as its aim was not to generalise the findings to other settings. In qualitative research, there is no predetermined sample size, however data were collected until category saturation, when interviewing two more participants yielded no new information. According to Lo-Biondo and Harber (2010) and Polit & Beck (2012), category saturation occurs when the full

range of themes or categories is identified from the data, so that interviewing additional participants yields no new data (Sandy, 2013).

The inclusion criteria applied for participation in the study was as follows:

- 18 years and older;
- receiving curative treatment for cervical cancer;
- in the second to sixth week of treatment;
- willing to participate in the study.

1.5 DATA COLLECTION

Qualitative interviews were conducted by the researcher as the key instrument (Creswell, 2009; Streubert & Carpenter, 2011; Polit & Beck, 2012; Creswell & Plano-Clark, 2007). Qualitative interviews are typically long and usually help participants in construction of their experiences after an in-depth dialogue. The advantage of qualitative interviews is that the researcher is able to follow up on ambiguous statements through use of probes in order to clarify participant's statements. Semi structured interviews (Appendix G) were used to explore the support needs of the participants, and probes and prompts were used to clarify and develop a better understanding of participants' views.

1.5.1 Phase 1 - Enquiry into the Needs of Women Receiving Curative Treatment for Cervical Cancer including Radiation

Data collection commenced after the ethical clearance certificate was issued from the university's Human Research Ethics Committee (M150272), (Appendix A) and the relevant permissions were obtained from the management of Charlotte Maxeke Johannesburg Academic Hospital (Appendix B) and the head of the radiation oncology department (Appendix C). Participants were requested to sign an informed consent (Appendix E), prior to being interviewed. Due to stigmatisation and sensitivity of the diagnosis, individual interviews were conducted in a private room in the department where patients received their treatment. The researcher collected data at the time convenient for participants and made efforts not to hinder daily processes in the department or patient's treatment schedules.

A voice recorder was used with permission from participants (Appendix F), as the researcher would not be able to capture and remember all information shared. The interviews lasted for approximately 45 minutes to an hour. Field notes were made after the interviews to allow the researcher to capture additional information, as she did not want to interrupt participants as they shared their stories. The first two interviews were used to pilot test participants' understanding of the interview questions. Due to the researcher foreseeing the possibility of not seeing patients, as data collection was done on specific days, the recorded interviews were played back to confirm with the participants if they agreed with what they had shared.

1.6 DATA ANALYSIS

Due to the extent of the interviews, it was not easy to transcribe data simultaneously, with data collection; at the beginning, the researcher had intended to analyse data concurrently with collection to maintain richness of the collected data. The interviews were experienced as long, and emotional. The researcher took a day in between to try and not become emotional herself as she reflected on the data, which entailed back and forth movement between data and the transcription to try to make sense of the information. Once satisfied and clarity obtained with meaning from the interviews, the researcher analysed the data (Appendix N), by compiling them into codes and categories, then developing themes (Vaismoradi et al., 2017). The process proved lengthy as the researcher was solely responsible for collecting and analysing the data. Audio-recorded data were transcribed verbatim without efforts to clean it. Content analysis was used to analyse data, according to Vaismoradi et al. (2017). Content analyses is a technique used to classify words into categories based on their theoretical importance (Burns & Grove, 2009). Once categories were identified, a template analyses style was used to group the categories into themes. Different levels of support were grouped, according to Cutrona and Suhr's (1994) Categories of Support, into the following themes: informational, tangible, emotional and network support. More about data analysis will be discussed in Chapter 3.

1.7 RIGOUR OF THE STUDY

1.7.1 Trustworthiness

According to Streubert and Carpenter (2011), rigour in qualitative research refers to the accuracy in which the participants' experiences are represented. The principles outlined by Shenton (2004) were used to enhance the trustworthiness of the findings. These principles are listed below.

1.7.2 Credibility

Credibility in the study was ensured by adhering to the constructs of qualitative research methodology. Data analysis was iterative between segments of data to ensure that the meaning was not lost, and to ensure truthful description of data as well as to confirm the prospective meaning with participants.

1.7.3 Prolonged Engagement

The researcher visited the prospective site prior to commencing with data collection to familiarise herself with departmental routines and prospective participants and acquaint herself with staff working in the department.

1.7.4 Triangulation

Triangulation was ensured through the use of multiple methods of data collection, as the researcher utilised mixed methods for data collection, interviews and group discussion at the end of the programme.

1.7.5 Audit Trail

A detailed study proposal would be available for peers from similar settings who would like to replicate the study. A doctoral qualified intercoder not familiar with the study also audited raw data to compare findings, and where there were discrepancies, issues were discussed and clarified in order to reach a consensus, and to validate them.

1.7.6 **Member Checking**

The researcher played back the interviews at the end and verified meanings with participants as there were challenges with time schedules to come and verify transcribed data.

1.7.7 **Peer Review**

The study proposal was presented to the university's Departmental Research Committee, who were not part of the research, for their input to make the study as clear and as credible as possible. Recommendations from other peers at conferences or academic proceedings may be used to improve on methods or refine findings.

1.7.8 **Transferability**

The researcher will provide an in-depth report of the study so that colleagues in almost similar settings would be able to replicate the study. A full thesis will be available at the university for peers aspiring to undertake a similar study.

1.8 **ETHICAL CONSIDERATIONS**

Data collection commenced after the researcher obtained ethical clearance from the Human Research Ethics Committee (Appendix, A) of the University of the Witwatersrand and permission from the management of the Charlotte Maxeke Johannesburg Academic Hospital and the Head of the Radiation Oncology Department (Addenda B & C). Informed consent was obtained from the participants who were willing to participate in the study (Appendix D), as well as permission to record the interviews (Appendix F). Participants were informed of the possibility of triggering sad emotions as they discussed issues pertaining to experience of support whilst admitted for treatment. Counselling was arranged with a qualified oncology nurse working in the department for participants showing signs of emotional distress, for participants showing severe emotional distress they would be referred for further management by the social worker in the department. Although patient's names were used during interviews, pseudonyms were used to report the findings which will not be linked to participants' personal information. Confidentiality was maintained on all data collected and stored by means of password protected hard drive storage, which was kept safe in a locked cupboard at the researcher's home. The

study supervisor was afforded access to the raw data for verification and cross checking and validation of the findings. Should there be a need to share findings at completion of the study, the researcher was to maintain confidentiality of the information as it would not be linked to participants' details.

1.9 DEVELOPMENT AND VALIDATION OF THE SUPPORT PROGRAMME

The findings of the interviews and literature guided the development of the support programme. Although there is an array of programmes for support of women treated for cervical cancer, this was done with a different population and in different settings. Literature describing a support programme for cervical cancer patients from the perspective of an African context could not be traced. Although the support programme was developed according to the different levels of support, which are informational, tangible, and emotional and network support, the researcher would be sensitive to what women had identified as needed support. Once developed, the programme was subjected for validation by a selected team of experts involved in the day-to-day care of patients in the radiation oncology unit, as well as patient's six months post treatment when they came for follow up. The programme content was assessed for relevance for the intended target group, feasibility, acceptability, supportive in nature, as well as comprehensiveness relating to support intended (Bakas, Farrran, Austin et al., 2009).

1.9.1 Phase 2: Implementation of the Support Programme

1.9.2 Research Design

A pre- and post-test design guided data collection in Phase 2 of the study. The intervention design is new methodology used in nursing for investigating the effectiveness of interventions in achieving the desired outcomes in a natural setting (Burns & Grove, 2009). The intervention developed in the current study, a support programme, was assessed in terms of a primary outcome, perceived support, and a secondary outcome, quality of life (QOL). The researcher explored the participants' opinions of the programme.

To assess the primary and secondary outcomes, a pre- and post-intervention approach was used. This approach is frequently used in nursing intervention studies (Burns &

Grove, 2009). The pre- and post-test approach is applicable to the study, as the researcher would test the effectiveness of the support programme. In the pre-test phase the Berlin Social Support Scale (BSSS)(Schultz & Schwarzer,2003), was used to test the primary outcome, perceived support (Appendix J), and The European Organisation for Research and Treatment of Cancer (EORTC) QOQ-CX 24 (Appendix L) questionnaire (Greimel, Vlasic, Waldenstrom et al., (2006) to test the secondary outcome, quality of life (Appendix H) with permission from the authors (Appendix I & K).

The Berlin Social Support Scale was developed for and validated with an adult population of cancer patients and has been recommended for use across different clinical adult populations. The multifaceted structure of the instrument allows for comprehensive assessment of social support in various research contexts in individuals and across dyads. The internal consistency for the subscales in the validation sample was perceived support: Cronbach's alpha = .83; received social support=. 83; need for support = .63; support seeking =.81; protective buffering = .82. Internal consistency for provided social support in partner sample = .75 (Schulz & Schwarzer, 2003).

The EORTC QLQ-CX24 measuring quality of life was developed in a multicultural, multi-disciplinary setting to supplement EORTC QOQ - 30 core questionnaire. The EORTC QLQ – Cx 24 consisted of three multi-item scales and five single item scales. Multi-trait scaling analysis revealed high internal consistency with a Cronbach' s alpha coefficients ranging from 0.72 to 0.87; symptom experience, 0.72; body image, 0.86; sexual/vaginal functioning, 0.87 (Greimel, Vlasic, Waldenstrom al., 2006).

1.9.3 **Population and Sampling**

For the assessment of the primary and secondary outcomes, the population consisted of all women who participated in the support programme (approximately 56 participants). According to Thabane et al. (2010), there is no specific formula dictating the sample size for pilot studies. The only prerequisite for such a sample is that it should be large enough to indicate whether the treatment (intervention) would work. A census sample (n=56), referring to the inclusion of everyone, was used and included all the women who participated in the support programme (De Vos et al., 2005). To determine the women's opinion of the support programme, a group discussion was facilitated on the last day

consisting of 8 purposively selected women. The criteria for inclusion entailed the following:

- > 18 years and older
- receiving curative treatment for cervical cancer
- from the first week to the sixth week
- having completed the pre-test
- attended all of the six sessions of the support programme
- completed the post-test questionnaires

1.9.4 **Data Collection**

To assess the primary outcome, perceived support and the secondary outcome QOL, structured interviews were conducted to complete the data gathering instruments, the Berlin Social Support Scale and QOQ-CX24 questionnaire with permissions from the authors. Structured interviews are used mostly in quantitative studies and consist of a pre-set list of questions that each participant is asked (Streubert & Carpenter, 2011). This type of interview allowed the researcher to explore specific questions relating to phenomena.

1.9.4.1 **Planning for data collection**

The first two interviews pre-tested both questionnaires to determine whether there were challenges noted with understanding of the questions in order to effect such changes, as well as to determine the duration to complete.

1.10 **DATA ANALYSIS**

Descriptive statistics was used to analyse the quantitative data. Data was analysed using computer programme SPSS 22. Descriptive statistics are summary statistics that allow the researcher to organise data in such a way as to give meaning and facilitate insight, such as frequency distribution and measures of central tendency (Burns & Grove, 2009). Chi-square was used to determine significant differences between the pre- and post-test results, and significant differences will indicate the success of the intervention. Chi-square test are a statistical test to investigate the relationship between two categorical variables to determine significant differences between observed frequencies within the

data and frequencies that were expected by chance (Burns & Grove, 2009; LoBiondo-Wood & Harber, 2010).

1.11 VALIDITY AND RELIABILITY

Validity concerns the soundness of the research evidence, whilst reliability refers to the consistency of the information obtained (Creswell.2014). Validity was achieved through subjecting all participants to the same measurements and questionnaires throughout the research process.

Reliability refers to the consistency of an instrument to measure an attribute or concept that it was designed to measure (Streubert & Carpenter, 2011). Reliability of data was maintained through intercoder agreement where several coded transcripts were compared to determine whether similar meanings were achieved from the data (Creswell & Plano-Clark, 2011).

1.12 DEFINITION OF CONCEPTS

Cervical cancer: Cervical cancer results from neoplastic alteration of the squamocolumnar junction. Abnormal cells progress to invade stromal tissues of the cervix (Gebreegziabher et al., 2016; Denny, 2009).

Pilot-test: This is a small-scale methodological test conducted to prepare a main study. It is intended to ensure that methods would work. Pilot studies can be done to pre-test a research instrument (Thabane et al., 2010; Teijlingen & Hundley, 2001).

Support: Support is an interpersonal process embedded in an array of social exchanges involving recognising and feeling supported. Studies conducted are cognisant of elements of reciprocity and perceived available support amongst members of a network (Jacobson, 1986; Dunkel-Schetter, 1984; Shumaker & Brownell, 1984).

Quality of life: The World Health Organization defines quality of life as an individual's perception of their position in life in the context of their culture and value system in which they live and in relation to their goals, standards and concerns (Pasek, Suchoka & Urban'ski, 2012; WHOQOL: 1991).

1.13 SUMMARY

Chapter 1 discussed the background and overview of cervical cancer as a disease. An outline of the research design and methods guiding the study was discussed. Chapter 2 will discuss literature pertaining to cervical cancer, its treatment, support as a factor in cervical cancer and quality of life issues in relation to cervical cancer.

CHAPTER OUTLINE AND SUMMARY

Chapter 1 : Background and rationale for the study.

Chapter 2 : Literature review pertaining to cervical cancer diagnosis, staging and treatment. Support and quality of life in relation to cancer.

Chapter 3 : Research methods and design guiding the study

Chapter 4 : Results and findings of qualitative phase of the study

Chapter 5 : Scoping reviews of programmes developed to support women treated for gynecologic cancers

Chapter 6 : Development and validation of a programme to support women receiving curative treatment for cervical cancer

Chapter 7 : Implementation and evaluation of the support programme

Chapter 8 : Results and outcomes of the programme

Chapter 9 : Discussion of results

Chapter 10 : Justification for the study, limitations and recommendations

List of References

Addenda of the Study

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 2 will discuss the published literature reviewed regarding the incidence of cervical cancer, aetiology, signs and symptoms and screening methods, diagnosis, staging, treatment support and the quality of life of patients who have cervical cancer. The purpose of conducting a literature review is to lay a foundation for new studies, and to identify studies done with almost similar topics aimed at identifying gaps. A literature review can be done to replicate the studies with a different population, identify a problem from recommendations of previous studies or to review studies done on specific topics, to identify strengths or weaknesses of particular methodologies or to identify scholars in a particular field of study. The following databases were consulted ACADEMIC SEARCH PREMIER, CINAHL via EBSCO host, MEDLINE, PSYCH INFO and PUBMED, and the exact keywords used were cervical cancer, cancer, support, quality of life and treatment to extract relevant sources.

2.2 OVERVIEW OF CERVICAL CANCER

According to the International Atomic Energy Agency (IAEA; 2012), cervical cancer morbidity and mortality remains a public health challenge. Cervical cancer has a longer pre-invasive period, averaging 10 -15 years, for changes to the cervix to progress to invasive cancer (Dunleavey, 2009; Behtash & Mehrdad, 2006), whilst a whole spectrum of events may occur before development of cervical cancer. According to Curmi et al. (2014), the Pap smear is used worldwide to screen for pre-invasive abnormalities before they can progress to cancer. Development of cervical cancer is preceded by cellular atypia, with cervical intraepithelial neoplasia (CIN) in squamous cell carcinoma and adenocarcinoma in situ, followed by various grades of dysplasia and finally invasive disease (Dunleavey, 2009; Stanley 2008). Cervical cancer begins with a neoplastic alteration of squamocolumnar junction. The junction is the area where the columnar epithelium of the endo-cervix joins the squamous epithelium of the exocervix (Dunleavey,2009; Allan, 2007). There are two types of cervical cancer. Squamous carcinoma is the most common, and involves squamous epithelium lining the ectocervix

and identified in 80-90% of cervical cancers. Adenocarcinomas comprise 10-20% of cervical cancers and carry a poor prognosis, owing to tumours arising from the endocervical mucus producing gland cells that are bulky and difficult to treat (Behtash & Mehrdad, 2006; Allan, 2007). However, there is a small percentage of cervical cancers of rare histological types, such as lymphomas, sarcomas and neuroendocrine tumours (Dunleavey, 2009). Mortazavi et al. (2002), in a study conducted in Iran to determine prevalence of HPV 16, 18 and 33 in cervical cancer cases, found the majority (87%) were squamous cell carcinoma.

Denny (2009) reported that squamous cervical cancer has long been noted to have characteristics of a sexually transmitted diseases, which lead to the search of an infectious agent responsible for causing cervical cancer. It has been reported that epidemiological studies done on virginal and HPV negative women clearly indicated that sexual intercourse was a necessary step in acquiring HPV (Castells ague, Bosch & Muñoz, 2003), as well as through skin to skin contact (IAEA, 2012). According to the World Health Organization (WHO) (2006), HPV infections are common among women less than 25 years. Furthermore, Anorlu (2008) stated that several studies reported an association of HIV with HPV, as supported by Sibiya and Grainger (2010) in a study conducted in Kwazulu-Natal to identify women at risk for cervical cancer, as the disease has been considered an Aids defining illness. Ntekin (2012) also asserts that the onset of the HIV/AIDS epidemic in sub-Sahara has elevated the problem of cervical cancer to a serious level. However, Denny and Anorlu (2012) reported that an increase in women diagnosed with cervical cancer during the HIV pandemic in Africa was not observed, as most (women) died of other opportunistic illnesses prior to the development of cervical cancer. This statement is supported by Ononogbu et al. (2013), who found that positive lesions for cervical cancer were marginally increased among HIV infected women in Nigeria compared to reports from other African countries. The concern is that despite the availability of primary and secondary preventative measures, cervical cancer is still the second most common cancer, after breast cancer, responsible for deaths of women worldwide.

It is widely accepted that detection and treatment of HPV-related dysplastic epithelial change in the form of CIN-2 and CIN-3 can prevent the development of invasive cervical cancer in individual patients**.** Women who received inadequate screening for cervical cancer presented late with advanced disease associated with an overall worse prognosis (Ramondetta et al., 2006). Women diagnosed with cervical cancer in developing countries tend to struggle with access to treatment and to cope with its physical and psychosocial impact, as there is little or no support to assist them with the illness (Alliance for Cervical Cancer Prevention, 2004).

Ramondetta et al. (2006) reported that in the United States, deaths from cervical cancer had decreased since initiation of routine cervical cancer screening in 1941, however the decline plateaued due to the inability to screen all women. Whilst the decline was reported in developed countries, this was attributable to the stability of cytologic screening for early detection of precancerous lesions in sexually active women in public hospitals (Alliance for Cervical Cancer Prevention, 2004). Even though the incidence has declined in developed countries, the age of cervical cancer patients tends to be younger (Xie et al., 2013). Dunleavey (2009) reported that mortality rates were found to have increased in a number of developed countries such as Spain and Rumania where there has been a decline in diagnosis of carcinoma with a concomitant increase in carcinoma situ. Cervical cancer is referred to as disease of poverty, as worldwide research found that women of low socio-economic status were at risk of increased mortality as they were less likely to know and access screening due to being less educated, poorer and unemployed (Anorlu, 2008; Denny, 2006; Mosavel, Simon, Oakar et al., 2009).

2.3 INCIDENCE AND PREVALENCE OF CERVICAL CANCER

According to Denny (2010), it is estimated that 78 897 women in Africa are diagnosed with cervical cancer annually, and 61 671 (78%) will die from the disease, which means a significantly higher incidence and mortality ratio than found in developed countries. Denny (2010) further reported that in contrast, the USA, with a population of 121.32 million women aged 15 years and older, 13 162 women develop cervical cancer per year and 5 214 (40%) die from the disease. This statement is asserted by Jemal et al. (2011)

who found that worldwide, the highest incidence of cervical cancer has been reported in Eastern, Western and Southern Africa, as reported by Hank, Hogue and Zungu (2013). Garland, Bhatla and Ngan (2012) found that in the Asian Oceanic region the disease accounts for more than 50% of cases and deaths from cervical cancer, as each year 315,000 women are diagnosed, with an overall incidence of 15.2 per 100 000 women. Behtash and Mehrdad (2006) reported that in the Middle East, the incidence rates ranged from 0.4 per 100,000 women per year. Accordingly, in the European Union (EU) 34 000 new cases of cervical cancer were reported with 16 000 deaths annually, with the burden of the disease increasing in new member states. The highest annual world-standardised mortality rates from the disease were reported in Romania and Lithuania at 13.7/100 000 and 10.0/100 000 respectively, and the lowest rates in Finland at 1.1/100 000 (Arbyn et al., 2010). The Canadian task force (2013) reported that in 2011 an estimated 1300 new cases of cervical cancer were diagnosed in Canada, with 350 deaths. Denny, Quinn and Sankaranayanan (2006) acknowledged that a significant number of women with cervical cancer die without a diagnosis being made nor histological sampling performed suggesting the number of reported cases is an underestimation of the true number of cases.

In South Africa, age standardised incidence rates for cervical cancer according to the WHO are 26.6 per 100 000 women (Richter et al., 2013).

2.3.1 **Aetiology of Cervical Cancer**

Allan (2007) states that epidemiological evidence suggests a strong association between sexual history and practices and an increased risk for cervical cancer. Men were implicated in the chain of infection as they contributed to the risk of developing cervical cancer in their female partners. Acquisition of cervical HPV infection is the main biologic precursor of a series of events leading to development of cervical cancer (Franco et al., 1999; Forman, de Martel, Lacey et al., 2012). This was evidenced by recurrent infections with certain oncogenic types of human papilloma virus associated with integration of the viral genome into the host genome leading to subsequent transformation (Brown & Trimble, 2012). Behtash and Mehrdad (2006), who found that certain high-risk human papilloma virus strains played an important role in the

development of cervical cancer, asserted the aforementioned statement. HPV infection has also been associated with other cancers and non-cancerous conditions in both men and women**.** According to Harries et al. (2009), almost all individuals are infected with HPV within 2-5 years of initiating sexual activity. HPV's consist of small double strand DNA viruses that infect squamous cells with potential for maturation (Stanley, 2008); in addition, the viruses are host and tissue specific, meaning that a complete infectious cycle would occur within a fully keratinised squamous epithelium. Altaf (2001) reported that it is widely accepted that squamous carcinoma of the cervix and adenocarcinoma, as well as precursor lesions are caused by specific HPV infections of the genital tract, with HPV 6 and 11 subtypes responsible for benign lesions, while HPV 16, 18 and 31 are responsible for high grade cytological atypia. The statement, confirmed by the IAEA (2012), states that HPV types 16 and 18 are responsible for 70% of all cervical cancers and high-grade squamous intraepithelial precancerous lesions (CIN 2 & 3). Brown and Trimble (2012) reported that transient HPV infections correlate with low-grade squamous intraepithelial (LSIL) cytology or cervical intraepithelial neoplasia (CIN1) histology, whilst persistent oncogenic infections correlate with HSIL cytology or CIN 2 and 3 histology.

The rate of prevalent infections in young adult females in many industrialised countries is as high as 40-80%, and a lifetime probability of ever encountering HPV is as high as 80-90% (Bosch et al., 2012). The statement of Bosch et al. (2012) was confirmed by Apgar et al. (2009), who found that HPV was prevalent among 20-24-year olds, with a gradual decline in prevalence amongst those aged 59 years. According to Basu, Ngan and Hseon (2009), each year 5% of women over 25 years acquire new infections with an oncogenic HPV and 1% over 25 years acquire new infections with either HPV 16 or 18. Furthermore, Harris and Botha (2007) also report that HPV 16 is associated with 50% of invasive carcinomas, whilst HPV 18 is 16% and HPV 31 with 8%.

The key determinants of HPV infection are related to sexual behaviour in men and women (WHO, 2006). Denny and Anorlu (2012), reports that transmission of HPV occurs through mechanical abrasion of infected epithelium with uninfected epithelium. Accordingly, high risk HPV's need to penetrate deep layers of the epithelium to establish chronic infection. Makua (2008), in a study conducted in Tshwane, South Africa, found

that male hygiene practices play a role in development of cervical cancer, as it was reported that if an uncircumcised male does not practice good hygiene the smegma that accumulates under the foreskin harbours HPV, which could be transmitted to their partner during sexual intercourse. To endorse the statement of Makua (2008), it has been reported that HPV – DNA could be detected in vulval, vaginal, cervical, oral, as well as anal tissues of women, on the penis, glans, foreskin, scrotal tissues and anus in men (Denny, 2010; Bosch et al. 2013). Sexual initiation at a young age, was implicated in the development of HPV infection, as it was believed to infect three quarters of the reproductive age population, with the highest rates of genital HPV infection occurring between ages 15 and 25 years (Dunleavey, 2009). In addition, Oshima and Maezawa (2013) found that cervical cancer screening programmes are not offered in higher education institutions and vocational schools. To confirm this statement, Apgar et al. (2009) found that intercourse before 18 years of age carries a two to fourfold increased risk of subsequent development of invasive cervical cancer.

Most women infected with high risk HPV do not develop cervical cancer as most infections disappear within several months to 2 years (Allan, 2007), which may be attributed to acquired immunity, hormonal factors and decrease in the number of sexual partners. Persistent infection with other sexually transmitted viruses, such as herpes simplex virus type 2(HSV-2) and human papilloma virus subtypes 16, 18, 33, 35 and 45 (Allan, 2007), has been implicated in the development of invasive cervical cancer, as well as high viral load. Stanley (2008) also reported that in approximately 99% or more of invasive cervical cancer biopsies worldwide, HPV DNA sequence could be detected. He further postulated that HPV infection does not only cause cervical cancer, but that oncogenic HPV DNA sequence was present in a proportion of anal, vulval, vaginal, penile as well as head and neck cancers. Persistent infections, as well as viral types and load, and oncogene expressions, were found to increase tendency for development of high grade squamous intraepithelial lesions in women infected with HIV (Lillo & Uberti-Foppa, 2006).

Women infected with human immune deficiency virus (HIV) are at risk for development of cervical cancer resulting from HPV progression due to their immunocompromised

state (Allan, 2007; WHO, 2006), as well as those who are chemically supressed or transplant recipients (Dunleavey, 2009). Women infected with HIV have the potential of being diagnosed with an invasive disease 10 years earlier than average women do. Having a high number of sexual partners as well as having partners with multiple partners (WHO, 2006) have been associated with risk for development of cervical cancer. Specific ethnicity were found to contribute to the development of cervical cancer, as reported in the study of Konno et al. (2008) conducted in Japan and Korea where other subtypes, such as 52, 58 and 33, were responsible which differs slightly with other parts of the worldwide distribution. In some sub-populations, women who are lesbians may pose an additional risk to develop cervical cancer (Ali, Kuelker & Wassie, 2012; Cumi, Peters & Salamonson 2014). Other factors that could influence screening are missed opportunities, whereby a woman had contact with a healthcare provider but received no recommendation or offer to take a screening test when it was appropriate to do so (Decker, Demers, Chateau et al., 2009). However, failure of both clinician and patients to act on abnormal results, as well as underscreening of populations at risk, has been cited (Wright, Denny, Kuhn et al, 2000). At risk populations, such as women in lesbian relationships, those who initiated early sexuality and women with high parity, to name a few, need to be encouraged to access screening.

High parity and large number of pregnancies have been associated with the development of cervical cancer, as the suggestion is that multiple pregnancies may have a cumulative traumatic effect on the cervix resulting in progression of infection with HPV (Dunleavey, 2009). Cigarette smoking reportedly induces carcinogenic effects on sites not directly exposed to cigarette smoke. Dunleavey (2009) reported that it has been possible to find nicotine derivatives on the uterine cervix, which could be implicated in the local immune suppression to HPV infection. Long-term use of oral contraceptives also has an association with HPV infection independent of sexual behaviour. History of anal intercourse is implicated due to presence of HPV DNA detected in most anal cancers in both males and females (Bosch et al., 2012). Lack of perceived personal risk of cervical cancer, unavailability or lack of screening services, as well as women's inadequate knowledge of the disease have been linked to the development of the disease (Mosavel et al, 2009).

2.3.2 Signs and Symptoms of Cervical Cancer

Women can remain asymptomatic during the pre-invasive stage, which is detectable on investigation of an abnormal Pap smear (WHO, 2006; Allan, 2007). Symptoms usually do not appear until abnormal cervical cells become cancerous and invade nearby tissue (Richardson et al., 2008). Camilleri and Blundell (2009) reported that early symptoms of cervical cancer present with thin watery blood tinged vaginal discharge that is frequently unnoticed by the patient, whilst other symptoms commonly present with malodorous vaginal discharge, decrease in the interval between menstrual periods, an increase in length or amount of menstrual flow, intermenstrual bleeding or postmenopausal spotting or bleeding, episodes of contact bleeding or postcoital bleeding in women of any age. Failure to act on abnormal symptoms may lead to complications leading to reporting late when disease has progressed.

Late symptoms include development of pain referred to the flank or leg, usually this is secondary to involvement of the ureters, pelvic wall or sciatic nerve routes. Other symptoms are complaints such as difficulty in starting a urinary stream, urinary frequency, urgency, or pain with urination and haematuria due to bladder invasion, dyspareunia or backache. Advanced disease may present with constipation or bleeding from the rectum resulting from pressure or invasion of the rectum, persistent oedema of one or both lower limbs due to involvement of regional lymph nodes and venous blockage (Camilleri & Blundell, 2009; Allan, 2007; WHO, 2006). Very late symptoms usually present with severe backache, decreased urinary output from obstruction of the ureters or renal failure, leakage of urine or faeces through the vagina due to a fistula, weight loss, breathlessness due to anaemia or rarely, effusion or lung metastasis.

2.4 SCREENING FOR CERVICAL CANCER

Cervical cancer screening aims to test the largest proportion of women at risk for the disease and ensure follow up for those with abnormal test results. Screening and education about screening programmes plays a vital role in the prevention of cervical cancer as well as premature deaths from the disease. Screening is a public health intervention used on populations at risk; it is not used to diagnose but to identify individuals at risk of having or developing a disease. However, according to the

Canadian Task Force (2013), early and frequent annual screening is un-necessary as similar outcomes were achieved from other countries with less frequent testing.

According to the WHO (2006), the disease must have a detectable pre-clinical stage without symptoms. Screening tests should be simple and non–invasive, specific and inexpensive and acceptable to the target audience. Treatment at pre-clinical stage must favourably influence the long-term course and disease prognosis. Any further testing and treatment needed must be available, accessible and affordable for those who have a positive screening test. Cervical cancer fits the criteria, being a worldwide problem especially in developing countries where resources are still limited. In most developed countries, cervical cancer has declined due well- established prevention programmes and well organised mass population screening (Behtash & Mehrdad, 2006; Ali, Kuelker & Rasie, 2012). However, in developing countries the opposite is the case as most women present with advanced disease and some even die from it. Cervical cancer is one of few preventable cancers through comprehensive screening and treatment of precancerous lesions. In sub-Sahara, it is still a challenge as cervical cancer mortality in the developing world is one of the many priorities competing for scarce resources.

The American guidelines of the Cancer Society (2006), recommend that cervical cancer screening begins approximately three years after commencing sexual intercourse or after the age of 21 years, whilst the United States Preventive Task Force (USPSTF), advocates for screening every three years from the age of 21 to 29 years, and no screening prior to the age of 21 years regardless of age of first coitarche. Furthermore, women 30 to 65 years need to screen every five years, with co-testing with cytology and HPV or cytology alone if HPV is not available (Fields, 2013).

van Rosmalen, de Kok and van Ballegooijen (2012) stated that in the Netherlands, cervical cancer mortality reportedly declined steadily in the last decade, largely due to a well-functioning, cytology-based screening programme in which women were invited for a Pap smear every 3 to 5 years from the age of 30 to 60 years. Australia has a comprehensive screening programme in place in which women from 18 years should be screened once or twice yearly, or 2 years after their first sexual intercourse (Garland,

Bhatla & Ngan, 2012; Cumi, Peters & Salamonson, 2014). Mass screening was introduced in Japan at the end of 1950s but in 1982, the government enacted the Health and Medical law, which recommended annual screening for women above the age of 30 years. This however, led to a decline in screening nationwide due to the absence of national funding, as women were expected to make out-of-pocket payments of 10-30% of the total cervical cancer screening cost (Konno et al., 2008). The National Department of Health screening policy in South Africa has introduced three free Pap smear screenings every 10 years for women aged 30 and older (Mosavel et al., 2009). It is imperative that resources are prioritised for those who have never been screened, as disparities exist with regard to accessing healthcare especially women in rural areas, as studies found that these groups of women present at the healthcare facility late, when the cancer has advanced.

Introduced originally by George Papanicolaou in 1941, the Pap smear has been the traditional method of screening for cervical cancer worldwide. The method was deemed an effective screening tool to detect abnormal precancerous cervical lesions, which could be treated early to prevent progression to cervical cancer (Curmi et al., 2014). The method was effective in developing countries due to a well-organised infrastructure and quality assurance, as well as availability of human resources. Despite caution exercised during the taking of samples, false negatives were reported resulting from sampling errors, which could be due to the presence of obscuring blood and inflammation (Nandini et al., 2012). Manual liquid-based cytology has been found to be more cost-effective technology than conventional cytology, as it was effective in detection of precursor lesions and adequacy of collected specimens (Nandini et al., 2012). Initiating and sustaining such programmes are found to be a challenge in developing countries as both methods are prohibitively complex, which could be attributed to infrastructure, human resources and finances to sustain them (Denny & Anorlu, 2012; Ononogbu et al., 2013). The World Health Organisation (WHO) and the International Agency for Research on Cancer (IARC) established efforts to curb the burden of cervical cancer in the developing world, by adopting alternate screening methods, such as HPV DNA testing, Visual Inspection With Acetic Acid (VIA), or Visual Inspection with Lugol's Iodine (VILI). Currently, another method of primary prevention through Human Papilloma Virus (HPV)

vaccine seems promising and has been implemented in most of the developed countries, although the method is still at a pilot stage in these countries. Discussed below are different screening methods.

2.4.1 **Pap Smear**

Samples of the smear are taken from the transformation zone of the cervix using an extended tip of a wooden spatula or endocervical brush. The entire transformation zone should be sampled since this is where almost all high-grade lesions develop. The focus of the clinicians, when collecting the samples, is to minimise sampling error through effective sampling of the transformation zone to include endocervical cells and avoiding drying of the artifact by rapid fixation of the cells. The sample is smeared on to a glass slide and fixed immediately with a solution to preserve the cells. The slide is sent to a cytology laboratory, where it is stained and examined using a microscope to determine whether the cells are normal and to classify them according to the Bethesda classification (WHO, 2006; IAEA: 2012). According to Denny (2009), the Bethesda classification of cervical cytology was introduced in 1988 to standardise the terminology because of the many definitions used for cervical precursors. Akbar, Nasir, Pervez et al., (2015). Moosa (2014) reported that Manual Liquid Based Cytology (MLBC) was comparable as a better alternative to the conventional Pap smear. Technologies such as Thin prep or Auto cytoprep are used in the Manual Liquid Based Cytology technique. The cervix is sampled in a similar manner to the Pap smear however, cells are suspended in a monolayer, which is a liquid medium for transport to the laboratory. The method has been successful to enhance detection of neoplastic and pre-neoplastic infections due to more well-preserved cellular structures in MLBC slides and improved specimen collection (Nandini et al., 2012; Behtash & Mehrdad, 2006).

Denny and Anorlu (2012) reported that the most tested approaches are Visual Inspection with acetic acid (VIA)/ Visual inspection with Lugol's iodine (VILI) and Human papilloma deoxyribonucleic acid (HPV DNA) testing as primary screening, or in combination with cytology, or as an adjunctive test. Progress has been made in developed countries with use of alternate screening methods, such as HPV DNA testing. The tests seem promising compared to conventional cytology testing, as supported by Wong et al.

(2016), who found the test most effective compared to conventional cytology, although the method still poses challenges to developing countries. In South Africa, Vijayaraghavan et al. (2009) found that use of HPV DNA testing could yield better results in detection of cervical HPV and the role that high prevalence HIV plays in the development of cervical cancer.

2.4.2 **HPV DNA Testing**

Bosch et al. (2012) reported that persistent detection of HPV DNA across carcinogenic stages led to the evaluation of DNA assays as a screening tool for early detection of cervical intraepithelial neoplasia (CIN2), or (CIN2+). Results show absolute sensitivity to HPV DNA test compared to conventional or liquid based cytology tests. Akbar, Pervez and Shah (2015:579) reportedly found evidence from the use of residual Manual Liquid Based Cytology (MLBC) residual samples that could also be used for testing of HPV DNA and immunocyto chemistry thereby increasing utilisation of MLBC; however, this is still not readily available in the public sector in sub-Saharan countries. In a study conducted in Montreal and St Jones in Canada to compare HPV DNA and cytology testing, it was found that the sensitivity for CIN 2-3 for HPV was 94.6% compared to 55.4% for cytology (Mayrand et al., 2007). Sankaranayanan et al. (2009), in a study conducted in India to measure the effect of single round testing for human papilloma virus in a low resource setting, found a significant reduction of cervical cancer or related deaths from the disease compared to VIA or cytologic testing. In Korea, HPV DNA testing is used to triage women with abnormal cytology, as the latter is still the method of choice for cervical screening (Konno et al., 2008). Although HPV DNA testing has been found to be an effective method to screen for cervical cancer in developed countries, it seems to be a challenge to implement in low resource settings. This is due to high costs and affordability to implement large-scale programmes as well as other co-factors related to training in primary healthcare settings in the developing world; studies done in developing countries were mostly pilot tests. The scourge of HIV infection in women in sub-Saharan countries led to a rise in human papilloma virus infections in this group; this has led to consideration of other cheaper but effective methods to detect cervical cancer, such as VIA/VILI and low cost care HPV DNA testing. Low cost HPV DNA testing for the detection of carcinogenic genotypes of HPV has recently become

available in response to more robust needs for cervical cancer screening in low resource and middle income countries (LMIC); for use in a screen-and-treat approach in the reduction of prevalent CIN 2+ infections (Jeronimo et al., 2014); which has led to the development of C*are* HPV, which is simplified and affordable for use in low resource settings. C*are*HPV is a new technology developed from the partnership between public and private companies via Qiagen Inc (Gaithersburg, MD) and PATH (Seattle, WA, USA). C*are*HPV is affordable and easy to use, as it does not need running water or air conditioning and can be completed by people with limited laboratory training.

According to guidelines from the United States Preventative Task Force, women aged 30 to 65 should be screened every 5 years with co-testing cytology and HPV, or every 3 years with cytology alone if co-testing is not available (Fields, 2013). In addition, a study conducted in Costa Rica on age trends in acquisition and persistence of cervical cancer found that a second peak occurs in older women in some populations making it necessary to screen women in this population (Castle et al., 2003). Use of self-collected HPV-DNA samples appears more convenient and a promising strategy to encourage screening uptake in low resource areas, although less specific when used alone. Self-collection of HPV DNA entails collection of vaginal samples by the women through insertion of a sterile Dracon swab into the vagina and rotating it three times. The specimen is placed into a HPV DNA specimen collection tube for transport in the media. Self-collection of the specimen entails collection of the specimen by the women themselves while in a squatting position. The method seems a promising strategy, as it offers women the opportunity to do screening in their own home, thus encouraging the uptake of screening.

Lazcano-Ponce et al. (2011), in a study conducted in Mexico to assess the use of HPV screening in different settings, found self-sampling to reduce the need for cervical cytology and tended to be more sensitive for detection of cervical cancer and precursor lesions. Wright et al. (2000), in a study in conducted in South Africa on self-collected HPV DNA vaginal samples, reported the test had sensitivity to detect high grade lesions, whilst clinician collected samples were more sensitive to detect high grade lesions and invasive cervical cancer. The need for simple and cost-effective measures for cervical

cancer screening in LMIC led to low intensity screening, which is a single screen and treat approach, which led to evaluation of visual screening with acetic acid. The screen and treat approach also have the advantage of eliminating investigations to confirm diagnosis before treatment and minimises losing women to follow up and delay in treatment and missed disease (Sankaranayanan et al., 2012).

2.4.3 Visual Inspection with Acetic Acid (VIA) Screening

Visual inspection with acetic acid is referred to as Acetic acid testing (AAT). In other settings, low magnification, 2-4 times (VIAM), is used after application of acetic acid on the cervix. Sauvaget et al. (2011) stated that Schiller (1933) published an article reporting on application of iodine solution to the cervix to detect neoplastic lesions. In the early 1990s, the use of diluted acetic acid application or Lugol's Iodine had been extensively used to screen women mostly in low resource settings where high incidence or mortality from cervical cancer prevailed. Visual inspection with acetic acid involves inspection of the cervix with naked eyes using a bright source of light and one-minute application of 3-5% dilute acetic acid to the cervix using a cotton swab or spray. The application of acetic acid coagulates the protein of the nucleus and cytoplasm and makes the protein opaque and white. The dysplastic cells have large nuclei and acetic acid causes dysplastic lesions to turn white (Keshavarzi et al., 2013).

The changes that occur in the cervix, in relation to the squamocolumnar junction (SCJ) after application of acetic acid visible to the naked eye can be categorised as a negative or positive test for cervical neoplasia. In young women of early reproductive age, the SCJ is located away from the external os, however as a woman progresses to her 30s it moves closer to the external os, whilst the new SCJ moves to the external os in perimenopausal women. The SCJ is not visible with post-menopausal women, as it has receded into the endocervix (Sankaranayanan & Wesley, 2003). The location of the original SCJ varies with the women's age, hormonal status, and history of birth trauma, pregnancy status and use of oral contraceptives. Visibility of the transformation zone is critical for accurate Interpretation of VIA results.

The transformation zone is the area between the cervix where the columnar epithelium is replaced by metaplastic squamous epithelium. The transformation zone is primarily located on the ectocervix in pre-menopausal women. Consequently, after menopause and old age, the cervix shrinks due to decreasing levels of oestrogen and the transformation zone may move partially and later fully into the endocervical canal. While VIA is considered simple, feasible and affordable interpretation of the results in post-menopausal women tends to be a challenge due to a brittle degenerating cervical epithelium (Sankaranayanan et al., 2012). The test (VIA) may also pose a challenge in women with partially visible or invisible squamocolumnar junction. The assumption is that it may be difficult to perform VIA in women 50 years and older due to the SCJ receding into the endocervical canal (Cremer, Conlisk et al., 2011). The changes that occur in the cervix, in relation to the Squamocolumnar Junction (SCJ) after application of acetic acid, visible to the naked eye can be categorised as negative or positive test for cervical neoplasia.

A negative test is characterised by one of the following: no acetowhite lesions, ill defined, faint, translucent acetowhite lesions, acetowhitening of endocervical polyps, nabothian cysts, prominent acetowhitening of the SCJ, dot-like acetowhitening scattered all over the cervix, and geographic satellite acetowhite lesions not touching the SCJ. A positive test is characterised by well–defined, opaque acetowhite lesions in the transformation zone close to the SCJ, or the entire cervix turning white (Murillo, Luna, Gamboa, Osorio, Bonilla, Cendales & the National Cancer Institute of Colombia (INC) Cancer Screening Group, 2010). Invasive cancer is suspected when the entire cervical growth turns acetowhite. Furthermore, VIA tests are subjective as well as provider dependent owing to different levels of experience of providers in different settings (Sherigar, Dalal, Durdi et al., 2010). According to Russo, Kupek and Zanine (2011), visual inspection with Lugol's Iodine is recommended immediately after collection of cytology sample in order to minimise false negative results as well as delayed treatment.

2.4.4 **Visual Inspection with Lugol's Iodine (VILI)**

Use of VILI has been advocated in other settings to confirm or disconfirm false positive tests, as well as delayed treatment (Russo, Kupek & Zanine, 2011). After application of

3-5% acetic acid solution to the cervix, initial diagnosis would be according to the thickness, extension and surface morphology of the opaque acetowhite lesion. Lugol's Iodine 5% solution is applied to the cervix, followed by examination by the naked eye. Negative diagnosis includes a normal cervix, where the squamous epithelium turned black brown, and the columnar epithelium remained pale, colourless, partially brown or pale yellow in the transformation zone, with Ill-defined non-iodine uptake areas located away from the SCJ without extension to the vagina.

Positive diagnosis would appear as a well-defined mustard–yellow area touching the SCJ. Studies done on VILI have shown specificity and sensitivity considerably higher than VIA or Cytology (WHO, 2006; Zhang et al., 2010). Despite that the use of VIA/ VILI is subjective as it relies on findings of the person conducting screening, it has been found to be feasible, affordable and effective in screening for cervical cancer in LMIC which could help in early diagnosis of cervical intraepithelial neoplasia and prevent further progression of the disease (Thistle, 2019; Luciani, Munoz, Gonzales et al, 2011). Whilst other methods of screening have their challenges, another promising strategy, HPV vaccination, could bring a better promise for eradication of cervical cancer if used early in conjunction with screening for the disease.

2.4.5 **HPV Vaccination**

Studies conducted in developed countries have shown that prophylactic vaccination against viral infections has been effective in the control of the infections (Stanley, 2008; Basu et al., 2009; Konno, Shim et al., 2008). The Food Drug Administration licensed two commercially available Human Papilloma Virus (HPV) vaccines. The prophylactic bivalent vaccine Cervarix (GlaxoSmithKline), targeted at HPV 16 and 18, and a quadrivalent vaccine, Gardasil or Silgard, targeted against the two most carcinogenic subtypes HPV 16 and 18 as well as 6 and 11, have the potential to prevent cervical cancer in 70-80% of HPV naïve women (Basu et al., 2009; Beer et al., 2014). The vaccines prevent acquisition of HPV 16 and 18 infections that are responsible for approximately 70% of cervical cancers and offer cross protection against certain oncogenic strains further. Westra et al. (2013), in a study conducted in Netherlands, found that Bivalent Vaccine offers cross protection against other strains of HPV types

not included in the vaccine, such as HPV 31,33 and 45, whilst Quadrivalent vaccine offers cross protection against HPV 31. Colombo et al. (2012) reported that in 2010, most developed countries introduced HPV vaccines into their routine vaccination programmes. The availability of efficacious vaccine against HPV16 and 18 presented the opportunity to prevent development of associated cytological and histological changes based on the distribution of HPV 16 and 18 in precancerous lesions and cervical cancer. Further evidence showed that previously infected women, now cleared of infection, can completely benefit from the protection against HPV types contained in the vaccines, however, it is not meant to increase clearance of existing HPV's and is not therapeutic (Basu et al., 2009; Stanley; 2008); this warrants women continuing with screening for cervical cancer at regular intervals.

Hofstetter et al. (2014), in a study conducted in New York, found that despite the recommendations from the Advisory Committee on Immunisation Practices (AICP), for females between 11 and 12 year olds, parents tend to delay initiation of vaccination of adolescent children due to the low perception of risk of the children developing the disease as well as age related concerns. Beer et al. (2014) reported that in the United Kingdom (UK), the vaccination programme with Cervarix commenced in 2008, with the recommended three doses administered to schoolgirl's aged 12-13 years, with a 2 year catch-up arm to girls 18 years and above, who would still benefit from immune response induced by the vaccine.

Although the advent of vaccination against HPV brought some improvement in the control of cervical cancer in developed countries, developing countries are still faced with challenges of availability of the vaccines due to cost and other co-factors surrounding implementation issues. The WHO (2009) recommends that HPV vaccines be included in the national immunisation programmes in order to make it a public health priority and accessible for adolescents in low-income countries. Studies conducted on HPV vaccination programmes in developing countries were implemented as pilot programmes to test feasibility and acceptance, which were found to be high but with knowledge gaps that need to be addressed to make it successful (Cunningham, Davison & Aronson, 2014; Perlman et al., 2014; Crann, Barata, Mitchell et al., 2016). Studies

conducted in schools in two provinces in South Africa found the vaccine to be acceptable to both the community and political leaders (Botha et al., 2015), whilst Moodley, Tathiah, Mubaiwa et al., (2013), in a study carried out in a school environment conducted in Kwa Zulu - Natal, South Africa, found the uptake of vaccine to be high among 9-12 year olds. Whilst vaccination with HPV vaccines was recommended for girls, studies conducted on vaccination of boys aged 16 to 26 with quadrivalent vaccines has been found to be effective against HPV 6,11, 16 and 18, as well as related external lesion with 92.4% reduction (Marty et al., 2013).

Despite vaccination seemingly bringing hope in reducing morbidity and mortality from cervical cancer, it is imperative to educate and encourage women and teenagers to continue period screening in an effort to detect the disease early while it may be possible to treat.

2.5 DIAGNOSIS AND STAGING

The first consultation of a patient with an abnormal cervical smear is used for history taking and counselling to discuss colposcopy and other treatment options (Lindeque, 2009). Exfoliative cytology has been the most widely used method to detect cervical precursors. Current practice is to refer women with a cytological diagnosis of atypical squamous cell of undetermined significance (ASCUS), high grade squamous intraepithelial lesion (HSIL) or any suspicious cancer lesion for a colposcopy (Denny: 2009). ASCUS is a term used when cytological findings are more suspicious than benign changes. Women older than 50 years tend to present with more glandular cells than younger women, which tends to present as atypical glandular cells of undetermined significance (AGUS) and have significantly been associated with precancerous or cancerous conditions. The recommendation is to perform colposcopy and endocervical curettage (Camilleri & Blundell, 2009).

Colposcopy is an assessment tool allowing visualisation and magnification of abnormal areas of the cervix and the entire genital tract and can be used during the treatment process because of its magnification capabilities. According to Denny (2009), if a diagnosis of HSIL is confirmed during the colposcopy, most centres practice a “see and

treat" approach whereby treatment is instituted without a histologic sample to confirm a diagnosis, whilst in other instances a Loop Electrosurgical Excision Procedure (LEEP) may be performed under local anaesthesia to provide a histological sample for evaluation (IAEA: 2012). LEEP is the removal of abnormal areas of the cervix using a thin heated electric wire to treat the lesion and remove the entire transformation zone. Whilst pregnancy does not accelerate cervical lesions, five/100,000 cervical cancer may occur during pregnancy; however, to rule out invasion in this group of women, colposcopy and directed biopsy may be performed (Apgar et al., 2009; Lindeque,2009), but endocervical curettage is not recommended.

According to Colombo et al. (2012), there are three categories of epithelial tumours of the cervix, squamous, glandular (adenocarcinoma) and tumours including neuro endocrine tumours and undifferentiated tumours. Some early tumours are not appreciable even some deeply invasive tumours may be deceptive on gross examination warranting examination under anaesthesia if there is uncertainty regarding vaginal or parametrical involvement. Harris and Botha (2007) suggest that when patients with a suspicious lesion for cancer are examined a biopsy of the lesion and cytology should be taken and referred for further management; the IAEA (2012) supports this and states that a biopsy of the lesion is mandatory in order to confirm a histologic diagnosis of cervical cancer. A biopsy is a small sample of tissue taken from the cervix or inside the opening the cervix (endocervical canal) for further examination in the laboratory. Staging of the disease is necessary to determine the extent of the disease and to assist the clinician in planning the treatment and determining the patient's prognosis.

2.5.1 **Staging and Assessment of Risk**

Staging is done according to the classification of the International Federation of Gynaecology Obstetrics (FIGO), and based on the tumour size, vaginal or parametrial involvement, bladder or rectum extension and distant metastasis (IAEA, 2012; Colombo et al., 2012; Harris & Botha, 2007). The extent of the cancer is assessed clinically through history and physical examination, including a pelvic examination, consisting of rectovaginal examination supplemented by a number of unsophisticated investigations consisting of simple chest X-rays, Intravenous Pyelogram (IVP), barium examinations of

the lower colon and rectum or ultrasound, cystoscopy and proctoscopy as well as blood chemistry. In low resources settings, speculum vaginal and rectal examinations are the only feasible methods for staging, done under general anaesthesia preferably in conjunction with the gynaecologist or gynaecologic oncologist if the conditions for a thorough pelvic examination are suboptimal. For patients with advanced disease or citing urinary or rectal complaints, cystoscopy or proctoscopy is required. Other improved modalities, such as CT and MRI scans, have improved the ability to detect lymphadenopathy and better delineate local spread. Position Emission Tomography (PET) scanning allows exclusion of lymphadenopathy but most of these complex modalities are not readily available in most developing countries, although they are available in tertiary hospitals that have the challenge of burden of disease with patients from satellite hospitals and clinics. Research is ongoing to investigate the role of sentinel lymph node biopsy to determine lymph node status in early stage (stage I-IIA) cervical cancer; however, this is not included in FIGO staging. Sentinel lymph node (SLN) biopsy is a diagnostic technique used to determine the local and regional lymph node involvement of cancer by examining a targeted lymph node sample instead of performing a complete lymphadenectomy. Evaluation of the tumour and histopathological confirmation should be in place prior to commencement of treatment.

Assessment of tumour risk includes tumour size, stage of disease, depth of tumour invasion, lymph node status and Lymphovascular Space Involvement (LVSI). Lymph nodes are the most prognostic factors status and the number of lymph nodes involved (Colombo et al., 2012). Table 2.1 FIGO staging for carcinoma of the cervix.

Table 2.1: FIGO Staging: Carcinoma of the cervix

Stage I		
Stage 1	:	Cervical carcinoma is strictly confined to the cervix (extension to the corpus should be disregarded).
Stage IA	:	Invasive carcinoma diagnosed only by microscopy. Stromal invasion with maximum depth of 5.0 mm measured from the base of the epithelium and horizontal spread of ≤ 7.0 mm. Vascular space involvement, venous or lymphatic spread does not affect classification.
Stage IAI:	:	Measured stromal invasion >3.0 mm in depth and ≤ 7.0 mm in horizontal spread.
Stage IA2	:	Measured stromal invasion > 3.0 mm and ≤ 5.0 mm with horizontal spread of ≤ 7.0 mm.
Stage IB	:	Clinically visible lesion confined to the cervix or microscopic lesion >TIA/IA2.
Stage IBI	:	Clinically visible lesion ≤ 4.0 cm in greatest dimension.
Stage IB2	:	Clinically visible lesion > 4.0 cm in greatest dimension.
Stage II		
Stage II	:	Cervical carcinoma invades beyond the uterus but not to pelvic wall or lower third of vagina.
Stage IIA	:	Tumour without parametrial invasion.
Stage IIA1	:	Clinically visible lesion ≤ 4.0 cm in in greatest dimension
Stage IIA2	:	Clinically visible lesion > 4.0 cm in greatest dimension.
Stage IIB	:	Tumour with parametrial invasion.
Stage III		
Stage III	:	Tumour extends to pelvic wall and/or involves lower third of vagina, and /or causes hydronephrosis or non-functioning kidney.
Stage IIIA	:	Tumour extends to lower third of vagina, no extension to pelvic wall.
Stage IIIB	:	Tumour extends to pelvic wall and/or causes hydronephrosis or non-functioning kidney.
Stage IV		
Stage IV	:	The carcinoma has extended beyond the true pelvis or has involved (biopsy proven) the mucosa of the bladder or rectum. A bullous oedema does not permit a case to be allotted to stage IV.
Stage IVA	:	Spread of the growth to adjacent organs.
Stage IVB	:	Spread to distant organs

Source: FIGO Committee on Gynecologic Oncology: 2009

Staging is also important to evaluate the response of cancer cells to treatment. It is possible to accomplish successful treatment of cervical cancer through periodic screening and treatment of women presenting with premalignant cervical lesions, as well

as encouraging adolescent girls who have been vaccinated against HPV to go for regular screening.

2.6 TREATMENT METHODS

Treatment for cervical cancer involves a multidisciplinary team approach comprising an oncologist, gynaecologist, surgeon, radiation oncologist, physicists, nurses and counsellors. However, other studies conducted on this group of women have reported patients' interest to be involved at initial stage of diagnosis and treatment planning as this could help them in making decisions regarding the treatment choices. Treatment of cervical cancer is multimodal consisting of surgery, radiation and chemotherapy; depending on the stage of disease treatment may be a combination of radiotherapy and chemotherapy (Colombo et al., 2012). The use of radiation therapy is to eradicate cancer cells or to control the disease when cure is not possible, while chemotherapy is the systemic use of cytotoxic drugs to treat cancer. Other factors to consider are patient's age, general health status and presence of other compounding illnesses or disability (Camilleri & Blundell, 2009). Treatment of cervical cancer should be curative, according to the recommendations of the IAEA (2012). Treatment of cervical cancer is possible through early diagnosis and treatment of premalignant lesion before they can progress to cancer. Cervical intraepithelial neoplasia (CIN) lesions may resolve spontaneously by elimination through the host's intact immune system. However, if it seems that the women are unlikely to return for follow up, such lesions may be treated. In cases of CIN2-3 (high-grade) lesions may be treated with electrocautery, LEEP or conisation procedure (IAEA, 2012; Colombo et al., 2012).

The discussion of the management of cervical cancer will be according to the recommendations of IAEA (2012).

2.6.1 Management of Early Cervical Cancer (IA – IB1 – IIA1 – IB2 and IIA2 ≤ 4cm)

Stage IAI: with clear margins following a cone biopsy

If ≤ 1mm invasion

Fertility desired observation

Fertility not desired - class I, total abdominal hysterectomy (TAH), with or without bilateral salpingooophrecteomy (BSO)

If 2-3mm invasion: class I, TAH with/ without BSO

If ≥ 3mm invasion or evidence of lymph vascular space involvement (LVSI) class II modified radical hysterectomy. For patients with contradictions to surgery treatment can be with intracavitary brachytherapy

Stage IA2: with clear margins following cone biopsy

Fertility desired - radical trachelectomy and pelvic lymph node dissection (PLND) if,

Lesion < 2cm measured microscopically in the conization specimen;

Limited endocervical involvement at colposcopy

No evidence of LVSI.

Fertility not desired –

Class II modified radical hysterectomy and PLND with/without tailored adjuvant radiation therapy (RT)

Stage IAI – IA2 with margins involved with cancer or CIN-3

Repeat the cone biopsy or perform a class II modified radical hysterectomy and PLND with/without adjuvant RT

For patients with contradictions to surgery treatment can be with intracavitary brachytherapy alone or combination with external beam radiation therapy (EBRT).

Stage IBI-IIAI

Medically fit for surgery

Class II modified radical hysterectomy and PLND with/without tailored adjuvant RT

Definitive RT

Source: International Atomic Energy Agency (2012)

2.6.2 **Management of Advanced Cervical Cancer (IB2 and IIA ≥ 4cm – IIB –IIIA- IIIB – IVA)**

Stage IB2 – IIA2

Surgery: Class II modified radical hysterectomy and PLND in selected patients.

Adjuvant therapy: most patients will require postoperative radiotherapy/chemo I i-radiotherapy based on histopathology features

Neoadjuvant chemotherapy

Definitive radiation- chemotherapy

Stages IIB – IVA

Standard treatment is EBRT with brachytherapy with/without concomitant chemotherapy

Stages IVB

Imaging should be utilised to distinguish patients with microscopic positive peri-aortic nodes and those who present with gross peri-aortic nodes at diagnosis.

A complete diagnostic work- up needs considering for patients with positive peri-aortic nodes aimed to exclude extra abdominal or distant metastasis

Definitive radiotherapy, with/without chemotherapy, with curative intent for patients with micro-invasive disease

For patients with bulky disease to the pelvic wall, it may be necessary to treat the pelvis first and determine response before subjecting patient to radical irradiation of the para-aortic region.

2.6.3 **Cervical Cancer in Pregnancy**

Treatment of cervical cancer in the first trimester of pregnancy is either surgery or radiotherapy depending on the stage of disease. An evacuation of pregnancy could be the upfront recommendation. If therapeutic abortion is not done definitive radiotherapy with external beam radiation with frequent ultrasound to monitor foetal viability.

In the third trimester, definitive treatment has to be delayed until the foetus is mature. A classical caesarean section should be performed followed by treatment. Treatment of early stage disease is often radical hysterectomy and a pelvic lymphadenectomy. However, if surgery is not feasible, radiotherapy will be the treatment of choice but will be delayed until evolution of the uterus.

Management of the second trimester requires division according to the early half, which is treated according to the early stage, whilst the latter half will be treated according to the third trimester.

Source: World Health Organization. 2006

2.6.4 **Treatment of Recurrent Disease**

The general principle is to use modality not used previously. Each recurrence needs to individual evaluation and treatment instituted accordingly. For patients with distant metastasis with/without local regional recurrence, palliative treatment is offered (Camilleri & Blundell, 2009).

For loco-regional recurrence after radical surgery, radical irradiation or pelvic exenteration is recommended. For loco-regional, recurrence following definitive radiation, if recurrence is central and limited, pelvic exenteration is the potential choice and is curative in selected cases. For patients treated primarily with radiation with small central recurrence and not candidates for pelvic exenteration, the recommendation is treatment with brachytherapy alone. In recurrence, involving the pelvic sidewall, cure is rarely possible, and the treatment option should be individualised. Patients undergoing treatment for cervical cancer will undergo radiation therapy as well as other forms of treatment based on the stage of the disease (Colombo et al., 2012). Whilst developed countries have managed to control the disease, there are challenges for women in developing countries to access tertiary centres where treatment is available. Countries in sub-Sahara are facing challenges of treatment facilities and resources, as well as human capacity to deal with the burden of disease (Moodley, 2009), which leads to the admittance of patients to other facilities to receive treatment and monitoring by specialists. Despite this, most patients receive treatment in ambulatory care settings; these patients find themselves having to receive treatment away from their homes and families, which in turn disrupts family routines and life patterns. Support and assistance with daily life activities is crucial during this time, as they endeavour to reduce and compensate for disadvantages arising from cancer and its treatment (Ozkan & Ogce, 2008). Patients who perceive support from their natural and formal networks adjust well to the disease, its treatment as well as adverse life events (Costa-Requena, Arnal & Gil, 2013; Shiozaki et al., 2011; Hinds & Moyer, 2007; Cutrona, 1996). The nature of the disease and its stigmatisation might lead to patients having difficulty in requesting support.

2.7 SUPPORT

The concept support appears to be a broad and complex construct to discuss. Despite many studies being conducted to date, a consensus has not been reached as to what constitutes support and how it works (Pedro, Rocha & Nascimento, 2008; Bloom, 1990; Heller & Swindle, 1983; Prosidano & Heller, 1983; Cohen & Syme, 1985; House & Khan, 1985; Jacobson, 1986). The use of the concept in many fields such as sociology, psychology and health, to name a few, has compounded its meaning. Patients diagnosed with cancer desire significant support throughout the illness trajectory as they attempt to make sense of their illness and adjust to treatment and the uncertainty they face. Social support influences the cancer patient's health behaviour and disease outcomes, as well as appraisal of the threatening nature of events related to the diseases and its treatment (Prosidano & Heller, 1983). Support buffers against the negative effects of the life-threatening illness by mitigating distressing symptoms and forms an essential dimension in nursing practice to improve patients' quality of life (Usta, 2012; Chan et al., 2004; Jacobson, 1986).

Although support tends to buffer the effects of stress related to diagnoses of cancer, its relevance, the type and timing of support in relation to the stressor may determine the likelihood of observing the buffering effect (House, Umberson & Landis, 1988; Cohen & Syme, 1985). Additionally, the implication of stress buffering effect lies in the characteristics of the network relationship in mitigating health response to the stressful life events (Heller & Swindle, 1983). According to House et al. (1988), Kessler and McLeod (1985), buffering effects of support are primarily observed in studies using measures of perceived availability of support in times of stress. Perceived social support refers to the impact the networks have on the individual, characterised by belief that their support needs, are fulfilled by members of their network (Usta, 2012; Prosidano & Heller, 1983).

Prosidano and Heller (1983) however caution that perceived support and available support from the network are not identical, nor used interchangeably. Partners, community, social networks and health professionals may be responsible to render social support. Research pertaining to social support should be understood within the context of culture, as well as the characteristics that shape the receiving and giving of

support. Despite this, the construct of social support is multi-dimensional. Studies examining the concept do so as a global construct, but analyse it as a single aggregate score or report only on a single aspect, making it difficult to assess its impact on various aspects of support and patient health outcomes (Arora et al., 2007).

Aurora et al. (2007), in a study to explore helpfulness of emotional and informational and decision-making support from family, friends and healthcare providers, found that patients receive support during the time closer to diagnosis; but the support drops as the disease progresses. Peters-Golden (1982), in a study conducted to examine perceived social support and anticipated support among cancer patients, found that patients receive too little or inappropriate support from their networks resulting from misconceptions of their priorities or needs.

2.7.1 **Definition of Support**

Support is a multidimensional construct and debated among the scientific community on the precise definition of the concept. Studies conducted are cognisant of an element of reciprocity and perceived availability of support among network members (Gottlieb & Bergen, 2010; Bloom, 1990; Pearlin, 1985; Shumaker, 1984). Definitions of social support are complex and multidimensional (Gottlieb & Bergen, 2010; Hogan, Linden & Najarian, 2002; Campbell, Phaneuf & Deane, 2004; Hinds & Moyer, 1997; Cohen & Syme, 1985) with great diversity in its components and structure. Several theories have been instrumental in the conceptualisation of support and most are basic to social support research (Jacobson, 1986) and focused mainly on needs, transactions and transitions. The theories are not for discussion in this study. Barreira (1986) suggests that construct of social support be abandoned in favour of narrow models of stress-distress relationship, which is concerned with social embeddedness, perceived support, and enacted support. According to House, et al., (1988), the meaning of social support has not been clearly defined, instead social support, social networks, and social integration are used interchangeably, encompassing a broad range of phenomena relating to consequences of social relationships for individual health and well-being. However, these concepts tend to overlap when discussing social support.

Cutrona (1996) states that the key assumption in conceptualisation of social support lies in the importance of relationships with others for mental health and ongoing social needs. However, the needs are not limited to a crisis or adverse life events only, but rather as a life requirement for well-being and adjustment (Wortman, 1984). According to Hogan et al. (2002), and House and Kahn (1985), the most important aspects, of social support lies in the structural components of network, functional aspects as well as enacted support. Support is an interpersonal process embedded in an array of social exchanges involving encountering support, recognising, and feeling supported (Campbell, Phaneuf & Deane 2004; Hinds & Moyer, 1997; Shumaker & Brownell, 1984). Usta (2012), defines support as the perception that the social resources are available from the formal and informal networks consisting of non-professionals and lay support groups; however, the actual support lies in the expression and mobilisation of available support (Barreira,1986) from the network members without the individual initiating the process. Lin (1986) is of the opinion that social support should be characterised by an observable indication of support provision and information regarding the support gathered independent from the individual receiving the support.

Another concept frequently used in health services field is the term support system, implying the functional and structural aspects of social ties, suggestive that people's social ties are unconditionally supportive (Gottlieb & Bergen, 2010; Peters-Golden; 1982). Support is highly contingent on numerous personal, environmental, and cultural factors; however, no assumptions should be readily available and adequate in quantity and quality when people appraise resources at their disposal (Gottlieb et al., 2010). Sources of support are determined based on different categories of social ties available to an individual. The published literature postulates that people with a strong sense of psychological support fare better in the face of adversity than those who do not. Support does not reside with the provider only, but there is some form of reciprocity between parties involved (Baider et al., 2000; Gottlieb & Bergen, 2010).

According to House and Kahn (1985) and Cohen (1988), there are three categories of measures of support, which are social networks, social relationships, and social support. An individual's support network consists of personal contacts through which he/she

maintains their social identity, and their functions may vary depending on their importance during the times of crisis (Baider et al., 2000; Cutrona, 1996; Peters-Golden, 1982). Structural properties of a network provide information with regard to social integration concerning the number of social ties or interconnectedness, as well as sources of support (Israel & Rounds, 1987). Social integration is the existence or quantity of social ties or relationships within a social network structure, which is distinguishable by type, as well as frequency, of contacts. Relationships such as marital, kin or non-kin are distinguishable by type (House, Umberson & Landis, 1988). Social support relates to the function and types of support, which are concerned with the provision of specific functions to meet identified needs. Broadhead et al. (1988) state that the quality of social support is a strong predictor of health outcome than structural measures and quantity of social support; which often are not significant to the individual well-being. Social support is time-related, in that its significance may vary along the course of life, structure, strength and type, (Pedro, Rocha & Nascimento, 2008; Cutrona, 1996). Whilst the timing and type of support are crucial, it is important that the intended support satisfy the unmet needs of the specific patients/individuals' contexts, as well as determining sources of support (Krishnasamy, 1996). Different problems evoke different stressors whereby the same basic problem may evoke different kinds of support as it moves thorough different stages or transformation.

2.7.1.1 **Dimensions of support**

According to Chan et al. (2004), two basic dimensions constitute support, structural, and functional support. However, many investigators have ignored distinct differences between structural and functional measures of social support, between the multiple dimensions of functional support, and between supportive functions and social determinants of support (Broadhead et al., 1988). Structural dimension of support focuses on the nature of the quality and quantity of contacts with support networks. Social network structure entails structural properties characterising a set of relationships among network members. A support network consists of personal contacts through which an individual maintains their social identity and the functions may vary depending on their importance during the times of crisis (Peters-Golden, 1982; Baider et al., 2000). Natural support networks have been reported to be enduring during crisis (Hogan et al

(2002), whilst formal networks are transient; however, studies conducted found them to compensate for deficient support from the natural support (Hogan, Linden & Najarian, 2002; Kroenke, Kwan, Neugut et al., 2013). Prosidano and Heller (1983) caution against perceived and available support used interchangeably as their meanings are not identical. Whilst network members are in a position to supply the needed support, equally the need identified should meet the intended support.

Functional support is concerned with specific functions to meet identified needs, which may be achieved through provision of emotional, instrumental, informational, and appraisal support. Spiritual support is another concept that comes to the fore during a crisis, such as cancer. Spirituality plays an important role in coping with adverse life events and crisis and has a protective role in preventing psychological morbidity. Spirituality deals with a person's search of meaning and purpose in life (Mesquita et al., 2013). Partners, family members, and close friends can provide natural support, whilst professionals such as nurses and other healthcare professionals can provide formal support, as well as self–help groups consisting of individuals with similar problems or community ties, such as religious groups.

2.7.1.2 **Structural support**

Structural support focuses on the structural properties of the network and provides information about social integration in relation to the number of social ties, interconnectedness and different roles the central person occupies in relation to the ties (Gottlieb & Bergen, 2010; Baider et al., 2000; Pearlin, 1985; Peters-Golden, 1982). Structural support measures the number of relationships or social roles an individual has, as well as the frequency and intensity with which an individual interacts with the network members (Cheng et al., 2013). It also allows for the investigation of the effects of support defined in terms of the characteristics of networks in a group or society. Social network defines the outer boundaries of support upon which individuals may draw; however, despite the availability of resources an individual may not expect to draw more resources than actually can be provided from the network (Peters-Golden, 1982). The size of the network, density and degree of social integration within one's social network is a necessary condition, but not sufficient to gain resources to buffer stressful life events

(Baider et al., 2000). The assumption is that an individual well, encased in the social network/fabric receives good support, but this has not been case. The affirmation of this is in the study of Kroenke et al. (2006), who found partners of women with breast cancer were not necessarily supportive in providing the needed support, as well as a larger network of friends or religious groups.

Social integration refers to the existence or quantity of social ties or relationships within a social network structure, distinguished by type, such as marital, kin or non-kin, and frequency of contacts, density, and proximity with members of the network (House, Umberson & Landis, 1988; Cutrona, 1996). Social integration is an important construct in clarifying support as it signifies the importance of interconnectedness, as the absence of such relations may be a potential for health risks (Kroenke et al., 2006). When conducting studies pertaining to social support, it is crucial that the quantity, structure and types of support are considered, as these concepts are interlinked (Krishnasamy, 1996; House & Kahn, 1985). Structure of the network may partially contribute to the functional content or qualities of the support influenced by the proximity and accessibility of perceived available support by the recipient (Hamilton & Sandelowski, 2004). Other important aspects to consider in the provision of support is to ensure that the timing and the type of support offered satisfy identified needs. Functional measures assess whether interpersonal relationships serve particular functions expected of them. Although different networks are responsible for specific types of support, the observation in practice is that different types of supports tends to overlap across networks.

2.7.1.3 **Functional support**

Functional measures used in chronic illness studies include satisfaction with the network, and perceived availability of resources and emotional support (Cohen, 1988). Functional support is crucial in meeting individual activities of daily living and improved quality of life. Social support may be determined in terms of functional content of relationships (Broadhead et al., 1988; Leung, Pachana, McLaughlin, 2014); furthermore, the quality of social support has been found to predict health outcomes, rather than structural measures that have not being significant for improved wellbeing (Tan, 2007; House, Umberson & Landis, 1988). Functional support can be supplied by specific members of

the network who offer mutual help through interpersonal interactions depending on the need identified at the time (Pearlin, 1985). House and Khan (1985) identified four types of support consisting of emotional support, appraisal support, informational, and instrumental support, whilst other studies (Mesquita et al., 2013; Mosalo, 2011) found that spiritual support assists patience in coping during stressful events, such as cancer. Emotional support deals with esteem, affect, trust, concern, and listening. Appraisal support is concerned with affirmation, feedback, and social comparison. Information support deals with advice, directives, information, suggestions, and lastly, instrumental support that deals with tangible support, such as assistance with activities of daily living and provision of financial aid. Spiritual support offers an individual beneficial effect, such as seeking love and protection of God or greater connection with transcendental forces (Mesquita et al., 2013; Meraviglia, 2006). Network support takes on an increased importance during the time of crisis and can provide for absent feedback from formal networks.

According to Wortman (1984), the importance of assessing adequacy of support from different sources, such as with cancer patients, may be advantageous to ask about different providers of support, types and the situation where support is needed, as well as perceived effectiveness of the support provided (Hlebec, Mrzel & Kogovšek, 2009; Bloom & Spiegel, 1984). Women tend to seek and utilise support more frequent than men, however not all social relationships are supportive, as societal expectations are that one maintains such social relations at all times; Implying that one has to also reach out to other members of the network in times of need as this should be a reciprocal process. According to Israel and Rounds (1987), the quantitative nature of support can determine the type and amount of support an individual may receive. Measures relating to social support vary considerably pertaining to its availability, size of network, actual perceived and received support, or the lack thereof. Different cultures influence how support is experienced. Different types of support will be discussed in relation to how they influence the cancer patients' adaptation to illness processes.

2.7.1.3.1 Emotional support

Emotional support is the empathic communication between patients and their support networks aimed at enhancing self-esteem and self-confidence in order to reduce negative feelings (Campbell et al., 2004; Hogan et al., 2002). According to Bloom and Spiegel (1984), emotional support is one's perception of family milieu based on degree of expressiveness, cohesiveness, and absence of conflict among members. It further relates to an individual's perception of being loved and cared for, esteemed, and valued, regardless of their achievements. Hamilton and Sandelowski (2004) in their study found that participants believed in the presence of others shaped by network members communicating their availability and willingness to help. The availability of emotional support from family and close friendships contributes to emotional wellbeing and coping during stressful situations (Usta, 2012). This is attributed to the availability and ease with which an individual can access and receive support from family, friends, and closer members of the network ties. Other network members, such as peers with similar conditions and religious groups/organisations, have been able to provide emotional support in situations where support from formal networks is lacking. Peer support reportedly enhances other's self-esteem by sharing similar experiences, rather than focusing on the self. In addition, Arora (2007) found that cancer patients who received information and emotional support adapt well to illness and treatment. Emotional support helps re-assure individuals of love and support during a crisis, such as with patients who have received a diagnosis of cancer. Mosalo (2011) confirms this statement in a study to explore women's perception of life partner support during a cancer diagnosis, where family members were supportive in the absence of partner support. Indeed, when patients feel an affirmation from significant, others, they seem to cope better during their illness trajectory. Having received a devastating diagnosis of cancer can shake the patient's network, as well as making plans, as fear, doubt, and anxiety sets in. Members of the patient's close network can help the patient to appraise the situation by giving re-assurance of their unconditional support and presence when needed.

2.7.1.3.2 Appraisal support

Appraisal is a process whereby an individual classifies a stressful encounter as harm or loss, threat or a challenge. The basis of appraisals is what is at stake for an individual and the potential ability to affect well-being (Moore, Ford & Farah, 2014). Appraisal support is concerned with affirmation, feedback, and social comparison (Nascimento et al., 2008; Hamilton & Sandelowski, 2004; Israel & Rounds, 1987). Appraisal support involves expression of agreement with or acknowledgement of a person's beliefs, interpretations, or feelings leading to self-validation (Wortman, 1984; Hamilton & Sandelowski, 2004). Family and close friendship networks can also render appraisal support by accepting a patient's situation and being non-judgemental, or try to divert conversation relating to the illness, rather re-assuring him/her of their committed presence, in case they feel a need to discuss issues relating to their situation (Tempelaar et al., 1989; Taylor et al., 1986). Whilst close network members can supply appraisal support, the experience of some situations as negative, especially where significant others are overly protective or perceived to have avoidance behaviour around issues pertaining to the illness (Cheng et al., 2013). Peer support is invaluable as they give emotional support and information, and they can resonate with the patient based on their experience of similar situations. Peers offer appraisal support by encouraging an individual to appraise their condition and supply information pertaining to the disease, which can serve a dual purpose, as they also get satisfaction from sharing their stories (Chan et al., 2004).

2.7.1.3.3 Informational support

Informational support involves provision of information meant to guide or advise to solve problems, and is believed to enhance perception of control, by providing patients with strategies to cope with their difficulties (Hogan et al., 2002; Usta, 2012). Patients diagnosed with cancer require information regarding illness, diagnostic tests, as well as prognosis. Arora et al., (2007) found informational support to have a positive influence on patients' adaptation to cancer. Families and other members of the close network, such as peers or support groups, can assist with information pertaining to illness, and understanding medical

information, as well as support with medical decision-making. Furthermore, network members can be a source of support, such as assisting with sourcing helping agencies or referrals when one needs to contact specialists in a particular field. Whilst patients who are supported are found to adapt well to the disease and the treatment, nurses have been found to act as providers of information as they are constantly taking care of patients and clarifying information from the time the patient undergoes diagnostic tests to the illness trajectory (Usta, 2012). Hamilton and Sandelowski (2004), in their study, found that patients relied on church support for advice to go to hospital or for seeking medical advice. It is crucial that communication should be encouraged during this period, as well as clarifying information, as patients who are well informed about the nature of the illness are found to adapt to the disease and challenges, they face during treatment.

Studies found that patients often receive information about their diagnosis in isolation with no one accompanying them (Mosalo, 2011; Pelcastre–Villafuerte et al., 2007). In addition, patients felt doctors concealed details pertaining to their illness, as discussions were hurried and superficial (Mosalo, 2011). This could be traumatic and confusing, as patients have to deal with the stress of diagnosis and making sense of what they have been informed can be overwhelming. Having someone present when the patient receives information regarding their illness gives the patient the perception that she is not alone, and this helps them accept their situation and may further wish to discuss to confirm the information received. Being accompanied, during consultation forms part of instrumental support expected from family and close network members.

2.7.1.3.4 Instrumental/Tangible support

Instrumental support includes a wide range of activities in kind, including supplying financial needs, labour and time (Usta, 2012; Pedro et al., 2008). Tangible support from friends and family is associated with well-being and improved quality of life. A cancer diagnosis and treatment can interrupt normal day-to-day activities resulting in role changes. Patients may need to rely on others

for support and assistance with coping during stressful life events. Providing instrumental support can help reduce stress and improve patient's perceived quality of life (Hamilton & Sandelowski, 2004). However, it is also important to assess what the level of support was like prior to the patient's illness state. Formal networks, such as partners, family and close friends, provide emotional and informational support. Instrumental support from close networks may not necessarily be perceived as helpful, as the assumption is that it forms part of family obligations (Cheng et al., 2013; Tan, 2007). In other cultural contexts, the expectation is that female family members or relatives provide instrumental support, such as cooking and attending to household chores, in spite of the patient living with her partner (Cheng et al., 2013; Mosalo, 2011; Chan et al. 2004). Partners or close networks may accompany patients to the hospital or treatment centres. Sometimes members of a designated support group, such as community carers or religious organisations, can provide instrumental support, especially in cases where close networks are unavailable to provide instrumental support (Lee, Burnette, Liddell et al., 2018; Hamilton & Sandelowski, 2004).

2.7.1.3.5 Spiritual support

A cancer diagnosis can have impact an individual's spiritual needs, as sometimes patients tend to believe that it can be a test of their faith or relationship with God during a crisis. Spiritual support plays a significant role in enhancing coping and adaptation to illness through existential concerns, such as the search for meaning of life and hope (Mesquita et al., 2013; Lim & Yi, 2009). Spirituality is an essence of human existence causing human beings to experience transcendence and consistency with existence beyond his/her own, or finding bonds with others (Hatamipour, Rassouli, Yaghmmaie, Zendedel & Majd, 2015). Spiritual support is important for coping in cancer patients, by the provision of a protective role against psychological morbidity, and assistance to cope with adverse life events. A cancer diagnosis can destabilise relationships, causing individuals to be isolated and lonely, as she may not be able to interact with network members as before the illness ensued (Leung et al., 2014; Ussher et al. 2006). This can instil fear, doubt, and anxiety, as women with poor social support have a tendency to

experience morbidity from the illness (Kroenke et al., 2014). During this period, informal network members, such as peers with similar conditions or religious groups, commit towards patient spiritual support through encouragement with prayers and more regular visits aimed at strengthening hope and improved health outcomes (Lee et al., 2018; Ussher et al. 2006). Further research has shown that cancer patient's spirituality has an effect on their health outcomes (Zamaniyan, Bolhari, Naziri et al., 2016). Nurses are in a strategic position to attend to patient's spiritual needs. Hence, it is also important that members of the healthcare team are encouraged to acquire special skills to detect patient's spiritual needs and be able to provide care beyond just physical care (Hatamipour et al., 2015).

2.7.1.4 Perceived support

Perceived support is essentially the belief and faith that support is available from network members (Gottlieb & Bergen, 2010; Prosidano & Heller, 1983), whilst Prosidano and Heller (1983) and Krishnasamy (1996) are of the opinion that perceived support is the extent to which an individual believes that his/her needs for support, information and feedback are fulfilled. Perceived social support is linked to strong psychosocial and health outcomes. According to Krishnasamy (1996), the central element in promoting wellbeing within a relationship is the ability to induce the client to adapt while maintaining the individual to be in control. Conversely, patients may perceive professionals as engaged in attempts to influence as they provide support. However, in some instance's patients tend to perceive professional helpers as not having the relevant skills needed to provide support.

Natural networks provide feedback and emotional support as patients expect unconditional support from them. Support from natural networks is not perceived as help, as it is assumed a family obligation, especially in a marital relationship or in cultures where females are expected to provide tangible and emotional support in times of illness/crisis (Arora et al., 2007; Hamilton & Sandelowski, 2004). Close patient networks tend to display avoidance behaviour when engaging patients in relation to their illness, in an effort to protect them; however, the behaviour is

perceived as unhelpful. Cancer patients have reportedly perceived support from their informal networks to be available, as peers are able to relate to them in the same level based on their experience (Usta, 2012; Campbell et al., 2004). Furthermore, nurses are in a position to provide feedback and correct confusion related illness information.

2.7.1.5 Received support

Cancer patients received support close to the period of diagnosis, however the support was found to decrease as the illness progressed. Bloom and Spiegel (1984) are of the opinion that social activities are necessary, although not a sufficient condition for supportive exchange and the receipt of other forms of social support. It is postulated that one's involvement in social activities provides opportunities to interact with others and receive support, however if interaction decreases due to inactivity or ill health, support tends to decrease (Leung et al. 2014; Bloom & Spiegel, 1983). It is during this crucial time that a cancer patient can subjectively determine availability of support from network members. Support provision can be confirmed by observable acts of experiencing the support freely without having to initiate the process, such as experiencing presence or sharing the pain or verbalisation of comforting acts from significant others, and allowing a patient to voice her fears and anxiety without fear of being judged or experiencing avoidable behaviour (Cheng et al., 2013). These acts could be characterised by the spouse or close family members providing transport and company to the hospital. Others could be observable presence with the patient during discussions relating to illness, and the unfolding of treatment. Other studies have shown an overlap of support functions, as documented by (Mosalo, 2011; Chan, 2004) where partners shared the emotional pain with their partners, family and close network members, and the willingness to accompany them during treatment sessions. Patients who experienced support from family and partners seemed to adapt well during treatment and the disease trajectory. Whilst literature is replete with studies that advocate for improved quality of life, it is not clear how patients experience support they receive from hospital staff whilst receiving treatment for radiation therapy.

2.8 QUALITY OF LIFE

2.8.1 Definition of Quality of Life

The World Health Organization (1998), defines quality of life as the way an individual perceives his own position in the context of the culture and value systems in which he or she exists in relation to their goals, expectations, standards and concerns. It is a broad concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (Pasek, Suchoka & Urban'ski, 2012). Quality of life depends on the subjective meaning an individual ascribes to it, whilst good quality of life is ascribed to hopes matched and fulfilled by an individual's experiences (van Rensburg & Maree, 2016; King, 2012; Calman, 1984). In addition, quality of life is a multidimensional concept comprising both positive and negative facets of life. Whilst quality of life is not a new concept in cancer care or chronic illness, assessment of quality of life is complicated by the lack of a universal definition of health-related quality of life (HRQOL). According to Grant and Dean (2012), the definition of HRQOL is based on the subjective assessment of the impact of the disease and its treatment across physical, psychological as well as social wellbeing. However, due to the availability of complex treatment modalities, it is evident that patients are surviving effects of cancer leading to more challenges with quality of life and prognostic factors. This implies that patients can view their situation differently as the disease progress during the cancer trajectory (Sabulei & Maree, 2019).

King (2012) is of the opinion that whilst cancer treatments are associated with greater toxicities and morbidities that have an impact on the quality of life, there should be an increased need to move beyond the focus on morbidity, as survival of this population lengthens due to the increase in new therapies. Of note is that studies conducted on quality of life outcomes of gynaecologic patients treated with radiotherapy regardless of disease site, point to compromised physical and social functioning including sexuality (Mirabeau-Beale & Viswanathan, 2014). It is imperative that once a suspicion of cancer diagnosis looms, supportive care measures are mobilised in order to buffer the effects of stress and aim to improve patient's quality of life early. It has been noted that patients who perceive poor support are prone to poor quality of life during the cancer trajectory.

2.9 SUMMARY

In Chapter 2, the literature pertaining to the study described cervical cancer as a life-threatening disease. The description of cervical cancer was in terms of the epidemiology, risk factors, development of cervical cancer, prevention, signs and symptoms, diagnosing and staging, and treatment. Support was also addressed in terms of definitions, conceptual construct of support structures, and functional social support. Issues of quality of life pertaining to cancer was discussed. Chapter 3 discusses the research methods.

CHAPTER 3

3. RESEARCH METHODS AND DESIGN

3.1 INTRODUCTION

The previous chapter discussed literature pertaining to studies regarding the overview of cervical cancer and the extent of the burden of disease, as well as screening and treatment. Support, in the context of cancer and the various kinds, was the basis for the present study. Quality of life as a measure of quality of life was briefly discussed. This chapter outlines the research methods and design that guided the study. The study used a mixed methods design. Mixed methods approach involves the use of both quantitative and qualitative methodologies in a single study and used when either method on its own would not be sufficient to answer a research question (Ivankova, Creswell & Stick, 2006; Creswell, 2014). Researchers who have conducted mixed methods studies referred to them as multi-method, integrated, hybrid, combined and mixed methodology (Driscoll, Appiah-Yeboah, Salib & Rupert, 2007). Leech and Onwuegbuzie (2009) reported that mixed methods was still at its prime, with a plethora of designs to choose from rendering the student, beginner researcher and more seasoned researcher with a challenge to select an optimal design. There are several typologies of mixed methods based on specific disciplines. Three basic designs were discussed in order to give direction pertaining to the choice of the design for the current study; based on Creswell and Plano-Clark (2011) mixed methods. The designs were convergent parallel design, explanatory sequential design and exploratory sequential design.

In the case of convergent parallel design, both quantitative and qualitative methods receive equal priority. The convergent design was initially conceptualised as a triangulation design (Creswell & Plano-Clark, 2011), as two methods were used to triangulate the results of a single study (Creswell, 2014). Data collection is done concurrently, however analysis is conducted separately and the findings compared to see if they confirm or disconfirm each other.

In the case of an explanatory sequential design, data collection occurs in two distinct but interactive phases. Quantitative data collection may take priority followed by the analysis

of data; in which case the results can be utilised to build the subsequent qualitative phase. Usually the use of this type of data (qualitative) is to explain the results of the quantitative phase of the study.

An exploratory sequential design uses sequential timing, in which case qualitative data collection takes priority, followed by data analysis. The results of the qualitative phase inform the quantitative phase, either to test the initial results or to generalise the findings depending on the purpose of the research. This type of design is useful when a researcher wants to develop or test an instrument or an intervention in cases where one is unavailable. Whilst this design is more quantitatively oriented, researchers may be tempted to follow a post positivist approach, however it is important that each approach is given due attention and presented accordingly. In most cases of this design, an intermediate step between the two phases is usually utilised. The current study utilised an exploratory sequential design, in which case the qualitative phase took priority followed by a quantitative phase to test and evaluate the programme at completion.

3.2 HISTORY OF MIXED METHODS RESEARCH (APPROACH)

Mixed methods approach emerged from paradigm wars involving philosophic and methodologic debates between post-positivist and constructivist camps during the 1970s and 1980s (Polit & Beck, 2010; O'Cathain, 2009). Mix methods gained popularity around 1960s, from disciplines such as education, sociology, psychology, nursing and management fields (Tashakkori & Teddlie, 2003). Most published studies in fields such as social and human sciences, communication, education and AIDS prevention have incorporated mixed methods research (Creswell, 2014). Paradigm debates developed when scholars argued whether qualitative and quantitative data could be combined, as each favoured a specific philosophical assumption. In addition, around the 19th century, the quantitative research paradigm with its multiple designs was the only research design used in many disciplines (Leech & Onwuegbuzie, 2009).

In the United Kingdom, health service researchers utilised quantitative research on randomised controlled trials to test efficacy of interventions (O'Cathain, 2009). Quantitative research gained popularity by its success in measurements, analysis and

replication (Morse, 2012). According to Pope and Mays (1995, in O' Cathain, 2009), two researchers made a stand for qualitative research as a way of answering questions that remained unanswered with quantitative research.

In the 20th century, researchers who refuted quantitative paradigm assumptions and its principles turned to qualitative research (Leech & Onwuegbuzie 2009). Those who subscribed to qualitative research were believed to oppose quantitative research, were treated as ignorant and their research as invalid and not worth paying attention to (Morse, 2012), evidenced by medical students being taught experimental designs and epidemiology whilst qualitative studies were ignored. Morse (2012) further reported that only later did quantitative researchers come to the realisation that their methods left gaps that could not be answered, as it could not answer questions relating to personal nature and emotions. This led to the inclusion of small qualitative components in quantitative studies, leading to the birth of a new approach called mixed method. Accordingly, around 1995 only a few qualitative studies had been published from the field of nursing, as nurse researchers were receiving training from sociologists, psychologists and anthropologists on how to use these methods to generate new nursing knowledge (Streubert & Carpenter, 2011). According to Polit and Beck (2012), several factors can affect choosing a mixed method, such as priority decisions in choice of design and the researcher's worldview.

3.3 PHILOSOPHICAL ASSUMPTIONS IN RESEARCH

Different worldviews guide research studies as well as philosophical assumptions the researcher brings to the study (Creswell, 2014; McKie, 2014). Furthermore, Creswell (2014) states that philosophical orientations, the nature of research, and the researcher's contribution to a study are shaped by the discipline orientations and past experiences. Philosophies shape how researchers formulate problems and research questions in a study, and how they seek to answer them (Creswell, 2013). According to McKie (2014), a philosophical approach is a way of thinking and critically questioning knowledge claims established from different forms of enquiry by the community of scholars. Creswell (2014) is of the opinion that worldviews are all encompassing, as they may or may not be associated with a community of scholars with shared believes and values in research,

whilst other researchers use the word paradigms. Paradigms are a set of generalisations and beliefs by a community of scholars. It is a philosophical stance taken by the researcher in order to provide a set of beliefs guiding the actions during a research process (Creswell, 2013). Additionally, it is assumed that close ties exist between the philosophies that one brings to the research as well as using it as a framework to guide the research process (Creswell, 2013; Creswell, 2011). Although many authors wrote on worldviews that could inform mixed methods research (Teddlie & Tashakori,2009; Andrew & Halcomb, 2009), this study will briefly discuss the most common ones cited by Creswell and Vick Plano-Clark (2011); post positivism, constructivism, participatory worldviews and pragmatism.

3.3.1 **Post-Positivism**

Post positivism relates to quantitative approaches to research. According Teddlie and Tashakkori (2009), the original view of post positivists was that the conduct of their research was objective and value free, implying that their values did not affect how they conducted research and interpreted the findings. Knowledge that develops from a post positivist perspective is based on careful observation and objective measurements that exist in the world “out there” (Creswell, 2014; Polit & Beck, 2012). However, researchers utilising this approach believe in knowledge claims based on a single reality, based on cause and effect or manipulation of certain variables to reach an objective answer (Creswell & Plano-Clark, 2011). In addition, Creswell (2014) purposefully refers to post positivism, as he is of the notion that post positivists are not hard and fast on cause and effect due to the possibility that the occurrence may or may not realise. Creswell (2014) further states that post positivists challenge traditional claims regarding absolute truth of knowledge, as studying human actions and behaviour is not static, He asserts that post positivist claims are based on objective observation of reality “out there,” which can be measured through observations of human behaviour using numerical scales.

3.3.2 **Constructivism**

Originally, constructivism was developed from a social constructivist’s worldview. In this approach, the researcher’s ontological views are based on multiple realities, obtained from engaging with research participants as they share their experiences shaped by their

interaction with others (members of health team, other communities with whom they come in contact) and their subjective interpretation of their situation relative to a specific phenomenon (support). In this worldview, meanings are socially constructed and not just imprinted on the participants, as this is influenced by their culture, upbringing, and context in which their environment is constructed. In the current study, the researcher negotiated access (Appendix A, B & C) and informed consent (Appendix D& E), before she could engage with research participants. The researcher made a conscious attempt to engage with participants and listen to their stories or narratives without imposing her values or understanding of their situation, nor changing its meaning to suit her own beliefs or assumptions (Creswell, 2014). Participants were encouraged to discuss their experiences and how they wished to be supported (Appendix G) based on their values and contexts from the moment they accessed the healthcare system to the actual treatment phase. The researcher equally brought her values in the study (as co-creator of knowledge) and although she trying to be true to participant's stories, some biases may have occurred as she collected data.

3.3.3 **Participatory Worldview/ Transformative Worldview**

Participatory worldviews or transformative worldviews represent the marginalised individuals and are more often associated with qualitative approach; Creswell and Plano-Clark (2011) are of the opinion that this worldview is shaped by political concerns, as it was felt that post positivist view imposed structural laws and theories that did not include marginalised individual (Creswell, 2014). Therefore, the recommendation is that researchers using participatory worldview collaborate with communities that are marginalised in one way or another in order to represent their interests to reduce further marginalisation. Researchers utilising this worldview strongly advocate for equal justice addressing specific issues such as empowerment, inequality, oppression, domination, suppression, and alienation. Although the majority of participants were from marginalised communities this worldview will not be utilised in the study.

3.3.4 **Pragmatism**

Pragmatism is a worldview associated with mixed methods research. Polit and Beck (2012) state that pragmatism is concerned with induction and deduction, whereby

theories can be developed and verified, as well as encouraging pluralistic views. According to Creswell and Plano-Clark (2014), mix methods research resides in the middle of the continuum within quantitative and qualitative research. However, Onwuegbuzie's (2012) stance is that mixed method researchers should not strive for a comfortable middle within the continuum of quantitative and qualitative research; but to strive for a radical middle (called "third space"), wherein a new sociocultural terrain on what counts as meaning, and meaning making, co-exists and where the epistemologies are recognised to promote co-existence and productivity among researchers. Accordingly, this worldview is concerned with the research question or problem (Creswell & Plano-Clark, 2011; Polit & Beck, 2012). Teddlie and Tashakkori (2009) defined pragmatism as a deconstruction paradigm that debunks concepts such as "truth" and "reality "and rather focuses on what works in a particular study valuing both objective and subjective knowledge (Creswell & Plano-Clark, 2011). Mixed methods research uses multiple methods to collect data to inform the study. Of significance in this paradigm is the process of mixing, which can occur through connecting, merging or embedding (Creswell & Zang, 2009). Merging is when distinctiveness of each method dissolves. Whilst connecting means the result of one database is used to inform the data collection of another phase. Embedding is when an investigator nests a supportive database such as using information from a secondary data source (e.g. quantitative data source) to support the findings of the qualitative phase such intervention design). This study utilised mixed method, as neither qualitative nor quantitative methods alone would yield well in answering the primary and secondary questions. The researcher opted for pragmatism as it would yield better results in the study to answer the research questions. In the following paragraphs, the philosophical worldviews guiding the study will be discussed.

3.4 **ONTOLOGY**

According to Creswell (2011), ontology refers to what is the nature of reality, and how do we know what we know. Ontology relates to a specific reality and its characteristics. In quantitative research, this reality is guided by determinism or cause and effect thinking. However, in the case of qualitative research it is guided by multiple realities. In present study, the ontology is based on pragmatism, which means the focus is on the research questions rather than the methods (Creswell, 2011). The researcher will

address each phase of the study to answer a specific research question. In phase one, the researcher utilised multiple realities as presented by the participants using qualitative interviews to answer the research question “How participants wish to be supported during the period they are treated for cervical cancer,” which in this case was guided by participant’s experiences as they engaged with different members of the health team. The researcher strived to stay true to the voice of the participants in an endeavour to interpret and construct meaning from what was shared with her pertaining to phenomenon of support.

3.4.1 **Epistemology**

Epistemology relates to questioning and understanding how we know what we know (Creswell & Plano-Clark, 2011; Griffiths, 2009). In this instance, the constructivist’s assumptions guide the study, wherein the researchers view is influenced by the family values. Family values contributed in shaping how the researcher views the world, however, there were changes when she joined the nursing profession. In this study, the researcher’s worldview was shaped by undergoing training as a nurse. This was influenced by prominent figures, such as nurse managers and mentors in the profession as she progressed in the profession, as well scholars in the field who wrote broadly on nursing issues and conducted research. Sometimes this epistemology is shaped by situations as they present themselves during the professional journey whilst rendering patient care. Furthermore, a constructivist may become aware of a situation through communicating with peers and observation of situations encountered in our daily contact with patients. To inform Phase1 of the study, the researcher strived to be close to the views of participants, by immersing herself in the data shared through the narratives during the interviews. To ensure the researcher truly represents participant’s views, it is crucial that the study is conducted in the context in which participants are familiar. The interviews guiding data collection were conducted in the radiation oncology department where participants undergo treatment.

In Phase 2 of the study an intervention design guided this phase, using a pre- and post-tests to guide data collection using existing scales (BSSS)(Appendix J) and a structured questionnaire (EORTC QOL-Cx 24)(Appendix L) with author permissions (Appendix I &

K). The researcher and a trained assistant from the field of nursing were responsible for conducting structured interviews. Phase 2 answered the second question, “Would a support programme improve the participants’ perception of being supported and would it also improve their perception of an improved quality of life after attending the programme?” The programme was evaluated on the last day to determine its effectiveness based on needs identified by the participants, literature pertaining to needs and support of cancer patients and survivors, as well as the experience the researcher, an oncology nurse brings to the study. Although the study followed a mixed method approach, the researcher used a constructivist lens to guide data interpretation from the researcher’s point of view. However, the researcher strived to present each approach based on its tenets.

3.4.2 **Research Paradigm**

Whilst the researcher was inclined towards a constructivist stance, the nature of the phenomena being explored in the “women’s preference of support during the period they are treated for cervical cancer” presented challenges, as using either method alone could not address the research problem. This called for the use of both methodologies in the same study to address the identified research problem, hence the study was guided by a pragmatic worldview. As the problem being studied presented in such a way that it could not be solved by a specific approach, combining both approaches seemed relevant to answer the research questions. The qualitative phase of the study explored how women wished to be supported, whilst the quantitative phase assessed the effect of the support programme. The researcher noted that combining both approaches would enable her to fully explore and present participants’ concerns, hence, moving forward, the study was guided by pragmatism.

3.5 **THE RESEARCHER’S PHILOSOPHIC STANCE**

The researcher philosophical stance follows constructivism. This has mainly been informed by several years in the field as an oncology nurse who has always been in contact with the patients, and an interest in exploring how they view certain phenomena. The researcher’s opinion was that multiple truths can inform the study, based on participant’s views. Since not only one paradigm was able to answer the research

question a mixed method paradigm best suited the study. The researcher's aim was to explore and discern meaning based on stories shared by the participants during the Interviews. The study's aims to report on the outcomes and effects of support offered to women receiving treatment for cervical cancer.

3.6 STUDY DESIGN AND METHODS

An exploratory sequential mixed method design guided the study. In the study, the qualitative phase influenced the quantitative phase that followed. The intent was to collect and analyse data, and integrate findings at the end to draw inferences using both methodologies in a single study in order to have a better understanding of a research problem aimed at addressing patient identified needs (Polit & Beck, 2012; Creswell, Plano-Clark, 2011; Ivanka, Creswell & Stick, 2006). Exploratory studies are conducted when a problem or a complex issue needs to be explored, or to gain new perspectives on issues where much is already known (Creswell, 2013; Gray, 2009). According to Polit and Beck (2012), exploratory studies are used to shed light on the ways in which phenomena manifests based on subjective reports of those who experienced it. In this study, a qualitative approach took priority, whilst the subsequent quantitative approach tested and guided evaluation of the support programme. The initial qualitative phase (Phase 1) of the study aimed to address the first two objectives, which were:

- To explore how women, preferred to be supported during the period they are receiving curative treatment for cervical cancer including radiation
- To develop and validate the support programme

The objectives of phase 2 (quantitative study) were to:

- pilot- test the effectiveness of the support programme in terms of one primary outcome, perceived support and a secondary outcome, quality of life.
- The effectiveness of the programme would be evaluated on the last day

Below is a schematic presentation of the study methods and design for Phase 1 and 2:- Shown in Table 3.1.

Table 3.1: Summary of the Research Methods and Design of the Study

PHASE 1: DEVELOPMENT AND VALIDATION OF THE SUPPORT PROGRAMME			
Objective 1: Explore the support needs of women treated for cervical cancer and how they would prefer to be supported			
Approach	**Population and sampling**	**Data collection**	**Data analyses**
Qualitative exploratory	All women treated for cervical cancer at the academic hospital Purposive sampling (n=22)	Qualitative interviews (Individual interviews).	Content analyses using template style
Objective 2: Validate the support programme			
Qualitative	Group of experts in the field of cancer treatment and care as well as patients treated for cervical cancer (n=11) Purposive sampling	Delphi technique and individual discussion resultant from time factor and staff allocated	Content analysis
PHASE 2: PILOT TESTING OF THE SUPPORT PROGRAMME			
Quantitative pre and post intervention	All women who participated in the support programme (n=56) Census sampling	Structured interviews using existing tools: Berlin Social Support Scale & QLQ-CX24 (structured-self report)	Descriptive and Inferential statistics
Qualitative post intervention evaluation	Group of women who participate in the programme Purposive sampling (n=8)	Group discussion	Content analysis

3.6.1 Phase 1: Qualitative Method

Objective 1 of Phase 1 was to explore the needs of women receiving curative treatment for cervical cancer including radiation. Phase 1 of the study utilised a qualitative approach. Qualitative research is conducted where little or no research has been conducted on the phenomena. Qualitative research helps researchers understand the meaning people ascribe to their experiences, aimed at making it visible to people who were not part of the study (Sutton & Austin, 2015). Although studies were conducted on the support for people diagnosed with cancer, most have been conducted in developed countries (Leung, Pachana & McLaughlin, 2014; Salonen, Tarkka, Kellokumpu-Lehtinen et al., 2013; Liao, Chen, Chen, Chen et al., 2009; Brix, Schleussner Fűller et al., 2008). Similar studies could not be traced for the Sub-Saharan context. Qualitative approach was relevant to this phase of the study, as the researcher wanted to engage participants and be as close as possible to their course by being present as they narrated their stories and explained how they wished to be supported. Qualitative research involves

investigating phenomena in an in-depth holistic manner through the collection of rich narrative data using a flexible research design (Polit & Beck, 2012).

The researcher's aim was to listen and immerse herself in the participant's reality. The intent was to clarify what she had been told in order create meaning and explore how women wish to be supported. It is for this reason the researcher strived to collect participant's stories in the setting where they received treatment. The researcher made attempts to discern meaning in order to share with others who were not part of the research without losing meaning from the original information (Creswell & Plano-Clark, 2011; Streubert & Carpenter, 2011). The researcher became part of the research, as she co–created meaning. Although the researcher comes with her own values, it is important that this should not be imposed on the participants. The researcher made efforts to describe experiences of participant's subjective experiences and multiple truths (Erlingsson & Brysiewicz, 2013; Streubert & Carpenter, 2011). The researcher was solely responsible for collecting data, using a self-developed interview guide (Appendix G). The interview guide had one broad question, "Can you explain how you wish to be supported during the time you are treated for cervical cancer;" this interview guide contained probes relating to concepts addressing different levels of support. Being solely responsible to conduct interviews was an added advantage, as the researcher grew from the same context as the participants; this had an added advantage as she could communicate well in the common languages spoken in the hospital. The interview guide was meant to guide the researcher on specific questions to ask to ensure that she covered specific topics relevant to this phase of the study.

3.7 SETTING OF THE STUDY

Qualitative research is conducted in the naturalistic setting, and makes the world of an individual visible to others in an attempt to preserve the meaning an individual attached to a situation (Bengtsson, 2016; Creswell, 2014; LoBiondo-Wood & Haber, 2010).

The study was conducted at an academic hospital in Gauteng, South Africa. The tertiary institution was chosen because it renders highly specialised services to all categories of patients, including those diagnosed with cancer. Although the study was conducted at an academic hospital, the researcher included the satellite services and clinics that the

patients accessed to be diagnosed with cervical cancer in order to have their comprehensive view about the support they encountered from different members of the health teams during the process. Cancer patients have access to surgery, cancer chemotherapy, and radiotherapy as primary treatment modalities. Patients with cervical cancer received treatment at the department of radiation oncology, generally on an outpatient basis as most were admitted to satellite hospitals in the Gauteng region/district. However, some from rural areas and had resorted to moving in with relatives in search of better treatment and care. The majority of the participants used public transport to travel early from their homes in order to catch the hospital bus. This enabled them to utilise the transport provided to the radiation oncology centre at a specific hospital in Gauteng. Referrals are made because the healthcare settings (primary health clinics and secondary care facilities/hospitals) lack the appropriate resources to provide specialised services. Although the tertiary healthcare hospital operates daily on a 24-hour basis, the specialised services operates daily from 7am - 4pm Mondays to Fridays. Whilst the majority of the patients are treated as outpatients, a minority are sometimes admitted together with other oncology patients to a 25-bedded ward of the hospital. Patients are sometimes admitted to this ward for nutritional support or hydration and treatment due to their disease process, physical disability, or old age. Approximately 75 patients receiving curative treatment for cervical cancer including radiation are treated per day for six consecutive weeks; the same number of patients were treated per week and per month. The diagram in Figure 3.1 shows the distance between the academic hospital and satellite clinics and secondary care facilities from which patient referrals are made for treatment.

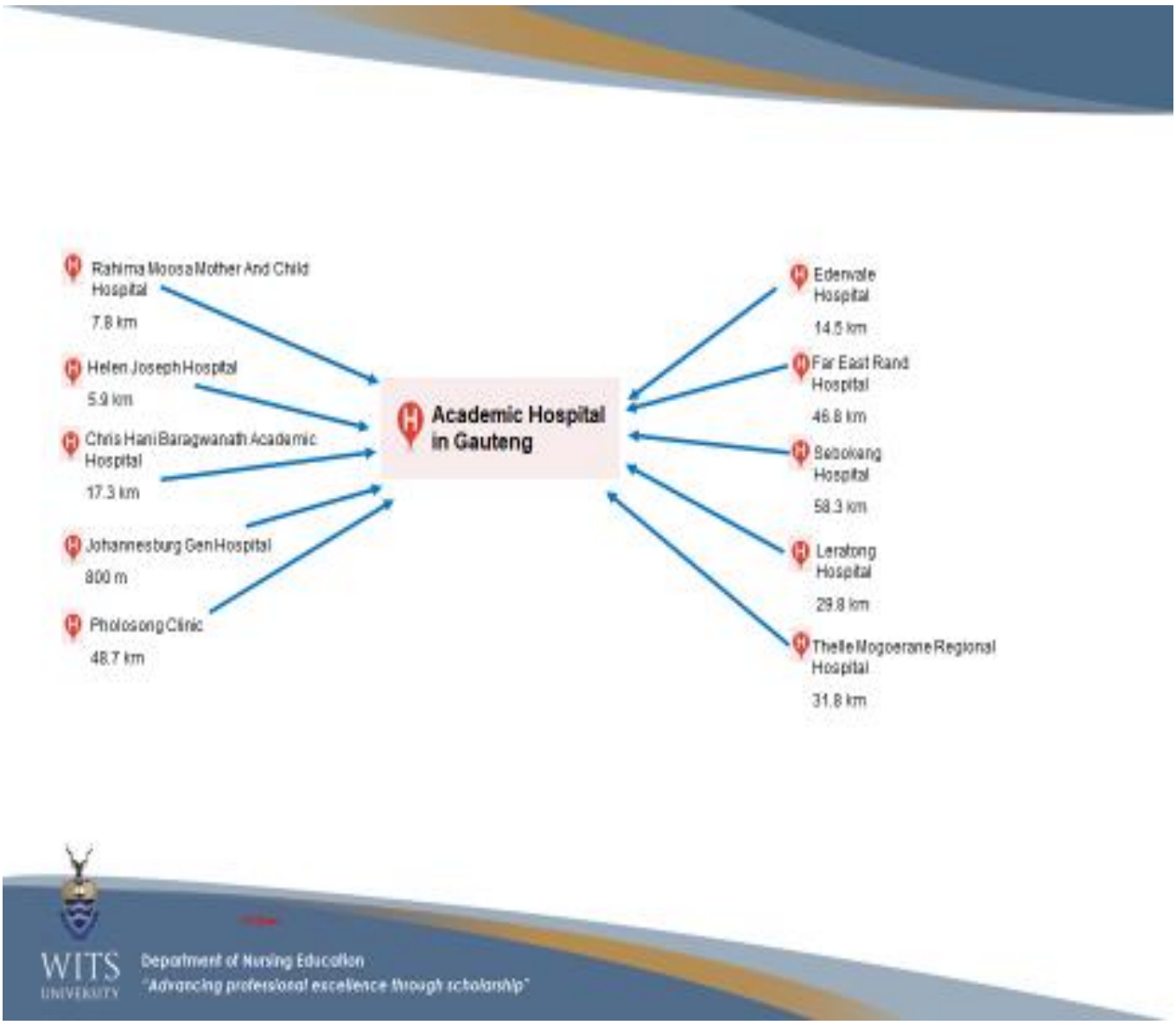

Figure 3.1: **Diagram showing the distance from the satellite services and clinics from which patients are referred to the Academic Hospital**

3.8 POPULATION AND SAMPLING

3.8.1 Population

The population consisted of all individuals having common characteristics (Polit & Beck, 2012; LoBiondo-Wood & Haber, 2010). In Phase1, the target population were all women receiving curative treatment for cervical cancer including radiation treatment at the specific academic hospital in Gauteng.

3.8.2 **Sampling**

Sampling is the process of selecting representative units of a population (Polit & Beck, 2012; LoBiondo-Wood & Harber, 2010). Sequential sampling strategy was used where both purposive and non-probability sampling techniques selected participants (Teddlie & Tashakkori, 2009). Purposive sampling strategy was used in phase 1 to select participants who could inform the study. The researcher sought assistance and support from professional nurses working in the radiation oncology unit to assist with selection of the participants. Purposive sampling is a selective sampling method where the researcher consciously selects participants who can inform the study (Gentles, Charles, Ploeg & McKibbon, 2015; Creswell, 2013; Harber 2010; Burns & Grove, 2009) based on their experience with the specific phenomenon. Purposeful sampling was relevant for the qualitative phase of the study as its aim was not to generalise the findings to other settings.

Although sample size was not predetermined in this qualitative phase, the researcher sought to interview sufficient numbers of participants who could answer the research question (Bengtsson, 2016; Creswell, 2013; Trotter, 2012; Malterud, Siersma & Guassora; 2015) based on redundancy of concepts even with further interviews. According to Polit and Beck (2012), sample redundancy as well as the size can be guided by the purpose of the enquiry as well as confidence of participants towards the researcher. However, Malterud et al. (2015) are of the opinion that researchers need to appraise their sample size continuously during the research to ascertain whether the information is adequate for analysis and publication.

The following inclusion criteria was relevant for participating in the study:

- 18 years and older
- willing to participate in the study
- had a histology confirmed diagnosis of cervical cancer
- receiving curative treatment for cervical cancer including radiation
- in the second to sixth week of treatment

3.9 DATA COLLECTION

Data collection commenced after obtaining ethical clearance from the Human Research Ethics committee of the University of the Witwatersrand (Cert M150272), (Appendix A) permissions from the management of Charlotte Maxeke Johannesburg Academic Hospital (Appendix B) and the Head of Radiation Oncology Department of the hospital (Appendix C). The researcher requested permission to interview the participants if they agreed to participate and met the criteria specified (3.8.2). Although a qualitative sample was not determined in advance, the researcher aimed to interview at least 20 participants as a starting point, with a contingency for those who would withdraw from the study, as well as accommodating those who were too sick to continue. Data collection commenced from February to April 2017. Semi-structured interviews were utilised to collect data using a self-developed interview guide (Appendix G). The interview- guide was validated by the study supervisor, who is a specialist in oncology and palliative care nursing, and peers in the field of oncology, as well as other members of the health team involved in day-to-day care of the patient.

The interview guide consisted of two sections. Section A consisted of participant demographic details, whilst section B consisted of one broad question, “Can you tell me how you would like to be supported during the period you are being treated for cervical cancer.” Although one broad question was asked, the researcher utilised a semi-structured guide with questions pertaining to different levels of support these were used to follow up on issues pertaining to support. Different kinds of support were informational support, which consisted of information related to cancer and its treatment, tangible/instrumental support, which entailed perceived support pertaining to travel to treatment centre, assistance during treatment, food supply and finances. Emotional support entailed having someone present to put you at ease when you are feeling down or depressed, or enquiring about progress made during the disease trajectory and network support, which entailed being part of similar groups of patients sharing similar experiences or providing comfort.

Due to the participants being from diverse cultures and speaking different languages, this worked to the researcher’s advantage during data collection. South Africa has 11

official languages, based on the constitution of the country (The Constitution of the Republic of South Africa, 1996) however, the most common languages spoken in the hospital are Isi-Zulu, Sesotho, Setswana, Sepedi and English for those who attained certain levels of literacy as well as those who could not communicate in the common languages used in the hospital.

The interviews afforded the researcher an opportunity to build a rapport with the participants (Creswell, 2009; Streubert & Carpenter, 2011; Polit & Beck, 2012; Creswell & Plano-Clark, 2007). Through qualitative interviews, the researcher was able follow up on ambiguous statements or clarify information she was unsure of and develop a better understanding of participant's views. The interviews lasted between 45 minutes to an hour. Qualitative interviews are typically long and usually help participants in the construction of their experiences after an in-depth dialogue. Probes were used to encourage the participants to provide further information pertaining to their support needs.

Initially two participants tested the interview guide after giving informed consent (Appendix E) to take part in the study. Due to the fact that the first interviewee could not give the expected response to the question "Can you please tell me how you wish to be supported during the period you are treated for cervical cancer," her response started off as "Initially how I found out that I had this disease..." This prompted the researcher to amend the question to "Can you then explain how you found out about the disease, followed by 'Can you tell how do you wish to be supported during the period you are treated for cervical cancer?" The researcher became aware that the first participant became emotional as she was questioned and started crying during the interview; the participant was offered water and the interview stopped. This made the researcher to be extremely sensitive and cautious as she conducted the interviews. When asked if she wished to be referred for counselling as there was an oncology nurse specifically arranged for this purpose, the participant preferred to continue with the interview. Throughout the interview the researcher was conscious to guard against further emotional triggers; the interview continued and finished without any further event. After amending the initial question, the second pilot test seemed better when asked "Can you

tell me how you found out about your illness" followed by "Can you tell me how you wish to be supported during the period you are treated for cervical cancer." The participant seemed to understand the questions better and was able to relate her story. No emotional trigger was observed with this pilot interview. Due to not many differences in the interview guide, once both interviews were conducted, they were included as part of data collected.

Due to the nature of the study, and the tendency to stigmatise, cervical cancer participants were approached whilst in the waiting area pending treatment. Additionally, the researcher informed them individually about the purpose of the study to make sure they fully understood the aim of the study, and to inform them about the tendency to trigger sad emotions in order that the participants became aware of this crucial information. The researcher clarified that there were arrangements for counselling should participants become emotional during the interviews, as there was no other manner in which questions could be asked except by asking those who had experienced this phenomenon. Interviews were conducted in a private room in the oncology department at a convenient time for participants that would not interfere with departmental routines. The researcher-built rapport with participants during this time and gained their co-operation to talk freely as they shared their views. Participants were informed of their right to withdraw from the study at any time without any consequences pertaining to their treatment in the department. Permission to use an audio tape, during the interview was requested (Appendix F). The interviews lasted approximately 45 minutes to an hour. Field notes were made with caution during the interviews to avoid distracting participants as they shared their stories. Summary notes were made at the end of the interviews as an additional source of information that could not be captured on the audio recording, such as gestures or sadness when some became emotional. Data collection was conducted on specific days, Wednesdays and Fridays, which were the days on which most new referrals were seen at the beginning of the study in order to limit interference with hospital routine and due to travel distance to the research site. Due to time constraints, and the possibility of losing participants due to the different treatment schedules, and changes that could affect returning to the participants, the

researcher replayed the recorded interviews in order to verify the information with them in an attempt to clarify meanings of the conversations.

3.9.1 Data Analysis

Data analysis is a systemic organisation and synthesis of research data (Schreier cited in Flick, 2014; Polit & Beck, 2012). The purpose of qualitative data analysis is to reduce big sets of data by coding, in order to group together several elements under one concept. The idea is mainly to describe phenomena in detail based on multiple truths, as guided by individuals (Schreier cited in Flick, 2014; Vaismoradi, Turunen, & Bondas, 2013). Content analysis was used to analyse the data and template analyses grouped it into themes (Bengtsson, 2016; Elo**,** Kääriäinen, Kanste et al., 2014; Polit & Beck, 2012; Burns & Grove, 2009). According to Graneheim, Lindgren and Lundman (2017), citing Berelson (1952), content analysis was initially used in quantitative studies, however, it later changed to an interpretive approach in qualitative research. Elo and Kyngäs (2007) states that content analysis is a research method for making replicable and valid inferences from data to their context. Furthermore, Elo**,** Kääriäinen, Kanste et al. (2014) state that qualitative content analysis represents a systematic and objective means of describing and quantifying phenomena. Polit and Beck (2012) and Vaismoradi et al. (2013) are of the opinion that qualitative content analysis is the analysis of narrative content to identify prominent themes and patterns.

Content analysis involves breaking down data into smaller units, then coding and naming according to the content they represent (Elo et al., 2014). Erlingsson and Brysiewicz (2016) and Schreier (2014) stated that qualitative content analysis was the systemic and objective transformation of large text data into concise summary of study results. According to Burns and Grove (2009); Hsieh and Shannon (2005), content analysis is a technique used to classify words in a text into categories based on their theoretical importance. Hsieh and Shannon (2005) state that content analysis is an analytic process ranging from impressionistic, intuitive, interpretive analysis to systemic textual analysis. According to Graneheim and Lundman (2004), concepts pertaining to content analysis are crucial and require consideration, as they are important to guide analysis of data.

The concepts are manifest and latent content, unit of analysis, meaning unit, condensing, abstracting, content area, code, category and theme. Manifest content relates to what is obvious from reading the text, meaning that the researcher strives to stay close to the participant's words, whilst latent content relates to extracting deep meaning through interrogating the text and finding relationships across different segments of the data (Bengtsson, 2016; Graneheim & Lundman, 2003). Once the categories have been identified, a template style was used to group categories into themes. Template style analysis is a preliminary template used in qualitative studies to sort the narrative data (Polit & Beck, 2010). Elo et al. (2014) state that a prerequisite for successful content analysis is that data should be reduced to concepts that describe the research phenomena. Data analysis commenced after the first interview, which proved to be lengthy due to the extent of data collected. Patient demographic information was entered onto an Excel spread sheet and analysed using descriptive statistics.

Due to the sensitivity of the information collected, and challenges with spoken languages at the radiation oncology unit, the researcher was responsible for verbatim transcription of all data. In the case of this study, data were reduced to concepts dealing with support, which consisted of informational support, tangible support, emotional support, network support, however spiritual support was added as it emerged from data analysed. Once the categories had been identified, a template style was used to group the categories into themes. Although data analysis commenced the day after the first interview, it proved to be lengthy and exhaustive.

3.9.2 **Participant Demographics**

Participant demographic data were analysed using a self-developed Excel spreadsheet consisting of columns with participant code numbers, instead of using patient's names, cultural groups, province - urban or rural, age, marital status, number of children, educational level, participant employment, income, partner's employment, stage of disease and histology type. Patient demographics analysed through counting entries in each column and adding them to get totals for each column, followed by combining similar information and clustering together in order to compile information, which will be

discussed fully in the results section in the following chapter. Chapter 4 will detail the results and findings.

3.10 RIGOUR/TRUSTWORTHINESS OF THE STUDY

Trustworthiness in qualitative studies is ways to establish truth or confidence in the findings of the study (Thomas & Magilvy, 2011). Polit and Beck (2012) reported that there has been debates around terms such as rigour and validity; the terms were shunned due to their association with positivist paradigm. However, qualitative scholars, such as Lincoln and Guba (1985) cited in Barusch, Gringeri and George (2011), proposed criteria such as credibility, dependability, and transferability, prolonged engagement and peer debriefing to ensure trustworthiness of the study. The concepts will be explained in 3.11.1.

3.10.1 Credibility

Credibility refers to the notion of generating confidence in the truth, and that the results of the study are worth paying attention to. The researcher provided a detailed transcription of the interviews in order to provide the intended audience with as much detail so they can understand the study despite not being present during the interviews (Polit & Beck, 2012).

3.10.2 Dependability

Dependability refers to stability of data over time, meaning that another person can follow the trail provided, where almost similar findings can be reached if the study can be conducted at another setting (Thomas & Magilvy, 2011). The researcher provided a dense description of the steps undertaken in the conduct of the study (detailed proposal has been submitted for review by the university's Human Ethics Committee).

3.10.3 Transferability

Transferability refers to the possibility of application of the study in other settings (LoBiondo-Wood & Haber, 2012). Detailed description of the study proposal was available for peers who wished to replicate the study in almost similar settings with different participants.

3.10.4 **Prolonged Engagement**

Prolonged engagement in the field refers to the investing of sufficient time during data collection to have an in-depth understanding of the population studied, thus enhancing credibility (Polit & Beck, 2012). The researcher visited the radiation oncology department several weeks prior to commencing data collection, in order to acquaint herself with the departmental routines so as to avoid interfering with patient treatment schedules, and to familiarise herself with the context of where data collection took place. During the period of data collection (February-April 2017), it became easier to form a rapport with prospective participants as they grew familiar with researcher's presence in the department.

3.10.5 **Peer Debriefing**

Peer debriefing entails discussing specific details of the study with a colleague who has no interest nor knowledge of the study in order to make explicit aspects of the study that may not be clear in the researcher's mind (Barusch, Gringeri & George, 2011). The researcher periodically discussed aspects of the study with colleagues who were not conversant with the study to clarify important aspects, such as choosing the methods for the study and provision of theoretical models. The study's proposal was presented to the University of Witwatersrand's Departmental Research Committee, who advised the researcher on developing a conceptual framework representing how the study will unfold for easy comprehensibility.

Objective two of the study which is to develop and validate a programme to support women receiving curative treatment for cervical cancer including radiation will be discussed in Chapter 6 after scoping of the studies to support women treated for gynecologic cancers.

3.11 **PHASE 2: QUANTITATIVE PARADIGM/APPROACH**

In phase 2, a non- randomised pre- and post-test design was utilised to evaluate the effectiveness of the support programme. Quantitative studies follow a set of orderly structures to acquire information (Polit & Beck, 2012). The researcher moves in

systemic, orderly planned steps following a specified plan of action to collect data. In this phase, structured interviews were conducted using existing scales BSSS and QOQ -CX-24 module to collect data. The aim was to test the outcomes of a support programme in terms of the primary outcome, perceived support, and secondary outcome, perceived quality of life. The participants received assistance with the completion of a pre-test after which they were invited to participate in a support programme. Pre- and post-test designs are experimental designs where data is collected from participants before and after introducing an intervention (Polit & Beck, 2012). Intervention design guided this phase of the study using single group pre- and post-test. Interventions are used to test innovations in care shaped by nursing goals and values (Polit & Beck, 2012), and/or families, in order to accomplish specific outcomes (Burns & Grove, 2009). An intervention design is new methodology used in nursing for investigating the effectiveness of interventions in achieving desired outcomes in a natural setting (Burns & Grove, 2009). Nursing interventions are deliberate cognitive, physical activities performed on behalf of patients.

3.11.**1 Setting**

The setting was the radiation oncology department of a specific Academic Hospital in Gauteng. This setting was the same as that used in phase 1 (3.7). Data was collected in a private room, arranged with staff in the department, closer to where participants await doctor's reviews. However, the researcher and the research assistant utilised separate rooms to collect data and to ensure privacy of the participants. Individual interviews were conducted privately for all the participants in the pre-testing phase to ensure confidentiality of the data collected.

3.12 **POPULATION**

The population in this phase consisted of all women receiving curative treatment for cervical cancer, at an academic hospital in Gauteng. To avoid biases in phase 2, participants who were involved in the qualitative phase (phase 1) of the study were not included in phase 2 (Creswell & Plano-Clark, 2011; Creswell, 2011).

3.12.1 **Sampling**

Census sampling was utilised to include all women receiving curative treatment for cervical cancer, including radiation at the radiation oncology department. The intention was to give all women meeting specific criteria an equal opportunity to participate in this phase, with the intent to generalise the results to a larger population representative of cervical cancer patients. The objective of phase 2 was to evaluate the effectiveness of a support programme on the last day of facilitation. Pilot studies are conducted to determine the initial sample for primary outcome measures in order to calculate sample size for a trial in a major study (Lancaster, Dodd & Williamson, 2004; Teijlingen & Hundley, 2001). Furthermore, the purpose of conducting pilot studies is to plan and justify random controlled trials, test the feasibility of treatment or interventions, or the feasibility of collaborations in multicentre collaborations (Thabane, Ma, Chu et al., 2010; Teijlingen & Hundley, 2001). Lancaster et al. (2004) suggested that the rule in pilot studies is to take 30 participants to estimate the parameter. Accordingly, calculating sample size for pilot studies may not be necessary, however, it is suggested that the sample size should be large enough to be representative of the population for which it is intended (Thabane, Ma, Chung et al., 2010). In addition, it may also provide an indication if methods used are complex or inappropriate. In this study, a pilot was conducted to test the effectiveness of the programme.

3.13 **DATA COLLECTION**

Data collection occurred from May to July 2019 utilising the same Ethical Clearance Certificate (Appendix A) obtained from the Human Ethic Research Committee of the university. The researcher tested both interview tools with two participants receiving radiotherapy for cervical cancer, to test their understanding of both questionnaires. Participants gave informed consent prior to completion of the forms. The researcher was responsible for testing the tools in order to determine if participants understood the questions, and to observe any reactions from the participants at any stage during data collection. The researcher noted during the first interview how the first participant became emotional when responding to the questions on support. This alerted the researcher that participants could become emotional early in the data collection phase. In turn, the researcher needed to make the research assistant aware in order to identify

any challenges, so that participants could receive counselling, and to arrange debriefing sessions for the assistant if necessary. No changes could be implemented to the questions as they were structured and not to be adapted as per author instructions.

The interview was paused due to the participant showing signs of emotional arousal, as she became upset and began crying, especially when asked questions relating to support (BSSS). The researcher stayed with the participant and offered her water. The researcher offered to terminate the interview and the opportunity to go for counselling, however, the participant calmed down and indicated her wish to proceed with the interview. The researcher proceeded whilst being cautious as she posed the questions. The participant was thanked at the end of the interview, and again offered counselling but she declined. The researcher communicated the issue to the counselling nurse so that the participant could be observed on the days she attended for treatment. The two interviews went well, however it became evident, when asked how they viewed their support, that the participants mostly received support from their children or other family members. As there were no changes during the interviews the researcher followed the same process throughout data collection.

The first group, consisting of 10 participants, were invited to take part in the support programme. The researcher once more explained the purpose of the study. As participants were chasing for transport, the following meeting was planned for a day later. All women in this phase of the study were assisted to complete the pre–test interviews; each woman was assisted separately in a private room. During pre-test data collection sessions, some of the participants became emotional whilst completing either the BSSS or EORTC QOQ CX-24. Despite this, observation participants were not keen on being referred for counselling citing their wish to continue with the interview. The researcher took cues from participants on noting that the interviews were becoming intense; she paused a little and asked if participants wished to terminate the interviews, however, they composed themselves and expressed the wish to proceed.

Due to the nature and sensitivity of the study, the researcher and a trained research assistant, with a basic nursing background and conversant with languages spoken at the

hospital and English, were responsible for collecting the data. Structured interviews were conducted using existing scales – the Berlin Social Support scale (BSSS)(Appendix J) and the European Organization for Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire Cervical Cancer Module (EORTC QOQ-CX24)(Appendix L) with permission from the authors (Addenda I & K). Appendix I shows author permission for BSSS and Appendix K, EORTC QOQ user agreement.

The BSSS, originally developed in German, was translated into English, French, Polish and Spanish. It was developed for and validated with adult populations of cancer patients and their partners. In addition, its use is recommended for use across different clinical adult populations. Although the support scale is self-administered, because of the educational levels of participants in the study and their health literacy and the language in which the printed format was presented, the researchers administered the questionnaires to ease the process and avoid taking too long, as this occurred during the hospital procedures. The BSSS was developed to measure cognitive and behavioural aspects of social support; to assess quantity, type and social support in general and stressful circumstances. The scoring format for BSSS is the same for all subscales and consisted of a Likert–type scale.

The **six** subscales of BSSS are Perceived, Actually provided, Received social support, Need for support, Support seeking and Protective buffering. This aspects measure both cognitive and behavioural aspects of social support. Actually, received support assesses participant's satisfaction with received support within a defined period. Items of received/provided support referring to unfavourable support behaviour were omitted, based on rejection from the cancer population in the original study.

3.13.1 **Validity and Reliability**

The reliability of BSSS was tested in cross-sectional, longitudinal and experimental studies in psychology, counselling and training. The multifaceted structure of the instrument allows for comprehensive assessment of social support in various research contexts in individuals and across dyads. The internal consistency for the subscales in the validation sample was reported as perceived support, Cronbach's alpha = .83,

received social support =.83, need for support = .63, support seeking =.81, protective buffering = .82; internal consistency for provided social support in partner sample = .75 (Schulz & Schwarzer, 2003). In the study, the same instrument was used to collect data on all participants. The researcher clarified areas where participants seemed challenged and received appropriate responses. The researcher and a trained research assistant were solely responsible for collecting data. The researcher debriefed the assistant, revised the questions, and enquired if there were any challenges with the use of the questionnaire. Equally, the researcher enquired about the emotional state of the assistant during collecting data, and if there was a need to refer for counselling, however there were no adverse reactions were reported. Participants in this phase received no intervention at pre-test phase except to answer the structured questions. Specifically developed for patients diagnosed with cervical cancer, the aim of the EORTC QLQ-CX24 module was to assess disease specific and treatment-related quality of life in the specific cancer population. The EORTC QLQ was developed in a multicultural, multi-disciplinary setting to supplement the EORTC QOQ - 30-core questionnaire. The multi-culture setting included nine European countries, Australia, Brazil, Korea and Taiwan. The EORTC QoL Expert group were extensively involved in module specific questionnaire development guided by EORTC policies. The EORTCQLQ-cx 24 provisional module was tested in 12 languages with the aim of solving potential translational problems. The EORTC cervical module was developed in four phases, which consisted of phase 1 - generating QoL issues, phase 2 involved construction of items and translation pertaining to symptoms, treatment related issues and dimensions of QOL relevant to the disease, phase 3 involved pre-testing to identify and solve problems relating to language translation and phase 4 related to psychometric properties comprising of 24 modified items in EORTC QLQ-CX24.

The QLQ -24 consisted of three multi-item scales and five single item scales. Multi-trait scaling analysis revealed high internal consistency with a Cronbach's alpha coefficients ranging from 0.72 to 0.87: symptom experience, 0.72; body image, 0.86; sexual/vaginal functioning, 0.87 (Greimel, Kuljanick, Waldenstrom, 2006). Groups of experts validated the EORTC QOL-CX24, with translational problems identified and addressed during module development.

3.13.2 **Data Analysis**

Participant's demographic data.

Participant demographics, together with data from both questionnaires, were transcribed on an Excel spreadsheet. Statistical support was sourced to analyse and report using SPPSS 22 software. Descriptive statistics analysed data. Descriptive statistics are a summary of statistics, which allows the researcher to organise data in an order to give meaning and facilitate insight, such as frequency distribution and measures of central tendency (Burns & Grove, 2009). Chi square determined significant differences between the pre- and post-test results and these differences indicated the success of the intervention.

3.14 **ETHICS**

In this section, issues pertaining to ethics in both phases of the study are discussed. The first discussion discusses the qualitative issues regarding collecting data in phase 1. The researcher invited women, who met specified criteria (Sec.3.8.2), to participate in the study. Although the researcher tried to avoid causing emotional harm, the nature of the questionnaires used were likely to trigger some degree of emotional harm. However, it was crucial that women who experienced the phenomenon were interviewed in order to get a picture of the situation, and plan for future studies. The Human Ethics Research Committee of the university was aware of such, based on study proposal. In order to mitigate the situation, prospective participants received information about free counselling services, if necessary, at any time during the study. The participants were informed of the possibility of triggering emotions before they could participate. Furthermore, they were also informed of their right to withdraw from the study if they so wished, without giving any reasons, nor losing benefits of being treated in the department.

Data collection commenced after ethical clearance (Appendix A), was obtained from the Ethics Human Research committee of the University of the Witwatersrand, as well as permission from Charlotte Maxeke Johannesburg Academic hospital management (Appendix B) and the Head of the Radiation Oncology Department (Appendix C). Permission was also requested from prospective participants (Addenda D& E) after they

gave informed consent to participate in the study. The researcher negotiated the use of an audio-recorder during the interviews (Appendix F), as she would not be in a position to remember every detail about the information shared. Participants were assured about confidentiality of information discussed/shared. The researcher would strive to keep information locked up and safe in a password-encrypted computer at the researcher's home.

The autonomy of the participants was upheld, as they were informed about the purpose of the study, their choice to participate or withdraw from the study without giving reasons and that they would not be penalised for non-participation. Furthermore, participants were informed about the nature and sensitivity of the study to trigger sad emotions, as there would be no other way to collect information other than interviewing those who had experienced the phenomena; they would however be referred for counselling without having to incur the costs of the services relating to counselling nor any further management should it be warranted.

Participant's personal information were kept separate from the interviews to prevent linking them and kept safe in a password encrypted universal storage at researcher home. The researcher allocated numbers to the transcribed interviews instead of using participant's personal details. Although the researcher pledged not to share any sensitive information shared during the interviews with unauthorised persons, the participants were informed of the necessity to share information with the study supervisor and the intercoder who assisted in coding data and entering into an excel spread sheet before it could be analysed and validated by the statistician. A group discussion was held on the last day of the programme where participants could be together as a group to obtain their opinions regarding the effectiveness of the programme; thereafter each would come to the clinic at different times and attend different health care facilities for follow up.

The researcher informed participants of a need to share the results with her peers at the end of the study, aimed at improving practice and the body of knowledge. The findings

and the results of the study including participant demographics will be discussed in Chapter 4.

3.15 SUMMARY

This chapter discussed the history of mixed methods, different philosophical worldviews, the researchers' philosophical stance and how it had an impact on the study, the methods and design guiding the study and different phases in the study.

CHAPTER 4

4. FINDINGS OF THE STUDY

4.1 INTRODUCTION

Chapter 3 discussed the history of mixed methods, philosophic assumptions, ontology and the researcher's philosophical stance, followed by the methods and design used to guide the study. Detailed information regarding data collection and pre-and post-test were discussed (section 3.9 in Phase1 & 3.13 in Phase 2). Chapter 4 will present the data management and analysis followed by the findings of the qualitative phase (Phase 1) of the study. The objective of the qualitative phase of the study was to explore how the women receiving curative treatment for cervical cancer including radiation preferred to be supported.

4.2 DATA MANAGEMENT AND ANALYSIS

Audio recorded data were stored in the researcher's personal computer, which was password protected. Once the researcher reached her home, data was transferred to an external hard drive, which was also password encrypted to ensure no un-authorised person could access confidential data. Due to the extent of the interviews and emotion-laden data, the researcher commenced analysis a day later, in order to step back from the data so this would not influence her thinking whilst analysing.

Participant demographics were entered into an Excel spreadsheet, followed by data transcription. The researcher was solely responsible for analysing the data to maintain confidentiality. The researcher grew up in Soweto, a formal settlement that came into existence after the group areas Act was initiated during the apartheid years. Different cultural groups reside there, and one had to learn the languages and common dialect used in the area. Since the researcher was proficient in the languages the participants spoke, she did verbatim transcription of all data sets.

4.2.1 Data Analysis

The purpose of data analysis is to classify and interpret verbal or visual data to make valid inferences from what is emerging from the data. Content analysis was used to

analyse the data (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017; Elo, Kääriäinen, Kanste et al., 2014: 1; Graneheim, Lindgren & Lundman, 2017). Content analysis is a research method for making replicable and valid inferences from data and its context, with the aim to produce knowledge and new insights (Elo & Kyngäs, 2007). However, the process was not linear, as the researcher had to move back and forth between the segments of data to confirm if meanings still represented phenomena being studied. Hsieh and Shannon (2005) stated that content analysis does not involve mere counting of words, but also extensively examining large text data to form categories representing similar meaning relating to the phenomena being researched. Graneheim and Lundman (2004) reported that initially, content analysis dealt with the objective and systemic quantitative description of manifest content; however, with time it expanded to include interpretations of latent content. Manifest analysis deals with what the text is about and involves description of the visible and obvious components from the text. Latent content deals with actual interpretation of what the text is about. Content analysis can be inductive, where the researcher uses open coding to create categories and abstraction. Open coding means the researcher makes notes in the margins of text as she reads the data whilst attempting to identify meaning units. The researcher is cautioned against using pre-conceived categories and follow what is elucidated from the data as the analysis unfolds.

The researcher organised the interview data, field notes made during the interviews and summary notes made at the end of the interviews, where gestures such as pauses or sad emotions, or silent cries could not be captured on audio recordings. The researcher listened to the audio-recorded data several times to immerse herself in the data to get a sense of what it was about before proceeding with transcriptions. Bengtsson (2016) termed this staying close to the text, meaning making sure not to lose meaning of what the participants were saying or gathered from the narratives. Once the researcher had a sense of what the data was about, she transcribed verbatim. Verbatim transcription entails transcribing information from participant's interviews, as being told during discussion without attempting to change the meaning as the stories unfold. The researcher made a conscious effort to reflect on her pre-understanding of the context where data collection occurred to avoid tainting the data. However, the process was

exhaustive and challenging as the researcher moved back and forth between transcripts and the audio-recorded data making comparisons in order to ensure she retained the meaning of the data.

Due to the long tedious process and the tendency of the data to affect the researcher's emotions as she listened and re-lived the interviews and the context, she resorted to taking a day or two between transcribing in order to step back from the data. This assisted the researcher to reflect on her pre-understanding and concentrate on what the participants said. The study supervisor debriefed the researcher when available. Once the first transcription was completed, the researcher read through the segments of data in order to determine if meaning from condensed segments of data still represented what the participants said. These are termed meaning units, and are created through highlighting segments of data according to their meaning and condensing them into small summaries, called condensed units, to develop codes based on specific concepts relating to support (Graneheim, Lindgren & Lundman, 2017); this is termed manifest content. In the study, the segments of data were highlighted, and coded to identify concepts related to support, as determined by levels stated by Cutrona and Suhr (1994).

The researcher-highlighted information pertaining to symptoms experienced, access and travel to the healthcare facility, referral for diagnostic tests and confirmation of the disease, patient experiences and staff actions and counselling received. These were followed by different levels of support pertaining to informational need, emotional support, need for tangible support, need for assistance and peer support, as well as spiritual support as it merged during data analysis. Although spiritual support was not included in the interview guide, the concept emerged from participant's narratives as data was analysed. Some of participants reported that watching some television programmes assisted them to accept their situation.

A data analysis sheet was created where codes were identified and grouped according to similarities and relationships in order to develop categories. Themes emerged based on the categories as they were clustered to present similar ideas. The emergent themes from the data encompassed symptoms experienced leading to accessing healthcare

(patient's experiences of symptoms prior to presenting at facility), information pertaining to disease and treatment, counselling as a process during diagnosis of cancer, emotional support needed during cancer trajectory, tangible support needed, network and peer support, and spirituality as a way of coping during the trajectory of cancer. In addition, media programme also became useful in helping participants to accept their situation.

4.2.2 Findings

The findings of the qualitative phase of the study are presented according to the participant's demographics (Table 4.1) and themes that emerged from the data presented in (Table 4.2).

4.2.3 General Characteristics of Participants

Table 4.1: General Characteristics of the Sample (n=22)

	(n=22)
Socio-Cultural Groups	
Coloured	**1**
North Sotho	**0**
South Sotho	**7**
Swati	**1**
Tsonga	**1**
Zulu	**10**
Other	**2**
Province	
Gauteng	**16**
Limpopo	**1**
Mpumalanga	**1**
Other	**4**
Region	
Rural	**5**
Urban	**17**
Age	
31- 40	**4**
41- 50	**11**
51 > 55	**7**

	(n=22)
Marital Status	
Married	**4**
Culturally married	**5**
Co-habiting	**1**
Stable relationship	**1**
Single	**4**
Widowed	**5**
Divorced	**2**
Educational Level of Participants	
Never went to school	**2**
Grade 1- 6	**3**
Grade 7	**1**
Grade 8- 10	**6**
Grade 11-12	**9**
Tertiary	**1**
Employment Status of Participants	
Un-employed	**4**
Day worker	**13**
Employed	**3**
Pensioner	**2**
Number of Children	
0-1	**3**
2-3	**9**
4-5	**10**
Monthly Income of Participant	
None	**5**
R1- R2000	**8**
R2001- R2500	**4**
R25001- R4000	**2**
R4001-R6000	**1**
> R60001	**2**
Employment Status of Partner	
Unemployed	**1**
Day worker	**5**
Employed	**2**
Pensioner	**1**

	(n=22)
Monthly Income of Partner	
None R1- R2000 R2001- R2500 R25001- R4000 R4001- R6000 R6001>	**2** **3** **1** **1** **1** **1**
Stage of Disease	
Stage II A Stage II B Stage IIIA Stage IIIB	**1** **10** **1** **10**
Histology Type	
Squamous Adeno carcinoma Other	**14** **1** **7**

Twenty participants, including two from the pre-test, were interviewed (n=22). Most participants (n=10) were Zulu speaking, while (n=7) spoke Southern Sotho; however other non-cultural language speakers, were able to communicate in English. Participant's ages varied between 30 and above 55 years. Most of the participants (n=16) were from Gauteng Province. Nine of the participants were in a marital relationship; however, thirteen were employed as day workers. Most participants (n=9) attained an educational level above grade 8-12. Most participants (n=10) had more than 4-5 children followed by (n=9) with more than 2-3 children. The majority (n=20) were at an advanced stage of the disease (n=10) stage iii and (n=10) stage ii respectively. Regarding histology fourteen were diagnosed with squamous carcinoma confirmed from participant's hospital records.

4.3 THEMES AND CATEGORIES THAT EMERGED FROM THE STUDY

Six themes and 18 categories emerged from the data are presented in Table 4.2. The results of qualitative phase informed development of the support programme.

Table 4.2: Themes and Categories Generated from the Study

Themes	Categories
Symptoms experienced leading to accessing the healthcare facility	− Experiencing the signs and symptoms − Patient experiences at the healthcare facilities − Referral for diagnostics and confirmation of disease
Information pertaining to the disease and treatment	− Received bad news in isolation − The responsibility to inform relatives about their illness − The need to be informed about the disease and treatment
Need for counselling during the cancer trajectory	− Counselling received after being informed about disease − Need for counselling throughout the cancer trajectory
Emotional support	− The need to be asked about concerns − The need to be encouraged to pursue treatment − The need to be treated with patience at all times
Needs for instrumental support	− The need for financial support for food and travel − The need for female hygiene products − The need for staff support after radiation
Network, peer and media support	− The need for nurse-led group support − The need for informational support − Spirituality as a way to cope with disease − Media support

The overarching theme for this phase of the study is “Patient’s experiences and needs highlighted during the trajectory of cervical cancer”.

4.3.1 Theme 1: Symptoms Experienced Leading to Accessing Healthcare Facility

Categories that emerged under symptom experience leading to accessing healthcare facility were most participants experienced that something was wrong, patient’s experiences relating to the care facilities, referral for diagnostics and confirmation of disease.

4.3.1.1 **Most participants experienced that something was wrong**

The majority of the participants experienced some abnormal symptoms that lead them to consider visiting a healthcare facility. This is supported by the following narratives:

"*At first I was bleeding underneath. Hei! It was a lot. I was bleeding with a lot of clots. I then decided that I must go to the clinic. At the clinic they looked on my palms and said you don't have blood (meaning participant is bled out/ or pale). We are transferring you to the hospital. I used to bleed a lot! I was weak! Very, weak! You see a five litre! I would bleed half of it with lo...ts of clots (Participant,* 2).

"I *started having pain around the abdomen sort of. It was around June (2016), then I was bleeding a little bit, but then my periods stopped. I stated experiencing back pains again, in November then I went to the clinic. When the doctor checked (examined) he said you've got eeh…. trying to remember, what!!Ee…rr, urinary tract infection. So, he then gave me some tablets; but after two weeks the pain came back again (Participant 4*).

"I became ill when I was four months pregnant, in June 2016; they were not able to see what's wrong. I was told that they see a black thing inside the womb. The doctors put the hands inside to check (examining) (*Participant, 9*)

"*Myself I was ill from the 13th of April last year (2016), as I was attending at the Clinic. I was bleeding and went to the clinic. Eish (exclaiming)!! Mam, I bled for a lo..ong time since 13 April till August. eeish! With clots and froth bi...g clots. Yoo! A big chunk! Mmh, (confirming)*. *They called an ambulance that took me to Natalspruit hospital, where I was examined and they took bloods"* (*Par*ticipant, 11).

4.3.1.2 **Patients experiences relating to the health care facilities**

Patients had various experiences at the care facilities. Some had to rely on information from other patients who had been longer in the system. It was evident that participants received information from others who had already commenced treatment. It appeared that there were no specific healthcare professional mandated to give health education/information. This was characterised by the following:

"*Ooh! When I first started, I was scared, because those who had already been treated would tell you that you are going to feel dizzy, you become like this and that. They really scare us (Participant*, 7).

"Like I said there are so many changes in our bodies then you get scared because you don't understand. You end up asking yourself how long is this going to take. Like myself, I am stage three (iii). When we are sitting at waiting area others start to talking saying now, I am starting to wet myself, this and that. I become truly scared! I hear all this! I become discouraged, as to why do I have to go through all this for nothing" (participant, 9)

"Whilst I was here sitting with other patients, we tell each other eey (exclaiming)! I did not sleep last night, running stomach, cramps Yo! I felt like rather than coming here, I'd rather stay home and not come back anymore" (participant, 10)

"*So, another lady was sleeping next to me in the ward…. Ye...es! I was admitted for a week at Natalspruit hospital. they kept on fetching her and taking her to Jo' burg hospital. So, I asked what was wrong with her. Then I was told that she has cancer. So, I heard when it was said that cancer is dangerous, it can kill" (participant 11).*

4.3.1.2.1 Staff actions

While patients were inundated with their experiences, it also came to the fore that some felt that they were failed by the system as they had to repeat procedures as their results were lost in transit. Some felt the healthcare system delayed them unduly, as they were not sensitive once the women presented at the facilities with symptoms such as bleeding or backache, leading them to consult with other service providers, narrated as:

"*We came as a group of six women that day, here in Jo'burg. The thing is that hospital processes are very slow! You know sister (professional nurse). I came here around June last year. But stopped going to the clinic about two years ago they could have found out what's wrong. Maybe I would not have reached the stage that I am in now! I ended going to a private doctor* (*Participant, 1).*

"I went to our clinic last year for Pap smear. then I was referred to the hospital. Unfortunately, the hospital on my side delayed with the results, so then I decided

on my own to go to a private gynae doctor; where he did sonar, tests, and also took pieces of flesh from my womb and take it for tests" (Participant,10).

"Since I was bleeding, I kept on going back to Bara (hospital) for check-up. Because they also kept on giving me dates to come back" (Participant, 7)

"*So he said that I must go to the clinic and do a pap smear, so I said aaish! our clinics they take forever long until even the year finish so I felt it's better to go to the special doctor so that they will be quick to assist rather than me being consumed by the illness" (Participant, 17)*

"*I got the baby via an operation. So, after delivery at hospital the baby was in ICU, I had to ask permission to go and get the biopsy result. It so happened that the doctor did not attach the sticker, (meaning patient information) so the results got lost. So, I had to go back and repeat the biopsy" (Participant, 9).*

"I went to a hospital (in Krugersdorp); it was in October 2016. I had done a pap smear and went back in November, to check the results. They did not tell me immediately. they informed me in December because I went back" (*Participant,6)*

For some patients, the care at the facilities was experienced as unsupportive; this was characterised with the following:

Aah!!, when I am on that machine, I tell them that I have cramps and a running stomach, they say you will be fine, its side effects of radiation. they just do! (meaning carry on with treatment) no, we are just there for radiation they put us under the machine and say nothing (implying that no one shows concern, they simply carry on with their task*). I almost pulled out!* (Participant, 10)

"*So, when he finished it then appeared like he attracted all the blood!! Yoo! Then the blood was oozing Yoo! With lots of clots, big clots Yoo! He jumped and called the nurse to come and help. Then there was blood all over now! So, this nurse became cheeky with me. She says now when there is blood all over on the bed what must I do? Aarch! (annoyed). She said now you going to cause trouble for me with the lady who is doing the laundry" (Participant17).*

4.3.1.3 **Referral for diagnostics and confirmation of disease**

It was evident that all the participants in the study consulted a health facility when they noticed some abnormal symptoms. Hence, they were seen at primary care facilities and were referred to tertiary care for further management due to lack of appropriate facilities to treat the disease. This is evidenced by the following narratives:

"Eish (exclaiming)!! Mam, I bled for a lo..ng time since 13 April (2016) till August. Eish! With clots and froth bi...g clots. Yoo! Bi...g chunks! Mmh! (confirming). They called an ambulance that took me to the hospital, where I was examined, and they took bloods. That's when I found out that I have cancer. I kept on bleeding with big clots and froth. then they transferred me here at Jo'burg, where they did a sonar and epilepsy as stated (implying biopsy) they took a piece of something from underneath (Participant,11).

"I was sick for some time, because they were unable to see what's wrong. They only saw a black thing. They said it appears like pieces of flesh but were unable to see! So, I was transferred to the hospital. So then, the doctor did a biopsy, so he then explained that after the biopsy I will wait for six weeks for the results" (*Participant, 9*).

"*I went to our clinic last year for pap smear, then I was referred to the hospital. Unfortunately, the hospital on my side delayed with the results, I decided to go to a private gynae doctor; where he did sonar tests and also took pieces of flesh from my womb and take it for tests. He urged them (laboratory services) that he wants results in two days. He told me that he is going to refer me to the hospital (Jo'burg) because this is where they can do radiation because he said that he found this thing, cancer! he told me that once I am in the hospital (Jo'burg) they will explain everything* to me (Participant,10).

"*I could not go home for December holidays, because the dates they gave the 28 in 2016 and 2nd the following year (2017) January. So, I decided that my health comes first. So I was supposed to return on the second of January to the hospital. So, when I returned to the hospital on the next appointment date I was told to go for X-rays of the chest because they wanted to see if the cancer did not spread, Ee! (yes) confirming! then I was informed at hospital that they would send me a message to say when I will be going for treatment!! (Participant, 7).*

4.3.2 **Theme 2: Information Pertaining to the Disease and the Treatment**

Patients found themselves having to deal with various types of information regarding their illness, characterised by the following: receiving bad news in isolation, patient left with the burden to inform relatives about their illness, and the need to be informed about the treatment and the side effects.

4.3.2.1 **Received "bad" news in isolation**

The majority of patients were informed about the bad news; however, this was done while alone with the doctor, without any support of family or health practitioner. This could be assumed based on the fact that women relied on the hospital transport for commuting to the treatment centre; however, no concession was given to relatives or significant others to accompany patients. This is narrated as follows:

"The doctor informed me that I have cancer, and if I want to get better, they will transfer me to Jo'burg Gen where it can be treated. He informed me that they will burn it (cancer) with a machine. I was alone! Hei! (Exclaiming) I just accepted. I did not cry, when I was at home I asked myself about the illness and that this illness when it has affected you, you will not live (Participant, 2).

"So, the nurse was doing Pap smear and she asked me about this thing. hehe! (nervous laugh) my status (implying HIV). So, I said yes I would like to know. When I went back for results, the doctor told me that I am HIV positive. I am not worried with HIV. The thing that makes me stressed is the thing about cancer of the mouth of the womb. I have seen people live with HIV. If you want to live, you'll live. Cancer I have seen my mother! (Participant, 7)

She further narrated, *"My mom was very ill; It was found that the cancer has spread. So, I even asked them what are the chances of removing the womb. So, they did explain to me that the doctor says when he looked on the sore on the mouth of the womb, he's not happy"*

"When I came back the doctor did say it is cancer. So, I said Yo! Yo! Yoo...! (shocked) what I'm I go to do now. Ee! (yee… s), he said it's on the mouth of the womb. I said Yoo...! doctor oh my God! What is this? Why…? He then confirmed! yes mom it is cancer! I said so doctor when I get there should I ask that they remove the womb. Hey! I almost died on that day because doctor said no! no! they will not be able to remove the womb,

because the cancer has spread shoo! shoo! (clap! clap! clap! (participant beat her hands together in frustration! Yoo! Hi! I asked him again. He said no! the cancer has spread" (Participant,17).

Although most of the participants received the bad news in isolation, there were some who had the opportunity to have someone present when they were informed of their illness. Their narratives were as follows:

"*You know like I am having cancer neh! you start having this bad smell, even when you are in the taxi(cab)people get irritated and impatient (when you sit next to them). Even my mother she was called at to the hospital to inform about what's wrong"? Immediately when the doctor informs you that you have cancer, he ask you if you want him to inform your family. So I said yes because my mom drinks." (Participant, 6). Participants started to cry (hi! hi! hihii...). The Interview was stopped, and participant was offered water. After a while the participant composed herself, she was then asked if she is wishes to continue with the interview. She said she is fine she will continue with the Interview*.

"*I was called on the 23rd that I must come to hospital on the 28th because the results came and it confirms cancer. It really hurt, because even when they were saying its cancer, I was not concerned because I did not have the symptoms. I really felt very, bad. I even stopped doing washing. So, my husband when he came from work he already knew, they had phoned him at work. So, we had to go to the hospital and consult the doctor who booked me for that biopsy. Indeed, he explained that the cancer had advanced so I will need to go to Jo'burg (here) for treatment. So that they can start to manage the illness" (Participant, 9).*

"The doctor at the hospital inserted that steel thing again (speculum), and then I was surprised because I winced with pain! Then he (doctor) came close and kneeled next to me. He said granny the cancer that you are having is quite large. Will need to burn it. It will heal but we cannot remove the womb. I was with a nurse here (Jo'burg, hospital) because the one who accompanied me went out" (Participant, 12).

4.3.2.2 **Patients were left with responsibility to inform relatives and significant others about their illness**

Despite patients being newly informed about their illness, most were left with the responsibility of informing their families and significant others about the illness. The following narratives attest to this:

"When I was at home, I asked myself about the illness, and that this illness when it has affected you, you won't live. I spoke to my fourth sibling and my mother and our last sibling. I had the results. Soo... I said at least its better because God has shown me what is my problem. I explained that I have cancer of the mouth of the womb" *(Participant, 2*).

"They informed us that in order for us to be free, it will be better if we if we stop having sex for a while whilst we are on treatment! my partner did not have any problems when explained to him. He understood since I have started treatment we have stopped" (Participant,8).

"*When I reached home, I spoke to another woman, an older woman, we go to the same church. She at least spoke to me, to ease my feelings. She at least counselled me. She said to me first take it like a person who has a headache! don't tell yourself you are ill. Continue to take treatment dear" (Participant, 19).*

"So, when results came it was that! I just said it's there! It's there, what can I do! (accepting defeat). I did not know anyone who had cancer before. But the nurses said once you start treatment, everything will be fine. I did tell him what they said. He said what we can do! We are in this together. What can I do"? (Participant, 13).

"The doctors here informed me that I have cancer of the cervix, so I need to attend the machine (radiotherapy). They informed me that the machine will burn the cancer. mhh! mhh! (exclaiming). I was frightened, truly! I was not feeling okay about the machine thing! I talked to my children, they would encourage me" (*Participant, 14).*

4.3.2.3 **Need to be informed about disease, treatment and side-effects**

Some of the participants expressed the need to be informed about treatment and the side effects. This was characterised by the following:

"I think people need to be informed/taught like when people were taught about HIV. They should be taught! They should be told what is cancer, what happens when you are

diagnosed with cancer of the mouth of the womb, it's not the end of the world. Because a lot of people think that when you suffer from it is the end" (Participant, 5).

She further narrated: "*mmh! (Confirming) women must be supported by talking to them. I think most people or women needs to be informed what is cancer, so they can be able to understand"*

"I was only informed when I have developed this rash and was enquiring about the cause. Maybe they should inform us before so that we know that since you are starting with treatment, be aware that this and that will happen, but it is not going to be like that for ever. Just to inform us otherwise people will end up stopping treatment because they do not understand" (Participant,19).

"Another thing we would like to know is how this illness attacks? In fact, what is that a person should be cautious about whilst you do not have the disease…" (Participant, 16).

"The doctor called me to a private room and told me ausie (sister), this and this and that [patients not ready to deal with possibility of diagnosis]. He told me that I have cancer on the mouth of the womb. Ye...s! (exclaiming) He even showed me the image of the cancer. It is a small black thing on the mouth of the womb" (Participant.11).

Women expressed a need to be informed about the treatment and side effects. This is supported by the following narratives:

"*You know these machines, I don't know, I can't lie. Hehe! (hesitant laugh) because I was even asking myself what are the machines doing? When I'm home, I ask myself what are the machines doing? Because I had not even commenced with treatment yet, and the pain was killing me" (Participant, 17*).

She further narrated: *"because they put you in these machines without explaining what it is doing? Or what is it testing for? For example, at the simulation I do not even know what it does hey! You know in this machine its soo cold, yoo! So cold. Even the nurses don't stay long. I even asked myself once I was out. What is this machine for? I thought they will explain maybe. Even today they have not explained." (participant,17).*

"I am asking because I noticed like sometimes when you are seating at the waiting area people say 'chemo is painful, ihashi! (meaning the horse), implying that brachy is frightening'. So, it's best that at the beginning we are informed about what will happen

during the time when you are undergoing treatment. Even myself I was worried at the beginning, when I was told that I will be going on the horse, I was really worried because I did not know what It was" (Participant,3).

"*The only thing I was told is not to wash on the tattoo (ama-tatoo) area. Ee! (yes) even when you go home the family also like to know why they make you go into the machines what is it for? Understand! (raising concern)" (Participant, 7).*

The participant further enquired, *"I want to know how long after treatment can one resume sexual activity, or do we still have to continue using condoms? I am asking because I noticed that this cancer affects young people as well".*

Women found they experienced symptoms they knew nothing about. They were only informed when they reported the side effects as the treatment progressed.

" Like if you have a problem like now, I am bleeding, I go into the machine then go. I have developed piles. I go into the machine then after that I just leave. At least they should inform us to say that if you see something unusual. Maybe they can teach us, it's alright like to say this and that "(implying that they should make them aware of the side effects), (Participant, 2).

Although some women reported not being informed about their treatment, there were those who at least came across some information while attending treatment. This was narrated as follows:

"I was told that we are going to treat you at the radiation machine until you get better, then you go to HDR. It does clean you until you are fine (Implying you are cured). They told us at the beginning that you are going to receive chemo, and you will develop dark marks, underneath (pointing towards the vulva), so they assured us not to be frightened because that's how the treatment works, as it cleanses you of the cancer" (Participant, 3).

"*Yesterday, I was at HDR, the doctor informed me that they are going to clean (the womb), because I was attending cobalt. Well I don't know; but the doctor told me that because I started at Cobalt, they are cleaning me because they burn the cancer, so at HDR they clean inside the vagina. At Cobalt, you lie down, and the machine moves over the cancer, it does not even take long, not even 30 minutes" (Participant, 6).*

"*They inform us not to use soap to bath around the marks until they will inform you to come for treatment. that seems to worry most women, because we worry a lot during the time because we think that the cancer) is eating away the cervix whilst waiting to start treatment" (Participant, 5).*

4.3.3 **Theme 3: The Need for Counselling during the Trajectory of Cancer**

Most participants received counselling only after being informed of the cancer diagnosis; however, women preferred counselling throughout the cancer trajectory. It is clear that not all women received the information that was due. Some were informed about the period when they would be called for treatment, whilst others were informed about care around the treatment marks; few received information regarding the actual treatment process.

4.3.3.1 **Received counselling once being informed about illness**

Women reported to have received counselling; however, they were informed about the time they will come for treatment, care around the treatment area (tattoo marks), as well as how the radiation machine works.

"When the doctor told me that I have cancer. He only said that I will come there every day for six weeks, and then was informed that there is a machine that will be attending for one (1) week. We were told not to wash with soap; we should not use dawn (skin lotion)." (Participant, 13)

"*As, I said when I came on the 15th after the tattoos, they said they will send a message to come for treatment. So, they explained to us that when you bath here (indicating pelvic area, you just wipe where the tattoos are, when I bath I just wash without soap around the tattoo area. Underneath I just wipe with a wet cloth only" (participant, 7)*

"I was first seen by the doctor at sim lab on the 8th so they did the tattoo, and then they informed me that I will wait for them to call and say when I can commence the treatment. The only thing they informed me was that I should not wash here with soap or put ointment (participant indicated mid abdomen to mid-thigh (Participant, 16).

Furthermore, only a few had the opportunity to be informed about the treatment:

"I *was just instructed to lie under the machine, so the sister had counselled us first when we came the first time we come for radiation. it's this type of machine, you lie down still the machine does what it is supposed to do, then, only at times you will experience those subtle pains, so when you go to the doctor you will inform him" (Participant,15)*

"*So once you are inside you are told to undress until a certain level. Then you lie in the machine and face up, then they do something that looks like you are undergoing some x-Rays, so then it will scan moving all round then in the sides. Ye...s, they explain to me that the machine works in a similar way like this very machine. It will burn the cancer" (participant, 21)*

"*Well I don't know; but the doctor told me that because I started at Cobalt, they are cleaning me because they burn the cancer, So at HDR they clean inside the vagina*" *(participant, 6)*

"You know the first day, I forgot exactly what was done, I just remember that I was now attending the machine; they told me that…silence! Looking up trying to think very hard! machine will reduce the cancer, to make it less" (participant, 4).

"The lady who was counselling us, explained that there is no fire, it's same as when you are doing an X-ray. You will get in and lie down inside, whilst the machine is working inside and treats you" (participant, 5).

4.3.3.2 **Counselling needed throughout the cancer trajectory**

Some of the participants felt frequent counselling would help them pull through the cancer trajectory. This was reported:

"Counselling would be ideal, at least we can be put in a class (group) and be told that "mama it will be okay because with me as I am having children. Yes! It really bothered me emotionally" (participant, 4)

"With treatment I mean to encourage us not to default, because yee...s! There are those who default. Others don't come because they attending to own issues. So like if they talk to us and explain that it's important to continue with treatment because it will help you, just to encourage us to attend. (Participant, 14).

"Eer, like I said when we are sitting with other patients, I could hear we go through the same things. I suggest that the sisters (nurses) do daily counselling, like in a room.

Because on a day when you are not feeling well when the sisters and other patients talk about a situation. It will make one to at least feel a bit better (*Participant, 10)*

"*Yes because at least if they explain, then it will help because even now we are mixed up. It so disturbing because we are many there on the benches you meet so many people with lots of conditions. Anything!" (Participant, 17).*

4.3.4 **Theme 4: Emotional Support Needed**

While emotional support is important in helping patients adapt to the illness, it appears some patients viewed support in a different light. Patients expressed the need to have staff enquire about concerns during the trajectory of cancer, as well as to encourage them to pursue treatment. Patients further expressed the need for staff to exercise patience and empathy as they deal with them, characterised by the following:

4.3.4.1 **Staff should enquire about patient's concerns**

"*Yees...eeh! eer! (a bit doubtful). Here there must be nurses! …, like myself I almost pulled out. Whilst I was here sitting with other patients' we tell each other eey(exclaiming) I did not sleep last night, running stomach, cramps. Yo! I suggest there must be someone! Must come around asking how we feel. Maybe they can explain (encourage) to keep us going (participant, 10)*

"like I said when we are sitting with other patients, I could hear we go through the same things. I suggest that the sisters (nurses) do daily counselling, like in a room. Because on a day when you are not feeling well when the sisters and other patients talk about a situation. It will make one to at least feel a bit better" (participant, 8).

"My concern is that I wish to complete the treatment Eeish!! If you can help us to get better! My only concern is to get healed, so that I can get better and look for a job (participant, 13)

"At the beginning, I was afraid because we do have a family member from my aunt side who died because of this illness. No one says anything once done at the machine we just go!! Mmh! mmh (no! no!) no one asks except if you decide to report on your own maybe" (participant,16).

4.3.4.2 **Needs to be encouraged to pursue treatment**

Many of the participants expressed a need to be encouraged to pursue treatment, as some can be derailed due to getting information from other patients, whilst some had other social concerns.

"*Another thing is treatment. If you can support us with treatment the very one, we receive from machines, ee! With treatment I mean to encourage us not to default, because yes there are those who default. So, like if they talk to us and explain that it's important to continue with treatment because it will help you, just to encourage us to attend. Ee! As I was talking to my children, they would encourage me, because I would tell them hey! I am from the machine, but it was tough!" (participant,14)*

"At least we can be put in a class (group) and be told that mama it will be okay because with me as I am having children, I will be attending the machine, so you will be attending this machine, this machine! (Exclaiming) then after ten years where will you be" (participant, 4)

"*first told my daughter she is 32yr old. I told her I am HIV+ and have cancer. So, I felt better because I spoke to someone. She encouraged me and said aah! mom HIV won't do you anything as long as you take your treatment at the correct times. I take it at 8pm. Cancer they will get you treatment*" (*participant, 1).*

"It hurts at times you feel sad, but like I said I felt better having spoken to my family. Also, one of my neighbour's when I spoke with her she was discouraging me from coming. She told me that there were some ladies that she knew, and were coming for treatment, they burnt the cancer and they died (participant, 16)

"Like when we arrive in the morning maybe one staff member can come whilst we all sitting to explain, because some people when they are alone it's a bit difficult to understand, but maybe when they explain when with other people it's better. They can re-inforce what you told us" (participant,16)

"I wish at times in the rooms at the radiation area, they must not just tell us sleep here. At least they should tell us what happened during the time when you are lying on the bed in the rooms" (participant, 7)

4.3.4.3 **The need to be treated with patience at all times**

Most patients reported that staff at the treatment centre extended themselves in trying to give the needed support. However, the situation is perceived differently regarding care experienced at primary care services, as well as travel to the care centre.

"They were taking a sample to test for cancer, because they were suspecting that its cancer. So when the results came it was that. They said once you start treatment, everything will be fine. They will send you to Jo'burg there are specialists! they will decide what they gonna do, cut or treat" (participant, 8)

"*On my first day I felt dizzy and I had nausea (actual patient is words). I had to walk all the way, though at times you feel fine when you come out of the machine but later on when you waiting for transport you find that you feel somehow, you do feel that you are not okay" (participant,16).*

"*So, when he finished it then appeared like he attracted all the blood! Yoo! Then the blood was oozing Yoo! With lots of clots, big clots Yoo! He jumped and called the nurse to come and help. There was blood all over now he did not know what is happening. So this nurse became cheeky with me. She says, now when there is blood all over on the bed what must I do" (participant,17)*

"*I was late yesterday because the staff (health care members) have a meeting. I told the nurses that I have been not been attended yet, not one even took notice of me. When I finished the transport had already left. I had to make a plan*. *At least you can talk to the nurses and the drivers, to say at least if a patient is not finished to wait. Because others will be left behind only to find they do not have money, what will you do? Mmh! (exclaiming*). *Umuntu! (a human being) appearing sad" (participant, 7)*

"*When we first arrived, they counselled us; we were counselled by the nurse (professional nurse). Mmh! I'm trying to think because we could not stay long, as well because we were hurrying for transport because we stayed for 20 minutes! Shoo! struggling trying to think (Participant,11)*

"No*! now, I'm using public transport but on the first day when I came with the hospital bus I saw that they (other patients) do not get help. I saw on that day some women was weak but she did not get any help (participant, 16).*

"Those ones! (feeling hopeless), they do not help us. They only help those who are from the wards! (satellite hospital patient), for us who comes from home they do not help" (participant,20).

4.3.5 **Theme 5: Need for Instrumental Support**

4.3.5.1 **Need for financial support to compliment food and travel**

Patients had various challenges pertaining travel and food assistance. Patients needed a period of six to eight weeks at most to attend treatment, as at times treatment had to be paused for few days in cases condition changed and warrants stabilisation. This affected their means of generating income as most were in a day employment. Most patients relied on hospital transport. Some stayed far from the primary or secondary care centre though still needed to utilise other means to reach the primary care where they would catch transport taking them to the treatment centre where they received radiation. The following excerpts attest to that:

"(participant looks down and appears shy as if in doubt) "For me I think you can support us with …if you can assist with money for transport. It's a lot because we attend treatment for one month and two weeks (Participant, 4)."

Eer… last week when my stomach was running, I kept on asking myself what if my stomach runs while in the taxi. I kept on thinking what will I do. Ee! (yes) because I am an outpatient (meaning she travels to treatment centre daily from home, because there is no bus from her hospital*). I have to use a taxi to commute to hospital. I don't know in my case I am only one patient (implying from her hospital at the time) I'm not sure if the hospital can help" (Participant, 10)"*

"I wish to be assisted with transport you know, because I'm sick, because my employer said I must stop working, she said I must stay at home free (un-paid) for six weeks. My problem It's money, oh God! I don't have money. I don't know what is going to happen next week, because I am not working" (Participant, 17)

"When I came here, I was given a date to come back. I could not come because I did not have the money for transport. I became worse, I was very ill. As for myself, money is the main problem; another concern is for lack of food! Because my big concern is the money for transport to come here (Jo'burg gen). It is *very difficult travelling from where I*

stay to come to the hospital and get transport that brings us here (Jo'burg) *is a challenge* (*P*articipant, 13)

"Eeish! as women we are experiencing lots of problems such as money is our big problem, to come here (Jo'burg) is a challenge. we are allowed to use hospital transport, but sometimes if you are left behind like us, you are an outpatient you need to travel to the hospital in order to get transport to here" (Participant,16)

"I struggle because I haven't been to my day job. I have to walk to Leratong hospital, if I do not have money! I do walk to the hospital (Leratong), so that the transport should not leave me behind" (Participant, 6).

"*You know my child it's difficult to say what needs to be done [embarrassed to talk] however an individual can decide how they can help us because we are many, I'm struggling a lot, really a lot! One of my children had to sell simba chips (crisps) just so that I can get money for transport. So that with twenty-four rands(R24) I can get twelve rands (R12) to get a bus to the hospital, in order to go and commute with hospital transport to come here (Jo'burg)" (Participant,15).*

Despite that, some of the patients did receive some kind of food assistance. This was not the case for all, as narrated by the following: Most participants had to make their own provision, as they were not given any food during the time, they are attending treatment sessions, as supported with the following narratives:

"Haai! during the day whilst we are waiting, we get nothing we are not given any food and we are not working. So, once we left home, we can eat when we get back. So, we do come even when we are hungry! We would appreciate something to eat. Even when it is not much. But we would appreciate something small to fill the stomach" Participant, 11).

"If we can get food at least, so that we can have some food assistance! Because we do not eat right. At least food parcels" (Participant, 4)

"*We do get hungry indeed! mmh! (stressing her point). We do not get any food from the hospital. Only now when the tea trolley was passing, (on this particular morning) I ask the hospital lady if maybe she can pour me some tea. Just to remove this feeling of hunger" (Participant, 22)*

"*We have to provide our own food. If you are an in-patient, you are provided with food, but if you come from home you are to provide for yourself. Hei! It's difficult but you have to try something, so for us if they can provide us with food eeya! (yes)(Participant,14).*

Some of the patients were confronted with variety of challenges whilst attending treatment; some of the problems were of complex nature that needed referrals in order to assist:

"Like where I stay, I am a stepchild; they do not want to share anything with me. Like when I was admitted at Leratong *hospital, my child would sleep at crèche! The crèche is only a day care centre, but because they know my situation, the lady used to take her in and sleep with her at her home (Participant, 6)*

"when I think about this issue and my life I just cry. So actually, what makes me sad is that I cannot live with my children I am looking for a place to stay. I stay with my mother at the old age home, because as I am sick, living at someone's place, you are expected to get up and to this and that" (Participant, 4)

"I do not speak to no one, as I live with my child only. I just get into the house and keep quiet. My only concern is that I can get better and look for a job. my child is now attending crèche. It is very difficult" (Participant, 13)

"*At the moment I worry a lot because of the problem of seeking a job. I think about children, because I am a single mother, it all stresses me, I really think a lot, because additional I have cancer. I battle to fall asleep" (Participant, 4)*

"*At the hospital (primary care facility) they give us quarter (1/4) of bread with mango atchar (this is some local delicacies consisting of bread and mango atchar), however this does not provide much nutritional value). Here in the hospital we are only been offered tea" (Participant, 15)*

"When we leave from (the hospital) Bara they provide us with bread. Then when we arrive here, the sisters give each one her share of bread" (Participant, 21).

4.3.5.2 **The need for staff support after radiation**

Although patients are accompanied by staff from different care facilities, once at the treatment centre, they are left on their own. Patients felt concerned that it is most critical for someone to be present to see to their wellbeing post therapy.

"Eish! you know when we come from machine there's many of us. So maybe it's not possible to attend all of us, because you are busy, but maybe you can observe us and see that we don't fall because at times when you are from the machine you feel dizzy. Not to walk all by yourself. Others vomit, they rush to the toilet with diarrhoea. At least nurses should assess and help at least not to mess on your way to the toilet" (Participant, 14).

"Aah! now the nurses are no longer counselling us, but at least the doctors still counsel us. Like if there is something new, you notice you ask. Like now, I am bleeding since I went to the "ihashi" (brachytherapy). I bled heavily yesterday; I could not come for treatment. I am only going to see the doctor now" (Participant, 2).

"Myself, I felt like I'm not coming here, because of cramps and running stomach. I felt like rather than coming here, I'd rather stay home and not come back anymore: Ja! (Ye...s), because of the diarrhoea, I felt like I don't want anymore" (Participant,22).

Some participants felt that accommodation closer to the treatment facility would be appreciated, evidenced with the following:

"Just the accommodation, I cannot utilise that now, my daughter has two children, but she works in Durban. So, I cannot stay. They already broke in twice at my place. So, it will not be possible for me to use the place and go home on Friday" (Participant, 14)

She further has this to say

"Yee...s! but travelling from where I stay to come to the hospital (Natalspruit) and get transport that brings us here is a challenge!"

4.3.5.3 **Need to be assisted with products for female hygiene**

Some of the women were challenged in terms obtaining necessities such as items regarding female hygiene. Women cited variety of reasons such as not having money or being unable to go to the shops as attested by other cultural reasons or being too weak as a result of being ill.

"For me if they can try and help with ladies' stuff (sanitary pads) because I cannot go to the shops to buy for myself (participant bit hesitant, withdrawn *and shy). I don't know it's a very difficult situation. (patient is from a different cultural group and this could affect*

what she can discuss with her partner regarding female issues). I am unable to go myself…. (silence) [participant is a bit hesitant], you know he can go but sometimes it's difficult to go buy ladies stuff, he is too shy "(Participant,8)

"For us women we really have lots of problems. Especially us who has this illness. Like myself I am constantly bleeding. They can at least supply us with sanitary pads! Like I am not working" (Participant, 20).

"There are those who bleed a lot, and they are old. As I told you she is all by herself. All what they do is to ask if you are finished nothing more. No one helps the old lady, unless other patients. They just sit there at the benches at the corner, they don't come" (Participant, 14).

4.3.6 **Theme 6: Network, Peer and Media Support**

4.3.6.1 **The need for nurse-led group support**

Although women talked to family members or significant others regarding their illness, they felt that a professionally led group support could help them accept and cope with the illness. This was narrated as follows:

"*My child if we can have support group, because some of us we don't have partners, no one! So even at home, you don't have anybody "I wish to have support group. So at least if we have support groups it will help us to get out of this thing (meaning to finish treatment" (Participant, 15)*

"*At least when we are sitting in a group, you get to be comforted*. *Realising that we are many with this condition. So, I am not the only one! For us we need a nurse who will be responsible to teach us! People who know about the condition (Participant, 11)*

"*But to get the feeling off my mind it's better to be around people. At least listening while they talking you know it's not only myself going through the stuff, also the person next to me is also going through that then its ok." (Participant, 10)*

4.3.6.2 **Peer support group**

Some participants felt that being among others with a similar condition gave them strength to accept their situation. The narratives were as follows:

"*Because there are those who have already been on treatment, they counsel each other. They encourage us to tell the cancer that "**I am not your friend**" so when you are talking*

and sitting in group, you find that you are much better if you look at others around you" Participant, 2)

"*Even if I don't know ;(patient appears hesitant)! but as a group we should be able to talk. …. silence (participant seem to be thinking deeply)!! Well I will talk for myself." (Participant, 7).*

4.3.6.3 **Spirituality**

Spirituality was found to help patients cope with a cancer diagnosis. This is supported with the following:

"Ee!Ee!(acceptance) You know I gave up everything to God. I said because the doctor has seen what's wrong with me, rather let me go where I can be helped. Eeh! (Participant, 17).

"*Also, the other thing is because my mother in law died of the same thing and it was already spread when it was found. Ee!!(exclaiming) when I heard that it was this cancer (of the cervix), I told God to give me strength, I feel alright, God has helped me because I even have the strength to encourage others, telling them that I'm from there myself" (Participant, 5).*

"I told them [shared information with family]. I was from the hospital at the time. So, I said at least its better because God has shown me what is my problem. I explained that I have cancer of the mouth of the womb" (Participant, 2).

"You know what I wish that God should help me give me strength to get better" (Participant, 14).

Some of the participants attested that media, such as television, helped them accept their situation when they realised that prominent people can also be attacked by cancer. Hence, it became easy to accept their situation.

"I counselled myself! I did not have that much knowledge. Until I watched at TV (television) programme Muvhango when Busi (an actor) was suffering from cancer" (Participant, 2).

"*You know for me, really I did not see anything bad, because nothing had changed. So, I did not feel bad, to me it was like any other illness. I was not disturbed. I don't want to*

lie. I do see bo-mme (mom) Lillian Dube (an actress) on TV (she has also been diagnosed with cancer), they are still women and they are alive" (Participant, 11).

4.4 SUMMARY

Chapter 4 presented the findings of the qualitative phase of Phase1 of the study in terms of the participant demographics, as well themes that emerged from the data. Participants were in age ranges of 30-55+ years, with the majority from Gauteng Province. Only few were married. Thirteen were employed as day workers. Most had more than 4 or 5 children. Six themes and 18 categories emerged from the data. The emergent themes were symptoms experienced leading to accessing health care facility; information pertaining to disease and treatment; need for counselling during the cancer trajectory; emotional support needs; need for instrumental support; network, peer and media support. The themes guided the development of the second objective of Phase 1 of the development and approval of a programme to support women receiving curative treatment for cervical cancer, including radiation. In the light of a need to develop a support programme a further scoping review of studies developed to support women treated for gynecologic cancer was conducted. The main findings of this chapter will be discussed in the discussion section in Chapter 9. The following chapter will present a scoping review of studies conducted to support women treated for gynaecologic cancer.

CHAPTER 5

5. SCOPING REVIEW OF STUDIES TO SUPPORT WOMEN TREATED FOR GYNAECOLOGIC CANCERS

5.1 INTRODUCTION

Scoping reviews gained popularity through reviewing evidence from cancer or health research (Levac, Colquhoun & O' Brien, 2010; Davis, Drey & Gould, 2009). Whilst this is a new concept in health research, there is still no consensus on the definition for this type of review (Levac et al., 2010; Daudt, van Mossel & Scott, 2013). However, in this study, Arksey and O' Malley's (2005) definition is adopted.

Scoping review are studies that generally aim to map the key concepts for a particular field and identify main sources and available evidence in a particular field. Davis et al. (2009) are of the opinion that for some researchers, it is synonymous with preliminary investigative process to identify a research question. According to Dijkers (2015), scoping reviews are aimed at rapidly mapping the key concepts in a specific area and evidence available. Several authors also reported that scoping reviews are conducted when the body of literature has not been comprehensively reviewed before (Peters, Godfrey, Khalil et al., 2015; Pham et al., 2014, Daudt et al., 2013; Arksey & O'Malley, 2005). Additionally, scoping reviews could be conducted to map the existence of literature in the specific field in terms of their nature, features and volume, further suggesting that scoping reviews can be conducted as a stand-alone project where a complex area has not been comprehensively reviewed (Daudt et al., 2013; Arksey & O' Malley, 2005). Equally, the extent to which a scoping review tends to report on available literature depends on the purpose of the review.

The scoping review for the study was conducted as part of a bigger project consisting of two phases utilising a mixed methods approach. The project aimed to develop, and pilot test a programme to support women treated for cervical cancer. The aim of the scoping review was to explore and identify programmes available to support women treated for cervical cancer, mapping out different methods utilised in studies conducted. The objective of the qualitative phase of the study aimed to explore the support needs of

women treated for cervical cancer. The findings and the recommendations from this phase in the study informed the development of a support programme for women treated for cervical cancer. It was crucial that a scoping review be conducted in order to confirm the need for development of such a programme, should one not be close or available to meet the identified needs. Although Arksey and O'Malley's (2005) methodology (Figure 5.1) guided the programme.

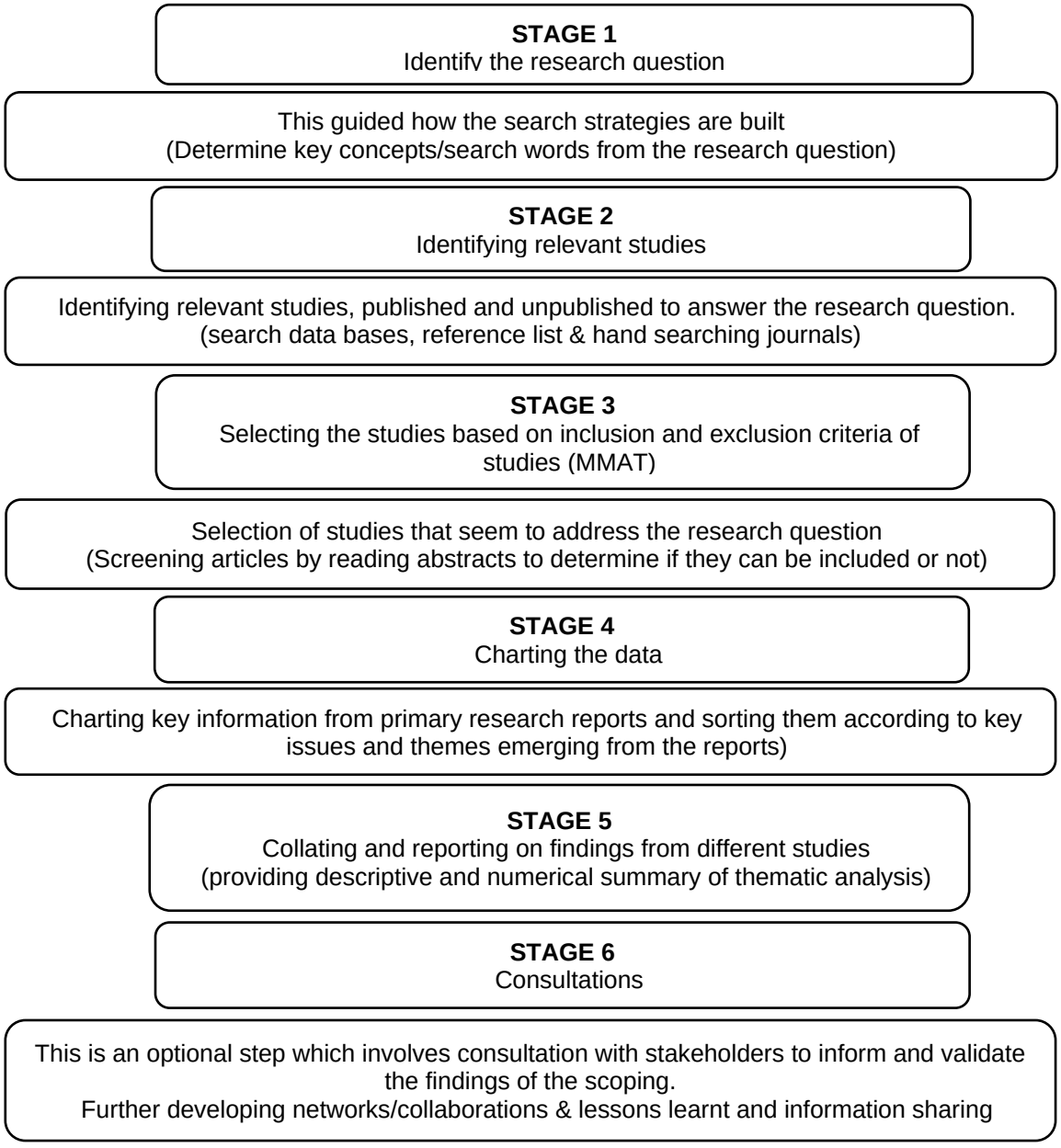

Figure 5.1: Schematic Presentation of Arksey & O'Malley's Framework (2005)

The Mixed Methods Appraisal Tool (MMAT) version 2018, Hong et al. (2018), was used to appraise relevant studies after refining those that were identified from the databases. The MMAT was developed based on critical reviews of different appraisal tools and involvement of opinions of MMAT users, as well as utilising Delphi with international experts. Mixed Methods Appraisal Tool version 2018, recommended appraisal of empirical studies using different methodologies except appraising diagnostic accuracy of studies. It also recommended that at least two experts should be involved in the appraisal process using MMAT. In the case of this scoping review, the experts consisted of the researcher and the study supervisor who ensured the rigour of the scoping review.

5.2 THE QUESTION

The question for the scoping should align with the aims, as it guides search terms and data extraction (Levac et al. 2010).

The question for this scoping review is: What programmes are available to support women treated for cervical cancer?

5.3 OBJECTIVES OF THE SCOPING REVIEW

The objectives of this scoping review are:

- To identify and explore studies that developed programmes to support women treated for cervical cancer irrespective of contexts in which they were developed.
- To determine the scope and focus of programmes developed to support women treated for cervical cancer
- To map different methods used in the studies identified and reporting on evidence.

5.4 METHODS

The scoping review followed specific guidelines as suggested by Arksey & O'Malley (2005) (Figure 5.2). This method uses a narrative approach or synthesis to contrast and appraise different studies, or methodologies, to explore a specific issue or concern. In the case of this study, the aim was mapping of studies addressing support of women treated for cervical cancer, delineating different methods guiding the studies and determining the breadth of studies relating to the topic of interest.

The researcher sought guidance from the librarian to discuss how best to identify data bases and determine key words (search words) for the scoping, based on the research question and the objective of the scoping review. The databases consulted were: Academic Search Ultimate, formerly known as academic search premier, Africa wide info, APA psych articles, APA psych info, Cinahl plus with full text, Global health, Health source: Nursing Academic, Medline, PubMed, Sabinet, Social Science Index, Scopus and Web of Science. The scoping review conducted for the study was not restricted to a particular context. The researcher purposefully included other contexts that could inform development of the support programme to determine the breadth of similar programmes, and to delineate a need for such a programme (especially within a sub-Saharan context, as one could not be traced).

5.4.1 **The Search**

The search terms used are support programme, cervical cancer/gynaecologic cancer and treatment, not screening and or prevention. Further refinement aimed at scholarly peer-reviewed articles. At the initial search, articles were demarcated by the researcher between 2016 and 2019, however not much information yielded from the databases. The researcher, after consultation with the study supervisor, sought not to cap the periods in order to include many available studies to embrace their width. Articles accessed included programmes addressing cancer support in general (Usher et al., 2006; Deans et al., 1988; Montazeri, 1996), whilst others addressed cervical cancer, or programmes that aimed at gynaecologic malignancies (Sekse et al., 2014; Li et al., 2016). Other articles consulted were from reference lists of articles retrieved during the scoping review. The databases consulted were from health sciences, social sciences and psychology, as well as thesis from the same fields, if present. Whilst the researcher noted that available programmes were mostly piecemeal, addressing only a specific issue, comprehensive programmes addressing the topic were limited but from developed countries. Other programmes involved addressing psycho-social issues, sexuality or dealing with recurrence, and involving families of patients diagnosed with cancer and post-operative issues in early stage cervical cancer (Li, Huang et al., 2016; Chow et al., 2014; Ussher et al., 2006; Carlsson & Strang, 2009). However, similar programmes could not be traced from an African context.

5.4.1.1 **Inclusion criteria**

Articles written in English, which addressed support programmes for patients with cervical cancer or gynaecologic cancer or any programmes regarding the support of patients with other types of cancer. Other studies included patients diagnosed with cancer attending rehabilitation post gynaecologic cancer treatment or inclusive programmes affording support to carers of patients treated for cancer in general; these programmes needed to include women treated for cervical cancer. The treatments could be single or combination with radiation therapy as one of the treatment modalities used. The participants should have a confirmed cervical/gynaecologic cancer diagnosis and receiving or have had radiation treatment.

5.4.1.2 **Exclusion criteria**

Exclusion criteria included palliative care treatment, site specific other than cervical cancer, randomised clinical trial study; studies still in progress stages; literature or systemic review studies or policy related studies; studies of recurred cancer on treatment; knowledge, attitudes and perceptions, benefits of vaccinating adult women or cancer prevention.

5.5 **RESULTS OF THE SEARCH**

A total, 145 articles were retrieved from databases (Figure 5.2). A further refinement to include only scholarly peer reviewed articles yielded (n=124) and further removal of duplicates(n=96) yielded 28 articles that met inclusion criteria. The researcher conducted further screening of the remaining articles by reading the abstracts to determine if they met the inclusion criteria. After further screening of the articles, only one (n=1) article met the inclusion criteria. Reading the articles retrieved from the reference lists of the selected articles, led to retrieving five (n=5), resulting in a total of six (n=6). The researcher read full texts of all articles to determine if they were relevant to answer the research question for the scoping review. Two (n=2) articles were removed as they focused on group support, which did not include cervical cancer patients. After the remaining articles were read, four (n=4) articles were finally selected for scoping. The search process is presented Figure 5.2 PRISMA flow diagram of the search process conducted (Hong et al, 2018).

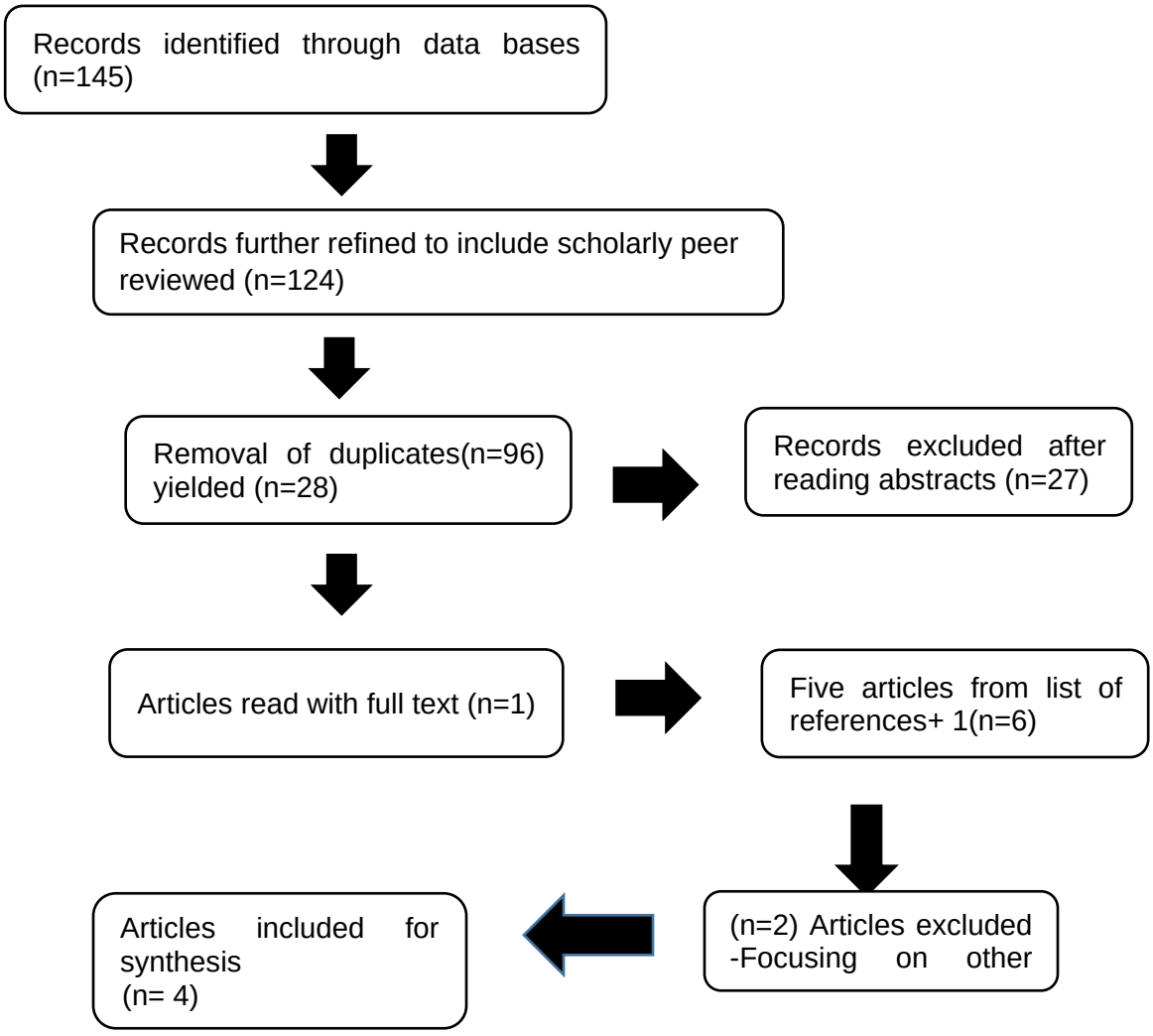

Figure 5.2: Prisma Flow Diagram of Articles Reviewed

In order to appraise the studies included for scoping, a data extraction sheet was developed. The data extraction sheet consisted of author and date of publication, purpose of study, design and data collection methods, country of origin, population and sampling and the programme facilitator. Hong et al.'s (2018), Mixed Method appraisal tool (MMAT), 2018 version, was utilised to appraise the quality of selected articles. To ensure that articles meet inclusion, it was critical to clarify two questions as guided by the tool. The questions highlighted whether the clear research question was available from selected studies: Is the data collected addressing the research question determined

in the study. Hong et al. 2018, is of the opinion that if the answer is no or can't tell to either of the screening questions, no further appraisal is possible. Table 5.1 shows characteristics of articles included for the scoping review.

5.6 RESULTS

Table 5.1: Characteristics of the Studies Included for the Scoping

Author and year of publication	Purpose of the study	Designs and data collection methods	Country of origin	Population & Sample	Programme facilitation
Sekse; Blaaka et al, 2013	To provide insight into women's lived experiences of participating in in an education and counselling group intervention after curative treatment for gynaecologic cancer.	Qualitative Method (focus groups)	Norway	All women from three of the six education and counselling groups Women who had completed treatment of gynaecologic cancer in the last 2 years and were free from recurrence 17 women (three groups each intervention and focus groups)	This was a professionally led education & counselling intervention (nurse and trained counsellor) Education and counselling session over seven weeks Interventions were facilitated by two nurses from the gynaecological cancer units The interventions consisted of 2.5 hrs meetings/week. The sessions consisted of two parts. A lecturer presented by a health professional and free counselling session, with conversation focused on women's experiences and needs The seven standardised topics focused on bodily changes, coping & coping strategies, fatigue and nutrition, social rights and getting back to work, sexuality and life beyond cancer.
Carlsson & Strang,1998	To evaluate whether educational groups had an effect on perceived level of knowledge, and whether the programme had positive effect on mood	Quantitative & quasi-experimental design	Sweden	Gynaecological cancer patients & next of kin The intervention, consisted of 36 cancer pts, eight next of kin and 25 controls from distant parts of the region. Groups consisted of three to eight participants and a group leader.	The sessions were facilitated by a group leader present at all sessions. Four sessions were attended by speakers, a doctor three sessions and a dietician once. Groups consisted of patients and next of kin or patients only The patients were at different stages of their disease. Some were newly diagnosed, some had undergone treatment, whilst others had regular follow ups at outpatient departments. The groups consisted of patients living reasonably close to the hospital and their next of kin were invited to participate in the programme. Patients from distant parts of the hospital, who had undergone six-week radiotherapy were invited to participate as controls. Patients and next of kin who participated in more than half of the sessions took part in the evaluation. The programme consisted of seven sessions to address psychosocial issues. The approach was based on patient experiences related to crisis and coping theories. The support groups focused on education & exchange of experiences with patients in similar situations.

Author and year of publication	Purpose of the study	Designs and data collection methods	Country of origin	Population & Sample	Programme facilitation
Chow et al. 2014	To test feasibility of implementing a psycho-educational intervention for gynaecological cancer patients	Mixed methods design, single blinded randomised controlled trial.	Hong Kong	Newly diagnosed gynaecologic patients scheduled for cancer surgery (26 participants)	This was programme was led a clinical specialist nurse involved in oncology and teaching. The programme consisted of complex series of multiple components. Participants were randomised to an intervention or control group. The intervention group received psychoeducation that consisted of four sessions The first session was held at point of recruitment to discuss treatment planning, the other three were implemented postoperatively and during rehabilitative period The first three interventions were individual sessions and the last session was a group session to conduct group counselling and provide participants with an opportunity to discuss their feelings and gain support from other people with similar situation.
Li et al. 2014	To investigate the effect of a home-based, nurse-led health programme on quality of life and family function for post-operative early stage cervical cancer	Randomised controlled trial	China	226 cervical cancer patients	This was a nurse-led home-based health programme to investigate the effect of home-based programmes post operatively for early stage cervical cancer. Patients diagnosed with stage IA- IIA cervical cancer who underwent first operation without any signs of recurrence were randomly assigned to the intervention or control group. Patients in the intervention group received additional nurse led home-based care Patients in the control group were subjected to conventional nursing only.

A further analysis on content and focus of the studies was conducted. This will be presented in table 5.4

Table 5.2: Focus and content of the Studies Reviewed

Programme focus	(n=4)
Education &Counselling	1
Psychological support	2
Home-based support	1

All four (n=4) studies focused on the gynecological cancer population, including cervical cancer. Furthermore, one was mainly aimed at education and counselling of the patients after treatment of cervical, two aimed at psychosocial support, and one focused on home-based care after early stage cervical (1A-11A) surgery. Whilst it was evident that all four programmes were led by nurses, three of four studies (Chow, 2016; Li et al., 2014; Carlsson et al., 1998) included different levels of health professionals' consultative roles to address specific issues, as the need arose. Table 5.5 presents type of professional involved in the programmes

5.7 TABLE OF THE TYPE OF PROFESSIONALS LEADING THE STUDIES

Table 5.3: Table of Types of Professional Leading the Study

Type of professional	(n=4)
Nurse led	4
Others (other health or external person)	1

5.8 SUMMARY

This chapter presented a scoping review of the studies conducted to support women treated for cervical cancer. Arksey and O'Malley's (2005) framework guided the scoping of the studies. The question for the scoping was "what studies are available to support women treated for cervical cancer. Hong et al.'s (2018), Mixed Methods Appraisal Tool (MMAT) was utilised to appraise relevance of the programmes in terms of the research question and data collection methods. Four studies met inclusion for the scoping and were nurse led. However, in some other studies health professionals were included on a consultative role. It is clear that programmes aimed to support women treated for

cervical cancer are limited, particularly when considering those included in this scoping exercise are not representative of African context.

Chapter 6 will present the development of a programme to support women receiving curative treatment for cervical cancer including radiation. The programme is informed by the needs highlighted by the women receiving curative treatment for cervical cancer including radiation at an Academic hospital in Gauteng. Literature pertaining to the support of people diagnosed with cancer, as well as literature for development of information for people with limited literacy was consulted. Due to the kind of information, highlighted and the recommendation of a group support which is educational in nature, led the researcher to consult theories guiding such studies. In this study Knowles theory of Adult learning seemed relevant to guide the programme, more so the inclusion of the beneficiaries in determining their needs to develop such a programme. The researcher consulted theories that can inform teaching adults as well.

CHAPTER 6

6. DEVELOPMENT OF A SUPPORT PROGRAMME FOR WOMEN RECEIVING CURATIVE TREATMENT FOR CERVICAL CANCER

6.1 INTRODUCTION

Chapter 5 presented a scoping review of studies conducted on programmes developed to support women treated for cervical or gynecologic cancers. The outcome from the scoping review showed a lack of similar programmes within an African context. This highlighted a need for the development of a programme to support women receiving curative treatment for cervical cancer, including radiation at an academic hospital. Due to the needs highlighted by the women receiving curative treatment for cervical cancer at an Academic hospital in Phase 1. This chapter will discuss the second objective of Phase 1: The development and validation of a programme to support women receiving curative treatment for cervical cancer at an academic hospital. Due to the needs highlighted which were information pertaining to the symptoms experienced leading to access health care facility; Information pertaining to the disease and treatment, need for counselling during the cancer trajectory; emotional support; Instrumental support and network and peer support. Based on the needs highlighted the researcher's opinion was that an information and educational support programme would be relevant to address the needs identified. Hence, Malcolm Knowles' adult learning theory was relevant to guide the development of the support programme (Knowles, Holton & Swanson,2012)

6.2 KNOWLES ADULT LEARNING THEORY

According to Merriam (2001), different scholars (Taylor & Hamdy, 2013; Hartree, 1984; Knowles, Holton & Swanson, 2012) attempted writing about adult learning, however to date there are no specific models or theories that explains how adults learn. Merriam (2001) contends that there is a mosaic of theories, models, and sets of principles that compose the knowledge base for adult learning. Accordingly, much of early research focused on whether adults could learn or not. Research on adult learning were influenced from fields of philosophy (Hartree, 1984), and behavioural psychologist's perspective by Thorndike and others (Merriam, 2001). Until the mid-20th century research on adult, learning relied on psychology and educational psychology. However,

as part of research to differentiate adult learning from other forms of education a new drive began, which is whether adult learning can be distinguished from childhood learning.

The drive to professionalise adult education included a need develop knowledge base unique to adult education based on two of the field's most important theory building efforts which are andragogy and self-directed learning (Merriam, 2001). According to Merriam (2001), andragogy became the focus for those trying to define adult education from other forms of education. Further, Taylor and Hamdy (2013) reported that Knowles introduced the term andragogy to differentiate adult learning from pedagogy. Hartree (2013) states that Knowles defines pedagogy as the art and science of teaching children and andragogy as the theory of adult learning. Further, Hartree (2013) asserts that Knowles defines pedagogy as the art and science of teaching children and andragogy as the theory of adult learning.

Draganov, Andrade, Neves and Sanna (2013) described andragogy as the art and science leading adults to learning. Andragogy gained support and aroused academic's interests in the second half of the 20th century whereby it filtered to those teaching nursing (Draganov et al., 2013). Through these definitions, lots of criticisms were levelled against Knowles as others question whether his debates are based on teaching or learning (Hartree, 2013; Taylor & Hamdy; 2013; Tennant, 1986; McGrath, 2009). Further, to add to this debate Knowles supports the notion that andragogy can be applied to teaching children as learning is said to stretch across the continuum (Taylor & Hamdy, 2013). What is of essence in the study is how the assumptions of Knowles will guide the development of programme to support women receiving curative treatment for cervical cancer.

Definition of an adult in the study relied upon the psychological definition described by Knowles' et al. (2012) wherein an adult is defined as someone who is capable of being responsible for own life, being capable of self-direction. Several assumptions underpin Knowles' androgogical model (Knowles' et al., 2012; Mitchell & Courtney, 2005; Merriam, 2001). Further, the recommendation is that elements of androgogical model

may be adapted or adopted in whole or in part (Knowles' et al., 2012). Accordingly, Knowles' et al. (2012) asserts that an essential feature of andragogy lies in its flexibility. Although assumptions cited from Knowles' et al. (2012) are applicable in the study, their application will not be sequential as in the original model. Further, each assumption is applied based on how it relates to specific period during the trajectory of cervical cancer.

6.3 ASSUMPTIONS OF KNOWLES ANDRAGOGICAL MODEL (2012)

1. **The Need to Know**

   Adults needs to know why they need to learn something before undertaking it. Further. it is asserted that adults will strive to learn something if they consider some benefits in doing so, versus negative consequences of not doing it. It has been suggested that the first task of a facilitator in adult learning is to help leaners become aware of the need to learn.

2. **Learners' Self-Concept**

   Adults have a self-concept of being responsible for own decisions. Once they have reached that that self-concept, there is a psychological need for recognition by others as having self-direction. Adults resent situations where it is felt that others are imposing their wishes on them. Adults resent the assumption of required dependency, where someone needs to dish out commands and expect them to act on those instructions. This tends to create conflict within the persons intellectual model and deeper need to be self-directed.

3. **The Role of Learners 'Experience**

   The believe standing is that adults bring into the educational milieu a variety of experiences based on exposure of having lived longer. The assumptions are based on the premise that having lived longer they bring with them an array of life experiences that are rich resource for learning. Difference in quantity and quality of experiences also contributes to the experiences that adults bring in an educational situation. Also, with emphasis on peer support. Another subtle reason for emphasizing learner's experiences has to do with self-identity. Children have their identities from external definers such as parents, siblings or extended families,

exposure such as schools or church. In the case of children, their experiences are further shaped by the experiences they encounter with maturity.

4. **Readiness to Learn**

   In this assumption, it is emphasised that adults become ready to learn things that they need to know in order to cope effectively or apply in real life situations. An important issue to note is the importance of timing the learning experience to coincide with the task at hand

5. **Orientation to Learning**

   Adult learning is life centred, as opposed to children or youth whose' learning is subject centred. Adults are motivated to learn if they perceive that learning will help them perform certain task or attend to life problems. It is assumed that adults will learn knew knowledge, skills and values when presented in context of real life situations

6. **Motivation to Learn**

   Adults are motivated by external factors such as job promotions or rewards such as higher incentives; however, the most important motivation lies with intrinsic factors such as quality of life or experiencing high self -esteem. In some instances, the motivation may frequently be blocked by negative self-concept or inaccessibility of opportunities or resources.

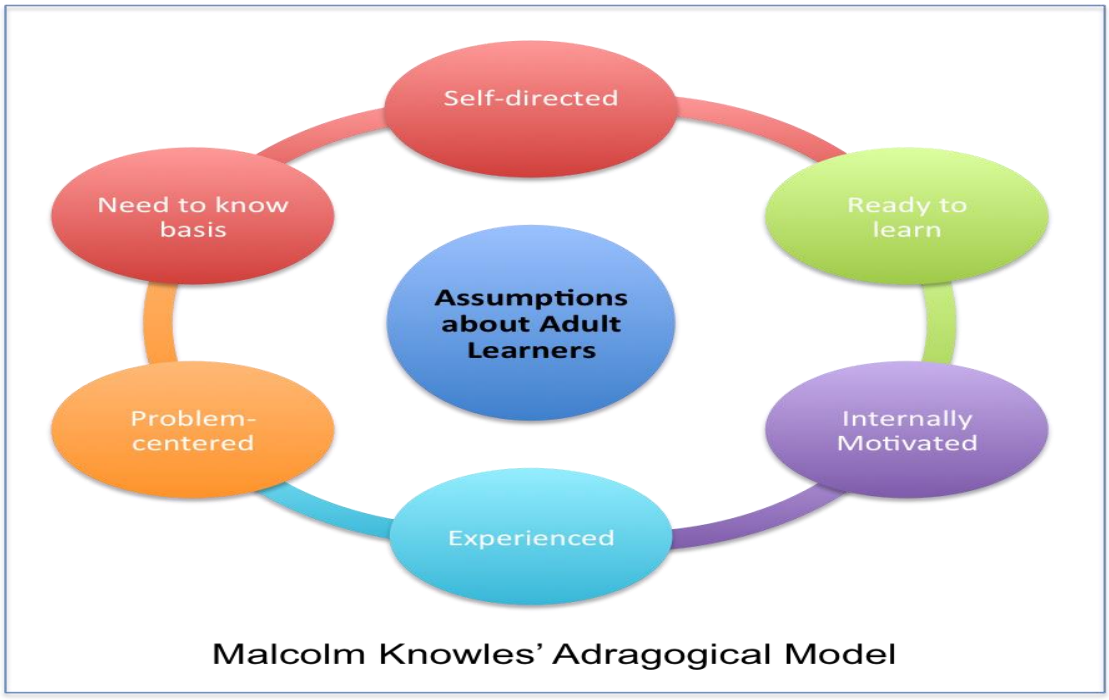

Figure 6.1: Malcolm Knowles' Androgogical Model

(*courtesy: teaching learning.com*)

6.3.1 Application of Knowles Theory

Knowles androgogical model aligns well with the aims and objectives of the study. According to Mitchell and Courtney (2005), the underlying principle in Knowles' et al. (2012) theory is recognition that adult learners are autonomous and capable of self-direction, motivated by choices and being responsible for own learning. These principles applied in the study were based on enquiring how women wished to be supported during the period they are treated for cervical cancer. The researcher's assumption is that women in the study are adults who are capable of self -direction and making choices pertaining to situations they confronted. Once women became aware of abnormal signs, they took decisions to access health care facilities in order to seek help. Despite confrontations with financial constraints and distance expected to travel to the health facility women made efforts and devised means to access the health facility, guided by their self-concept in order to source help regarding their situation. Their situation aligned well with assumption number two. Furthermore, women asserted themselves by highlighting how they wished to be supported and be treated and respected as individuals during the trajectory of cancer. This assumption addressed the primary outcome to explore how women wished to be supported.

The experience or knowledge of someone affected by cancer was a strong motivation to seek medical support. As pointed out in Knowles' et al. (2012) theory of adult learning, previous knowledge or experiences form the bases for adult learning. Various experiences about cancer or stories told related to cancer and the experience of pain or suffering motivated the women to seek help. This also aligned with assumption number three, which embeds knowledge or activity relating to previous experience. Indeed, majority of the women felt that lack of knowledge about the disease and its treatment failed them. However, at this critical stage because it was crucial for them to be informed about treatment and tests that they had to undergo as part of disease process, women expressed a need to learn. Women felt that in order to adapt to their disease and be able to share information with their families and partners it was necessary to be empowered with information pertaining to the disease as well as the treatment.

Women expressed need to be informed about their situation, as they felt it would help them adapt and comply with treatment. This period aligns with assumption four, which addressed the readiness to learn. This period is indeed crucial for any adult who aspires to learn something new. Adult learners are interested or feel a need to learn something new if they are of the opinion that it will add value or address an important issue in their lives. In the case of the women in the study, it was crucial for them to learn about cancer, different treatment modalities and diagnostics so that they can be able to share information with family and significant others. This also helped them to adapt to the diseases and to encouraged compliance.

The last assumption for the study (internal) motivation encouraged women to pursue the treatment in an attempt to get cured and attain improved quality of life through adhering to treatment despite challenges faced such as treatment side effects or having to strive even when they felt like giving up. The motivation was for women to get better in order to go back to their families, to contribute and earn a living and to be part of the society again.

6.4 CONCEPTUAL FRAMEWORK OF THE PROCESS FOLLOWED BY WOMEN ONCE THEY EXPERIENCED SYMPTOMS RELATED TO THE DISEASE (based on Malcolm Knowles' Theory)

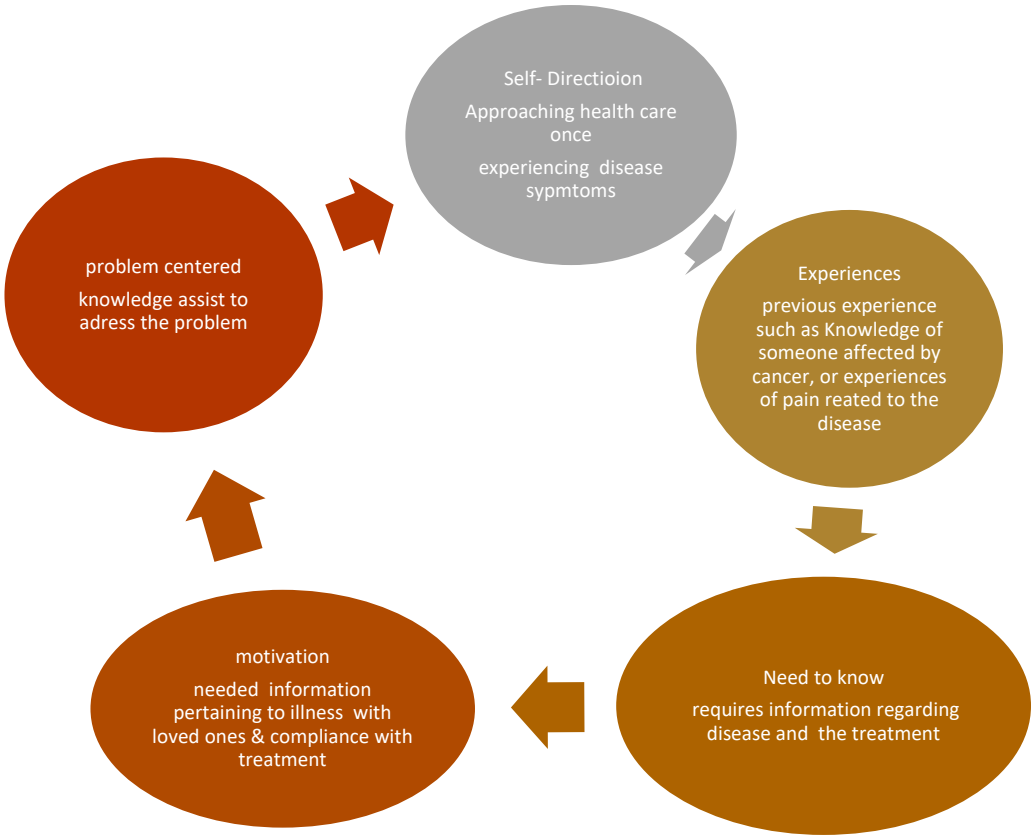

Figure 6.2: Conceptual Framework of Process Followed by Women during Cervical Cancer Trajectory

6.5 DEVELOPMENT OF A PROGRAMME TO SUPPORT WOMEN RECEIVING CURATIVE TREATMENT FOR CERVICAL CANCER

There are several programmes pertaining to cancer support (Zamaniyan, Bolhari, Nazini et al., 2016; Schofield, Juraskova, Bergin et al., 2013; Oz, Dill, Inci et al., 2012; Salonen, Tarkka, Kellokumpu-Lehtinen et al., 2012; Barrere, 1992; Helgeson, Cohen, Schultz & Yasko, 1999). The majority of the programmes were developed from different contexts, which are not representative of developing countries such as sub-Sahara. Most programmes aimed at psychosocial, informational or sexuality issues, whilst others

addressed quality of life after treatment of cancer (Paterson, Jones, Rattray & Lauder, 2013), or survival after treatment of breast cancer or Unmet needs (So, Chow, Chan et al., 2014; Edib, Kumarasamy, Abdullah et al., 2016). Others addressed informational needs of families of partners and family members of cancer patients (Adams, Boulton & Watson, 2009), however, some addressed unmet needs of ethnically diverse cancer population (Moadel, Morgan & Dutcher, 2006). The development of the programme is informed by the recommendations from participants in phase 1 of the study, literature and the researcher's experience a qualified oncology nurse, recommendations from other health care members involved in day-to-day care of participants. It is crucial that in developing a programme of any kind the suggestions from the intended population be considered (Garcia, Kalecinski, Oriol et al., 2018; Krishnasamy, 1996).

The highlighted needs included information pertaining to development of cancer as a disease and cervical cancer and its symptoms; tests to confirm a cancer diagnosis, and treatment for cervical cancer. The participants further expressed need for instrumental support such as financial assistance to cater for travel, food and other miscellaneous items such as sanitary pads as they tend to leak with serous fluid or bleeding after treatment. Some had to be laid off work temporarily, to afford them time to undergo treatment. However, others were unemployed and had no source of income to attend their daily needs and afford travel to the health facilities.

Emotional support was most important need reported. The participants reported feeling like abandoning treatment at times due to the side effects experienced and having no knowledge to deal with them. They further found themselves relying on information from others who knew very little. Women recommended that they would appreciate support/ assistance with walking from the treatment room as some felt weak from medication administered to them before getting into the treatment room whilst some had diarrhoea and others vomited. In an effort to be relevant to the needs highlighted by the women the researcher took cognisance of patient demographical profile as this would assist in determining culturally sensitive, age appropriate, also meeting the literacy of the women for whom the programme is developed.

6.5.1 **Stages of Development of the Programme**

6.5.1.1 **Stage 1**

The researcher met with the senior staff who oversee the department in order to discuss logistical issues pertaining to the daily running of the department, identification of stakeholders to participate in the programme. Issues discussed were patient arrival times, admission of new patients and follow up consultations, treatment schedules, estimated number of patients treated in the department at one time per week, as well as the busiest days when team of doctors and multidisciplinary consultations took place. This was to assess possible challenges that needed to be addressed at the earliest, whilst planning the programme. The researcher visited the department frequently to familiarise herself with the departmental routine as well to build rapport with prospective participants. Another important issue was to identify experts working in the department and involved in daily care of patients identified with assistance of two senior staff members. The senior staff consisted of charge nurse in the radiation oncology department, and the senior (head radiographer). The researcher together with one of the senior staff members met with the health care team including nurses working in the department to inform and invite them to take part in the study to validate the programme and share their inputs. Figure 6.3 showing the six sessions of the programme. Discussion pertaining to validation of the programme and experts will follow.

The experts consisted of:

- two professional nurses working in the department involved in day-to-day care of patients;
- two registered oncology nurses who counsel patients should need arise;
- two radiotherapists - one working in the simulation room where treatment fields are calculated and demarcated, and one working in the treatment area where the actual radiation treatment takes place;
- two oncologists conducting follow ups and reviewing patients whilst on treatment;
- one radiation oncologist administering brachytherapy to the patients; and
- three patients who were coming for post treatment follow up, on their six months follow up schedule according to the treatment protocol.

Although it was necessary to involve the social workers who saw the patients referred to them, it was difficult to get their co-operation despite efforts to get their input.

6.6 SCHEMATIC PRESENTATION OF PHASES OF THE SUPPORT PROGRAMME FIGURE 6.3

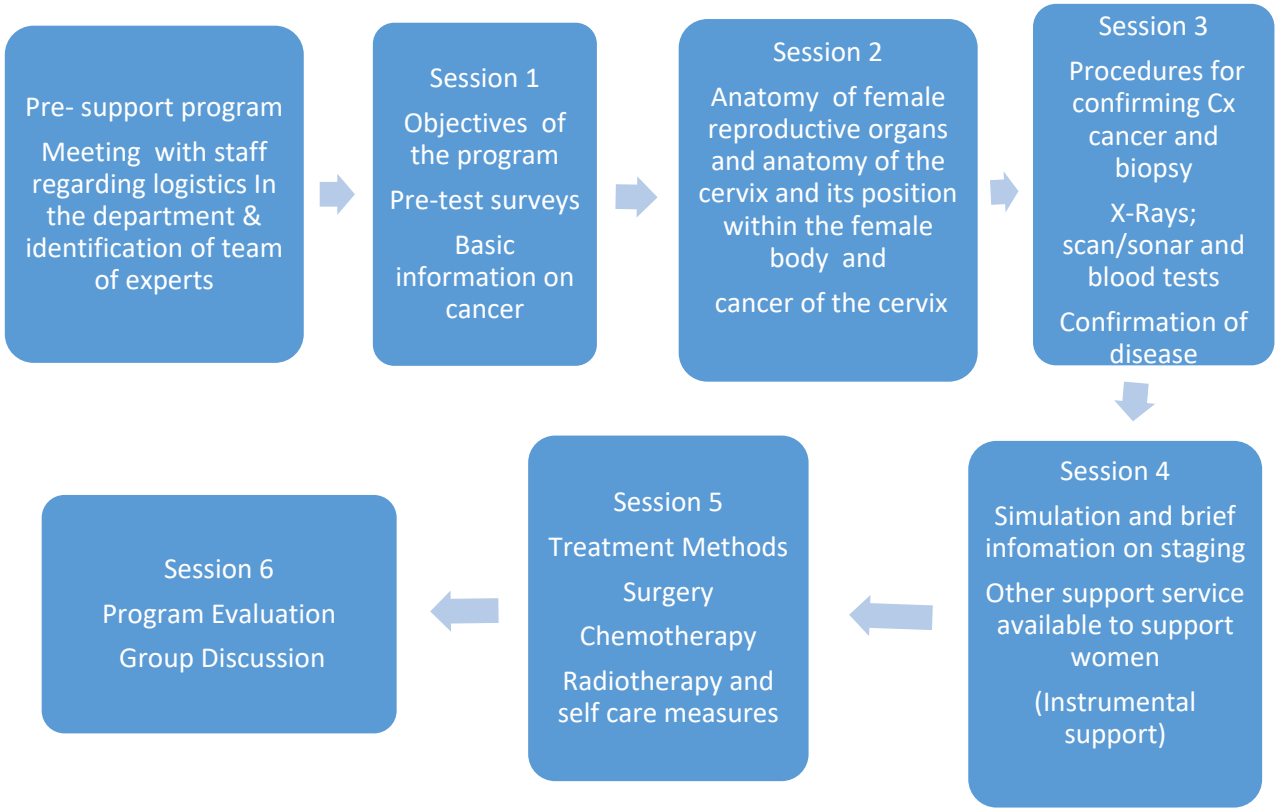

Figure 6.3: Schematic Presentation of the Programme Sessions

Literature pertaining to development of programmes for patients with cancer and low literacy were consulted (Wilson, 2011; Cornett, 2009; Garbers & Chiasson, 2004). Despite that most women (n=16) in the study were above grade eight literacy, the remainder (n=6), were below reading level of grade 6. This finding compelled the researcher to consult widely in the field of developing health information in an attempt to embrace the women in the study, as reported by studies of Berger, Inkelas, Myhre and Mishler (1994), where it was found that most immigrants from inner city lacked functional literacy levels to understand patient information literature. To accommodate all women receiving treatment for cervical cancer, further research conducted on materials for

patient information found that either medical language or reading level was beyond patient's comprehension (Seligman et al., 2007; Maat & Lentz, 2010). Development of the support programme informed by literature developed for adult with low literacy (Durand, Alam, Grande & Elwyn, 2016; Wilson, 2011; Houts, Doak, Doak & Loscalzo, 2006; WHO, 2006; Seligman, Wallace, DeWalt et al., 2007).

The suggestions from the authors developing or facilitating health information for adults with low literacy had valuable recommendations whereby it is important to consider using literacy level of grade eight or even below (Wilson, 2011; Berger et al., 1994). This was to accommodate and respond to the literacy level of all women in the study as well as their readability to comprehend content with relative ease (Neuhauser & Kreps, 2008; Singh, 2003). It is suggested that in developing materials for patients with low literacy, text and layout design and artwork should be taken into consideration (Seligman et al., 2015). Further, use of pictures or photographs to illustrate difficult concepts that may be difficult to communicate is recommended. Seligman, et al. (2015) is of the opinion that any health materials should improve knowledge, influence health outcomes and be able to achieve short-term goals. It was assumed that once the short-term goals are addressed, which in the case of this study were to identify the support needs of women treated with radiation, it would help facilitation towards long-term goals, which was to improve patient perceived support and improve their perceived quality of life.

6.6.1 **Stage 2**

A Power-point presentation on topics pertaining to cervical cancer was prepared. Topics involved screening, basic information about cancer, cervical cancer screening, anatomy of the female reproductive organs and treatment modalities used to treat cervical cancer. The programme consisted of six session that would each be presented twice weekly to participants, in an effort to accommodate those who missed either session until the last day of attending the treatment.

Session 1 consisted of an overview of the programme and the reasons why it was developed. Participants would be invited to come up with three names and vote the one which best represent the interest of the group of women. The purpose was mainly to

encourage a sense of ownership and encourage commitment as beneficiaries of the programme. The first session would inform women about forming a group to support them during the trajectory of cancer. This would include informing women about members of the multidisciplinary team they would engage with during the process of undergoing treatment. Basic information about cancer as a disease, accompanied by images of normal and cancerous cells would be presented.

Session 2 addressed information pertaining to anatomy of female reproductive organs and the position of a normal cervix within the female body would give participants and idea what the cervix looks and its position within their bodies. The aim was to prepare for when the participants are informed about screening and how the procedure is done. The names of the structures in relation to the cervix were also included. As well as early and late signs and symptoms of cervical cancer. The position of other structures in relation to the cervix would be shown to participants for them to conceptualise position of the cervix within their bodies have an idea for later discussion of how metastasis occur. A diagram of a diseases cervix would be shown as a starting point.

Session 3 was intended to inform participants about different screening procedures to detect pre-cancer and /or cancer and the equipment used for screening. Also included were images to show how screening procedures are performed by a nurse (Appendix R). Different types of equipment used to perform screening procedures and how speculum is positioned during screening procedures would be discussed. In addition, participants would be provided with actual equipment to handle and acquaint themselves with an effort to allay fears and anxiety regarding screening procedure. This would involve participants being shown the actual equipment to handle such as cervical brushes for them to touch and feel the softness of the brittles and pliability, disposable speculums, wooden speculums for scraping cervical smears and slides used to apply cervical cells and specimen holders. This was to change their perceptions that equipment used may be harmful or can cause damage in the cervix.

Session 4 was to inform participants about simulation, as well as application of tattoo markings and pre-counselling once a cancer diagnosis has been confirmed. The session

was designed to include brief information pertaining to the staging of the disease as this was discussed during simulation at this specific institution. Other support services available to women during treatment, such as the availability of and use of hospital transport and how to access temporary accommodation, were also included. Another important issue was to inform women about the pre-counselling they would receive once the diagnosis was confirmed, as they would be sent home to await a telephone call informing them of the date for commencement of treatment. This was highlighted as the most daunting time. Also, once they are due to commence treatment, they would be informed about self-care measures and things to avoid whilst on treatment such as not being sexually active once treatment is commenced, avoiding use of ointments and soaps on the skin from mid-abdomen through to mid-thigh area, which are the ones prone to radiation during treatment. Other issues included accessing temporary grants whilst being off work to assist attendance for the treatment and to encourage women to utilise support such as church groups or counselling to ease their emotions during this period.

Session 5 included detailed information pertaining to staging of cervical cancer and the importance of ensuring that treatments are given within determined field of treatment to protect nearby structures; However, this would be limited only to stage 3., as the researcher did not wish to trigger any sad emotions ; advanced stages of cervical cancer would be discussed when warranted. Various methods to treat cervical cancer would be illustrated for clarity; Different methods includes surgical procedures such as LEEP, hysterectomy, radiation therapy consisting of external beam and brachytherapy. An overview of how patient will be positioned during treatment and to stress that no actual fire would be used, but deep radiation rays which gradually penetrate the area targeted to destroy the cancer cells. It was important that the participants be aware that they will be alone in the room during the treatment; however, the therapist will observe them via a monitor to observe the condition throughout the procedure.

Session 6 included information about the side effects of treatment for cervical cancer and in particular, of radiation that can be expected and how-to self -manage these. Information included the importance of adhering to all sessions planned to avoid

disrupting the treatment regime. Tiredness as a common side effect and rest periods are advised as well as involving other family members to assist with household chores. To alleviate distress. Fluid intake would be encouraged so as to assist in flushing toxins from destroyed cells and in mediating the severity of a burning sensation when passing urine. Participants were informed to keep contact with satellites services should their condition deteriorate on non-clinic days such as weekends or at night when services are not operational so that they can report for assistance.

6.6.2 **Stage 3**

Once PowerPoint slides, were developed for the programme, six session booklets with space provided for comments on the right side of the document were designed. The booklets were printed and supplied to the team of experts for validation two weeks before the programme could be implemented (Eschalier, Descamps, Boisgard et al., 2013; Mitchell & Courtney, 2005). This was to ensure familiarisation with the programme with the view to facilitate discussion of the same. The programme was rated for relevance regarding content for the intended target group, feasibility , acceptable and being supportive in nature as well as comprehensiveness relating to the support intended (Bakas, Farrran, Austin, Given, Johnson & Williams, 2009; Haynes, Richards & Kubany, 1995).

Content validity of the measure is necessary in drawing conclusions about the quality of the scale (Backstead, 2009). In order to validate the developed programme, the experts had to agree on the feasibility of the content with regards to face validity, cultural appropriateness as well as ease of readability to meet the level of prospective participants were assessed. The experts assessed the face value of the content regarding addressing the intended outcomes, whether it was easy to understand and also if the language used was appropriate and easy to understand for the intended audience and if it was culturally appropriate. The booklets were supplied with instructions to the experts to provide comprehensive comments on the spaces provided in the booklet. The researcher preferred detailed comments and suggestions versus using Likert scales, as this would guide her to the extent of change suggested in order to apply to the programme. Although the intent was to have a focus groups to discuss issues of

concern as well areas of improvement to the developed programme, it proofed challenging to have all the team members in one sitting due to limited numbers of staff allocated at one time in the department.

The researcher utilised a Delphi technique so that each member could comment on the programme. In some instances, it was easier to meet face to face with individual staff to discuss their recommendations to improve the programme. As an additional measure to triangulate the programme the researcher supplied the programme to another oncology qualified nurse working at a similar setting, in Gauteng province where patients also received curative treatment for cervical cancer including radiation to comment and give her input. One of the recommendations was that an additional modality to treat pre-cancerous lesion be added which is LEEP procedure as a mode to treat pre-cancer. A recommendation from the radiographer was that the simulation procedure and staging be presented early once diagnosis has been confirmed so that it should be relevant based on how process works at the hospital. The suggestions were effected before the programme could be implemented.

Since patients who were part of the expert team came six months post treatment for follow up, and the challenges to travel back to the health facility to give their inputs (for the next follow- up visit) the researcher met individual participants' to explain each session in the programme and to verify if the language were appropriate, content relevant and easy to understand to meet the needs of the prospective beneficiaries. The three patients voiced that they wished t have received such support before undergoing treatment, it would have made their journey much bearable and easier if they had such. Once the researcher addressed the recommendations from the team of experts, it was ready for implementation.

6.7 SUMMARY

Chapter 6 presented the development and validation of a programme to support women receiving curative treatment for cervical cancer. The programme was guided by Knowles' theory of adult learning. Experts working in the department and involved in day-to day care of patients, including three patients who came for the six months post - treatment evaluation validated the programme. Chapter 7 will discuss the implementation of the

support programme for women receiving curative treatment for cervical cancer including radiation, and how it was evaluated on the last day of the programme.

CHAPTER 7

7. PHASE 2: IMPLEMENTATION AND TESTING THE EFFECTIVENESS OF THE SUPPORT PROGRAMME FOR WOMEN RECEIVING CURATIVE TREATMENT FOR CERVICAL CANCER

7.1 INTRODUCTION

Chapter 6 discussed the development and validation of the programme to support the women receiving curative treatment for cervical cancer including radiation. The Delphi technique and face-to-face discussions with experts involved in day-to-day care of the patients were utilised for developing and validating the programme This chapter will present phase 2 of the study, guided by Knowles' Theory of Adult Learning (2012). The objective of this phase was to pilot test the programme validated by the team of experts. The aim of the programme was to explore the primary outcome, perceived support, and secondary outcome, improved quality of life. The effectiveness of the programme would be evaluated on the last day.

7.2 RESERCH DESIGN

This quantitative phase of the study utilised one group pre- and post-test design as the was no manipulation of the participants. No control group was utilised. The pre- and post-test approach was applicable to the study, as only one group would undergo the same process of support; this approach is frequently used in nursing intervention studies (Burns & Grove, 2009). The researcher would evaluate the effectiveness of the programme at the end, which would be the last day of the participants receiving treatment and attending the programme. The researcher invited all women receiving curative treatment for cervical cancer including radiation, to participate in the study. Although participants were included based on the study criteria 3.8.1, it was also compulsory for them to complete a pre-test, as a condition, before being allowed to take part in the programme. The pre-test design assessed the primary and secondary outcomes before being admitted into the programme.

7.2.1 **Setting**

The quantitative phase of the study was conducted at the same academic hospital in Gauteng (3.7) as the qualitative phase. Similarly, participants come from various satellite hospitals where they were seen prior to being referred to the hospital. The participants undergo similar processes prior to admission for treatment at the hospital.

7.2.2 **Population**

The population consisted of all women receiving curative treatment including radiation to treat cervical cancer at the radiation oncology department of the specific academic hospital. Although the population consisted of all women treated for cervical cancer in the department, those who participated in phase 1 of the study were excluded to prevent bias (Creswell, 2014; Lancaster et al., 2004).

7.2.3 **Sampling**

Census sampling was utilised to select women (n=56) meeting a specified criterion (3.81). The aim was to give all women treated for cervical cancer a fair chance to participate in the programme, with an intent to generalise to this population. Whilst it is imperative to conduct sample size for random control trials (RCT) to test for efficacy or feasibility of interventions, Thabane et al. (2010) assert that it may not be necessary to calculate sample size for pilot studies; however, the sample should be large enough to represent the population studied. Calculating the size to determine the effectiveness of interventions could be biased due to the limited sample size, therefore sample size was not predetermined. Two participants meeting the specified criteria (3.8.1) were randomly selected at the waiting area after the researcher informed the women about the study. The researcher assisted the two participants to complete the consent forms after inviting them to pilot-test the questionnaire.

7.2.3.1 **Application of Knowles theory to the programme**

Knowles' (2012) Adult Learning Theory was applicable in the study as it took cognisance of an adult as a person who brings some form of knowledge or experience. In addition, it is important that adults (participants) have a reason to learn something new. This statement fits well with assumption number 1, which relates to the need to know. In the

case of the study, it was important that participants be informed and consulted when the programme commenced. This statement also fits with assumption number 2, which relates to learner's self-concept. This concept relates to adults being responsible, with decisions based on self-direction. Although participants are dependent on the healthcare facility, they initiated access to consult healthcare once they were confronted with illness (symptoms). Accordingly, adult learners aspire to be consulted with any issues or learning that they are expected to undertake. The statements coins well with the study as in the previous phase (qualitative phase), participants were involved in provision of information that guided development of the support programme. However, in phase 2, it was important that the researcher negotiate with prospective participants of the programme and give consent if they were of the opinion that this would assist them to cope with their situation. If the participants did not have a vested interest, or the need to learn the information they felt would assist them to cope with their situation, they would not have bothered to attend. Participant's experiences with illness played an important role in them reaching out for a source of help. This assumption fits well with assumption number three, where the role of experiences is important. The study participant's previous experiences with illness was a prompt for them to make efforts to present themselves to the health facility. This assumption can also relate to health belief, whereby acknowledging state of illness and acting upon it clearly shows that the participants were capable of self-direction, as they took the initiative to present themselves. Once the participants were informed about the study and the benefit to their well-being, they were ready to participate. This relates to assumption number 4, which relates to learner's readiness to learn. Our participants were eager to learn new information, which would give them insight about their condition and illness. Learning new information coincided with illness period; this information was crucial, as it applied to real life situation. This assumption relates to assumption number 5, which is orientation to learning. The programme came at the most needed time for the participants, as they truly needed information and motivation to pursue and adhere to treatment schedules. It was important that participants were provided with necessary support and information that would help them throughout the disease trajectory. This would provide necessary information relating to the disease and the treatment which they would be able to share with families and significant others. It is believed that adult

learners are motivated by internal or external factors, knowing that there is benefit at the end. This assumption relates to assumption number 6. The participants had intrinsic motivation, as they yearned to get better and experience a better quality of life at the end of treatment. However, another strong motivator, as observed in the study participants, was that they were sole breadwinners and the majority were single parents. Having to get better was an external motivation to be healed and re-incorporated with their families and communities.

7.3 DATA COLLECTION

A Pre- and post-test were utilised for Phase 2. A self-developed questionnaire based on Section A of the interview guide (Appendix G) was used to determine participant's demographics. BSSS (Appendix J) and EORTC-QOQ-CX 24 (Appendix L) module, specific for cervical cancer were used to collect initial pre-test data to determine participants' perceived support and quality of life prior to attending the support programme. Data collection occurred from May - July 2019. Two pilot interviews with structured questionnaires were conducted to determine participant's ability to understand and respond to both questionnaires since they were borrowed and developed from other contexts not representative of Sub- Sahara. The researcher obtained permission from the authors to use the questionnaires (Appendix I & K) without adapting nor translating to other languages. Although the questionnaires were meant to be self-completed, due to language and level of questioning the researcher was responsible to assist in completion of these. The same ethical clearance certificate (M150272) (Appendix A) was applicable in phase two. The researcher approached the prospective participants with whom the questionnaire was tested. The two participants were within the age range of 30- 39 years. The first participant became emotional when responding to the Berlin support scale; the participant became sad and almost on the verge of crying as she continued to respond to some of the questions.

The researcher stopped the interview and waited for the participant to compose herself, and even offered to stop the interview so the participant did not have to go through the emotions experienced. The participant managed to control her emotions and expressed the desire to continue with the interview. This alerted the researcher to be very sensitive

and observe other interviews based on the nature of the questions to arouse sad feelings or emotions. This called for provision of a designated oncology nurse to be available at any time during data collection. The second pre-test went much easier without much emotion noted however, it was noted that at times the second participant suppressed her emotions, however the researcher was on alert should participants experience any sadness.

The researcher invited all women receiving curative treatment for cervical cancer to take part in the study (n=56); it was made clear that there would be no payment for taking part. Women needed to commit their time as this would imply that they wanted to attend the support programme if possible until last session, unless there were compelling health reasons not to attend. The researcher met the women at Outpatients department early on arrival, whilst waiting to collect their files, and explained about the programme/study. The researcher noted that some of the women were reluctant at first but once she was supported by one member of the nursing staff to explain about the study, the response improved. The researcher and a trained research assistant with a nursing background assisted the participants to complete the questionnaires. The inclusion criteria were the same as section 3.8.2, however, women in week one of treatment were included as it was assumed that involving them early in the programme would help in the disease trajectory. Knowles' Theory of Adult Learning (2012) was applicable, as adults were interested in learning something new if it was relevant for the need identified by them.

Knowles' (2012) adult learning theory was applicable in the study as it took cognisance of an adult as a person who brings some form of knowledge or experience. In addition, it is important that adults (participants) have a reason to learn something new. This statement fits well with assumption number 1, which relates to the need to know. In the case of this study, it was important that participants be informed and consulted when the programme commenced. This statement also fits with assumption number 2, which relates to learner's self-concept. This concept relates to adults being responsible for decisions based on the self-direction.

Although participants were dependent on the healthcare facility, they initiated access to consult healthcare once they were confronted with illness (symptoms). Accordingly, adults prefer to be consulted with any issues or learning that they are expected to undertake. The statements fit well with the study, as in the previous phase (qualitative phase) participants were involved in provision of information that guided development of the support programme. However, in phase 2 it was important that the researcher negotiate with prospective participants to be part of the programme and give consent if they were of the opinion that this would assist them to cope with their situation. If the participants did not have a vested interest or need to learn information that they felt it would assist to cope with their situation, they would not have attended. Participant's experiences with illness played an important role in them reaching out for help.

This assumption fits well with assumption number 3, where the role of experiences is important. In this study, participant's previous experiences with illness was a prompt for them to make efforts to present themselves to a health facility. This assumption can also relate to health belief, whereby acknowledging state of illness and acting upon it clearly shows that the participants were indeed capable of self-direction, as they took the initiative to present themselves. Once the participants were informed about the study and the benefit to their well-being, they were ready to participate. This relates to assumption number 4, which relates to learner's readiness to learn.

The participants were eager to learn new information, which would give them insight about their condition and illness. Learning new information coincided with the illness period. This information was crucial at this point as it applied to real life situations. This assumption relates to assumption number 5, which is orientation to learning. The programme came at the most needed time for the participants, as they truly needed information and motivation to pursue and adhere to treatment schedules. It was important that participants were provided with necessary support and information that would help them throughout the disease trajectory. This would provide necessary information relating to the disease and the treatment which they would be able to share with families and significant others.

It is believed that adult learners are motivated by internal or external factors knowing that there is benefit at the end. This assumption relates to assumption number 6. The participants yearned to get better and experience a better quality of life at the end of treatment. This aligned with an intrinsic motivation, which is the most important in an individual's life. However, another strong motivator, as observed in the study's participants, were that they were sole breadwinners, and most were single parents. Having to get better was an external motivation to be healed and re-incorporated back with their families and their communities. Fifty-six (n=56) pre-tests were conducted as participants were allocated in groups of 6 or 9 depending on attendance of the participants during their treatment period. The next Chapter will discuss implementation of the programme

7.4 PROGRAMME FACILITATION

The programme envisaged running weekly over six sessions. Each session was facilitated twice between groups to accommodate those who might have missed due to treatment procedures in the department. Once the first group of women's pre-tests were completed, the programme commenced. The researcher was responsible for the facilitating the entire programme, although at the initial planning, the social worker would have been involved to explain processes addressing social work related issues, however due to time constraints and the limited number of skilled personnel, the social worker did not participate.

The researcher was solely responsible for facilitating the entire programme, as she was conversant with the languages spoken in the hospital and familiar with content to be shared in the support programme. The most common languages spoken were IsiZulu, South-Sotho, Setswana and English. The support training was convened early in the mornings, once the women arrived in the department waiting to collect their files; this was to avoid interrupting hospital processes once started in the department. In the case of the support programme, women in the first week of treatment were also included. The reason was that including these women would be beneficial, as they would be better informed about what to expect as they progress with the treatment.

SESSION 1: An overview of the programme was explained to the participants(n=56) who gave consent to participate in the study. In order to be eligible, women had to meet criteria for inclusion and complete the two pre-tests questionnaires, Berlin Support Scale (BSSS) (Appendix J) and EORTOC QOQ- CX-24 module (Appendix L), with the assistance of the researcher and the research assistant. To set the stage, the researcher asked participants to reflect on their experiences with the disease before they could access the healthcare. Most symptoms experienced were abnormal bleeding, foul smelling discharge, painful coitus, and severe backache, similar to studies conducted on cervical cancer (Mosalo, 2011; Schalkwyk et al., 2008). The participants relived their fears as the explained how they first experienced their trajectory. It was during this time the researcher invited the participants to name the support group; this was to give participants a sense of ownership and commitment to the programme. Three names were suggested and eliminated based on the meaning with which it resonated. The name that participants eventually agreed on was "***Ungesabe***" meaning do not be afraid, as this was their call and they had to confront it as a group. The researcher explained reasons for journeying together with the participants, which were an endeavour to make it easier for women to navigate the cancer trajectory as well as to comply with the treatment with support afforded.

The support training programme was facilitated in a special room arranged with permission from the Head of the Radiation Oncology Department (Appendix C), and the Manager of the hospital (Appendix B). This gave the researcher an opportunity to stress the importance of working as a group towards the participants' empowerment and support to be able to face the challenges of the disease.

Session 1

Figure 7.1: Diagram Depicting Women's support Group

The researcher had an opportunity to explain about feelings that participants might have experienced once the diagnosis of cervical cancer was confirmed. The participants' also felt a need to talk about their experiences and relived their fears when they were informed of the cancer diagnosis. This was an opportunity for participants to feel at ease as they relate how they felt and being at ease with the group.

The researcher gave brief information pertaining to different members of the health team whom participants could possibly be in contact with as they navigate the treatment. It was important for participants to be familiarised with members whom they would be working closely with, and to inform them that the doctors would need to ask questions pertaining to their general health and present condition despite what had been done previously. This was to allay their fears as woman felt that repetition of the same process at the hospital could unnecessarily lengthen the time before commencing treatment. Basic information about cancer was presented, and simple images of a normal cell and an abnormal cell were shown on PowerPoint to give participants an idea of what a cancer cell looks like. The sessions were meant to be interactive to assess the participants' ability to comprehend the content presented. In addition, information pertaining to basic signs and symptoms of cancer were also presented. The use pictures or images made it easier for participants to comprehend how cancer behaves, and spreads to other parts

of the body. At the end of the session, the researcher asked a few questions to determine if the participants had understood the information shared.

At the beginning of the support training it appeared that the participants were too shy to communicate, however once they started to do so the mood enlightened, and communication was better. The participants were relaxed and could ask questions relating to the content when they were unsure. The sessions were repeated once to accommodate those who were not able to attend in the one group.

SESSION 2: Covered the anatomy of the female reproductive system and organs in relation to the cervix

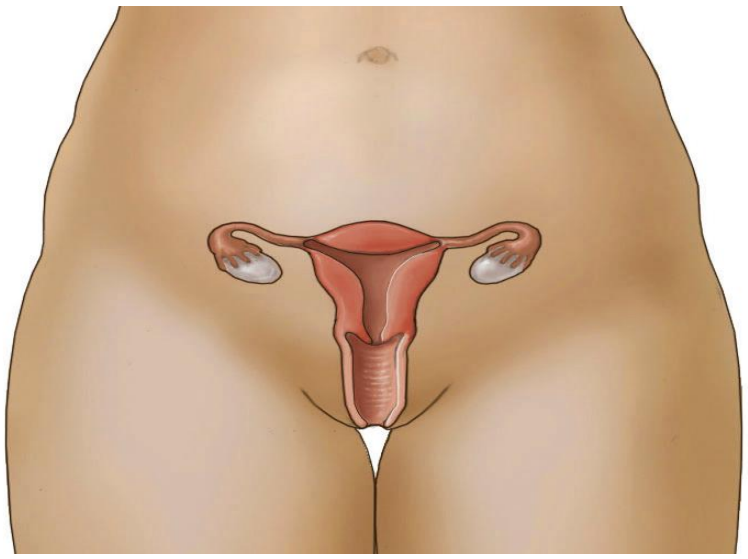

Figure 7.2: Position of the Cervix within the Woman Body

During this period, it was evident that women took ownership of the programme, as it became clear that they recognised the importance of it as it put things in perspective, especially when shown the position of the cervix within their bodies. Some commented as the programme progressed, which gave the researcher a feeling that the women were identifying themselves as members of the support group. The next session presented the information regarding the different screening procedures.

SESSION 3: is about screening procedures to detect pre-cancer and/or cancer and equipment used for screening (Figure 7.3).

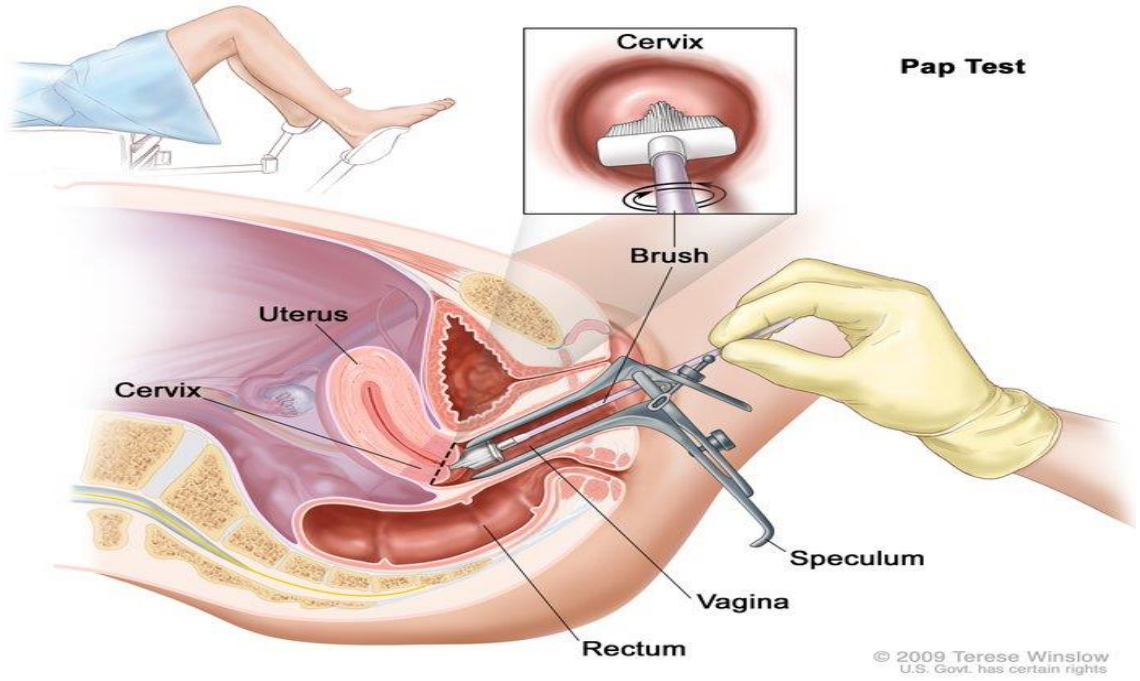

Figure 7.3: Position of the Speculum during Screening

In this session, information pertaining to screening and the different types of screening procedures were presented in detail. Additionally, some instruments were available for participants to observe and handle to familiarise themselves so that they were aware these were not as invasive as they thought, e.g. Pap smear kits, cyto brushes and disposable speculums. This was to re-assure the participants that the procedure was not invasive, and instruments used will not cause any harm. Women were encouraged to inform others to go for screening to avoid similar experiences.

SESSION 4: In this session**,** information was given regarding the simulation procedure and the tattoo markings as well as practical tips on counselling and other support services such as hospital transport facilities and accessing temporary social grants.

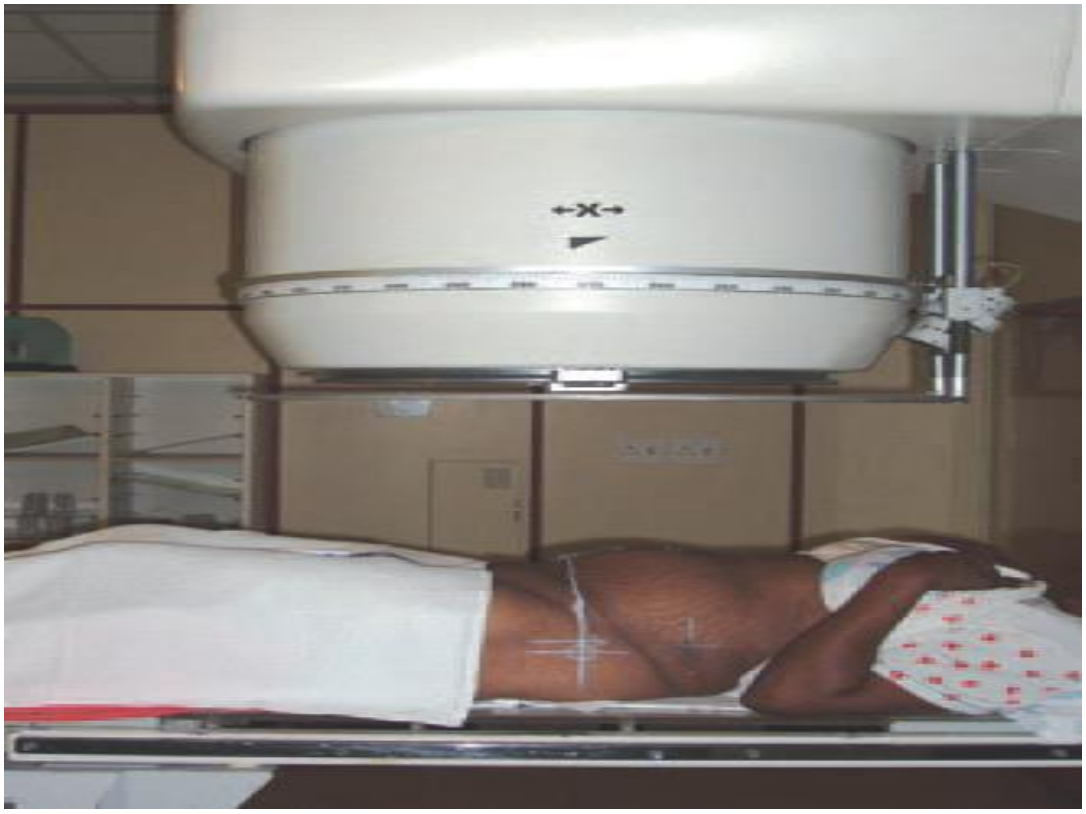

Figure 7.4: Simulation Procedure and Application of Tattoo Marks

Other support services available to women during treatment, such as the availability of and use of hospital transport, as most use taxi's (cabs) to go to the satellite clinics, in order to ease the burden of transportation and how to access temporary accommodation, were also included. Also, information pertaining a telephone call, informing them of the date when they were to commence the treatment at the specific facility would be addressed. This was highlighted as the most daunting time; Once they were due to commence treatment, participants were informed about self-care measures and what to avoid whilst on treatment such as not being sexually active during the time they are on treatment , avoiding use of ointments and soaps on the skin from mid-abdomen through to the mid-thigh area, which are prone to radiation during treatment. It was important that the participants are informed about the duration of treatment which was five days Monday to Friday for six consecutive weeks.

SESSION 5: included detailed information pertaining to staging of cervical cancer (FIGURE 7.5)

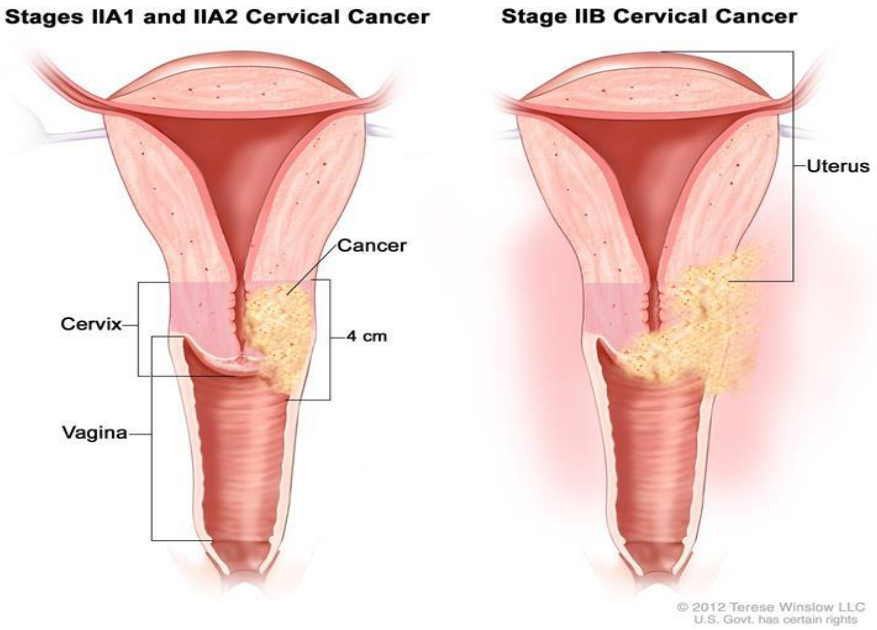

Figure 7.5: Stages of Cervical Cancer

In this session, the different stages of cervical cancer were presented and were limited to stage 3. Different treatment methods were discussed followed with images to make it clearer for understanding. Various methods to treat cervical cancer would be illustrated for clarity; Different methods includes surgical procedures such as LEEP, hysterectomy, radiation therapy consisting of external beam and brachytherapy. It was important that patients were aware of pre-positioning each day before commencing with treatment to ensure identification of correct treatment field. Furthermore, patients were informed that to maintain the safety of the therapists working with them, they would be alone in the treatment room, whilst the medical team would be observing through a monitor.

SESSION 6: In this session the side effect of chemotherapy including radiation as main modality to treat cervical cancer (Figure7.8). Participants were informed about self-care measures. Also, of importance was to encouraging involvement of other family members to relive distress. Maintaining contact with satellites was emphasised so that it would easier to contact them on non-clinic day when condition deteriorates or there's an usual changes observed.

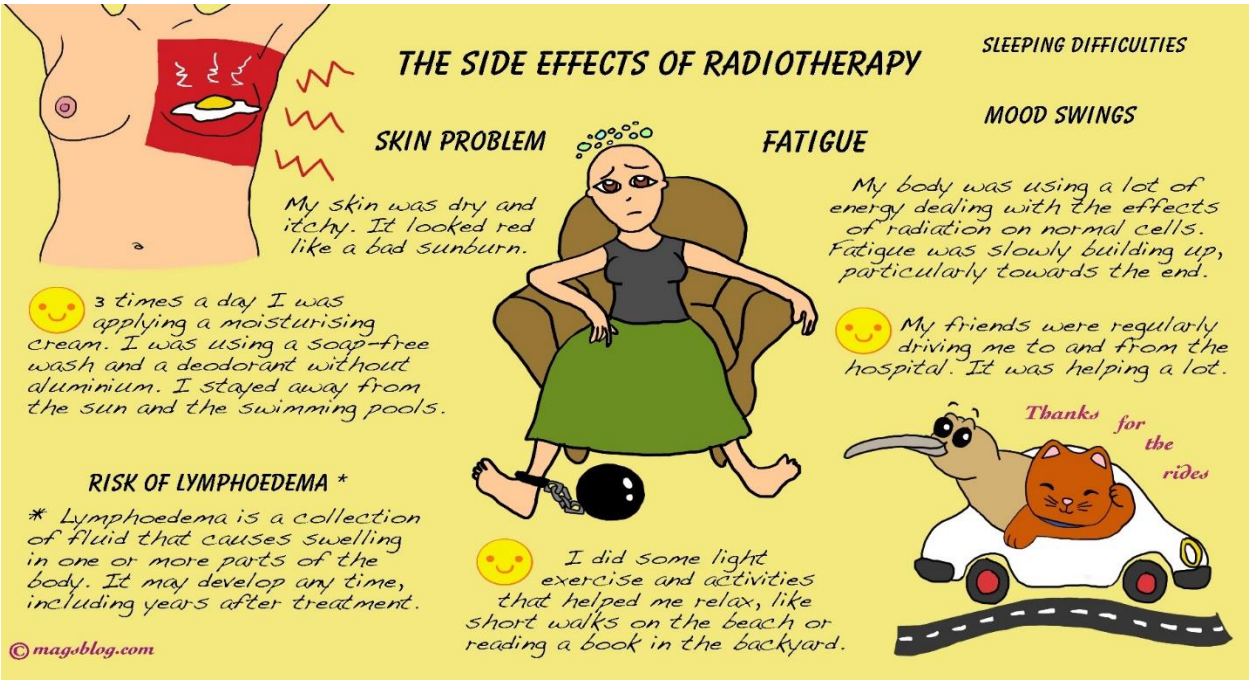

Figure 7.6: Side Effects of Treatment

It was at this period that the patients presented with side effects of the treatment. The researcher gave details on how to care for treatment sites, as well as how to identify side effects. Although not all patients received chemotherapy, it was important to address issues such as nausea, vomiting or other unusual symptoms experienced. Participants were encouraged to present themselves for treatment even when they felt like abandoning it, as it is important to maintain continuity for the radiation dose to work effectively.

Pain Analogue Scales

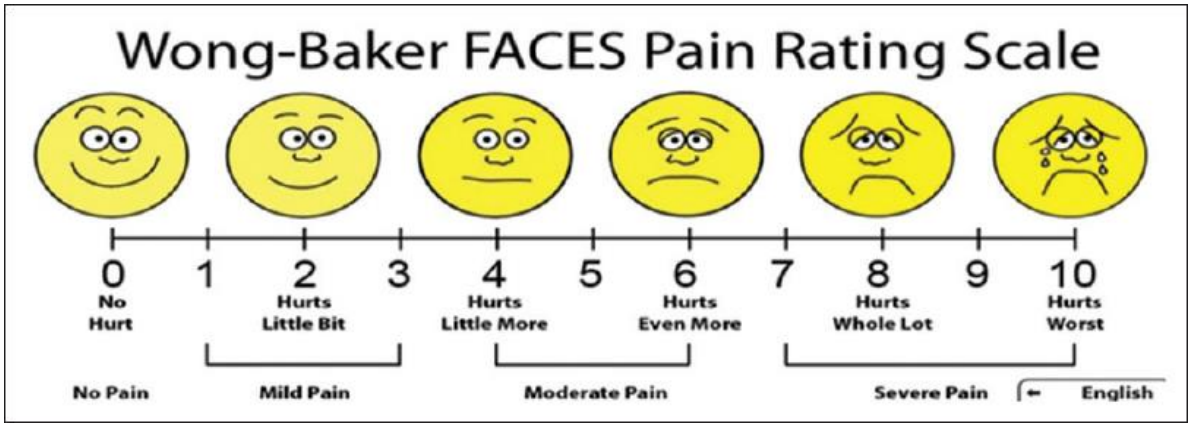

Figure 7.7: Pain Analogue Scale

Although pain control was not included in the support training programme initially, due to the observation that some of the participants were challenged with pain during the attendance of the programme leading to being released and sent to the doctor for further pain management, as this was limiting to performing activities of daily leaving.

It was crucial to inform the participants about pain control and to follow scheduled times as guided by the prescription especially in the morning before they come to the hospital, as it was noted that some do not take them as they leave home early without having anything to eat.

Once the last day the session was completed, a post test was conducted using the same BSSS (Appendix J), and the EORTC QOQ-Cx 24 questionnaire (Appendix L) used in the pre-test was conducted, however only 15 (n=15/56, 27%) took part. This was on recommendation of the statistician to compare the matched pairs.

7.5 DICUSSION

The researcher envisaged that the programme would be effective and exciting to all the participants; however, this was not the case. Whilst women were keen on attending the programme, it became a challenge to have the same group of women present at all times. As reported, the participants were from different health facilities, which affected the times to facilitate the programme. Some were using the hospital transport, whilst others came from informal settlements where it was reported to be more convenient to use taxis (cabs) than having to go to hospital and use the designated transport. This became a challenge to retain the same women in their group at all times. It also became evident that treatment was scheduled on a first come first served basis. This affected the grouping of the same people in order to maintain continued support.

To overcome this challenge, the researcher repeated the main issues of the previous sessions in order to accommodate the groups as they attended the programme. Most of the women attending were now at ease and willing to talk freely or ask questions when not sure. The researcher made a conscious effort to inform and advise about pain control

even though this was not part of the initial programme but was noted as the programme unfolded. At least the challenge regarding pain appeared manageable, although in between sessions there would be someone who experienced pain that needed intervention, whereby they had to pull out the programme to be referred to the doctor.

At the beginning of session three, some of the participants experienced severe pain, despite pain control afforded as part of routine treatment, and needed to pull out so they could be treated and left. Whilst this was one challenge to be confronted, another was that the machines in the radiation oncology department were serviced leaving only two machines to be used for all the people attending radiation, including those treated for cervical cancer. Patients were given the choice to come in at times suitable for them, which meant that those using public transport came very early for treatment and left when finished, which further affected the attendance to the support programme. Even patients from the satellite clinics were no longer coming at expected times. The researcher attempted to regroup patients according to the treatment weeks based on treatment sessions; this implied that the programme changed to accommodate the remaining women. The researcher communicated with the study supervisor about her concerns and was advised to adapt the sessions. The sessions were therefore facilitated twice weekly. This meant that two different topic sessions were facilitated in one week in an attempt to provide information earlier so that when participants reached week three, they would at least have been informed about treatment side effects and self-care measures.

Also, of note was that another, beauty programme was facilitated concurrently with the support programme. This affected attendance to the support programme, because there were incentives provided, and women chose to attend the programme. Another setback was that once a diagram of different stages of cervical cancer was shown to the participants, it was noted with sadness, how women's faces became sad although they were not vocal about it. Only two (n=2) openly vocalised that they were doing well in the programme however "now they have been set back two steps backwards once they see what advanced disease appeared like." The researcher was equally sad, apologised although there was no better way to address this, as she needed to be as open as

possible for the participants to learn. This led to two other participants (n=2) abandoning the programme.

Once the programme unfolded, it was clear even those who were not diagnosed with cervical cancer were keen to attend, however as they did not meet inclusion, they could not be accommodated in the group. It appeared that such a programme addressing needs of women was facilitated for the first time. A total of 56 participants (n=56) including the two pre-test participants who met inclusion criteria, and those from the first week of treatment, were included. As discussed, due to the content and language, researcher and assistant, who was trained, assisted to complete all the questionnaires in the presence of the participants. It became evident that younger participants were vulnerable as they responded to the questions from both questionnaires. The researcher became alert to guard against participants who may experience some emotional setbacks. Although the researcher offered to refer participants for counselling by the oncology nurses designated for this purpose, women declined referral feeling the need to continue. This could not be dismissed solely as not being keen for counselling. One of the possible reasons was that the participants used hospital transport hence; they feared being left behind, as money was an issue due to most participants not working.

During the second week of attending the programme, some of the participants were already experiencing treatment side effects, whereby pain control was an issue, whilst others experienced radiation burns. The researcher noted with concern that if participants were experiencing pain, this would hamper most participants' attendance of the programme. It was clear that the participants were not well informed regarding controlling their pain, which was a real set back and affected their quality of life. Another reason was that pain medication prescribed was not effective in treating cancer pain, as described WHO pain control ladder (WHO, 2006). The programme continued despite some participants missing, which impacted poorly on the attendance. However, at the end of session six a post-test was conducted with 15 participants (n=15) using the same questionnaires, as those used in the pre-test. These 15 participants (n=15) were matched pairs who attended all the sessions in the programme. The researcher and the assistant helped the participants to complete the post-test questionnaires. Despite that, 56 participants (n=56) completed the pre-test, and more than half of the group attended

the programme to completion. Due to challenges, encountered only 15 participants (n=15) were available to complete the post- tests in the last week of the programme. However, it is for this reason that the statistician suggested comparison of only the pre-tests of the same participants who completed their post-tests, to make true comparisons in the programme. On the last day of the programme eight (n=8) of those who participated to completion and completed the post-test were invited to a group discussion to evaluate its effectiveness.

The group discussion was held in the same room where the support programme was facilitated. Participants were asked how they felt about the programme; what was noted was that participants were hesitant to say how/what they felt. However, once the researcher tasked the participants to explain in one word how they felt about the programme. Immediately participants could summarise in one word how they viewed the programme, words such as empowerment, friendship, light, knowledge encouragement, conquered and healing spaces, and relationships were mentioned. These reactions truly implied that the programme had the ability to improve the perception that women are supported. Although these reactions are from a few of the women who participated in the programme, this calls for similar programmes to be tested in similar settings

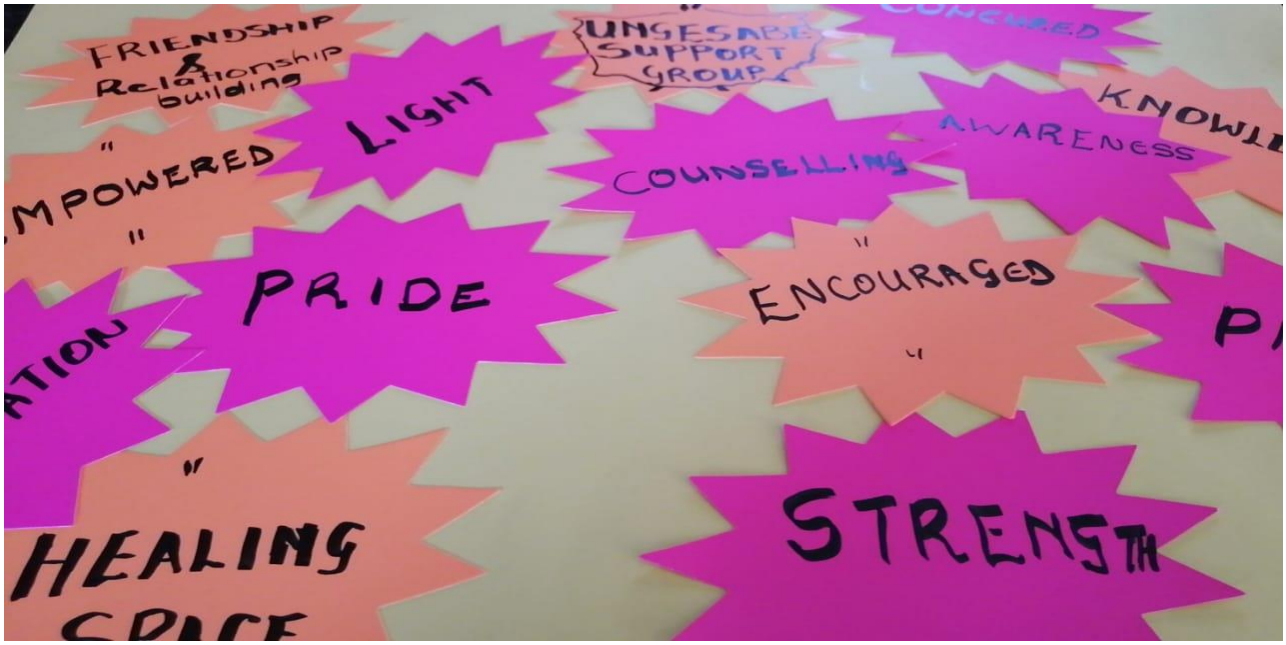

Figure 7.8: A Poster of Words Expressed by the Participants who Evaluated the Programme at the End of the Last Session

The participants recommended that such programmes be facilitated in satellite sites, as no such programmes were available. These could help women to adapt to their situation early in the cancer trajectory before even starting with radiation therapy. Furthermore, the feeling was that the programme was easy to understand as the language used was simple and culturally acceptable and the message clear. The participants expressed that it would be appreciated if they could be supplied with summary booklets of topics presented in different languages, however this was not possible due the financial constraints, the researcher would consider the issue of booklets in the next step when sharing the program with the satellite care. The other recommendation was that such programmes be facilitated about screening at old age homes, as these are where old populations are kept but seem to be forgotten.

7.6 SUMMARY

This chapter presented details pertaining to the implementation of the support programme. The importance of including participants from week one attending treatment for cervical cancer discussed. Different sessions pertaining to the programme were presented with the researcher being responsible to facilitate the programme. The importance of using written text and pictures to accommodate participants with limited literacy and accommodate patient readability was explained. Chapter 8 will present the results of the pre-test as well as 15 (n=15) post-test results of participants who attended all sessions in the programme.

CHAPTER 8

8. PHASE 2: DATA ANALYSIS AND INTERPRETATION OF RESULTS

8.1 INTRODUCTION

Chapter 7 addressed the objective for phase 2: to pilot -test the support programme in terms of one primary outcome, perceived support and a secondary outcome quality of life of women receiving curative treatment for cervical cancer. This chapter will present the results of the Pre- and post-test after implementation of the programme. The pre-test results are presented in subsequent tables accordingly followed by discussion of the post-test results using the same questionnaires. Data in Table 8.1 present characteristics and demographics of 56, participants who completed the pre-tests questionnaires.

8.2 PARTICIPANT CHARACTERISTICS

Table 8.1: Demographics Characteristics of Participants in the Pre-Intervention Study (n=56)

Variable	Categories	Frequencies	Percentage
Age Categories	18-25	1	1.79
	26-30	4	7.14
	31-40	11	19.64
	41-50	14	25.00
	51 and above	21	37.50
	Missing	5	8.93
Cultural groups	Ndebele	1	1.79
	North Sotho	3	5.36
	South Sotho	10	17.86
	Tsonga	2	3.57
	Xhosa	8	14.29
	Zulu	19	33.93
	Other	13	23.21
Province	Gauteng	40	71.43
	Limpopo	2	3.57
	Mpumalanga	2	3.57
	North West	6	10.71

Variable	Categories	Frequencies	Percentage
	Other	4	7.14
	Missing	2	3.57
Region	Rural	11	19.64
	Urban	44	78.57
	Missing	1	1.79
Marital status	Married	9	16.07
	Co-habiting	4	7.14
	Culturally married	8	14.29
	Stable relationship	9	16.07
	Single	18	32.14
	Widowed	6	10.71
	Divorced	2	3.57
Children	0-1	9	16.07
	2-3	26	44.06
	4 and above	21	37.50
Education	No education	2	3.57
	Grade 1-6	14	25.0
	Grade 7	8	14.29
	Grade 8-10	14	25.0
	Grade 11-12	15	26.79
	Tertiary	3	5.36
Employment status of participant	A day worker	19	33.93
	A pensioner	11	19.64
	Disability grant	1	1.79
	Employment	11	19.64
	Unemployed	12	25.00
Income of participant	None	4	7.14
	R1- R2000	5	8.93
	R2001-R2500	2	3.57
	R2501 –R4000	1	1.79
	R4001- R6000	7	12.50
	R6001>	4	7.14
	Missing	33	58.93
Employment status of partner	A day worker	6	10.71
	A pensioner	5	8.93
	Disability Grant	9	16.07
	Employed	5	8.93

Variable	Categories	Frequencies	Percentage
	Unemployed	31	55.36
Monthly income of partner	None	4	7.14
	R1 –R2000	5	8.93
	R2001-R2500	2	3.57
	R25001- R4000	1	1.70
	R4001- R6000	7	12.50
	R6001 >	4	7.14
	Missing	33	58.93
Disease	Stage I	3	5.36
	Stage IIA	1	1.79
	Stage IIB	40	71.43
	Stage IIIA	6	10.71
	Stage IIIB	6	10.71
Histology	Squamous	38	67.86
	Adeno	9	16.07
	Neuro endocrine	2	3.57
	Other	4	7.14
	Missing	3	5.36

The majority of the participants were Zulu speaking (33.90%; n=19) from Gauteng Province (71.4%; n=40), with most coming from urban areas (78.6%; n=44). The proportion of participants in a certain age group increased with age as most of the participants were older than 31 years; however, the majority (37.50%; n=21) were in the 51 and above age group. Most participants (53.57%; n=30) had an official partner; 16. 07% (n=9) was married, whilst 14.29% (n=8) were culturally married; 7.14 % (n=4) was in a cohabiting relationship; with 16.07% (n=9) in a stable relationship and 32.14% (n=18) were single. Most participants (46.73%; n=26) had 2-3 children, whilst 37.50 % (n=21) had four and above.

Most participants (51.80%; n=29) attained Grade 8-12, as shown by the high percentages of Grade 8-10 (25%; n=14) and Grade 11-12 (26.80%; n=15). A total of (33.90%; n=19) of participants were day workers, earning between R4001-R6000 per month (12.50%; n=7) and (20%; n=11) were in full employment. The majority of the partners were not employed (55.40%; n=31). Most of the participants (71%; n=40), had

stage IIB cancer and mainly of squamous histology, whilst 16% (n=9) had adenocarcinomas.

8.3 THE BERLIN SOCIAL SUPPORT SCALE (BSSS) PRESENTING DIFFERENT LEVELS OF SUPPORT

Table 8.2 presents results of the different levels of support measured. Approximately 70% (n=39/ 56) of the participants indicated, “strongly agree” to the perceived emotional support (PES), and 66 % (n=37/56) indicated “strongly agree” to the perceived instrumental support (PIS). Furthermore, it was found that on average, 62.90% (n=35/56) of the participants indicated “strongly agree” to the need for support (NS), while 63.90% (n=36/56) indicated “strongly agree” to the support seeking (SS). However, in the support seeking, “If I don’t know how to handle a situation, I ask others what they would do,” all the indicated responses were below 50% (n=28).

Table 8.2: The Berlin Social Support Scale (BSSS) presents the assessment of the participants before the intervention for perceived emotional support, perceived instrumental support, need for support and support seeking (n=56)

The responses were (1) strongly disagree (2) somewhat disagree (3) somewhat agree (4) strongly agree.

Variable	Categories	Frequencies	Percentage
Perceived Emotional Support (PES)			
There are some people who truly like me	strongly disagree	2	3.57
	somewhat disagree	4	7.14
	somewhat agree	13	23.21
	strongly agree	37	66.07
Whenever I am not feeling well, other people show me that they are fond of me	somewhat disagree	4	7.14
	somewhat agree	13	23.64
	strongly agree	39	69.64
Whenever I am sad, there are people who cheer me up	somewhat disagree	4	7.14
	somewhat agree	11	19.64
	strongly agree	41	73.21

Variable	Categories	Frequencies	Percentage
There is always someone there for me when I need comforting	strongly disagree	1	1.79
	somewhat disagree	4	7.14
	somewhat agree	11	19.64
	strongly agree	40	71.43
Perceived Instrumental Support (PIS)			
I know some people upon whom I can always rely on	strongly disagree	1	1.79
	somewhat disagree	5	8.93
	somewhat agree	11	19.64
	strongly agree	39	69.64
When I am worried there is someone who helps me	strongly disagree	1	1.79
	somewhat disagree	4	7.14
	somewhat agree	13	23.21
	strongly agree	38	67.86
There are people who offer me help when I need it	strongly disagree	1	1.79
	somewhat disagree	6	10.71
	somewhat agree	15	26.79
	strongly agree	34	60.71
When everything becomes too much for me to handle, others are there to help me	strongly disagree	3	5.36
	somewhat disagree	6	10.71
	somewhat agree	10	17.86
	strongly agree	37	66.07
Need for Support (NS)			
When I am down, I need someone who boosts my spirit	strongly disagree	2	3.57
	somewhat disagree	4	7.14
	somewhat agree	9	16.07
	strongly agree	41	73.21
It is important for me always to have someone who listens to me	strongly disagree	2	3.57
	somewhat disagree	4	7.14
	somewhat agree	9	16.07
	strongly agree	41	73.21
Before making any important decisions, I absolutely need a second opinion	strongly disagree	8	14.29
	somewhat disagree	5	8.93
	somewhat agree	5	8.93
	strongly agree	38	67.86
I get along best without any outside help	strongly disagree	7	12.50
	somewhat disagree	12	21.43
	somewhat agree	16	28.58

Variable	Categories	Frequencies	Percentage
	strongly agree	21	37.50
Support Seeking (SS)			
In critical situations, I prefer to ask others for their advice	strongly disagree	8	14.29
	somewhat disagree	3	5.36
	somewhat agree	7	12.50
	strongly agree	38	67.86
Whenever I am down, I look for someone to cheer me up again	strongly disagree	2	3.57
	somewhat disagree	4	7.14
	somewhat agree	8	14.29
	strongly agree	42	75.00
When I am worried, I reach out to someone to talk to	strongly disagree	5	8.93
	somewhat disagree	4	7.14
	somewhat agree	10	17.86
	strongly agree	37	66.07
If I don't know how to handle a situation, I ask others what they would do	strongly disagree	6	10.71
	somewhat disagree	7	12.50
	somewhat agree	19	33.93
	strongly agree	24	42.86
Whenever I need help I ask for it	strongly disagree	2	3.57
	somewhat disagree	2	3.57
	somewhat agree	14	35.00
	strongly agree	38	67.86

8.4 ACTUAL RECEIVED SUPPORT

Table 8.3 reports on actual received support (ARS) items on the Berlin Social Support scale. The observation during the pre-testing phase in the study was that of the 14 items asked, 11/14 items (85.70%), had the highest scores for the "strongly agree" responses, while three items "This person left me alone" (51.79%; n= 29/56) and "This person did not show much empathy for my situation (50%; n=28/56); and "This person criticised me (51.79%; n=29/56) had the highest scores in the "strongly disagree" responses.

Table 8.3 presents the assessment of the participants before the intervention for actual received support: (1) strongly disagree, (2) somewhat disagree, (3) somewhat agree and (4) strongly agree (n=56).

Table 8.3: Actual Received Support (n=56)

Variable	Categories	Frequencies	Percentage
Actual Received Support (ARS)			
The person showed me that he/she loves and accepts me	strongly disagree	1	1.79
	somewhat disagree	2	3.57
	somewhat agree	9	16.07
	strongly agree	44	78.57
This person comforted me when I was feeling bad	strongly disagree	2	3.57
	somewhat disagree	2	3.57
	somewhat agree	6	10.71
	strongly agree	46	82.14
This person left me alone	strongly disagree	29	51.79
	somewhat disagree	4	7.14
	somewhat agree	5	8.93
	strongly agree	18	31.14
This person did not show much empathy for my situation	strongly disagree	28	50.00
	somewhat disagree	5	8.93
	somewhat agree	7	12.50
	strongly agree	16	28.57
This person criticised me	strongly disagree	29	51.79
	somewhat disagree	4	7.14
	somewhat agree	6	10.71
	strongly agree	17	30.36
This person made me feel valued and important	strongly disagree	1	1.79
	somewhat disagree	3	5.36
	somewhat agree	9	14.29
	strongly agree	43	76.79
This person expressed concern about my condition	strongly disagree	2	3.57
	somewhat disagree	3	5.36
	somewhat agree	8	14.29
	strongly agree	43	76.79
This person assured me that I can rely completely on him/her	strongly disagree	2	3.57
	somewhat disagree	3	5.36
	somewhat agree	12	21.43
	strongly agree	39	69.64
This person encouraged me not to give up	strongly disagree	2	3.57
	somewhat disagree	2	3.57
	somewhat agree	9	16.07

Variable	Categories	Frequencies	Percentage
	strongly agree	43	76.79
This person was there when I needed him/her	strongly disagree	2	3.57
	somewhat disagree	3	5.36
	somewhat agree	16	28.57
	strongly agree	35	62.50
This person took care of many things for me	strongly disagree	1	1.79
	somewhat disagree	11	19.64
	somewhat agree	14	25.00
	strongly agree	30	53.57
This person took care of things I could not manage on my own	strongly disagree	1	1.79
	somewhat disagree	8	14.29
	somewhat agree	18	32.14
	strongly agree	29	51.79
This person helped me find something positive in my situation	strongly disagree	1	1.79
	somewhat disagree	7	12.50
	somewhat agree	9	16.07
	strongly agree	39	69.64
This person suggested activities that might distracts me	strongly disagree	3	5.36
	somewhat disagree	6	10.71
	somewhat agree	10	17.86
	strongly agree	37	66.07

8.5 PERCEIVED EMOTIONAL SUPPORT

Data in Table 8.4 illustrate participants' responses with regard to satisfaction with support received and protective buffering scale in the pre-test phase. In this phase participants were to respond on the perception with satisfaction they received as well as how they perceive the protective buffering.

Table 8.4 presents the assessment of the participants responses before the intervention for the recipient's satisfaction with support received and the protective buffering scale for support/provider and support recipient: (1) strongly disagree, (2) somewhat disagree, (3) somewhat agree and (4) strongly agree.(n=56)

The majority of the participants (73.21%; n=41/56) indicated a "strongly agree" response on the recipient's satisfaction with support received. The protective buffering scale

showed that most participants (58.93%; n=33/56) chose the “strongly agree” response in this study on 5/6 items asked, except for the “I avoided any criticism”

Table 8.4: Perceived Emotional Support

Variable	Categories	Frequencies	Percentage
Perceived Emotional Support (PES)			
Satisfaction with Support Receipt (**SWSR)**			
In general, I am very satisfied with the way this person behaved	strongly disagree	1	1.79
	somewhat disagree	3	5.36
	somewhat agree	11	19.64
	strongly agree	41	73.21
Protective Buffering Scale (PBS)			
I kept all bad news from him/her	strongly disagree	10	17.86
	somewhat disagree	6	10.71
	somewhat agree	6	10.71
	strongly agree	34	60.71
I avoided everything that could upset him/her	strongly disagree	7	12.50
	somewhat disagree	7	12.50
	somewhat agree	12	21.43
	strongly agree	30	52.57
I showed strength in his/her presence	strongly disagree	2	3.57
	somewhat disagree	6	10.71
	somewhat agree	10	17.86
	strongly agree	38	67.86
I did not let him/her notice how bad and depressed I really felt	strongly disagree	2	3.57
	somewhat disagree	7	12.50
	somewhat agree	12	21.43
	strongly agree	35	62.5
I avoided any criticism	strongly disagree	13	23.21
	somewhat disagree	6	10.71
	somewhat agree	18	32.14
	strongly agree	19	33.93
I pretended to be very strong although I did not feel that way	strongly disagree	4	7.14
	somewhat disagree	7	12.5
	somewhat agree	12	21.43
	strongly agree	33	58.93

Table 8.5 reports on the assessment of the symptoms experienced to determine the quality of life of the participants at pre-support (EORTC QOQ –CX 24). The responses are indicated as: (1) Not at all, (2) A little, (3) Quite a bit, (4) Very much.

Table 8.5: EORTC QOQ-CX 24: Symptoms Experience (n=56)

Variable	Categories	Frequencies	Percentage
Have you had cramps in your abdomen	Not at all	8	14.29
	A little	9	16.07
	Quite a bit	12	21,43
	Very much	27	48.21
Have you had difficulty in controlling your bowels	Not at all	16	28.57
	A little	2	3.57
	Quite a bit	15	26.79
	Very much	23	41.07
Have you had blood in your stools (motions)	Not at all	38	67.86
	A little	10	17.86
	Quite a bit	1	1.79
	Very much	6	10.71
	Missing	1	1.79
Did you pass water/urine frequently	Not at all	23	41.07
	A little	8	14.29
	Quite a bit	12	21.43
	Very much	13	23.21
Have you had pain or a burning feeling when passing water/ urinating?	Not at all	23	41.07
	A little	14	25.00
	Quite a bit	5	8.93
	Very much	14	25.00
Have you had leaking of urine	Not at all	31	55.36
	A little	15	26.79
	Quite a bit	6	10.71
	Very much	4	7.14
Have you had difficulty emptying your bladder	Not at all	28	50.0
	A little	8	14.29
	Quite a bit	13	23.21
	Very much	7	12.50
Have you had swelling in one or both legs?	Not at all	35	62.50
	A little	10	17.86

Variable	Categories	Frequencies	Percentage
	Quite a bit	4	7.14
	Very much	7	12.50
Have you had pain in your lower back	Not at all	17	30.36
	A little	6	10.71
	Quite a bit	7	12.50
	Very much	26	46.43
Have you had tingling or numbness in your hands or feet?	Not at all	32	57.14
	A little	8	14.29
	Quite a bit	8	14.29
	Very much	8	14.29
Have you had irritation or soreness in your vagina or vulva?	Not at all	20	35.71
	A little	9	16.07
	Quite a bit	11	19.64
	Very much	16	28.57
Have you had discharge from your vagina?	Not at all	10	17.86
	A little	11	19.64
	Quite a bit	9	16.07
	Very much	26	46.43
Have you had abnormal bleeding from your vagina?	Not at all	21	37.50
	A little	8	14.29
	Quite a bit	14	25.00
	Very much	12	21.43
	Missing	1	1.79
Have you had hot flushes and/or sweats?	Not at all	21	37.50
	A little	12	21.43
	Quite a bit	13	23.21
	Very much	10	17.86
Have you felt physically less attractive as a result of your disease or treatment	Not at all	28	50.00
	A little	5	8.93
	Quite a bit	13	23.21
	Very much	10	17.86
Have you felt less feminine because of your disease or treatment?	Not at all	27	48.21
	A little	8	14.29
	Quite a bit	12	21.43
	Very much	9	16.07

Variable	Categories	Frequencies	Percentage
Have you felt dissatisfied with your body?	Not at all	28	50.00
	A little	12	21.43
	Quite a bit	8	14.29
	Very much	8	14.29
Have you worried that sex would be painful?	Not at all	40	71.43
	A little	4	7.14
	Quite a bit	3	5.36
	Very much	9	16.07
Have you been sexually active?	Not at all	48	85.71
	A little	2	3.57
	Quite a bit	5	8.93
	Very much	1	1.79
Has your vagina felt dry during sexual activity?	Not sexually active	48	85.71
	Not at all	2	3.57
	A little	1	1.79
	Missing	5	8.93
Has your vagina felt short?	Not sexually active	48	85.71
	Not at all	1	1.79
	A little	2	3.57
	Missing	5	8.93
Has your vagina felt tight?	Not sexually active	48	85.71
	Not at all	2	3.57
	A little	1	1.79
	Missing	5	8.93
Have you had pain during sexual intercourse or other sexual activity?			
	Not sexually active	48	85.71
	Not at all	1	1.79
	A little	1	1.79
	Quite a bit	1	1.79
	Missing	5	8.93

8.6 SYMPTOMS AND PROBLEMS EXPERIENCED BY THE PARTICIPANTS, AS THEY OCCURRED DIFFERENTLY

Some of the symptoms were not experienced by the majority of the participants, such as “having blood in stools,” “swelling in one or both legs” and “having tingling or

numbness in your hands or feet" with responses above 50% (n=38/56) However, the most experienced symptoms or problems were "cramps in your abdomen" (48.21%; n=27/56), "difficulty in controlling your bowels" (41.07%; n=23/56); "pain in your lower back" (46.43%; n=26/56) and "having a discharge from your vagina" (46.43%/26/ 56). Most of the women (85.7%; n=48/56)) were not sexually active and therefore did not answer the four questions about symptom experience during sexual intercourse.

8.7 COMPARISONS FOR ASSOCIATION

Table 8.6 presents the comparison of responses of pre- and post-intervention for support received.

The comparisons of the (n=15) participants who completed the pre-test and completed the post tests were conducted based on the suggestions of the statistician as they were the only ones who completed both phases. The records of the pre-tests assessments and post tests were available to make these comparisons.

The comparisons of the participants'(n=15), assessments before and after the intervention for emotional support received. The same participants (n=15), assessed in the pre-test, took part in the post- test phase. Meaning that only n=15, participants were compared. The significant values indicating differences are bolded. (1) Strongly disagree (2) somewhat disagree (3) somewhat agree (4) strongly agree

Table 8.6: Comparison between Pre and Post Intervention Responses(n=15)

Variable	Categories	Pre-intervention n = 15 (%)	Post-intervention n = 15 (%)	Fisher exact P-value
Perceived Emotional Support (PES)				
There are some people who truly like me	strongly disagree	1 (6.67)	0	0.818
	somewhat disagree	1 (6.67)	0	
	somewhat agree	3 (20.0)	3 (20.0)	
	strongly agree	10 (66.67)	12 (80.0)	
Whenever I am not feeling well, other people show me that they are fond of me	somewhat disagree	1 (6.67)	0	1.000
	somewhat agree	2 (13.33)	3 (20.0)	
	strongly agree	12 (80.0)	12 (80.0)	
Whenever I am sad, there are people who cheer me up	somewhat disagree	2 (13.33)	0	0.651
	somewhat agree	2 (13.33)	3 (20.0)	

Variable	Categories	Pre-intervention n = 15 (%)	Post-intervention n = 15 (%)	Fisher exact P-value
	strongly agree	11 (73.33)	12 (80.0)	
There is always someone there for me when I need comforting	somewhat disagree	1 (6.67)	0	1.000
	somewhat agree	2 (13.33)	3 (20.0)	
	strongly agree	12 (80.00)	12 (80.0)	
Perceived Instrumental Support (PIS)				
I know some people upon whom I can always rely on	somewhat disagree	2 (13.33)	0	0.224
	somewhat agree	1 (6.67)	0	
	strongly agree	12 (80.0)	15 (100)	
When I am worried there is someone who helps me	somewhat disagree	1 (6.67)	0	**0.042 ***
	somewhat agree	4 (26.67)	0	
	strongly agree	10 (66.67)	15 (100)	
There are people who offer me help when I need it	somewhat disagree	3 (20.0)	0	**0.006 ***
	somewhat agree	4 (26.67)	0	
	strongly agree	8 (53.33)	15 (100)	
When everything becomes too much for me to handle, others are there to help me	strongly disagree	1 (6.67)	0	0.560
	somewhat disagree	2 (13.33)	0	
	somewhat agree	2 (13.33)	3 (20.0)	
	strongly agree	10 (66.67)	12 (80.0)	
Need for Support (NS)				
When I am down, I need someone who boosts my spirit	somewhat disagree	2 (13.33)	1 (6.67)	0.727
	somewhat agree	3 (20.0)	2 (13.33)	
	strongly agree	10 (66.67)	12 (80.0)	
It is important for me always to have someone who listens to me	somewhat disagree	2 (13.33)	0	0.231
	somewhat agree	2 (13.33)	5 (33.33)	
	strongly agree	11 (73.33)	10 (66.67)	
Before making any important decisions, I absolutely need a second opinion	strongly disagree	2 (13.33)	1 (6.67)	1.000
	somewhat disagree	1 (6.67)	2 (13.33)	
	somewhat agree	2 (13.33)	1 (6.67)	
	strongly agree	10 (66.67)	11 (73.33)	
I get along best without any outside help	strongly disagree	1 (6.67)	5 (33.33)	0.179
	somewhat disagree	4 (26.67)	2 (13.33)	
	somewhat agree	3 (20.0)	5 (33.33)	
	strongly agree	7 (46.67)	3 (20.0)	

Variable	Categories	Pre-intervention n = 15 (%)	Post-intervention n = 15 (%)	Fisher exact P-value
Support Seeking (SS)				
In critical situations, I prefer to ask others for their advice	strongly disagree	1 (6.67)	1 (6.67)	0.791
	somewhat disagree	0	1 (6.67)	
	somewhat agree	1 (6.67)	2 (13.33)	
	strongly agree	13 (86.67)	11 (73.33	
Whenever I am down, I look for someone to cheer me up again	strongly disagree	0	1 (6.67)	0.493
	somewhat disagree	2 (13.33)	1 (6.67)	
	somewhat agree	0	2 (13.33)	
	strongly agree	13 (86.67)	11 (73.33	
When I am worried, I reach out to someone to talk to	strongly disagree	2 (13.33)	1 (6.67)	0.477
	somewhat disagree	1 (6.67)	0	
	somewhat agree	1 (6.67)	4 (26.67)	
	strongly agree	11 (73.33	10 (66.67)	
If I don't know how to handle a situation, I ask others what they would do	strongly disagree	1 (6.67)	1 (6.67)	0.371
	somewhat disagree	3 (20.0)	0	
	somewhat agree	4 (26.67)	4 (26.67)	
	strongly agree	7 (46.67)	10 (66.67)	
Whenever I need help, I ask for it	somewhat disagree	1 (6.67)	2 (13.33)	0.386
	somewhat agree	6 (40.0)	2 (13.33)	
	strongly agree	8 (53.33)	11 (73.33	

Significance $p < 0.05$

8.7.1 Actual support received (n=15) at pre-intervention stage and post-intervention stage. It was noted that there were no statistically significant differences in most of the items asked except for the perceived instrumental support. Significant difference was observed in item, "There are people who offer me help when I need it" and "When I am worried, there is someone who helps me," as all the responses were "strongly agree" in the post-intervention stage.

Table 8.7 presents comparisons of the responses on Actual support received before and after the intervention: (1) strongly disagree, (2) somewhat disagree, (3) somewhat agree, (4) strongly agree

Table 8.7: Actual Receives Support (n=15)

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
Actual Received Support (ARS)				
The person showed me that he/she loves and accepts me	somewhat disagree	1 (6.67)	0	0.100
	somewhat agree	3 (20.0)	0	
	strongly agree	11 (73.33)	15 (100)	
This person comforted me when I was feeling bad	somewhat disagree	2 (13.33)	1 (6.67)	0.397
	somewhat agree	2 (13.33)	0	
	strongly agree	11 (73.33)	14 (93.33)	
This person left me alone	strongly disagree	9 (60.0)	8 (53.33)	0.842
	somewhat disagree	1 (6.67)	0	
	somewhat agree	1 (6.67)	1 (6.67)	
	strongly agree	4 (26.67)	6 (40.0)	
This person did not show much empathy for my situation	strongly disagree	9 (60.0)	7 (46.67)	0.326
	somewhat disagree	2 (13.33)	0	
	somewhat agree	1 (6.67)	1 (6.67)	
	strongly agree	3 (20.0)	7 (46.67)	
This person criticised me	strongly disagree	9 (60.0)	5 (33.33)	0.433
	somewhat disagree	1 (6.67)	2 (13.33)	
	somewhat agree	2 (13.33)	1 (6.67)	
	strongly agree	3 (20.0)	7 (46.67)	
This person made me feel valued and important	somewhat disagree	2 (13.33)	0	0.100
	somewhat agree	2 (13.33)	0	
	strongly agree	11 (73.33)	15 (100)	
This person expressed concern about my condition	somewhat disagree	2 (13.33)	0	0.533
	somewhat agree	2 (13.33)	2 (13.33)	
	strongly agree	11 (73.33)	13 (86.67)	
This person assured me that I can rely completely on him/her	somewhat disagree	2 (13.33)	0	0.095
	somewhat agree	4 (26.67)	1 (6.67)	
	strongly agree	9 (60.0)	14 (93.33)	
This person encouraged me not to give up	strongly disagree	2 (13.33)	0	0.100
	somewhat agree	2 (13.33)	0	
	strongly agree	11 (73.33)	15 (100.0)	
This person was there when I needed him/her	strongly disagree	2 (13.33)	0	0.100
	somewhat agree	2 (13.33)	0	
	strongly agree	11 (73.33)	15 (100.0)	

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
This person took care of many things for me	somewhat disagree	3 (20.0)	1 (6.67)	
	somewhat agree	4 (26.67)	0	
	strongly agree	8 (53.33)	14 (93.33)	**0.044 ***
This person took care of things I could not manage on my own	somewhat disagree	1 (6.67)	1 (6.67)	
	somewhat agree	7 (46.67)	0	
	strongly agree	7 (46.67)	14 (93.33)	**0.006 ***
This person helped find something positive in my situation	somewhat disagree	2 (13.33)	1 (6.67)	0.397
	somewhat agree	2 (13.33	0	
	strongly agree	11 (73.33)	14 (93.33)	
This person suggest activities that might distract me	somewhat disagree	2 (13.33	2 (13.33	0.394
	somewhat agree	4 (26.67)	1 (6.67)	
	strongly agree	9 (60.0)	12 (80.0)	

Significance $p < 0.05$

8.8 DIFFERENCES BETWEEN PRE- AND POST-INTERVENTION TESTING ON ACTUAL RECEIVED SUPPORT (N=15)

Of the 14 items asked under actual received support, 12 items showed no statistically significant difference between the pre-intervention and post-intervention assessments. One item that showed a statistically significant difference was “This person took care of many things for me,” as the “strongly agree” response increased from **53.33%** at pre-intervention stage to **93.33%** at post-intervention stage. The other item with a significant difference was “This person took care of things I could not manage on my own,” as the “strongly agree” response increased from **46.33%** at pre-intervention stage to **93.33%** at post-intervention stage (significant differences bolded in the table).

Table 8.8 presents the comparisons of the participants before and after the intervention for the recipient’s satisfaction with support received and the protective buffering scale for support/provider and support recipient: (1) strongly disagree, (2) somewhat disagree, (3) somewhat agree, (4) strongly agree.

Table 8.8: Satisfaction with Actual Received Support and Protective Buffering (n=15)

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
Perceived Emotional Support (PES)				
Satisfaction with Support Receipt (SWSR)				
In general, I am very satisfied with the way this person behaved	somewhat disagree	2 (33.33)	0	0.201
	somewhat agree	3 (20.0)	1 (6.67)	
	strongly agree	10 (6676)	14 (93.33)	
Protective Buffering Scale (PBS)				
I kept all bad news from him/her	strongly disagree	2 (33.33)	2 (33.33)	1.000
	somewhat disagree	1 (6.67)	1 (6.67)	
	somewhat agree	1 (6.67)	1 (6.67)	
	strongly agree	11 (73.33)	11 (73.33)	
I avoided everything that could upset him/her	strongly disagree	0	2 (33.33)	0.250
	somewhat disagree	1 (6.67)	2 (33.33)	
	somewhat agree	1 (6.67)	3 (20.0)	
	strongly agree	13 (86.67)	8 (53.33)	
I showed strength in his/her presence	strongly disagree	0	2 (13.33)	0.786
	somewhat disagree	1 (6.67)	1 (6.67)	
	somewhat agree	4 (26.67)	4 (26.67)	
	strongly agree	10 (66.67)	8 (53.33)	
I did not let him/her noticed how bad and depressed I really felt	strongly disagree	0	2 (13.33)	0.679
	somewhat disagree	2 (13.33)	1 (6.67)	
	somewhat agree	4 (26.67)	3 (20.0)	
	strongly agree	9 (60.0)	9 (60.0)	
I avoided any criticism	strongly disagree	3 (20.0)	5 (33.33)	0.615
	somewhat disagree	2 (13.33	0	
	somewhat agree	5 (33.33)	5 (33.33)	
	strongly agree	5 (33.33)	5 (33.33)	
I pretended to be very strong although I did not feel that way	strongly disagree	0	2 (13.33)	0.585
	somewhat disagree	1 (6.67)	1 (6.67)	
	somewhat agree	3 (20.0)	4 (26.67)	
	strongly agree	11 (73.33)	8 (53.33)	

Significance $p < 0.05$

In Table 8.9 the assessment of the participants responses before and after the intervention for the recipient's satisfaction with support received and the protective buffering scale for support/provider and support recipient showed no statistically significant differences.

8.9 SYMPTOMS AND PROBLEMS EXPERIENCED BY PATIENTS BEFORE AND AFTER INTERVENTION

Table 8.9 presents comparisons of the symptoms experience at pre- and post-intervention (n=15) of the same participants.

Table 8.9: EORTC QOQ-CX 24: Symptoms or Problems Experienced by Patients before and after Intervention Assessments (n=15): (1) Not at all, (2) A little, (3) Quite a bit, (4) Very much

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
Have you had cramps in your abdomen	Not at all	3 (20.0)	9 (60.0)	**0.022 ***
	A little	2 (13.33)	2 (13.33)	
	Quite a bit	4 (26.67)	4 (26.67)	
	Very much	6 (40.0)	0	
Have you had difficulty in controlling your bowels	Not at all	6 (40.0)	5 (33.33)	**0.021***
	A little	1 (6.67)	4 (26.67)	
	Quite a bit	0	4 (26.67)	
	Very much	8 (53.33)	2 (13.33)	
Have you had blood in your stools (motions)	Not at all	14 (93.33)	9 (60.0)	0.127
	A little	0	2 (13.33)	
	Quite a bit	0	2 (13.33)	
	Very much	1 (6.67)	2 (13.33)	
Did you pass water/urine frequently	Not at all	6 (40.0)	10 (66.67)	0.401
	A little	1 (6.67)	0	
	Quite a bit	5 (33.33)	4 (26.67)	
	Very much	3 (20.0)	1 (6.67)	
Have you had pain or a burning feeling when passing water/urinating?	Not at all	8 (53.33)	5 (33.33)	0.331
	A little	3 (20.0)	1 (6.67)	
	Quite a bit	1 (6.67)	4 (26.67)	
	Very much	3 (20.0)	5 (33.33)	

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
Have you had leaking of urine	Not at all	11 (73.33)	9 (60.00)	0.308
	A little	3 (20.0)	1 (6.67)	
	Quite a bit	1 (6.67)	3 (20.0)	
	Very much	0	2 (13.33)	
Have you had difficulty emptying your bladder	Not at all	11 (73.33)	7 (46.67)	0.169
	A little	0	4 (26.67)	
	Quite a bit	3 (20.0)	2 (13.33)	
	Very much	1 (6.67)	2 (13.33)	
Have you had swelling in one or both legs?	Not at all	9 (60.0)	12 (80.0)	0.545
	A little	3 (20.0)	1 (6.67)	
	Very much	3 (20.0)	2 (13.33)	
Have you had pain in your lower back	Not at all	5 (33.33)	6 (40.0)	0.240
	A little	1 (6.67)	1 (6.67)	
	Quite a bit	0	3 (20.0)	
	Very much	9 (60.0)	5 (33.33)	
Have you had tingling or numbness in your hands or feet?	Not at all	13 (86.67)	7 (46.67)	0.109
	A little	1 (6.67)	4 (26.67)	
	Quite a bit	1(6.67)	2 (13.33)	
	Very much	0	2 (13.33)	
Have you had irritation or soreness in your vagina or vulva?	Not at all	8(53.33)	2 (13.33)	**0.031***
	A little	0	3 (20.0)	
	Quite a bit	5 (13.33)	4 (26.67)	
	Very much	2 (13.33)	6 (60.0)	
Have you had discharge from your vagina?	Not at all	4 (26.67	4 (26.67	0.640
	A little	4 (26.67	2 (13.33	
	Quite a bit	3 (20.0)	2 (13.33	
	Very much	4 (26.67	7 (46.67)	
Have you had abnormal bleeding from your vagina?	Not at all	6 (40.0)	11 (73.33)	0.131
	A little	2 (13.33	3 (20.0)	
	Quite a bit	4 (26.67	1 (6.67)	
	Very much	3 (20.0)	0	
Have you had hot flushes and/or sweats?	Not at all	7 (46.67)	8 (53.33)	1.000
	A little	3 (20.0)	2 (13.33	
	Quite a bit	2 (13.33)	2 (13.33	
	Very much	3 (20.0)	3 (20.0)	

Variable	Categories	Pre-intervention n=15 (%)	Post-intervention n 15 (%)	Fisher exact P-value
Have you felt physically less attractive due to your disease or treatment	Not at all	9 (60.0)	7(46.67)	0.190
	A little	1 (6.67)	0	
	Quite a bit	2 (13.33	7 (46.67)	
	Very much	3 (20.0)	1 (6.67)	
Have you felt less feminine due to your disease or treatment?	Not at all	9 (60.0)	7 (46.67)	0.289
	A little	3 (20.0)	1 (6.67)	
	Quite a bit	1 (6.67)	5 (35.71)	
	Very much	2 (13.33	1 (6.67)	
	Missing	0	1 (6.67)	
Have you felt dissatisfied with your body?	Not at all	8 (53.33)	7 (46.67)	0.502
	A little	3 (20.0)	1 (6.67)	
	Quite a bit	2 (13.33	5 (35.71)	
	Very much	2 (13.33	1 (6.67)	
	Missing	0	1 (6.67)	
Have you worried that sex would be painful?	Not at all	11 (73.33)	9 (60.0)	0.632
	A little	0	1 (6.67)	
	Quite a bit	1 (6.67)	3 (20.0)	
	Very much	3 (20.0)	2 (13.33)	
Have you been sexually active?	Not at all	13 (86.67)	14 (93.33)	0.483
	A little	0	1 (6.67)	
	Quite a bit	2 (13.33)	0	

Significance $p < 0.05$

The statistically significant differences between the pre-intervention and post-intervention on the following symptoms and problems were reported by the participants in “having an irritation or soreness in your vagina or vulva,” “having difficulty in controlling your bowels” and “having cramps in the abdomen.” The changes regarding the symptoms experience, would be reported as either worsening or improvement as treatment progressed. Meaning that the changes noted during the pre- intervention phase and post intervention were likely to change as treatment progressed.

8.10 SUMMARY

The results of Phase 2 of the study presented the outcome of a programme to support women receiving curative treatment for cervical cancer. The study was conducted in the

same setting as Phase 1; however, participants in the first week of treatment meeting the inclusion criteria (3.8.1), were included. Structured interviews for the pre –and post–tests were conducted using the validated tools Berlin Social support Scale and EORTC QOQ-CX- 24 with permission from the authors. More than 50% of the participants (n= 28/56) were partnered, with more than 16% in a marital relationship, however more than 32% were single. Most of the participants attained an educational level above grade 8-12. The majority were employed as day workers with most of their partners unemployed. Most participants had more than 2-3 children. The Statistical package for the Social Sciences version 22 (SPSS22), using Chi-square was used to compare the differences on participants' experienced support, symptom improvement and quality of life. Due to only fifteen participants completed the post-test, they were eligible for a comparison of their pre-test responses to determine the significant differences in both their scores. The comparisons will be reported on, in detail in the next chapter.

The study demonstrated its potential to improve the participants' perception of being supported. Chapter 9 will discuss the findings of the qualitative phase 1, the scoping review of studies conducted to support women treated for gynecologic cancers and results from the quantitative phase 2.

CHAPTER 9

9. DISCUSSION OF THE FINDINGS, SCOPING REVIEW AND THE RESULTS OF THE STUDY

9.1 INTRODUCTION

This chapter will discuss the findings of the study. The findings of the study are informed by the needs highlighted by the participants who received curative treatment for cervical cancer at an Academic hospital. A scoping review to determine the availability of the programmes to address the needs of women treated for gynecologic cancers. The scoping of the studies provided evidence that despite availability of the programmes, they were developed in other contexts not representative of the African context. This called for the development of the support programme that addressed needs highlighted and relevant to the African contexts. A schematic representation of the process shown in Figure 9.1

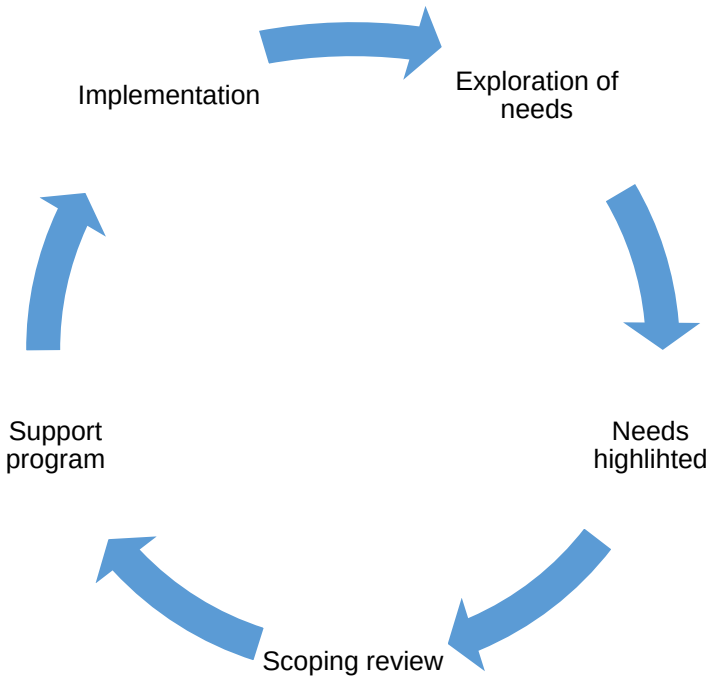

Figure 9.1: Schematic Presentation of the Results of the Study

9.2 DISCUSSION OF FINDINGS OF PHASE 1 OF THE STUDY

Fourteen of the (n=22), participants (25%) were between the ages 41-50 years, followed by the ages 51 years-and above (37.5%; n=21). The finding from the study confirmed what was found in the studies conducted in Tshwane (Maree et al., 2013; Sabulei & Maree, 2019), where most women's ages ranged from 40 years and above. The fact that most women in the study; were above 40 years confirms what is reported in previous studies, that cervical cancer affects women at the most crucial time in their lives, when they are contributing to the economic stability of their families (Moodley, 2009; Anorlu, 2008). Four of the women were within the age range of 31-40 years, which is of grave concern as this age group are within the target range recommended for free screening offered through primary healthcare (Maree et al., 2012). Further, this confirms that screening is still underutilised within these communities in the low- and middle-income countries in South Africa (Snyman & Herbst, 2013).

Four of the 22 participants were married under civil law, while five(n=5/22) were culturally married, which is recognisable under customary law in South Africa. One participant was in a cohabiting relationship, while five were widowed, one (n=1) was in a stable relationship. The finding from the study confirms what other studies conducted with patients diagnosed with cervical cancer reported, where the majority of the sample were married (Satwe et al., 2014; Maree et al., 2013; Snyman et al., 2013), whilst five were widowed, suggesting that most participants in the study had been married. This finding from the study contrasts that of of Dzaka and Maree (2016), in a study on a cervical cancer population where the majority of women were single or in a cohabiting relationship with their partners (Moore & Govender, 2013; Budlender et al., 2004).

Thirteen (n=13/22) participants were in day employment, whilst only three were in full employment, two received a pensioner's grant and four were unemployed. Participants' income ranged from R1-R6001. Eight participants received an income of R1000-R2000, whilst four received an income ranging between R2001-R2500, two earned an income between R2501-R4000, one (n=1) received R4001- R6000, and only two (n=2) earned above R60001; whilst five of the participants had no source of income. Although some of the participants were partnered, only five of the partners were in day employment.

The finding that most of the participants (n=13/22), were the sole breadwinners and responsible for providing the family income is not new, as the majority of South African women in this situations however, they are not allowed to exercise combined control of pooled resources (Denny, 2006).

Most participants(n=10) had a diagnosis of stage IIB cervical cancer, followed by stage IIIB (n=10), and one was stage IIA, and another had stage IIIA. Fourteen of the participants presented with squamous cell carcinoma, one (n=1) presented with adenocarcinoma, and seven (n=7) presented with other types of cervical cancers.

The aim of phase 1 of the study was to explore how women receiving curative treatment for cervical cancer including radiation preferred to be supported. It is evident that women faced various challenges during the trajectory of cancer. Although knowledge of cervical cancer was not explored in this phase, this emerged as an incidental finding as women reported their reasons for accessing health care prior to being diagnosed with cervical cancer. However, lack of knowledge of cervical cancer has been previously reported in other studies conducted on the topic (Maree et al. 2013; Moodley, 2009). Due to the route travelled by participants in an attempt to seek treatment when they became aware of abnormal symptoms, their experiences included the primary and secondary care facilities, where they first consulted as they had an impact on how they perceived the support encountered, as either negative or positive.

Only two cultural groups were prominent in this phase; ten were Zulu speaking, followed by South Sotho. However, it is not clear if women from certain cultural groups are prone to cervical cancer (Maree & Wright, 2010). Although similar trends were noted in other studies, the majority of the participants in the study were Black (Issah, Maree & Mwunituo, 2011; Mosavel et al., 2009; van Schalkwyk, Maree & Wright, 2008).

Most participants (n=17), were from the urban areas, with only five from rural areas. This finding from this study contrasts what other studies conducted on women diagnosed with cervical cancer, found where rural women formed the majority (Mosalo, 2011; Van Schalkwyk et al., 2008). What the researcher ascertained during the interviews was that

some of the participants moved in with families in order to access specialised care in the urban setting. The trend of moving in with families is not new to the researcher, as from experience of working in the healthcare and oncology wards, relatives encouraged loved ones to move in with them in an attempt to source specialised care.

The finding that almost all participants were Black; is in line with the general population trend and the fact that cervical cancer is the most common cancer in Black women (Cancer Registry, 2016). In addition, this finding asserts what Maree et al. (2013) reported, where it was found that public sector caters for most of the population, who are not covered by the health insurance.

Seventeen participants consulted the healthcare facility when they observed abnormal symptoms, even though they did not relate this to cervical cancer. This finding from the study concurs with that of van Schalkwyk et al. (2008), where women approached a healthcare facility once they discovered abnormal symptoms; only a few went for a routine Pap smear. However, this contrasts what Mosalo (2011) found in a study conducted in Tshwane, to explore how women perceived their life partner support. Women consulted traditional healers or health care chosen for them before they could visit health care facility. This is not new especially in Sub-Saharan Africa, as women will only approach a healthcare facility when experiencing disease symptoms despite that routine screening is afforded from the primary health care facilities. This confirms what Denny and Anorlu (2012), found that Black women would approach a healthcare facility only when they suspected something was wrong. The participants in this present study did not associate their symptoms with cervical cancer, which confirms findings from similar studies, where women lacked knowledge of cervical cancer and the symptoms (Issah, Maree & Mwunituo, 2011; Mosalo, 2011). The participants were confronted with various situations at the care facilities and staff actions.

What was of concern was that some of the participants felt that they were failed by the system, as they consulted the care facilities several times before being diagnosed with cervical cancer (Schalkwyk et al., 2008). However, others resorted to consulting private health facilities in order to speed up the process of being helped. Furthermore, the

participants reported having to repeat procedures or change healthcare facilities as they could not receive results of the tests undergone, as these were lost in transit narrated as follows:

“I went to our clinic last year for Pap smear. Then was referred to the hospital. Unfortunately, the hospital on my side delayed with the results, so then I decided on my own to go to a private gynae doctor”.

The finding from this phase of the study concurs with what Mosalo (2011) found in a study conducted in Tshwane, where women were subjected to repeated procedures or having to consult other facilities due to missing results. This reflects poorly on the care women received, as travelling brought its own challenges due to the distance and lack of financial means to reach the care facility.

Almost all the participants in this phase of the study approached a primary or secondary care facility once they became aware of abnormal symptoms. As confirmed by the following:

“*They called an ambulance that took me to the hospital, where I was examined, and they took bloods”*.

Some felt that staff at the care facilities were not sensitive evidenced by “*the doctor who admitted me on that day was thinking that I was coming to deliver, because they felt like the baby is near, and that time It was only five (5) months(meaning stage of pregnancy). He asked that the sister call another doctor, he then said that he thinks that it’s cancer it is not a baby, meanwhile they were talking among themselves*.

Some of the women were not informed of their diagnosis, as they only learned of their illness when the doctors discussed amongst themselves. Similarly, once informed of the illness, they had to rely on information from others who knew very little pertaining to the illness. The participants reported being fearful and unsettled, as they did not know what to expect with regard to the illness or treatment. This finding from the study confirms further what Maree et al. (2013) found, where women lacked knowledge of cervical cancer and its treatment, however they found themselves having to rely on others who also had no knowledge, or knew very little about the disease, narrated as follows:

"From the time that you've been here, you hear a lot of things from the others (implying other patients). Others will say hey, the treatment is painful, so, so, so!! others also tell us that some have abandoned treatment – as we talk. Some even say you know that person is no more, such things".

The participants received confirmation of the disease in isolation, leaving them with the responsibility of informing their loved ones about their plight. This finding is similar to the study of Maree et al. (2013), where participants had to inform the loved ones of their illness; meanwhile they did not know what to tell them about their situation. In addition, the participants felt that they would appreciate more information pertaining how the disease develops, what are the causes, and the signs one needs to be aware of in order to present timeously at a healthcare. This finding from the study is common to other studies conducted on similar population, where women expressed the need to be informed about the disease (Mosalo, 2011).

Although the participants reported that they received counselling, after being informed of the disease, this was not perceived as such by some; as they reported that instead they were informed about care of the treatment sites, whilst others were informed about the appointments to begin the treatment. It is still clear that counselling is an issue that is not clearly addressed.

The participants' were left with emotional concerns, as they expressed the need to have a health practitioner available at the radiation department (*waiting area*) to enquire about their concerns, as they were confronted with changes they did not know how to deal with. Some even felt that staff lacked empathy and were not sensitive to their pleas as they faced the trajectory of cancer. Women could not continue with their day employment, as they had to undergo treatment for six weeks or more. However, there were still concerns as most were breadwinners in their homes, and the challenge of not being able to provide had an impact on their quality of life. Most patients were treated as outpatients, which meant they needed to travel from their different destinations in order to get transport from primary care facilities so that they could be transported to the specialised care facilities. Indeed, women were challenged, as they needed to use taxis

(*cab*) or make other plans to reach hospital transport in order to be on time for commuting to the specialised care facility.

Although some of the hospitals provided food, this was not the case for all patients. Some even reported that they had to make their own provision for food and transport, which increased the burden on their limited finances. Some felt the staff at the hospital had so much to do that they did not wish to burden them with their problems; seemingly most went for their treatment and left without reporting their concerns so they could be referred for some form of assistance.

Of note was that patients relied on information from others (patients) who had been in the system for some time. Patients reported feeling anxious and wanting to abandon the treatment, whilst others felt that being in the group consoled them, as they noted that they were not alone. Patients expressed the need to have a professionally led support group so that they could adapt to the situation and complete the treatment. Although spirituality was not explored as part of the support, it was evident that some women sought support from their church members and it sustained their hope and ability to cope with the illness (Mesquita et al., 2013), whilst others also felt that God sustained their hope to get better. The finding asserts what Meraviglia (2006) reported; that women relied on their spirituality to sustain their hope during the trajectory of facing a cancer diagnosis. This finding calls for further investigation as to how women utilises spirituality during a cancer diagnosis as this can also give women a perception that they are supported (Denewer et al., 2011). Whilst the recommendations from this phase of the study informed how women needed to be supported, it led the researcher to conduct a scoping review to determine if there were programmes that could be used.

9.3 DISCUSSION OF THE SCOPING OF STUDIES TO SUPPORT WOMEN TREATED FOR GYNECOLOGIC CANCERS

The scoping review was intended to identify studies developed to support women treated for gynecologic cancers, to determine the scope of studies and mapping methods and reporting on evidence. Only one study (n=1) met inclusion from searching the databases;

whilst five (n=5) were selected from the reference list of other studies. This totalled to six (n=6), however after reading the full text of all the studies only four (n=4) qualified for inclusion in the scoping review. Two (n=2) other studies were excluded, although they were concerned with cancer support groups, as they did not include cervical cancer population. Of all the studies (n=4) reviewed, none had a clearly specified research question. The researcher was left with the task of searching for the questions to which the methodologies responded. Whilst each study had a clearly focused purpose or aim, the approaches identified for each seemed to align with the data collection methods specified. Participants in the studies were cancer populations. All the studies (n=4) reviewed were led by professional nurses with experience in cancer care, with other professionals involved in consultative roles.

All of the studies (n=4) aimed to support cancer populations at some point during the illness trajectory, as it is well known that in addition to living with a cancer diagnosis, women confronted with diagnosis of gynaecologic cancers are faced with significant psychosexual and psychosocial issues (Schofield et al., 2013). Although literature is rife with studies to support patients diagnosed with cancer, studies supporting women diagnosed with gynaecologic cancers are few. Most studies supporting this population were from the developed countries (Sekse et al., 2014; Scofield et al., 2013; Todd et al., 2002). The scoping review for the current study aimed to present evidence on studies included in this scoping review.

Two of four studies (Carlsson & Strang, 1998; Li et al., 2014), included patients and next of kin. The study of Carlsson and Strang (1998), involved gynaecologic patients at different stages of the disease, whilst Li et al. (2014) involved patients with early stage cervical cancer. However, it was not clear in the study of Carlsson and Strang (1998), which gynaecologic cancers, did the patients received treatment for, and which treatment methods were utilised. An important issue was that participants were encouraged to deliver questions that formed the bases for psycho-educational support (Krishnasamy, 1998). Doctors and a dietician conducted three of the seven sessions in the study of Carlsson and Strang (1998). This supports findings of the study of Schofield et al. (2013), conducted in Australia, where a multidisciplinary team approach in support

of patients with gynaecologic cancers has been linked to improved patient outcomes. However, it is unclear which aspects of the programme the nurses facilitated.

Another of the studies (one of four) by Li et al. (2014) focussed on home-based nurse-led supportive care on quality of life and family care. This is also another study that took cognisance of family into the picture, which shows importance of including the family as part of support. The study exclusively addressed patients diagnosed with early stage cervical cancer. The treatment for these patients was mainly surgery, no chemotherapy or radiation. Similarly, the programme did not address issues of patient involvement in development of the said programme; however, multidisciplinary team members were part of the programme. In addition, validated tools were used in the study.

The study of Sekse et al. (2013) conducted in Norway, which was an education and counselling study, was led by nurses with involvement of other health professionals. This finding confirms the importance of multidisciplinary care approach, which helps to improve patient outcomes. However, it is not clear what role the nurses played in the programme as the external professionals presented topics according to relevance? Furthermore, it is not clear how the programme was developed, whether there was an enquiry into the needs of the population, or how the needs of this population were determined. Considering the use of the theories as reported in the study (Antonovsky's Salutogenic Theory and Roger's Client-Centred Theory), one is left to ponder whether these informed the development of the programmes.

Two of the four studies intended to address psychological counselling (Carlsson & Strang, 1988; Chow et al., 2014). The study of Chow et al. (2014) consisted of a psycho-educational programme delivered prior to surgery, during and after. It is reported that three of the four sessions were facilitated by a registered nurse involved in the care of oncology patients, however, the programme was informed by a systemic review conducted by the researcher (Chow et al., 2014). No mention was made of the enquiring into the needs of the identified patients, which in this case was contrary to what literature suggested (Krishnasamy, 1998). Literature cautions of support that may be intended to support, while patients may not perceive it that way.

Other programmes were developed from other contexts that were also not representative of Africa, such as studies by Liao, Chen and Chen et al. (2009) and Chou, Lee-Lin and Kuang (2016). It is clear that the programmes in this scoping review aimed at a variety of needs, as two were rehabilitative in nature (Li et al., 2016; Chow et al., 2014). Two of the programmes (Sekse, et al., 2014 & Chow et al., 2014), addressed psychosocial issues.

Another important point was that three of the studies utilised validated scales/questionnaires. Carlsson et al. (1998) utilised the short version of Profile of Mood State (POMS), and an instrument developed for the study informed by literature, authors' experience, and a senior gynaecological oncologist to validate the questionnaire. The study of Li et al. (2016) utilised the Functional Assessment of Cancer Therapy for Cervical Cancer - Chinese version (FACT-Cx), the Female Sexual Function Index (FSFI), Chinese translated, and a family function was assessed using Adaptability and Cohesion Scale, second edition (FACES-II). The study of Chow et al. (2014) utilised the Chinese version of Sexual Function - Vaginal Changes Questionnaire (SVQ), and quality of life was measured using the Traditional Chinese version of Functional Assessment of Cancer Therapy - General (TCHI FACT-G) version 4. The Chinese version of Mishel's Uncertainty in Illness Scale (C-MUIS) measured perceived uncertainty, and the Chinese version of Hospital Anxiety and Depression Scale (HADS) assessed anxiety and depression levels in participants. To measure perceived social support among gynaecological patients, the Chinese version of Medical Outcomes Study Social Support Survey was used (MOS-SSS-C). The scoping review gave an indication that all studies were professionally led, with nurses being involved in all. However, some studies did not clarify the role the nurses played. What is encouraging is that three of the studies used validated scales in their support programmes. However, these programmes were developed in contexts not representative of Africa. The guidance from the scoping provided evidence of a need to develop a support programme based on the needs identified by the women in the study. Once the support programme was developed, experts involved in day-to-day care of the patients treated with radiotherapy were involved to validate it. The programme was pilot tested with similar population. The results of the implemented programme will be presented in the next section.

9.4 DISCUSSION OF THE RESULTS FOR PRE- AND POST -TESTS

The results of this phase study present the outcome of a programme to support women treated for cervical cancer at the same setting as phase 1 of the study. The Statistical Package for the Social Sciences version 22 (SPSS22), using Chi-square was used to compare the differences of participants' experienced support, symptom improvement, and quality of life.

Ten of the 56 participants (37.50 %) had between four and five children, followed by twenty-six (44.06 %) with two to three children. This finding from the study confirmed what other studies found (Satwe et al., 2014; Jensen et al., 2013; Moodley, 2009), where high parity exposes the woman to the risk of developing cervical cancer.

Most participants came from urban areas (n=44/56; 78.6%). The finding from this phase of the study supports what is reported by Sabulei and Maree (2019), in a study to explore the quality of life of women treated for cervical cancer in which the majority of participants were from urban areas. However, this contrasts the findings of other studies, conducted in similar populations, were most of the participants were from the rural areas (Snyman & Herbst, 2013; Mosalo, 2011). Also that more than 37.5 % (n=21/56) of the participants in the study had more than four children is not new as multiparty has been cited as one of the risks for the development of cervical cancer (Jensen, Schmeidel, Norrild et al., 2013; Anorlu, 2008; WHO, 2006 .

That most of the participants were Zulu (n=19; 33.9%), and South Sotho (n=10; 17.86%) speaking was not unusual in the setting as specific cultural groups reside within a certain geographical area, as noted in phase 1 of the study; despite this, participants were from different cultural groups. It was also noted that the sample consisted of mostly Black women (77%) including those who are migrants. Finding that the majority of the women diagnosed with cervical cancer was Black has also been reported in studies conducted on similar populations (Jordan et al., 2016; Snyman & Herbst, 2013; Mosavel et al., 2009). Furthermore, 13 of 56 (23.21%) from other cultural groups were recorded as others; possibly because migrant groups may be employed close to the facility and some may have been transferred from other satellite hospitals.

The proportion of the participants in a certain age group increased, as generally most of the participants were above 31 years; whilst the majority were in the ages 51 and above, with only one (1.79%) below the 18-25 age group. The finding from the study that most participants (n=21/56; 37.5%) were aged 50 and above supports what was reported in other studies conducted in cervical cancer population (Sabulei & Maree, 2019; Moodley, 2009). The concern is that (n=25/56; 45%) were within the ages 31-50, which is the age recommended for free screening based on the Department of Health's policy (Botha & Dreyer, 2017). Another reason that could have prevented women from going for screening was that women in these age groups are the ones supporting their families financially; hence, they faced challenges of losing a day's earnings going for screening (Ashing-Giwa et al., 2004). The finding that only one participant (1.79%) was present in the age group 18-25 was incidental, as the researcher did not enquire the finding could be speculated from early coitarche, which is a risk factor for developing cervical cancer (van Schalkwyk et al., 2008; WHO, 2006; Dunleavey, 2009).

More than 50% (n=28/56) of the participants had an official partner. Among the group with partners, 16.1% (n=9/56) were married according to civil law while 14% (n=8/56), were culturally married. In South Africa, customary law is still recognised as marriage, while 7.4% (n=4/56) were cohabiting. The finding from this study supports what is reported in the study of Maree et al. (2013), where most of the women were partnered. The fact that some of the women were in a co-habiting relationship supports the finding from the study of Mosalo (2011), conducted in Tshwane, which explored women's perception of partner support, where woman were probably in the relationship in order to benefit from resource pooling and the financial support.

Most participants attained Grade 8-12, as shown by the high percentages of grade 8-10 (25%; n=14/56) and Grade 11-12 (26.8%; n=15/56). Although participants in this phase attained grades above 8-12, their literacy level regarding health information was not explored. However, based on the literature it is assumed their literacy could be below that suggested for functional health literacy of grade 6-grade 8 (Williamson et al., 2016; Garbers & Chiasson, 2004). This is further supported by findings of the studies conducted with cervical cancer populations where participant's literacy was low (Snyman

& Herbst, 2013; Baillie, Pick & Cooper, 1998). The recommendation for health-related information is that it should be prepared at reading grade level 6 to grade 8 (Simmons et al., 2017; Williams, Muir & Rosdahl, 2016; Badarudeen & Sabharwal, 2010; Singh, 2003).

In total, 33.93% (n=19/56) of participants were day workers, with 12.50% (n=7/56), earning between R4001-R6000 per month, and 20% in full employment. The finding from this phase of the study that most participants were breadwinners supports the findings of Anorlu (2008), where it was reported that women contribute to the financial stability of their families. However, Denny (2006), reported that despite that women contribute to the household finances, they did not have control over pooled resources to run the household. The majority of the partners were not employed (55.4%; n=31) or earning equivalently to the participants within a range of R4001-R6000 per month (12.5%). Most of the participants (71.43%; n=40/56), had stage IIB cancer and mainly of squamous histology, whilst 16% (n=9/56) had adenocarcinomas.

The Berlin Social Support Scale displayed in Table 8.2, presents results of different levels of support measured. Approximately 70% (n=39/56), of the participants indicated, “strongly agree” to the perceived emotional support (PES). Fourteen (38%/n=21/56) of those who indicated perceived emotional support were married, whilst 11 (30%) were single. The fact that 38%; 21/56 perceived strong emotional support is positive and could be that married woman have support of partners, as well as family members (Chen et al., 2013; Maree et al., 2013; Isaksen et al., 2003). The finding from this phase of the study echoes what is reported by Izugbara and Undie (2008), in a study conducted in Nigeria, where ownership of the body is viewed in context of the wider community rather than the individual. A reasonable 30% of single women also reported positive support from families and significant others, asserting what was reported in studies where families serve a supportive role in case of illness (Mosalo, 2011; Chan et al., 2001).

Approximately 66%; n=37/56 of the participants indicated, “strongly agree” to the perceived instrumental support (PIS). Of interest was that participants who reported positive instrumental support were within the age range 40 and above. The difference in

the perception of instrumental support could be that needs for support shifts as the trajectory of cancer progresses; however, it may also be that younger participants view support in a different light, as it may not be deemed relevant to what is needed at the time (Hlebec, Mrzel & Kogovšek, 2009;Tempelaar et al., 1998). It is crucial to delineate from which network is the support provided and how is it perceived by the intended recipient? (Hlebec et al., 2009; Bloom & Spiegel, 1984). It is necessary to consider the cultural aspects from which the support is defined, its reciprocal aspect, and context within which the support is viewed.

On average, 62.9% of the participants indicated, “strongly agree” to the need for support (NS**).** The finding that most participants strongly expressed need for support is not new in this population of patients (Dunkel-Schetter, 1994). The assumption is that support is always beneficial in times of stress where it is assumed to buffer stressful life events (Ozkan & Ogce, 2008; Krishnasamy, 1996). The finding that more than 60%(n=34), of the participants expressed reaching out for needed support can be attested to the fact that cancer patients tend to be stigmatised in some communities, leading them to seek support outside their networks (Cheng et al., 2013; Ashing-Giwa, 2004). This was not enquired in this study, as the structured questionnaires used were borrowed from other settings not representative of the context where the study was conducted. In the African culture, the philosophy of “Ubuntu” is the cornerstone that emphasises connectedness among families and different cultures (Ross & Deveral, 2004). It is not surprising that family were involved when dealing with stressful events such as cancer. It is also common in African culture that elder women or elder daughters are expected to offer support during an illness trajectory. The finding from the study confirms what is reported from studies on cancer populations (Cheng et al., 2013; Chan et al., 2001), where family, spouse and children are viewed as the primary source for support.

On average, 63.9%; n=36 of the participants indicated, “Strongly agree” to support seeking (SS). However, in the support seeking: - item; “If I don’t know how to handle a situation, I ask others what they would do,” all the indicated responses were below 50%. This finding from the study is common, as in some African cultures, disclosure about

certain illnesses such as cancer is kept within the household versus western counterparts who will openly disclose their illness (van Schalkwyk et al., 2008).

Considering the actual received support (ARS) items on the Berlin Social Support Scale, the pre-testing phase of the study found 11 (85.7%) of the 14 items had the highest scores (strongly agree). Three items, namely “This person left me alone” and “This person criticised me,” had highest scores (51.79%), respectively in the “strongly disagree” category whilst “This person did not show empathy for my situation” (50%) also had a high score. The finding that participants report positively on actually received support contrasts with the findings of the study conducted by Maree et al. (2013), where some of the participants did not experience similar support.

The majority of the participants (73.21%; 41/56) indicated a “strongly agree” response on the recipient’s satisfaction with support received. The protective buffering scale showed that most participants (50%; 28/56) chose the “strongly agree” response in this study on 5/6 items asked, except for the “I avoided any criticism” item, with all responses below 50%. The finding that most participants chose “strongly agree” to protective buffering is subject to many interpretations, as using existing questionnaires that could not be adapted, did not provide the researcher with an opportunity to inquire how participants interpreted the protective buffering based on their culture and the context were the study was conducted. Of note was that referring to perceived instrumental support, older participants in ages above 40+ were reportedly reporting on the positive, whilst younger participants did not have the same experiences. This statement calls for further research on different aspects of support within Sub-Saharan contexts, with attention to how the different cultural groups negotiate support within their subgroups.

Some of the symptoms and problems investigated occurred differently among the participants. Some of the symptoms, such as having blood in stools, swelling in one or both legs and having tingling or numbness in the hands or feet were not experienced by most of the participants. This could be due to the different stages of the disease. The most common symptoms experienced were cramps in the abdomen (48.21%; 27/56), difficulty in controlling your bowels (41.07%;23/56), pain in in the lower back (46.43%;

26/56) and having a discharge from the vagina (46.43%;26/56). Having these symptoms are not unique to this population, however, these are commonly presenting symptoms for cervical cancer (Mosalo, 2011; van Schalkwyk et al., 2008; WHO, 2006).

Comparing the perceived emotional support, perceived instrumental support, need for support, and support seeking between same individuals at pre-intervention stage and post-intervention stages, no significant differences were noted in most of the items asked, except for the perceived instrumental support. Significant differences were observed on items “There are people who offer me help when I need it” and “When I am worried, there is someone who helps me” when all the responses were “strongly agree” in the post-intervention stage. This meant that the participants had a strong perception of receiving instrumental support. The observation was that the responses at pre-intervention, 53.3% (n=8), indicated strongly agree for the category “There are people who offer me help when I need it”; however a significant improvement was noted at post -intervention when all responses (n=15:100%) were “strongly agree.” These changes were noted among single women who initially were (n=2) at pre-intervention increased (n=5) at post-intervention. This could imply that women benefitted based on information attained during the programme.

Of the 14 items asked under actual received support, 12 items responses showed no significant differences between the pre-intervention and post-intervention assessments. One item which showed a significant difference was the “This person took care of many things for me,” where the “strongly agree” response increased from 53.33% at pre-intervention stage to 93.33% at post-intervention stage. Significant changes were observed among single women (n=1/5) at pre-intervention, to (n=4/5) at post intervention. Another item showing significant difference was “This person took care of things I could not manage on my own” with the “strongly agree” response increasing from 46.67% (n=7) at pre-intervention stage to 93.33% (n=14) at post-intervention stage. Although the participants in this group were prone to receive some kind of support prior to attending the programme, a statistically significant increase in the responses after attending the programme were noted. This could be due to the reason that the participants perceived the support from significant others in a different light, however,

after being part of a professionally led support group their views changed, possibly due to the change regarding the information received regarding disease, treatment, and its side effects. Equally, the presence of a health professional whom they could trust and ask questions relating to their illness and feeling supported was an added benefit for the participants (Chow et al., 2014; Sekse et al., 2013; Carlsson & Strang, 1998).

Being with people with similar experiences, where woman could express their sense of loss or isolation without being judged, created healing spaces, where they could openly discuss issues pertaining to their illness (Sekse et al., 2013; Chow et al., 2014).

With regard to significant differences between the pre-and post-intervention, on the symptoms and problems experienced by the participants; having irritation or soreness in the vagina or vulva, having difficulty in controlling your bowels and having cramps in the abdomen, the change in the participant's symptoms could be mainly due to effects of radiation treatment; however this is speculated due to the restrictive structured nature of questionnaires.

A limitation regarding sexuality is that participants treated at the facility are advised to refrain from sex once the treatment commences. It is not clear what the outcome of sexuality could have been if participants were allowed to continue with their sexual lives as before treatment which left the researcher pondering.

Due to the limited period of the programme, further research is needed to determine how women fared post-treatment, taking into consideration the effect of the programme as well.

9.5 SUMMARY

The results of phase one of the study informed the needs of women receiving curative treatment for cervical including radiation. This led to scoping of the studies developed to support women treated gynecologic cancer. The scoping review provided evidence that no studies were available from an African context. However, studies available were developed from other context not representative of Africa, leading to the development of

a programme based on the needs identified by women receiving curative treatment for cervical cancer at the specific Academic Hospital. The programme was pilot tested on a similar population treated at the same setting. Chapter 10 will present a justification for the study, limitations and the recommendations.

CHAPTER 10

10. JUSTIFICATION FOR THE STUDY, LIMITATIONS AND RECOMMENDATIONS

10.1 INTRODUCTION

Chapter 9 discussed the results of the different phases of the study including the scoping review conducted to guide the development of the support programme for women receiving curative treatment for cervical cancer including radiation. Different levels of support were assessed using BSSS and EORTC QOQ CX-24 to measure quality of life and symptoms experienced. This chapter presents the justification of the study, with regards to the objectives, limitations, recommendations and conclusions, followed by the researcher's experiences while conducting the study.

10.1.1 The Objectives of the Study

The first two objectives (Phase1) aimed to explore the support needs of women receiving curative treatment for cervical cancer including radiation and how they preferred to be supported, followed by development and validation of a support programme. The last objectives (Phase 2), was to pilot-test the programme in terms of one primary outcome, perceived support, followed by the secondary outcome, quality of life, and evaluate its effectiveness at the end. The study followed a mixed methods approach with a sequential exploratory design.

The qualitative approach explored the participants' needs, and how they preferred to be supported. In phase one, (n=22) structured interviews were conducted inclusive of the two used for pre-testing the interview guide, as no significant changes were made to the interview guide. The overarching theme for this phase is "Patient's experiences and needs highlighted during the trajectory of cervical cancer treatment." Six themes that emerged from the data were; 1. Symptoms experienced leading to access healthcare; 2. Information pertaining to disease and treatment; 3. Need for counselling during the cancer trajectory; 4. Emotional support needed; 5. Instrumental support needed and 6. Network and peer and media support.

The needs highlighted were based on participants' experiences, the literature, as well as the expertise and experiences of the researcher and other oncology qualified nurses involved in the care of similar patients informed the development of the support programme. To confirm a need for such a programme, a scoping review of studies conducted to support women treated for gynecologic cancer was conducted to determine the methods utilised, contexts, and focus of such studies. The scoping review proved beneficial as only four studies were identified; however, each addressed a different focus from what was identified in the study and not representative of Sub-Saharan context. The programme was developed and validated by a team of experts involved in day-to-day care of patients treated for cervical cancer and other patients coming for six months post treatment follow up. Although the aim was to have all the experts in one focus group to validate the programme, this was not possible due to the limited number of staff allocated in the units. The researcher had to use the Delphi technique and at times face-to-face discussions, as some of the staff cited lack of time to give their inputs.

The quantitative approach followed a pre- and post-test design, in order to pilot test and evaluate the programme. This addressed the last objective of the programme conducted in the same setting with a similar population of participants as those involved in the qualitative phase. However, the participants in week one were included to give an added benefit of attending the programme early, once a cancer diagnosis was made. The assumption was that this would acquaint participants with needed information early with the intent to improve their perception of being supported and improved quality of life. Whilst the programme was intended to run for six weeks, there were challenges as participants experienced treatment side effects early, at the end of week two. This affected participant's attendance as pain was a major hindrance. The researcher, after consultation with the study supervisor, facilitated the sessions on alternate days so that participants would be familiar with ensuing changes before experiencing them and be able to adjust or to report early. Other logistical challenges, such as breaking down of the radiation machine, affected participation in the programme as patients were no longer in the same groups. At times, participants were called from the programme if a person booked for an appointment was not present; the researcher attempted to facilitate each topic twice to accommodate those who were not able to attend the first sessions.

The programme was evaluated on the last day of facilitation by exploring the participants' opinions regarding the programme using a focus group. However, most of the participant's families were already present early to pick them up, as most needed to go to work after picking up their relatives. So only a few were left to take part in the evaluation. Due to this, the researcher was unable to record the proceedings, but managed to use a group discussion to evaluate the effectiveness of the programme.

10.1.2 **Limitations of the Study**

- Although the study was said to be culturally relevant and easy to follow, adjustment of the departmental logistics affected participant's attendance of the sessions.
- Although multidisciplinary team members took part in the validation of the programme, it was clear that the social workers were not always available to support as this was noted previously at the setting where the study was initially planned to be undertaken. However, their input would have been valuable as they see patients with other social challenges.
- The researcher noted with sadness that not all nurses were keen to participate in any research related activities, citing lack of knowledge even when not asked. This is worrisome, as the current nurse practice should be guided by research and evidence based.
- Having to facilitate the programme on alternate days versus weekly was an additional challenge, as not all participants can comprehend much of medical information due to their health literacy, despite their level of education. It would have been ideal if summary brochures of topics discussed were provided. However, due to the extent of the study, finances were an added burden in developing brochures. This will be another step when the programme is facilitated in similar settings.
- The use of borrowed questionnaires developed from other settings that could not be adapted to suit the African context did not make it easy, as one could not to enquire how participants interpreted different levels of support within African contexts and among various cultural groups.
- Due to the limited number of participants in the pilot study and those who took part in the post-test, the results of the study cannot be generalised to similar populations.

10.2 RECOMMENDATIONS OF THE STUDY

10.2.1 Recommendations for the Nursing Practice

- It is important to inform patients of a cancer diagnosis in the presence of a family/or network member who can act as a support system during the cancer trajectory, as being informed of the cancer diagnosis tends to weigh heavily on the patients' emotions.
- The recommendations are that the staff at the satellite clinics be trained to identify patients who are prone to psychosocial issues and, if possible, refer to a professional. They should be encouraged to be sensitive towards the needs identified by the patients early in the trajectory, so they can source the necessary support for travel and instrumental support and refer to the social workers if the need arises.
- It is suggested that a dedicated professional nurse be available at the radiotherapy treating site, at all times, to assess the patient and enquire about any changes or concerns they might have. This would allow them to report problems timeously and prevent a delay in supportive treatment until the day of the follow-up medical assessment. In addition, it is important that the patient receive emotional support, as it was clear that not all received the same support.
- Nurses accompanying patients from the satellite clinics should be tasked to care for the patients after attending treatment as some were reported to be dizzy, whilst some even vomited and had no one to tend to them, whilst the nurses who have been allocated to accompany them were at the waiting area far from the patients whom they accompanied.
- It is necessary to facilitate workshops at the end of the study to share the findings in order that staff can be empowered to run the programmes at their facilities to support the patients.
- The participants recommended that the programme be offered to staff at the old age homes, as it appears that staff do not know much about cervical cancer symptoms, thus making the aged vulnerable to late presentation.

10.2.2 **Recommendations for Research**

Whilst the programme had the potential to improve patients' view of being supported with regards to information pertaining to illness and treatment, it is suggested that similar research be conducted at other settings within an African context as this was the first of its kind.

It is suggested that research pertaining to support within different cultural contexts in Africa be conducted and compare what findings would yield.

Additionally, the suggestion is that researchers form collaborations to develop tools to explore or measure support across different cultural contexts in Africa.

10.3 **CONCLUSION**

The study explored the support needs of women receiving curative treatment for cervical cancer including radiation and developed a programme to support these women. The programme was evaluated in terms of one primary outcome perceived support and a secondary outcome quality of life. The scoping of programmes conducted to support women with gynaecologic cancers found that they were conducted in settings not representative of African context. The programme was developed based on the needs identified by women treated for cervical cancer at a specific academic hospital. The programme was culturally acceptable and easy to understand, as it reflected identified needs. Significant improvements were noted in terms of perceived support after attending the programme. Due to the limited duration of the programme, the quality of life could not be explored fully; however, further exploration of the quality of life of women after participating in the programme over a longer duration is suggested to see if the results would yield different results.

10.4 **RESEARCHER'S EXPERIENCES DURING THE STUDY**

The researcher's experiences are meant to look back at her journey during the study, and at what was learnt during the process, as well as to suggest what she could have done to improve her situation.

10.4.1 **Proposal Phase**

The study commenced at another tertiary institution where cervical cancer patients are treated with other oncology patients receiving radiation therapy. The study received ethical clearance within reasonable time from the time application were sought. At first, the researcher went to another academic hospital which she had initially approached to conduct the study. Once Ethical clearance was obtained, the researcher visited the radiation oncology department with an intent to meet the staff and inform them about the study. However, the study could not proceed due to demands made, such as the provision a social worker with an oncology background to support patients; whilst the request to use the hospital social workers was included in the granted Ethics clearance. To make matters more complex, the researcher had to provide her curriculum vitae regarding her experience as an oncology nurse. Although a social worker with an oncology background was sourced, it was a challenge as she was in full employment at another institution and only willing to provide her services telephonically at a cost. This was not helpful, as the demand was that a social worker avail herself at all times when the researcher was collecting data. What was of concern was that the same patients would be referred to the hospital social worker, whom the researcher was unable to utilise for the study. This behaviour did not help in any way, because in the end, the study did not receive support despite efforts to appeal to higher authorities to intervene. What became clear was that gatekeeping is an issue that needs to be clarified immediately; an application to conduct such studies is served. Eventually the study had to be moved to another Institution where the study was conducted; It was truly disappointing, as time and finances were lost, without any recourse, in an attempt to pursue the study.

To remedy such issues, it is suggested that department in which studies would be conducted be involved at the very beginning when applications are served. This will curtail un-necessary delays backed with facts about reasons for refusal, if at all. In the researcher's mind, it is clear that in some departments some patriarchal issues still prevail, as despite appeals to resolve the issue, the study could not proceed. The researcher took a decision to seek a new home for the study, as it was evident, despite

efforts to seek assistance, this was not forthcoming; this meant another year was lost whilst waiting processes to follow their course.

During the proposal phase of the study, the researcher attended a pre-doctoral programme hosted by Santrust in conjunction with an Irish company and some of the universities in the country. The programme was facilitated by highly skilled academics to support the course on proposal development in an effort to improve throughput of doctoral qualified nurses. The programme included academics from different universities who were pursuing doctoral degrees, although the programme seemed long as it meant taking time from the university to attend. I am thankful that I was part of such an enriching experience. The programme was extensive with different modules in preparation of writing feasible proposals for doctoral. The researcher wishes that similar programmes be made available in universities for students aspiring to register doctoral studies, as her assumption was that this would guide students and improve outputs for doctoral studies. Although this comes with the cost of time and commitment, it would curb spending time in an institution only to drop out after spending time and money. Furthermore, different universities should forge relationships with potential stakeholders in order to prevent unnecessary power struggles among colleagues at the cost of students.

10.4.2 **Study Approach**

Due to the study using a mixed methods approach, which was appropriate as neither method alone was sufficient to answer the research questions. This was equally challenging, as the researcher had to acquaint herself with methods, whilst at same time learning how to develop a proposal for doctoral study. This method, however, came with its own challenges. Utilising a mixed method for a study needs one to plan for time, manpower, availability of finances, and planning for unforeseen circumstances. The researcher had to attend a workshop on mixed method usage, hosted by the University of South Africa, to improve herself and be comfortable in the use of the methods in the study. This sapped the limited time, as the researcher was a student herself and an educator for undergraduate students, whilst also supervising Master's students. The researcher had to plan her time to collect data, which also involved travelling to the data collection site, which meant she had to travel early morning to be on time to reach the

prospective participants whilst in the waiting area to avoid disrupting the smooth running of hospital processes.

What the researcher has learnt is that she should plan her time and if possible, be mentored within her institution and supported with her studies. It is unrealistic to expect that one should have a quota undergraduate student load and to supervise a number of master's students, whilst being a student herself. Looking back, despite the challenges the researcher supervised five Master's students to completion of their studies. Apart from the researcher's expectations as an academic, a re-look is necessary into how staff who are pursuing their studies are supported within departments at the universities. According to the researcher, following an observation and talking to peers who studied within the same period, it would appear different departments are run differently. Another point is that whilst pursuing own studies it is necessary that one be allocated a lesser number of students to supervise, and to be allocated a co-supervisor as a way of providing support and peer support during. Staff should be afforded designated time for their studies as well.

10.4.3 **Data Collection**

The researcher chose to collect the data for the study as a way of acquainting herself with the study and to analyse it as well. Attempting to source participants was not easy and the researcher relied on staff working in the department, even though they were busy themselves. Although the researcher tried to collect data in the mornings, it was not always feasible. Although studies reported on challenges encountered by the doctoral students, each study comes with its own challenges. The processes in the departments are not standard, because on some days it would be doctors' meetings, whereby patients are presented making the interview room unavailable. Often it was difficult to get patients to interview, as some were in pain, while others were sleepy from the sedative received during treatment. This was a challenge in the beginning, as some days the researcher would leave without having interviewed any patients due to situations that presented themselves.

Interviewing patients was emotionally challenging when the patients narrated their stories. The researcher had to stop and ask the patients if they wanted to stop the

interviews; most would compose themselves and chose to continue. The researcher believed the participants' experienced the interview as the opportunity to heal themselves of the harboured sadness, as not much time was available for them between navigating treatment and going to different departments. To remedy such a situation, it is important that a nurse is available to enquire about patients' welfare and concerns, as this would give patients time to debrief.

Although the researcher tried to compose herself during the interviews, this proved to be emotionally draining. Although the researcher would talk to her supervisor about her experiences, the supervisor was also a lecturer herself and not always available as she had to attend to her academic duties. The researcher experienced the interviews as demanding and emotional that the she chose to go home afterwards and drown herself with sleep. This was experienced as tough and became too much to think about the day before she had to go for data collection. It would be ideal to have a counsellor available for debriefing after the interviews. The concern is how do those who are collecting data for others cope in similar situation; this is a thought to be pondered.

Whilst the intent was to analyse data on the same day it was collected, the researcher became emotional as she listened to the recorded interviews. The researcher resorted to taking a day in-between to step back from the data. It is necessary, in the absence of the supervisor; researchers have someone to counsel them if they become emotional as result of the data they are dealing with.

In phase 2 of data collection, the researcher observed that during the pilot test of the questionnaires, participants became emotional as they answered questions relating to support and sexuality from the EORTC QOQ-CX 24. This gave the researcher an indication to arrange someone qualified to counsel patients should the need arise. It was also crucial that the researcher acquaint herself with processes such as simulation procedure and brachytherapy. On the occasion the researcher attended simulation procedure, it was quiet disturbing to be in a dark room with the patient lying still with laser rays flashing on and off, slicing her body in sections, without explaining the process to the patients. The researcher had to ask the therapist repeatedly what was being done

in order to get an explanation, assuming that maybe this would be of help to the patient; this could be worse for the patient who knows less and cause anxiety. At night whilst sleeping, the researcher kept recalling the flashing of laser beams; it appeared like an "alien movie." This was unsettling feeling and the researcher could not remove this image from her mind. Thinking of how patients perceived this was another issue; it could evoke anxiety, especially if one is uninformed. For those patients who understand little, it is important that efforts be made to simplify the experience to avoid undue emotional strain and distress.

The researcher observed the preparation for a brachytherapy procedure and the patient undergoing treatment in order to inform patients what is expected during this period. Other issues regarding the experience were discussed with the departmental staff; the researcher is forever grateful to the staff and doctors for the support and willingness to share the information and their experiences of working with this population of patients. Another opportunity was to sit in during counselling sessions once patients were informed of a cancer diagnosis. The researcher observed that some of the patients did not understand the information. Although the nurses touched on most of the basic issues about the cervical cancer, it seemed it was still not clear in the patients' minds. This necessitates patients having someone to accompany them to reinforce what was said; it would be ideal to have the nurses who accompany patients to be present during this time to confirm what have been said. This was an opportunity to observe the staff and patient interaction, which was professionally handled. Most of the staff were supportive, but the social worker, who supposedly counsels' patients, was never available, therefore not giving the researcher the opportunity to join one of the counselling sessions. The researcher also utilised this period to inform patients of the programme to support women.

10.4.4 **The Support Programme**

The researcher had assumed the facilitation of the programme would be a smooth process. This was not to be, because, although women had been informed earlier of the programme, facilitating it became a challenge. Although the researcher tried her best to facilitate the programme as women were at waiting area, it was a challenge, as patients

would be called in for treatment, whilst others had not arrived at the hospital. At times, when patients had been treated, due to the discomfort experienced after treatment some preferred to go sit in the transport and wait, whilst others may need to see the doctor. Eventually, the researcher had to wait for the patients to finish and then facilitate the programme. The researcher had to change to alternate days in order to accommodate the participants. Having another programme running simultaneously was a setback.

Due to changes in the department resulting from breakdown of the machines, the groups were disbanded, as some were present while others came and left. This had an impact on attending the programme. However, the researcher attempted to regroup patients who were in the same sessions.

Other patients were not keen to attend, and the researcher had no choice but to continue with those who wished to do so. Two patients, after being shown stages of the disease, were upset stating that they had been fine until seeing the pictures, now they felt like they had moved three steps backwards. Even as the researcher showed the pictures to the participants, she noted with regret, the sadness on their faces. Although the patients continued, it was clear they were sad, but the researcher apologised and explained that there was no better way to explain to make sense of the situation. What the researcher took out of the programme, was that maybe the patients should be asked how much detail they would be willing to know or would like to see to avoid hurting or causing harm, or group patients according to stages.

Despite the programme, having the tendency to arouse emotions, being truthful and not deceiving patients would encourage trust and appreciation of what they learnt. On the last day, most participant's families came early to pick them up, and only few were left to evaluate the programme. The participants felt the programme had empowered them and created spaces where they were able to relate their feelings without being judged by others. It was also reported that the language used was simple and easy to comprehend. The researcher felt that the programme could have achieved more in terms of meeting the objectives. Due to the programme being only facilitated for six sessions,

evaluating the perception of quality of life would need the programme to be facilitated a few months post treatment.

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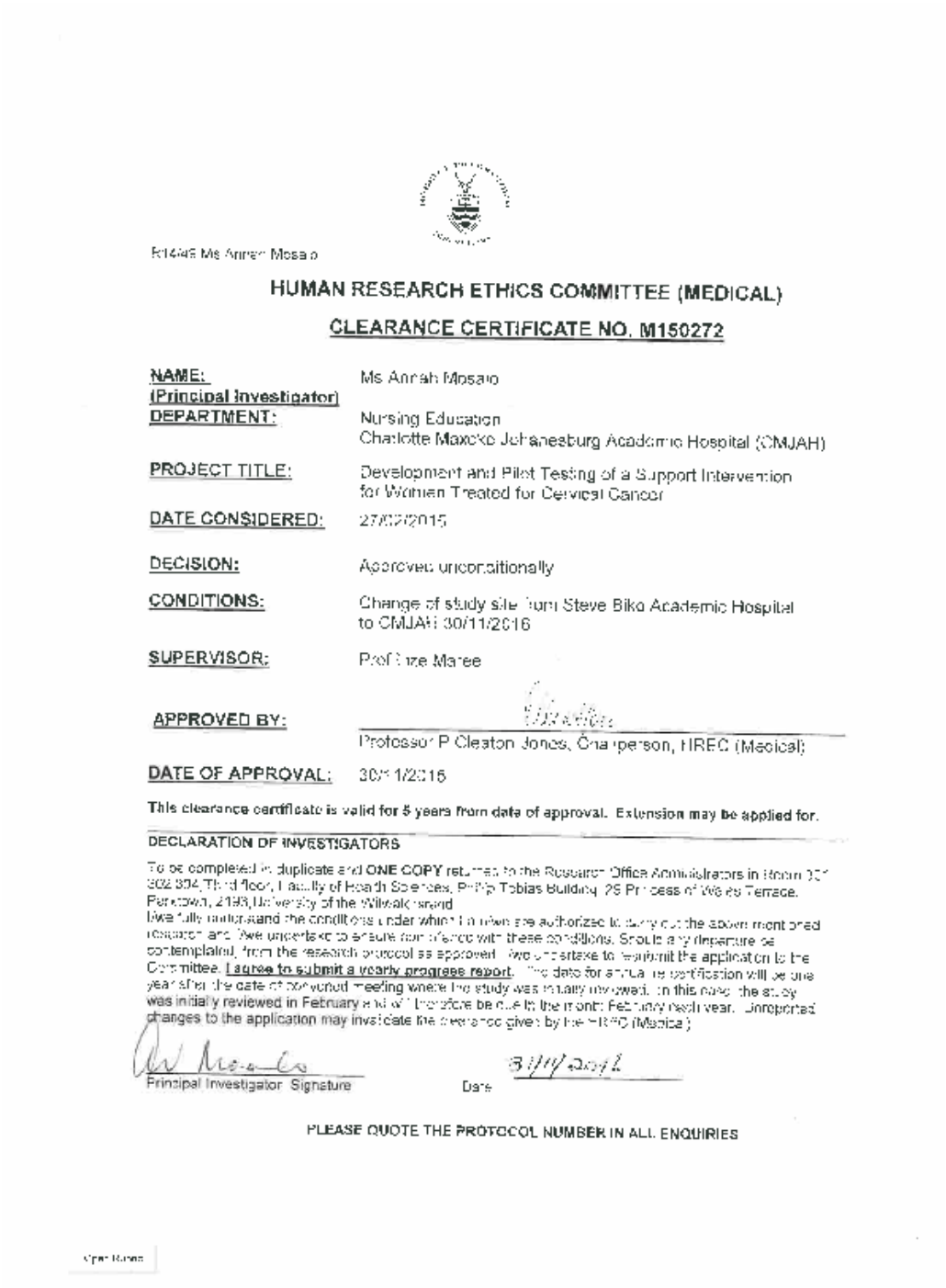
APPENDIX A

- **ETHICAL CLEARANCE**



Ms Annah Mosalo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150272

NAME: (Principal Investigator)	Ms Annah Mosalo
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital (CMJAH)
PROJECT TITLE:	Development and Pilot Testing of a Support Intervention for Women Treated for Cervical Cancer
DATE CONSIDERED:	27/02/2015
DECISION:	Approved unconditionally
CONDITIONS:	Change of study site from Steve Biko Academic Hospital to CMJAH 30/11/2016
SUPERVISOR:	Prof Ize Maree
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/11/2015

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Administrators in Room 307 302 304, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 28 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand

I/We fully understand the conditions under which I/we am/are authorized to carry out the above mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of approved meeting where the study was initially reviewed. In this case the study was initially reviewed in February and so I/we should be due in the month February next year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical)

Principal Investigator Signature

Date 3/12/2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Open Rooms

APPENDIX B

- **LETTER OF APPROVAL: CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL**

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL (CMJAH)
OFFICE OF THE CFO

Enquiries: Ms T. Ndlovu
Tel: 011 488 4211 Fax 011 488 3753
Email: Thokozile.Ndlovu@gauteng.gov.za
Date: 17 February 2020

Dear: Anna Mosalo

STUDY TITLE: "Development and pilot testing of a support intervention for women treated for cervical cancer"

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study

Please liaise with the HOD and Unit Manager or sister in charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Approved/not approved

Ms. G. Bogoshi
Chief Executive Officer
Date: 17/02/2020

APPENDIX C

- **LETTER OF APPROVAL: UNIVERSITY OF THE WITWATERSRAND**

Department of Radiation Oncology

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Radiation Science
Medical School, 7 York Road
Parktown 2193, Johannesburg, South Africa

Tel: +27-11-481 2137
Fax: +27-11-481 2141
Email: vinay.sharma@wits.ac.za

Dated 18-11-2016

To Whom So Ever It May Concern

This is to certify that Aurah Mosalo, a nursing student is granted permission to do her research project "Development and pilot testing of a support intervention for women treated for cervical cancer" towards PhD Degree in the Department of Radiation Oncology.

With best regards

Prof Vinay Sharma

APPENDIX D

- **INFORMATION LETTER**

Information document

Study title: Development and pilot testing of a support intervention for women treated for cervical cancer

Good day madam,

My name is Annah Mosalo. I am currently registered as student in the Department of Nursing Education at the University of the Witwatersrand. I am conducting a study as part of the requirement for the qualification. The title of the study is “Development and pilot testing of a support intervention for women treated for cervical cancer”.

I would like to invite you to consider taking part in the study. The reason why I am conducting the study is to find out how you would like to be supported whist you are admitted and receiving treatment for your illness (cervical cancer). I will interview you for about an hour. I will use the words that you tell me to develop a support intervention for women with similar illness. You will not receive any payment for taking part in the study, however by helping us to find out how we can support you during your stay in the hospital we will try and improve the support for other women with same condition when they are in hospital.

Due to the nature of your illness you may remember certain information that can make you sad; however, there is no other way that I can be able to get this information. I can only be able to know about this information is through talking to women who have the illness. Should you experience any sadness or other emotions that can be aroused due to the interview, I may stop and refer you to someone who is trained to deal with emotions. I can plan the interview for another time when you are able to talk to me. Should you feel that you do not wish to continue to take part in the study you can do so at any time. You will not be disqualified to receive treatment even if you decide not to continue to take part in the study.

I may request to use a tape recorder to collect the information as I may not be in position to remember everything you said. I have been given permission by the hospital and the University of Witwatersrand to conduct the study.

Even if I would call you by name during the Interview, the information shared will be confidential. However the result of the study will be will be shared with other peers (health practitioners) at the completion of the study and will in no way be linked to your name as pseudo name will be used when reporting the results. You are not under any obligation to take part in the study. Should you need any further clarification do not hesitate to contact me.

Thank you for making yourself available to listen as I explain the reasons for taking part in the research study.

Annah Mosalo
Cell: 0832795828
work: 012 4296447 (08h00- 17h00)
My Supervisor: Prof Lize Maree
Work: 011 488 4272

APPENDIX E

- **LETTER OF CONSENT**

Consent Letter

I hereby confirm that I have been adequately informed by the researcher Ms Annah Mosalo, student no: about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study, including personal details regarding my age, health status, monthly income, educational level and marital status will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: _____ (Please print)

Research participant's signature: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____

VERBAL INFORMED CONSENT

(Applicable when participants cannot read or write)

I hereby declare that I have been informed about the contents of the information sheet by the research participant. The nature and purpose of the study were explained, as well as the possible risks and benefits of the study. The research participant has been clearly informed that she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her relationship with the health care team.

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

Research participant's name: _____ (Please print)

Research participant: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____

APPENDIX F

- **PERMISSION TO RECORD THE INTERVIEWS**

Consent letter for use of tape record during study discussions

I hereby confirm that I have been adequately informed by the researcher Ms Annah Mosalo, student no: 772493., about the nature, conduct, benefits and risks of the study. The researcher has requested permission to record the discussion during the study; however, she will maintain confidentiality of all the discussion shared. Should there be a need to share information with her other peers it will be coded and will not be linked to my personal information at any stage. I understand that my participation is voluntary and if I am not comfortable with the process, I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: _____ (Please print)

Research participant's signature: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____

VERBAL INFORMED CONSENT

(Applicable when participants cannot read or write)

I hereby declare that I have been informed about the contents of the information sheet by the research participant. The nature and purpose of the study were explained, as well as the possible risks and benefits of the study. The research participant has been clearly informed that she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her relationship with the health care team.

APPENDIX G

- **INTERVIEW GUIDE**

INTERVIEW GUIDE						
SECTION A: DEMOGRAPHIC DETAILS						
A.1.	**CULTURAL GROUP**	Coloured	**1**	**Q1=**		
		Ndebele	2			
		North Sotho	3			
		South Sotho	4			
		Swazi	5			
		Tsonga	6			
		Venda	7			
		Xhosa	8			
		Zulu	9			
		White	10			
		Other	11			
A.2.	**PROVINCE**	Gauteng	**1**	**Q2=**		
		Limpopo	2			
		Mpumalanga	3			
		North -West	4			
		Other	5			
A.3.	**REGION**	Rural	**1**	**Q3=**		
		Urban	2			
A.4.	**AGE**			**Q4=**		
A.5	**MARITAL STATUS**	Married	**1**	**Q5=**		
		Co-habiting	2			
		Culturally Married	3			
		Stable relationship	4			
		Single	5			
A.6.	**NUMBER OF CHILDREN**					
		0-1	**1**	**Q=6**		
		2-3	2			
		4 >5	3			
A.7.	**EDUCATIONAL LEVEL OF PARTICIPANT**	Never went to school	0	**Q7=**		
		Up to Grade 7	1			
		Grade 8-10	2			
		Grade 11- 12	3			
		Tertiary	4			

A.8.	**EMPLOYMENT STATUSOF PARTICIPANT**	A day worker	1	**Q8=**		
		A pensioner	2			
		Disability grant	3			
		Employment	4			
		Unemployed	5			
A.9.	**MONTHLY INCOME OF PARTICIPANT**	None	1	**Q9=**		
		R1- R2000	2			
		R2001-R2500	3			
		R2501 –R4000	4			
		R4001- R6000	5			
		R6001>	6			
A.10.	**EMPLOYMENT STATUS OF PARTNER**	A day worker	1	**Q10=**		
		A pensioner	2			
		Disability Grant	3			
		Employed	4			
		Unemployed	5			
A.11.	**MONTHLY INCOME OF PARTNER**	None	1	**Q11=**		
		R1 –R2000	2			
		R2001-R2500	3			
		R25001- R4000	4			
		R4001- R6000	5			
		R6001 >	6			
A.12.	**STAGE OF THE DISEASE**	Stage I	1	**Q12=**		
		Stage IIA	2			
		Stage IIB	3			
		Stage IIIA	4			
		Stage IIIB	5			
		Stage IVA	6			
		Stage IVB	7			
A.13.	**HISTOLOGY TYPE**	Squamous	1	**Q13=**		
		Adeno	2			
		Neuro endocrine	3			
		Other	4			

SECTION B: INTERVIEW THEMES

The following question would be asked during the Interview: Can you share with me how you found out that you have cervical cancer?

The probes that we used

So how did you feel when you were informed?

Who was present when the doctor told you about the situation?

‘’Can you please tell me how you like us to support you during the period you are receiving treatment in the hospital”

The following themes would be probed in terms of support:

Informational support:

- Can you please explain to me which information would you like to get about your disease and treatment? Can you please explain further?
- Can you please explain how you want the nurses to involve your significant others concerning information about your illness?

Tangible support:

- Can you please tell me how would you like to be supported in order to make activities of daily leaving easier?

  Can you please explain which sort of activities they would be?

  Can you give an example please?

Emotional support:

- Can you please tell me how you want nurses/ therapists (radiation) to support you in order to feel mentally at ease?
- What is it that will make you feel that you are well supported by the nurses/therapists (radiation) whilst in hospital?

Network support:

- Can you explain to me what sort of support group would you consider helpful?
- Can you explain further how often would you want to attend a support group

  Can you please explain further?
- Please tell me how you would like to be supported by health professionals whilst admitted for treatment (radiation)?

APPENDIX H

- **PERMISSION LETTER**

Department of Nursing Education

WITS UNIVERSITY

Faculty of Health Sciences · Private Bag 3, Wits 2050, South Africa
Tel +27 11 [illegible] · Fax +27 11 [illegible] · Email [illegible] · www.wits.ac.za

30 August 2016

Prof V Sharma
Mr M Ngwanza
Department of Radiation Oncology

Dear Prof Sharma and Mr Ngwanza

Student: Anna Mosalo Student number: 772483

Mrs Mosalo is a registered oncology nurse with experience in oncology nursing practice and education and currently a PhD student in the Department of Nursing Education. The student presented her proposed study entitled *Development and pilot testing of a support intervention for women treated for cervical cancer* to the Department of Nursing Education and PhD Assessors Group of the Faculty of Health Sciences and her study proposal was approved by the University on 24 February 2014.

It would be highly appreciated if you would support this study. A copy of the proposal is attached for your perusal.

Kind regards

JE Maree

Prof JE Maree
Head: Department of Nursing Education

APPENDIX I

- **PERMISSION LETTER – BERLIN SOCIAL SUPPORT SCALE**

Mosalo, Annah

From: Schwarzer, Ralf <ralf.schwarzer@fu-berlin.de>
Sent: 26 August 2014 15:24
To: Mosalo, Annah; health@zedat.fu-berlin.de
Subject: RE: Re- social support

You are welcome to use all scales that you find at our websites

Prof. Dr. Ralf Schwarzer, Freie Universität Berlin, Psychology, Habelschwerdter Allee 45, 14195 Berlin, Germany
Email: ralf.schwarzer@fu-berlin.de Web: http://www.RalfSchwarzer.de/ http://www.fu-berlin.de/gesund

From: Mosalo, Annah [mosala@unisa.ac.za]
Sent: Tuesday, August 26, 2014 14:47
To: health@zedat.fu-berlin.de
Subject: Re- social support

This message (and attachments) is subject to restrictions and a disclaimer. Please refer to http://www.unisa.ac.za/disclaimer for full details.

Good afternoon Professor
May You Kindly assist me with the Berlin social Support Scale as I am conducting a study to explore how women would like to be supported, however in one phase of the study I need to measure women's perception of social support. Is it possible for me to use your questionnaire and also grant me written permission to use the questionnaire. Your support is highly appreciated

Annah Mosalo
Lecturer
Department of Health Studies
PO Box 392
UNISA 0003
Theo van Wijk Building F-1-43
Tel. 012 4298447
Fax: 012 4296688
E-mail: mosala@unisa.ac.za
"let your mind scan life's menu,whatever you want is available"

APPENDIX J

- **BERLIN SOCIAL SUPPORT SCALES (BSSS)**

Berlin Social Support Scales (BSSS), Ralf Schwarzer & Ute Schulz (2000)

(Originally designed for Coping with Cancer Surgery Settings)

Endorsements (for all BSSS scales):
(1) strongly disagree (2) somewhat disagree (3) somewhat agree (4) strongly agree

Perceived Emotional Support, Perceived Instrumental Support, Need for Support & Support Seeking

Please think of persons who are close to you.

	Perceived Emotional Support
1.	There are some people who truly like me.
2.	Whenever I am not feeling well, other people show me that they are fond of me.
3.	Whenever I am sad, there are people who cheer me up.
4.	There is always someone there for me when I need comforting.
	Perceived Instrumental Support
1.	I know some people upon whom I can always rely.
2.	When I am worried, there is someone who helps me.
3.	There are people who offer me help when I need it.
4.	When everything becomes too much for me to handle, others are there to help me.
	Need for Support
1	When I am down, I need someone who boosts my spirits.
2.	It is important for me always to have someone who listens to me.
3.	Before making any important decisions, I absolutely need a second opinion.
4.	I get along best without any outside help. (-)
	Support Seeking
1.	In critical situations, I prefer to ask others for their advice.
2.	Whenever I am down, I look for someone to cheer me up again.
3.	When I am worried, I reach out to someone to talk to.
4.	If I do not know how to handle a situation, I ask others what they would do.
5.	Whenever I need help, I ask for it.

Please note that in the 2001 cancer surgery study these items were presented in a mixed order. The present listing by scale has been chosen for clarity.

APPENDIX K

- **USER AGREEMENT – EORTC QUALITY OF LIFE GROUP**

EORTC
European Organisation for Research and Treatment of Cancer

EORTC Data Center
Avenue E. Mounierlaan 83 / 11
B-1200 Brussels
Belgium
Tel: +32 2 774 16 11
Fax: +32 2 772 11 45
E-mail: eortc@eortc.be
Web: http://www.eortc.be

USER AGREEMENT

Brussels 07/04/2014

The EORTC Quality of Life Group granted permission the ***07 April 2014*** to Ms. Annah Mosalo to employ the EORTC IN-PATSAT32 and QLQ-CX24 in an academic quality of life study entitled:

Development Of a Support Intervention for Women treated for Cervical Cancer ***(please fill in).***

Use of the EORTC IN-PATSAT32 and QLQ-CX24 in the above-mentioned investigation is subject to the following conditions:

1. Ms. Annah Mosalo confirms that this study is being conducted without direct or indirect sponsorship or support from pharmaceutical, medical appliance or related, for-profit health care industries.

2. Ms. Annah Mosalo will grant the EORTC Quality of Life Group limited access to the trial database. Access will be limited to the following: (a) the EORTC IN-PATSAT32 and module data; and (b) additional data will be made available to the EORTC at the sole discretion of Ms. Annah Mosalo as deemed appropriate for the purpose of validation of the EORTC IN-PATSAT32 and QLQ-CX24.

3. Ms. Annah Mosalo will not modify, abridge, condense, translate, adapt or transform the EORTC IN-PATSAT32 and QLQ-CX24 or the basic scoring algorithms in any manner or form, including but not limited to any minor or significant change in wording or organization of the EORTC IN-PATSAT32 and QLQ-CX24.

4. Ms. Annah Mosalo will not reproduce the EORTC IN-PATSAT32 and QLQ-CX24 or the basic scoring algorithms except for the limited purpose of generating sufficient copies for its own use and shall in no event distribute copies of the EORTC IN-PATSAT32 and QLQ-CX24 to third parties by sale, rental, lease, lending, or any other means. Reproduction of the EORTC IN-PATSAT32 and QLQ-CX24 as part of any publication is strictly prohibited.

5. Analysis and reporting of EORTC IN-PATSAT32 and QLQ-CX24 data by Ms. Annah Mosalo should follow the written guidelines for scoring of the EORTC IN-PATSAT32 and QLQ-CX24 as provided by the EORTC Group on Quality of Life.

6. This agreement holds for the above-mentioned study only. Use of the EORTC IN-PATSAT32 and QLQ-CX24 in any additional studies of Ms. Annah Mosalo will require a separate agreement.

I have read and I accept the user's agreement :

Signature: A Mosalo Date: 08/04/2014

Ms. Annah Mosalo

Open Public

APPENDIX L

- **EORTC OLO - CX**

ENGLISH

EORTC QLQ – CX24

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems, please answer by circling the number that best applies to you.

During the past week:		Not at all	A little	Quite a bit	Very much
31.	Have you had cramps in you abdomen?	1	2	3	4
32.	Have you had difficulty in controlling your bowels?	1	2	3	4
33.	Have you had blood in your stools (motions)?	1	2	3	4
34.	Did you pass water/urine frequently?	1	2	3	4
35.	Have you had pain or a burning feeling when passing water/urinating?	1	2	3	4
36.	Have you had leaking of urine?	1	2	3	4
37.	Have you had difficulty emptying your bladder?	1	2	3	4
38.	Have you had swelling in one or both legs?	1	2	3	4
39.	Have you had pain in your lower back?	1	2	3	4
40.	Have you had tingling or numbness in your hands or feet?	1	2	3	4
41.	Have you had irritation or soreness in your vagina or vulva?	1	2	3	4
42.	Have you had discharge from your vagina?	1	2	3	4
43.	Have you had abnormal bleeding from your vagina?	1	2	3	4
44.	Have you had hot flushes and/or sweats?	1	2	3	4
45.	Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
46	Have you felt less feminine as a result of your disease or treatment?	1	2	3	4
47.	Have you felt dissatisfied with your body?	1	2	3	4

Please go on to the next page

Open Public

APPENDIX M

- **EXAMPLE OF AN INTERVIEW**

INTERVIEW 11

R: Good day mam & how are you?

P: I'm fine mam, and how are you?

R: I'm doing a study on women who have been informed that they have cancer of the moth of the womb. [Information about treatment] Can you tell me how you found out about your illness?

P: myself I was ill from the 13th of April last year (2016), as I was attending at Thokoza. I was bleeding and went to the clinic[early signs of cancer] They called an ambulance that took me to Natalspruit hospital, where I was examined and they took bloods[first examined at clinic]. That's when I found out that I have cancer[confirmation of cx cancer].

R: When you said that you were bleeding, you bled for how long?

P: *Eish* (exclaiming)!! Mam, I bled for a long time since 13 April till August[duration of illness], *eish*! With clots and froth bi...g clots.[further signs] Yoo! A big chunk! *Mmh (confirming)*

R: Now because you're of the age where' you were supposed to have stopped menstruating, didn't you stop at some point?

P: No, I never stopped. You see this thing that when you using injectable contraception[confused with symptoms and failure to recognise early signs] you do not have problems. I used this injection for a very long time.

R: When did you stop the injection?

P: It was last of last year (2015), *Ee*! I kept on bleeding with big clots and froth. That's when I decided to go to the clinic[patient took initiative to consult at clinic], then at Natalspruit hospital they transferred me here at Jo'burg[referred to hospital] .

R: What did they do to you at Natalspruit hospital?

P: They examined me and told me cancer this and that. [constant information given pertaining g to possible cancer]

R: Can you explain what you mean?

P: They took me for sonar, so they can examine the womb. So they took epilepsy?.. trying to remember. I can't remember what they call it. But then they took something from underneath(biopsy she implied). They took a piece of flesh to check if it's cancer[further diagnostics].

R: ok, so how long it took you to know what is wrong?

APPENDIX N

- **QUALITATIVE ANALYSIS CODE BOOK (SAMPLE ANALYSIS SHEET)**

QUALITATIVE ANALYSIS CODE BOOK
(sample analysis sheet)

Interview CX: 1

Meaning Units condensation	Codes	Themes
Came to hospital for first time in December	Relieving initial access to health care	Route leading to diagnosis
Arrived as group of women for treatment	group of women coming to be treated	Route to access
Informed that the disease is not ordinary, bt cx	told we suffer from cancer not ordinary disease	Information pertaining to illness
Hospital has special machines to Rx cancer	special treatment machines	information regarding Rx machines
were re-examined to check the condition	Verification of condition	Re- evaluating of condition
Six of ours we seen on that occasion	There were six of us seen	route leading to investigation
Two of us re- examined once again	re- verification of our condition	route leading to diagnosis
Informed we suffer from cancer of the mouth of cx	confirmation of cx diagnosis	information pertaining to illness
Told to come for simulation in January	preparation for Rx	information regarding treatment
At sim they do tattoos and marks to guide the machines	preparation marks made in prep for Rx	preparation for treatment
Hospital process are slow	staff experienced to be slow in appraising symptoms	patient experiences
In Jun came with pains and continuous bleeding	presented with continuous bleeding & Pains	symptoms presented before route leading to diagnosis
Doctor gave me pills to stop the bleeding and later was done pap smear	bleeding controlled & pap smear done by doctor	route leading to diagnosis

referred to hospital for sonar sent for sonar to exclude cancer of diagnosis route leading to be diagnosed

stayed 3 days in hospital for blood tests and other investigations admitted for further tests route leading to diagnosis

doctor confirmed cx diagnosis confirmed cx diagnosis information pertianing to disease

hospital staff needs to be vigilant with abnormal symptoms staff to be vigilant with presenting symptoms symptoms presented

could have been treated since December
(2016)

Had several pap smears without getting results failed to get pap smear results on many occasions patient experiences

so, I gave up

Sister told me maybe it was difficult to see as pap smear had blood possible loss results patient experiences

Experienced pains during sex further pains experienced with sex symptoms presented

Need some explanation about signs of the cancer enlighten about signs & symptoms need for info pertaining to illness

Pains so severe would prefer taking any pain medication pains is soo bad one get confuses patient experiences

I am confronted with

Admitted for 3 days, found that HIV+ on test results positive blood tests (HIV+) routes leading to diagnosis

Doctor confirmed cancer, plan to transfer to Jo'burg confirmed Cx, planning for transfer information pertaining to illness

Went for counselling once diagnosis confirmed counselled after informed of cancer diagnosis need for counselling

Hospital staff helpful staff perceived to be helpful tangible support

We had counselling sessions we counselled together with others need for counselling

Told not to listen to someones stories informed that we are individuals, bodies are not same need pertaining to disease

as we are different

Informed not to use soap on marked areas no soap on tattooed areas information pertaining to Rx

Although hospital is good satellite and smaller clinics satellites experiences as delaying process of diagnosis patient experiences

needs to heed symptoms when one reports

Experienced treatment side effects experienced Rx side effects information pertaining to illness

Informed machine burns cancer and chemo collects cancer cancer is treated by burning information pertaining to illness Informed that chemo is like poison, it affects good cells too chemo affects the good and bad cells information pertaining to dise

We report to doctor when unwell informs the doctor when not well, to give medication information to illness

Doctor advised not to wear panties at home advised not wear panties, leaking due to treatment info pertaining to illness

Initially was down when told of the illness feeling defeated at the beginning patient experiences

Cancer is worse than HIV perceive cancer to be worse than HIV EXPERIENCES

Had to encourage myself at home, looking at the children gave looking at children gave me sense of fighting the disease Experien

reason to fight the illness

Told God had to get up and fight for my children Believed God will sustain me to beat the cancer Spirituality

My eldest daughter encouraged me to fight the illness eldest daughter motivates me to take treatment emotional support

and take treatment

do not want an intimate partner, coping well with my family no desire for relationship, family sustains support Emotional

I prefer to raise my grandchildren prefer raising grandchildren over having …. a relationship

APPENDIX O

- **LANGUAGE AND EDITING APPROVAL**

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, KwaZulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Mrs. A Mosalo
Address	Dept. of Health Studies, College of Human Sciences, UNISA
Date	06/04/2020
Subject	Thesis: DEVELOPMENT AND PILOT TESTING OF A SUPPORT PROGRAMME FOR WOMEN TREATED FOR CERVICAL CANCER
Ref	AM/GS/01

I certify that I have edited the following for language, grammar and style

Chapters 1 to 9, Abstract, Acknowledgement & References: Development and pilot testing of a support programme for women treated for cervical cancer, to the standard as required by the UNIVERSITY.

Gill Smithies

APPENDIX P

- **TURN-IT-IN REPORT**

- PhD Final submission_.pdf

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Annah Mosalo (Student number: 772493) am a student registered for the degree of Doctor of Philosophy in the academic year 2020.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature

Date: 20 April 20, 2020

APPENDIX Q

- **TECHNICAL EDITING**

Irene Janse van Noordwyk

Typing & Formatting Services

e-mail: irene.jansevannoordwyk@gmail.com / irene.jansevannoordwyk@wits.ac.za

Tel No: 0117172063

Cell No: 0828549225

WORK CERTIFICATE

To	Mrs Annah Mosalo
Address	Dept. of Health Studies, College of Human Sciences, UNISA
Date	29 April 2021
Subject	Thesis: Development and Pilot Testing of a Support Programme for Women Treated for Cervical Cancer

I certify that I have technically edited Ms Mosalo's thesis and have formatted her thesis according to the University of the Witwatersrand's style guide.

Mrs Irene H Janse van Noordwyk

APPENDIX R

- **IMAGE OF A NURSE INSERTING A SPECULUM**