A QUALITATIVEEXPLORATION OF A SUPPORT GROUP INTERVENTION AMONG WOMEN WITH CERVICAL CANCER AT TIYANJANE CLINIC FOR PALLIATIVE CARE, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI.

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DISSERTATION

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE MPHIL IN PALLIATIVE MEDICINE

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DECLARATION

I, MWANDIDA MATILDA MDAZEPA NKHOMA, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

HCW: Health Care Workers

HIV: Human Immune Virus

HPV: Human Papilloma Virus

NHSRC: National Health Science Research Ethics Committee

PCST: Palliative Care Support Trust

PLWHA: People Living With HIV AIDS

PPS: Palliative Performance Score

QECH: Queen Elizabeth Central Hospital

SEER: Surveillance Epidemiology and End Results

STI: Sexually Transmitted Virus

UCT HREC: University of Cape Town Human Research Ethics Committee

UCT: University of Cape Town

UNDP: United Nations Development Programme

UNICEF: United Nations International Children’s Emergency Fund

VIA: Visual Inspection of cervix With Acetic Acid

WHO: World Health Organization

ABSTRACT

Background: Cancer of the cervix is a common malignancy among women and is one of the leading causes of cancer morbidity and mortality in Malawi. The majority of women with cervical cancer present with advanced disease where cure is not possible. These women face many challenges that affect their lives holistically. In particular, the psycho-social impact is common for women living with cervical cancer and psychosocial care does not have sufficient attention as the focus is management of the disease and physical symptoms. However, research shows that support groups are associated with improvements in intimacy, emotional support and becoming better informed for women living with cancer of the cervix.

Methodology: This was a qualitative research study. Semi structured interviews were used to collect data and were audio-taped. A purposive sampling technique was used in selection of participants. One to one interviews were conducted with eight (8) women diagnosed with cervical cancer because data saturation was reached at that number. Thematic analysis was undertaken where four phases of organisation, familiarization, reduction and analysis were used.

Results: The following themes were identified: intimacy, emotional support, becoming informed and drawbacks of support group.

Conclusion: A support group intervention is found to reduce psychosocial and intimacy distress associated with cervical cancer diagnosis. This leads to improved quality of life of these women and their families. Thus, a support group intervention has a potential to enhance appropriate holistic management plans for women with cervical cancer.

CHAPTER ONE: INTRODUCTION

1.1 Background

This qualitative study investigated the impact of support group intervention among women with cancer of the cervix. Cervical cancer is the type of cancer that starts in the hollow cylinder that connects the lower part of a woman's uterus to her vagina (Weatherspoon 2019:2)

As with all cancers in most developing countries, cervical cancer is usually diagnosed at an advanced stage (Ali et al., 2016:2). In agreement with Malawian setting, researchers suggest that late presentation to the health facility by women with cancer of the cervix rests on the following reasons: lack of screening programmes, geographical reasons, financial reasons and cultural reasons.

From the study which conducted by Nkhoma et al., at QECH shows that for a woman who is diagnosed with cervical cancer, it can be very difficult to accept holistic changes that comes with cervical cancer progression(Nkhoma et al., 2015:71).

Culturally in Malawi, sexual activities are some of the key womanhood chores and they make women proud of being a woman. Again, at the end husbands take over the other womanhood roles and this stretches them because they have to combine with manhood roles. When they fail to cope with all these changes, some men end up spending nights outside in the name of seeking happiness (Nkhoma et al., 2015:67)

1.2 Epidemiology of cervical cancer globally, Africa and Malawi

A study conducted by Parkhurst et al., indicate that globally, cervical cancer is the second leading cause of cancer deaths for women (Parkhurst et al 2013; 1093). It is estimated that more than 88% of deaths occur in low income countries and this is predicted to climb to 91.5% by 2030 (Anorlu, 2012: 41-49).

Ntekim reports that in sub-Saharan Africa cervical cancer accounts for 22.2% of all cancers in women and it is also the most common cause of cancer death (Ntekim, 2012:52). Again, the incidence of cancer of the cervix in sub-Saharan Africa is 52.8 per 100,000 women. Most cases of cervical cancer are diagnosed in their reproductive years (15-45years) (Ferlay et al., 2010: 2893-2917).

Nationally, Malawi has the highest rate of cervical cancer worldwide, estimated at 33.6 per 100,000 populations (Phiri, 2016: 2). It is the second common cancer overall (25.4%) of all cancers in the country and the most common (45.4%) cancer among women in Malawi (Msyamboza et al., 2012:10).

From the figures above, cervical cancer is one of the major public health problems globally, regionally and nationally. As Malawi has the highest rate of cervical cancer globally, there is need to develop a comprehensive management approach, ranging from preventive to palliation.

Table 1 (below) shows that cervical cancer is the leading cancer among women in Malawi with incidence rate of 33.6 per 100,000 per year.

Table 1: Top 5 cancer incidence rate per 100,000 population per year among females in Malawi

Cancer type	**Incidence rate (per 100,000 per year)**
Cervix	33.6
Kaposi’s Sarcoma	11.9
Oesophagus	6.8
Breast	3.5
Non-Hodgkin’s Lymphoma	1.7

Source: Msyamboza et al. BMC Research Notes 2012, 5: 149

1.3 Impact of cancer of the cervix on women themselves and family

First impact of cancer of cervix in these women is stigma and discrimination. Women with an illness whose causing micro-organisms is spread by sexual intercourse, for example cervical cancer whose causing micro-organisms is HPV, have self-stigma because they are afraid to be called prostitutes, which is socially unacceptable. Marlow et al. report that women who tested positive for HPV (via a blood test) reported feelings of self-stigma and shame. The main reason these women sometimes have self-stigma is because it is shameful to have a condition related to sexually transmitted infection. Women with HPV have embarrassment to link between HPV and its transmission as unprotected sex (Marlow et al., 20017: 82).

Van Brakel and others reported that other consequence of health-related stigma is discriminatory or stigmatizing behaviour towards people with a stigmatized illness such as cervical cancer (Van Brakel et.al., 2012: 3).

Furthermore, in this study, the community assumes that a person with sexually STI related condition has participated in immoral or unacceptable sexual behaviour, such as unprotected sex or sex with multiple partners (Van Brakel et.al, 2012: 3).

Women also reported limited disclosure of their diagnosis to their husbands because of fear of being stigmatized because of the nature of their disease which will eventually lead to divorce. Again, their concerns about disclosing were partly due to the stigma and shame associated with having an STI and concern about how others would respond (Bennet et.al.2020:3)

Another impact is emotional distress. At times, the patient might also have fear of the uncertainties of the disease such as the disease prognosis, treatment options and impending death (Perrin et al., 2016: 93-100). The patient might not be sure of whether signs and symptoms will improve or worsen and also potential associated complications. She may also not sure of progressive decline or sudden or unpredictable crisis (Perrin et al., 2016: 93-100).

The emotional impact of living with cervical cancer is common among women with cervical cancer (Ali et al., 2016: 5). The patient may have signs of depression. These include feeling sad, hopeless and losing interest in things one used to enjoy. Again, the patient experiences mood swings being cheerful at times and then feeling sadness.

The disease burden of cervical cancer is not only directly to the patient but also to the family members (Arrossi et al., 2015:32). In Malawi, when a family member is sick, the entire family is affected because of the extended and value of family systems. Therefore, cervical cancer affects every family member directly or indirectly (Arrossi et al., 2015: 32).

1.4 Late presentation of cervical cancer cases

As with many cancers in developing countries, cervical cancer is often diagnosed at an advanced stage (Ali et al., 2016:2). Researchers suggest that late presentation to the health facility by women with cancer of the cervix rests on the following reasons: lack of screening programmes, geographical challenges, financial and cultural dimensions.

Phiri conducted a study which reveals that only seven out of twenty-one health facilities surveyed in Malawi were providing both cervical cancer screening and treatment. All seven health facilities are secondary health facilities and are one in each health district (Phiri, 2016: 1**)**. This denies access to appropriate healthcare for women in the other districts despite that access to healthcare being one of the elements of the Right to Health. (International Covenant on Economic, Social and Cultural Rights, 2012:12)

Furthermore, it is revealed that 38.6% of all patients presenting with cancer of the cervix at Queen Elizabeth Central Hospital present with late stage (II1B to IV) disease (Rudd et al., 2017: 124-129).

Although, there is emphasises that women with Visual Inspection of cervix with Acetic Acid (VIA) negative should be screened every five years at a minimum, to prevent late presentation (The Malawi Ministry of Health, 2005:4), this is not the case because of complex problems that come with access to screening cervical cancer.

1.5 Barriers to early detection of cervical cancer

1.4.1 Gender issues

Gender issues are significant in the experience of women with cervical cancer in Malawi. Zulu, indicates that the lower status and power of Malawian women as compared toMalawian men affect household decision-making in health seeking behaviour, as well as the health and well-being of women and their families (Zulu, 2003: 9).

Health seeking behaviour is compromised because a woman cannot go for screening programmes without the husband's consent. This becomes a problem when the husband is not around or does not understand the importance of the screening initiative. Thus, gender issues play an important role in cervical cancer prevention and screening.

1.4.2 Cultural beliefs

People in remote areas of Malawi seek health care from traditional healers first because traditional healers stay with them in their communities so they are easily accessible. When they resolve seeking medical care from health facilities it is mostly late hence late presentation of cervical cancer disease (Nkhoma et al., 2015:67). Therefore, cultural beliefs play a big role in cervical cancer prevention and detection.

1.4.3 Poverty

Malawi is one of the poorest countries in the world. Although Sustainable Development Goal number one states that there should be no poverty by 2030, 52% of the Malawian population live below the poverty line of US $1 per day (WHO and UNICEF Joint Monitoring Programme 2007:6).

The 2007 United Nations Development Programme (UNDP) Country Fact Sheet for Malawi on Human Development Indicators reports that the Human Development Index of Malawi is 0,437 thus ranking Malawi 164th out of 177 countries with data. On health financing, Malawi government allocated 9.7% of its total budget of MK 635.6 billion in fiscal year 2014/15 (Mwansambo, 2015: 7).

Families and women have to stretch themselves because they need to have money for food for their families and money for schooling their children and or dependants. For these women to go for cervical cancer screening, they also need money for transport to and from the hospital and pay hospital bills. As a result, families and women do not prioritise cervical cancer screening which leads to early detection for early treatment. Therefore, poverty is another factor that has impact on cervical cancer prevention and screening.

1.4.4 Geographical inequalities

Donkor et al. indicate that geographical inequalities in health care service provision and utilisation are a major concern in Africa (Donkor et al., 2015: 7**)**. In Malawi, some places have screening programmes, but women have difficulties in accessing them. This is because health centres are far apart and Malawians cite distance to health facility as a key barrier to health access because patients have to travel long distances (UNICEF 2016:3). In addition, a poor road network is also a barrier to access to health (Valera et.al 2019:5) including screening programmes. Most of the roads in rural areas are impassable during rainy seasons because connecting bridges are washed away and have dangerous potholes.

1.4.5 Level of education

The study conducted by Dunyo and others reveal that approximately two thirds (65.97%) of the cases presented in advanced stages of cervical cancer. They further revealed that level of education is included in a regression model and adjusted for age (Dunyo et al., 2018: 1243)

All the above factors lead to late presentation to health facilities with advanced disease of cervical cancer which is very common in Malawi. This leaves palliative care (which comprises of physical, psycho-social and spiritual aspects) as the only treatment option.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The analysis of the literature below was from primary and secondary data. A systematic, organised and effective literature search of available resources from 2010 to date published books, journals and other databases of good quality information relevant to my study was conducted. The topic of this study is to explore the impact of support group intervention among women with cancer of the cervix. From the literature themes such as impact of cervical cancer on women's psychosocial and spiritual aspects, impact of cervical cancer on intimacy, benefits of support group intervention and challenges of support group intervention were identified.

Search terms and how they were written included WHO+cervical cancer,Cancer of cervix+ epidemiology + Malawi and Cancer of cervix+ BMJ 2018: Sexuality+cancer of cervix+Africa+2012 to recent, Magnitude+sexuality+cancer of cervix and Cervical cancer+disclosure+spouses; Cancer+supportgroup+benefits,Malawi+healthfacility+mapping, Malawi+health+transportation, and Qualitative research+rigour+assess+criteria. See Appendix 1 for the information of data base used.

The questions guiding the literature review were: how to understand the impact of cervical cancer on psychosocial well-being and intimacy for women diagnosed with cervical cancer and to discover how support group interventions can either improve or not improve these aspects of women's experience living with cervical cancer.

2.1 Impact of cervical cancer on women's psychosocial and spiritual aspects

Owen et al. indicate that several psychosocial emotions happen after receiving a diagnosis of cancer. The study found that most of the participants were shocked, fearful, angry and anxious about diagnosis, surgery and treatment (Owen et. al., 2007: 2580).

Contrary to these psychosocial and emotional experiences identified by Owen et al., a study conducted by Foster and Fenlon indicate that where there is a high degree of comprehensive care in people affected by cancer, a number of improvements in health outcome including increased self-care behaviours and decreased physical and psychological symptoms (Foster& Fenlon, 2011:23) are observed. These include high quality physical, psychological, social and spiritual support. The comprehensive package is interdependent to each other, for example uncontrolled physical symptoms can cause severe psychological, social and spiritual symptoms and vice versa.

Therefore, the study by Owen et al. and the study by Foster and Fenlon show that women living with cervical cancer have psychosocial emotions that may be addressed by a comprehensive package of care including support group attendance where they have access to holistic care. This study indicates that including support group intervention in the care of women with cervical cancer might be helpful to these women.

In a study conducted by Maboko and Mavundla on African women diagnosed with cervical cancer in South Africa, a number of emotional experiences were reported. These included fears of death, not wanting to face reality, and fear to leave children behind. Stress, depression and feelings of isolation were also reported. Some of the women had faith in God and hoped to live long (Maboko and Mavundla, 2006:27-28). In addition, other problems revealed in study include stigma, unemployment, lack of income or financial resources to cover living and health care costs, inability to do certain household work, and family and friends' inability to adapt to the demands of the illness (Maboko & Mavundla, 2006: 38). It would be important to include these aspects of life with cervical cancer in research studies to improve care of women living with cervical cancer.

Another study conducted by WHO indicates that women living with cervical cancer face many emotional challenges after diagnosis with cancer of the cervix. The same report identifies psychological distress of 28% faced by cervical cancer patients. Other problems were lack of food, lack of social support, irregular supply of drugs, and shortage of clothing and social isolation (WHO, 2005: 37). These elements are relevant to women living in Malawi.

Atara reveals that an avoidant coping style and low perceived social support were significant correlates of psychological distress (Atara, 2013:43). Diagnosis with cervical cancer seems to be more distressing than with any other cancers because of its nature since it involves reproductive systems of women. The beliefs around HPV as a cause of cervical cancer and knowing that that it HPV is transmitted through unprotected sexual intercourse worsen the psychological distress. It is not easy to live with cervical cancer taking into consideration the impact it has on these women.

In addition, the WHO, identify that problems like pain, dyspnoea, wasting and confusion and other devastating symptoms worsen psychological and social distress (WHO, 2005:37). This is because these physical symptoms are interdependent with psychological and social aspects of the illness.

Cervical cancer is still perceived as a fatal diagnosis, and that may cause depression and anxiety (WHO, 2005: 38).In Malawi, this perception is generally the same as with any other life limiting illness (Mukhula et.al., 2017:131)

Cervical cancer can also be distressing to the families of those affected, and profoundly impacts on both family functioning and their economic situation (WHO, 2005:38). Family members have a critical role of sourcing funds to support the patient on any cost in relation to health care access.

When a patient is admitted at the hospital, some family members have to complete a variety of tasks in the wards like cooking for the patient and wash their patients daily (Hoffman et.al., 2012:78) and this negatively impact how family functions.

In a study conducted by Shyu et al., life stress can negatively affect the health status of the woman. Stress can also trigger some psychiatric conditions. Stress had been reported to cause depressive disorders and the lifetime rate of major depression among women with cervical cancer was reported as 79% which is very high (Shyu et al., 2017:138).

A study conducted by Ashing-Giwa et al., indicate that some religious beliefs also increased the stigma; some women thought they had cervical cancer as a divine punishment (Ashing-Giwa et al., 2011: 13). These beliefs delayed seeking health care services including cervical cancer screening and treatment and thereafter have serious negative outcomes.

Cervical cancer women also think that if they pray and have faith to God, healing can be obtained from God (Khazaee-Poo et.al., 2018:8).

2.2 Impact of cervical cancer on intimacy

Sanchez indicates that gynaecological cancers and their treatments are likely to result in some form of sexual dysfunction as they directly affect women's sexual organs. Unfortunately, sexual problems following gynaecological cancers are not solely limited to organ function but also to side effects of treatment (Sanchez V, 2013: 326).

In addition, Hubbard et.al., report that there is disruption to intimacy changes and the way the woman feels about her body and being a woman (Hubbard et al., 2012: 217). Embarrassing symptoms such as offensive vaginal discharge, vaginal bleeding and sometimes rectal/vascular vaginal fistula experienced by women with advanced cervical cancer exacerbate relationship problems with partner hence compromising intimacy and sexuality.

There is an indication that 80% of all cervical cancer patients experience sexual problems due to body image, pain and loss of desire due to cancer itself and its treatment (Atara, 2011:42).

Atara reveals that low sexual desire which may be due to anxiety and depression, less vaginal moisture and reduced vaginal size; painful sexual intercourse, trouble reaching orgasm, infertility and low self-esteem are common sexual problems caused by cancer as a disease and cancer treatment in women with cervical cancer (Atara, 2011:43). A study conducted by Sanchez indicates that cancer of the cervix and its treatment makes patients lose interest in having sex.

In a study conducted on African women diagnosed with both HIV/AIDS and cervical cancer in South Africa, a number of emotional experiences were reported that exacerbate intimacy challenges (Maboko and Mavundla, 2006: 27-28). This, then, changes the way she feels about her body and being a woman as also described by Hubbard et al. (2012:128). When cervical cancer advances the woman develops symptoms that she finds embarrassing and discomforting.

Asystematic study conducted by Barbara et al., indicate that there are fewer studies on the exploration of sexuality issues in patients with cancer of the cervix than studies on physical aspects of cervical cancer. However, women with cervical cancer experience marital problems such as difficulties in attempting to maintain their household, marital and maternal tasks. All these are sources of stress because as a woman, one is proud when is able to perform womanhood chores (Barbara and Anderson 2010: 7).

Furthermore, the study by Hubbard et al., state that while there remain many opportunities for contributing to the theoretical study of sexuality issues; there is insufficient evidence to propose the development of intervention programmes to supporting people and their family members affected by cancer of cervix (Hubbard et al 2012:128).

This indicates that more research is needed to support intervention programme for women with cancer of the cervix if holistic care is to be achieved. The more evidence available for effective interventions, the more advocacy strategies can be used. Currently in Malawi, the existing literature indicates that there is no study specifically for the exploration of intimacy issues in cervical cancer patients.

Msyamboza studied sexuality and reproductive health in people living with Human Immune-Deficiency Virus (HIV). This study reveals that cervical cancer is one of the types of cancer common in HIV infected women and recommends that further studies are required to ensure effective policy development and interventions on intimacy issues (Msyamboza, 2010:3). The lack of literature on exploring sexuality issues in women with cancer of the cervix can cause Health Care Workers (HCWs) to have difficulties in improving the quality of care and advocating or lobbying for support group intervention for these women.

Msyamboza reports that while there has been much attention to the spiritual, psychological and physical aspects of care for women with cancer of cervix in Malawi, their sexuality issues are rarely mentioned, discussed and addressed (Msyamboza, 2010:3).

From above studies, it is known that cervical cancer women face many intimacy challenges which may be better discussed when women with the same problems and diagnosis are in a group.

2.3 Benefits of support group intervention

There are few articles that have studied the role of support groups in people living with HIV/AIDS in Malawi. In these studies, it was not clear whether patients' psychosocial and intimacy needs of PLWHA are adequately addressed.

Mayo Clinic staff conducted qualitative study which was analysed using thematic analysis and it reveals that an individual facing a major illness does not have to face it alone (Mayo Clinic staff, 2018: 3). A support group can help. The study further revealed the following benefits of a support group intervention: feeling less lonely, less isolated or less judged, gaining a sense of empowerment and improving coping skills and sense of adjustment: talking openly and honestly about your feelings, reducing distress, depression, anxiety and fatigue (Mayo Clinic staff, 2018: 3).

Support groups bring together people who are going through or have gone through similar experiences hence improvement in holistic care. Zabalegui et al. reveal that the best method of improving opportunities for interaction is through support groups tailored to a particular group, sometimes defined by a health condition (Zabalegui et al., 2015: 376). Zabalegui et al. continue indicating that for example, for individuals with cancer, support groups are associated with improvements in anxiety and depression, enhanced quality of life and improved marital relationships (Zabalegui et al., 2015: 376). Women living with cervical cancer who reported regular interaction and talking with people in peer support group were significantly more likely to report reduced distress than those who did not have such peer support. Participation in a group programme can have impacts beyond the therapeutic effect of prevention, treatment and care. This indicates that support group forums, participants discuss issues beyond prevention of their conditions, treatment of their disease and care of their illnesses.

Fanelli &Moyo indicate that support groups are effective because members receive first-hand advice and the approaches that they learn from peers who are coping with similar circumstances, help them in coping with their own challenges. This means that the guidance is not only theoretical but practical, personal and relevant (Fanelli &Moyo, 2018: 1).

Cross reveals that there is some evidence that support group interventions improve patients' compliance with their treatment. For example, group members are twice as likely to take their medication as prescribed and less likely to drop out of treatment compared to patients who are not part of the group. Support groups offer a friendly, safe, social environment for patients to come together and share their experiences in confidence (Cross, 2018:3). Groups talk about the challenges they face during their illness journey and good strategies on positive living with their diseases. Members are eager to learn more about their condition and invite specialists to give a talk so that they understand the problem in detail. As such these women are well informed and they know how to deal with distressing symptoms hence developing better coping skills and attitude. A study conducted by McRae indicates that support group therapy has advantages in that participants feel that they are not alone and they see and hear first-hand information from people who have had similar experiences (McRae K. 2013:14). Mc Rae added that there is a sense of belonging when surrounded by people who understand the experience as they are passing though it themselves. In addition, McRae revealed that in support groups, individuals learn new strategies of overcoming some problems, learning from other group members (McRae K. 2013:14). Everyone in the group will be at different places in their own recovery or treatment and will be able to offer unique perspective, skills or ways of coping mechanisms (McRae K. 2013:14).

Lyndsey et al. discovered that when women living with cervical cancer are in a group setting, they discuss their sexuality issues freely (Lyndsey et al., 2013:302). However, this happens after sometime, when trust has been developed because culturally sexuality issues are still taken as sensitive issues.

2.4 Challenges of support group intervention

Though support groups have many advantages, there are some challenges that are associated with this intervention such as reluctance to share personal issues with unknown people. At first group members may prefer simply listening until there is trust between them. This usually compromises active participation by group members in the initial stages.

The Transverse Myelitis Association reveals that members fear that other members will violate the members' right to privacy by revealing to others what is known about them. Lack of confidentiality and privacy are the most dangerous pitfalls for support groups (Transverse Myelitis Association, 2012:35).

In addition, Schechter indicates that sometimes a group member may dominate the discussion. In the same qualitative study by Schechter, sometimes group-sharing and discussion can reveal disagreement in opinions and cause conflict between group members. Sometimes comments from one person can trigger old resentments or upsets that a second person ascribes to insensitivity but are actually just a reminder of something painful from long ago (Schechter, 2012: 36).

McRae conducted a study that describes that human beings are social by nature, but each one of us has individual and unique personalities which at times can collide, leaving a more harmful effect than a positive one (McRae, 2013:3). If collusion is not handled sensitively and diplomatically, it will end up damaging to the entire support group with high member dropout and eventually the whole group ends there.

Support groups are created differently, and it is important to minimize any risks to drawbacks during formation period. If these risks are not minimized support groups can be harmful to group members. These risks are factors that make the support group not run well, and when a support group is not run well it can actually do more harm than benefits to group members.

The conclusion is that, globally there is some existing literature about support group interventions that revealed many related issues. Notably some studies indicate that there are some common psychosocial and intimacy challenges faced by women with cervical cancer and benefits and challenges of employing support group intervention in these women. However, generally it is revealed that in Malawi, there is scanty or no literature on impact of cervical cancer and impact of support group intervention on these women despite that cervical cancer causes a lot of psychosocial and intimacy challenges which are exacerbated by complex physical symptoms compared to any other cancers. Local studies that are available are on impact of support group intervention in People Living with HIV/AIDS (PLWHA). These local studies support the impact of support group intervention on PLWHA.

Problem statement

In Malawi there is scanty or no evidence or data on the impact of support group intervention specifically for women with cancer of the cervix. However local studies on impact of support group intervention in People Living with HIV AIDS indicate that support groups are associated with improvements in quality of life and marital relationships. Participation in a group programme can have impacts beyond the therapeutic effect of prevention, treatment and care. This study therefore aims to explore the impact of support group intervention among women with cancer of the cervix.

Rationale of the study

Cancer of the cervix is a common malignancy among women and is one of the leading causes of cancer morbidity and mortality in Malawi. The majority of women living with cervical cancer in Malawi present with advanced disease where palliation become the best management.

Literature from other parts of the world revealed that these women have multidimensional palliative care needs and have complex psychosocial and intimacy needs which are improved by support group intervention. However, in Malawi, there is almost no literature describing support groups when managing and caring for women with cervical cancer; especially the impact of support groups on their psychosocial and intimacy experiences. This lack of literature can make it difficult for health care workers to offer comprehensive holistic care to these women. A study of the impact of support group intervention among women with cervical cancer can highlight the pros and cons of group therapy and may assist health workers in their care.

Research question

What is the impact of support group intervention among women with cancer of the cervix at Tiyanjane clinic for palliative care?

Aim of the study

The aim of this study was to explore the impact of support group intervention among women with cancer of the cervix at Tiyanjane clinic for palliative care.

Objectives of the study

1. To explore the psychosocial impact of support group intervention among women with cervical cancer.
2. To explore the impact support group intervention on cervical cancer women’s experience on intimacy.
3. To evaluate the outcomes of attending the support groups among women with cervical cancer.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

The study explores the impact of support group intervention among women with cancer of the cervix at Tiyanjane Clinic for palliative care at Queen Elizabeth Central Hospital in Blantyre Malawi.

3.2 Study design

The design for this study was a descriptive qualitative study on palliative care amongst women living with cancer of the cervix.

3.3 Study site

The study site was Tiyanjane clinic for palliative care which is located at QECH, Blantyre, Malawi. The clinic is within the department of medicine at the university teaching hospital. The study site gets referrals of patients from all wards, other clinics, district hospitals, health centres and communities within southern region of Malawi.

3.4 Study population

The study population were women with advanced cervical cancer attending the palliative care day clinic at Tiyanjane clinic. An equal opportunity to participate in the study was provided to all women patients diagnosed with advanced cervical cancer.

3.4.1 Inclusion criteria

Women who were eighteen (18) years old and above, women who were registered with Tiyanjane clinic, women who attended not less than five (5) out of six (6) total support group meetings and women with Palliative Performance Score (PPS) of above 70%. (For PPS refer to appendix 2

3.4.2 Exclusion criteria

Women under the age of 18years, women who were unable to provide verbal consent, women who were frail (those who had PPS of below 70%) and women who attended support group for less than 75% of the meetings.

3.5 Sample size

The study recruited fifteen (15) women for support group formation. Eight (8) women were interviewed at three (3) months post support group formation. Data saturation occurred at his point with no new data is emerging from participant interviews so no further participants were recruited. During the process of data collection, interviews were transcribed and read until it was evident that no new data/topics/ themes were emerging. (Marshall et.al., 2013:11)} was reached at that number.

3.6 Sampling method

Purposive sampling method was used to select study participants.

3.7 Data collection

3.7.1 Development of data collection tools

Semi-structured interview guides were developed to collect data on exploration of support group intervention in women with cancer of the cervix. They were in both English and Chichewa (the local language) (refer to appendices3 to 4). These guides had open-ended questions.

The guides were developed by the researcher on the basis of the literature reviewed in chapter two and after consultation with the research supervisor and co-supervisor. The open-ended questions in the semi-structured interview guides allowed the interviewer and interviewee discuss more detailed issues with in-depth information gathering.

3.7.2 Data collection process

Data collection started after obtaining University of Cape Town Human Research Ethics Committee (UCT's HREC) and National Health Science Research Committee (NHSRC). Written authorizations from The Hospital Director of QECH and from Head of Department-Tiyanjane Clinic were obtained before data collection.

One research assistant was recruited on temporary basis who helped on data collection with the aim of reducing data collection bias. The assistant signed a letter of confidentiality and was a fluent speaker of Chichewa (the national's local language). This research assistant was experienced in research.

Before data collection, the research assistant was trained for a half a day. The training focused on the research topic, rationale of the study, how to screen patients and how to give informed consent; how to select patients, administer the questionnaire, ethical issues like patient confidentiality, protection from harm in terms of disclosure and the need not to coerce patients to participate in the study in any way. It was emphasized to a research assistant that all patients had to be told that their participation was voluntary and that their choice not to take part in the study would not compromise the care they received from Tiyanjane Clinic. The training was held in the afternoon in one of the rooms at Tiyanjane clinic.

3.7.3 Introduction of research to study site

The researcher then set up a meeting with the Head of Tiyanjane Clinic to discuss study logistics. The researcher introduced the research study to the whole palliative care team at Tiyanjane through a presentation.

3.7.4 Recruitment and enrolment

The research assistant eliminated any bias in the recruitment process. This research assistant has experience in research and palliative care with good communication skills but was not involved in the usual care of the patients at Tiyanjane clinic. The aim was that patients should be able to make informed choices without being influenced by the health professional who was involved in the usual care of the patients.

All patients attending Tiyanjane day clinic were targeted for recruitment and enrolment for possible participation in the study. Women with cancer of the cervix were approached while waiting for their check-up at the study site.

The research assistant introduced the study to the prospective study participants. Potential participants received treatment first before being taken into the closed room within the clinic. Study information sheet about the research, support group involvement (refer to appendices 5 and 6) and fully informed voluntary consent forms (refer to appendices 7 and 8) were given individually to the potential participant as a private conversation in a closed room. Women who indicated willingness to take part in the study were then be asked a few questions independently to determine fully their eligibility. Recruitment of study participants was done and information sheets and consent forms were used to recruit participants from the group.

Those who chose not to take part in the study were assured that their refusal would not affect their care. The ones eligible were accorded an appointment the following week to start meetings for support group.

3.8 Support group intervention

3.8.1 Formation of support group

Women with cervical cancer and those who were eligible for being in support group were involved in support group formation and operation. Although the researcher played a role in forming, nurturing and facilitating this support group, the primary drivers and decision-makers were the women living with cervical cancer. These women had ownership over the group because they knew their needs and interests. It was the responsibility of each member that any information shared with the group would not be discussed outside group boundaries without the consent. This was so because support groups only work when members trust each other and have free and open discussions.

3.8.2 Forming constitution

Cervical cancer women developed their constitution that governed and outlined how the support group would function. The constitutions provided clear guidance and direction about what was allowed and not allowed within the group, and they establish the framework for the group’s norms and values. The constitution included the followings: rights and responsibilities of group members, confidentiality, teamwork and conflict resolution; leadership and meeting frequency which was every fortnight.

3.8.3 Duties of group leaders included

Group leaders had roles to play. These included upholding active participation of every member, maintaining the constitution, organising meetings and overseeing scheduled activities.

3.8.4 Operations and Logistics

The meeting venue was at Tiyanjane clinic for palliative care because it was easily accessible, free of charge and safe. Meeting time was in the afternoon at 1pm (Malawian time).

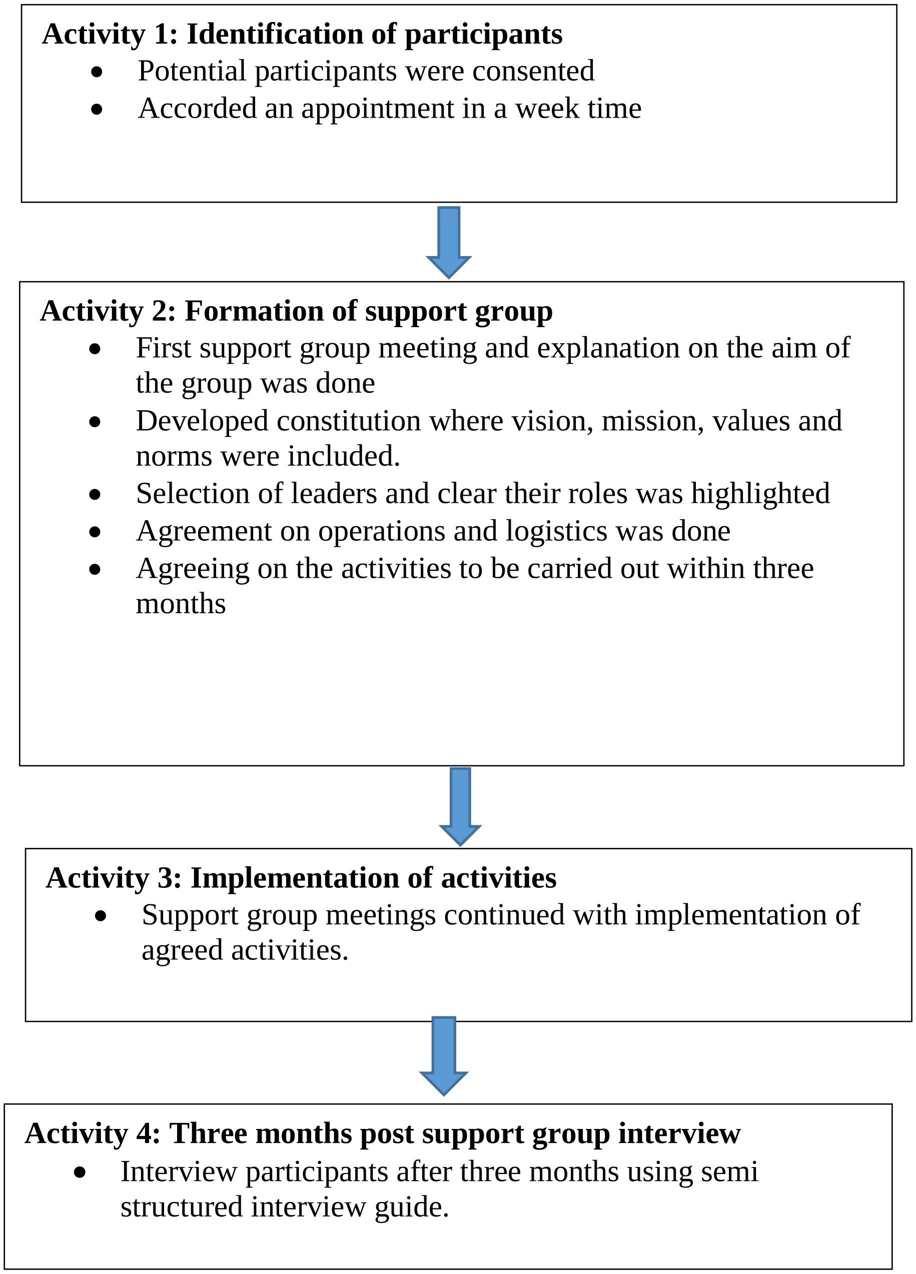
During each meeting members were having refreshments and snacks because members had to travel to the hospital so they might be hungry. Leaders could communicate to researcher if group members need outside facilitator for a specific topic. The researcher could arrange for this in advance at no cost. The group established meeting ground rules. These rules included the following: there should be one person speaking at a time, respecting and supporting each other. At the end of each meeting group members agreed on the next topic according to majority wishes.

3.8.5 Topics covered

Description of cervical cancer and this included definition, causes or risk factors, its management in Malawi and prevention. They also included nutrition in cervical cancer patients, use of natural herbs in cervical cancer, how to support patients with cervical cancer and alternatives to sexual intercourse in cervical cancer patients.

The Flow Chart below further explains the support group intervention.

Flow chart 1: Support group intervention



Activity 1: Identification of participants

- Potential participants were consented
- Accorded an appointment in a week time

Activity 2: Formation of support group

- First support group meeting and explanation on the aim of the group was done
- Developed constitution where vision, mission, values and norms were included.
- Selection of leaders and clear their roles was highlighted
- Agreement on operations and logistics was done
- Agreeing on the activities to be carried out within three months

Activity 3: Implementation of activities

- Support group meetings continued with implementation of agreed activities.

Activity 4: Three months post support group interview

- Interview participants after three months using semi structured interview guide.

After one (1) month, one (1) woman dropped and the support group remained with fourteen (14) women. All the fourteen (14) had attended not less than five (5) out of total six (6) support group meetings.

3.9 Conducting interviews

After three (3) months of support group participation, informed consent was also sought from participants to take part in interview. If the participant agreed to take part, then permission was sought to use digital recorder and consent form was signed before actual interviews (refer to appendices 7 and 8). This was so because individuals are autonomous beings, they have the right to decide whether or not they get involved in the research.

The developed semi-structured interview guide was piloted in two (2) patients from the support group to assess its ability to collect the desired information. No changes were encountered during piloting.

An audio tape-recorder was also used to capture data. Writing pad and pen were also used during the face to face interview for field notes of any observations, cues, behaviours and interruptions that came up during the interview.

All the interviews were conducted by research assistant. The researcher had no chance of meeting the participants during interview time so that there was no influence of the participants. The research assistant provided and explained the study information sheet and consent form to each participant. Thereafter the participant was given time to ask questions. Once the participant was satisfied that all questions about the research had been answered, the participant signed a consent form.

On completion of this, the research assistant did actual data collection by interviewing the participant with the tape recorder on in the preferred language using semi-structured interview guide.This interview was done in a private and well-ventilated room within Tiyanjane Clinic. That was so to ensure that the interviews were conducted in a familiar environment with no disruption. Field notes were collected in a writing pad to record observation like non-verbal communication during interviews.

The approximate length of the interview was 32 to 44 minutes. Participants were each provided with a bottle of soft drink, snack, and transport reimbursement of an average of MK2, 000 (R40) at the end of the interview.

During interviews, data saturation had been achieved after the research assistant identified statistical demonstration of redundancy in codes; where last few interviews did not provide new insights making sample size appropriate for this study (Marshall et.al., 2013:16). This happens because data analysis is conducted alongside data collection interviews.

3.10 Data storage

To ensure that confidentiality was maintained, audio data collected from recorded interviews was stored in password-protected computer files. The audio and hard copies of transcripts as well as field notes were stored in a lockable cabinet to which only the research team had access.

3.11 Ethical considerations

The study commenced once approval had been obtained from the UCT HREC (refer to appendix 9), HSREC (refer to appendix 10)and written authorization from QECH Hospital Director (refer to appendix 11) and from Head of Department- Tiyanjane clinic (refer appendix to 12).

Confidentiality was upheld by informing participants that any information provided would not be used for any purpose apart from the researcher's academic interest. The researcher was a student. The research was part of the fulfilment of the researcher's master's degree.

Autonomy was promoted by giving participants permission to stop the interview at any time if they experienced any distress. Participants could withdraw from the study at any time without explanation and such a decision would not compromise the quality of care they were receiving at Tiyanjane Clinic. Participation in the study was voluntary and this was stated in an informed consent form, which all participants signed.

There was no distress encountered during individual in-depth interviews. If a participant displayed or expressed physical or psychological distress, then she would be allowed to stop the interview, or the research assistant would use his own discretion to do so. A documented distress protocol was developed by the researcher with the social worker prior to application for ethical approvals (refer to appendices 13 and 14).

3.12 Data analysis

The researcher listened to the recorded data and did the transcription. Then the researcher compared again the recorded data with the transcripts to make sure that the translation reflected was what the patients had said. Finally, the research assistant listened to a few recorded interviews and compared those with the transcripts to make sure that what was in the transcripts reflected what the study participants had said.

Thematic analysis was done by a researcher and then checked by supervisors. Thematic analysis approach where four phases of organisation, familiarization, reduction and analysis was adopted (Miles et.al 2014: 75-87).

All the interviews were transcribed verbatim and typed in word processing documents. Data and field notes were transcribed from the local language to English and back translation was done to check accuracy.

Familiarization with the data was achieved through transcription, listening to audiotapes and reading and re-reading the transcripts resulting in immersion in the data.

A coding and development category system was utilised where there was careful reading of transcribed data line by line and the data was divided into meaningful analytical units. Thereafter the reading of transcripts, assigning categories, coding and summarizing codes by theme and subthemes were repeated. Then the texts concerning impact of support group intervention in women with cancer of cervix were extracted.

The texts were coded according to the priority levels in relation to the aim of the study. The underlying meaning of the different categories of the codes was formulated into refined themes and subthemes.

Table 1 below shows the activities done during each stage of framework for thematic analysis approach.

Table 1: Framework for thematic analysis approach (Adopted from Miles, Huberman &Saldana 2014)

STAGE	**ACTIVITIES**
One: Organisation	• Ensure all contents in the digital recorder and field notes are transcribed. • Check transcriptions against digital recordings and field notes.

Two: Familiarisation	• Readings of the narrative to aid familiarisation. • Begin first thoughts list of the potential ideas that may arise during this process. • Check field notes kept during data collection, gain a sense of the narrative and identify potential topics or emerging themes and subthemes. • Start a preliminary list of categories.
Three: Reduction	• Review narrative and reduce to significant statements. • Reduce data to the smallest points that can stand on their own. • Apply preliminary categories/codes list to the reduced points/statements. • Review preliminary category/codes list and expand as required. • Apply completed category/codes list to the reduced data.
Four: Analysis	• Complete cross case and case analysis of the data. • Identify any emerging themes and subthemes. • Return to original complete narrative to ensure a completeness of data. • Conclusion- draw up significant themes and subthemes.

The research supervisors analysed some of the transcripts to ensure that there was consistency in the coding and to eliminate bias.

3.13 Trustworthiness

For trustworthiness of the study, below four key components were addressed accordingly.

3.14.1Credibility

The purpose of this is to establish confidence that the results are true, credible and believable (Forero, 2018:3).

All the procedures used in conducting the study, including explaining the research setting as well as the data analysis methods used, have been described for readers to be able to make appropriate judgements about the degree of fit, and/or to use the same procedures in order to replicate the study under different circumstances. There was constant interaction with the supervisors during all levels of conducting the study, from inception of the research idea, to the proposal writing stage, through data collection and during data analysis. The research supervisors are experienced qualitative researchers.

3.14.2Confirmability

The purpose of this is to extend the confidence that the results would be confirmed by other researchers (Forero, 2018:3). Research supervisors followed the path of the research to see how the themes and interpretations were arrived at to maintain objectivity and neutrality of the study.

3.14.3 Transferability

The purpose of this is to extend the degree to which the results can be generalized or transferred to other setting (Forero, 2018:3).That was accomplished by developing interview guide sample in order to allow for adequate comparisons with other interview guide samples when necessary.

3.14.4 Dependability

The purpose of this is to ensure the findings of this qualitative inquiry are repeatable if the inquiry is occurred within the same cohort of participants, coders and context (Forero, 2018:3). Dependability was ensured by conducting a pilot study to determine whether the research question and the semi-structured interview guide questions were clear before the author proceeded to the main study.

CHAPTER FOUR: RESULTS

4.1 Introduction

The researcher conducted a qualitative study that focused on an exploration of the impact of support group intervention at Tiyanjane Clinic for palliative care, Queen Elizabeth Central Hospital, Blantyre, Malawi. The participants had confirmed diagnosis of advanced cervical cancer. The interviews were conducted over a period of one month. The first interview was conducted on 3rd December 2018 and the final interview on 28th December 2018. The average time of each interview was approximately 40 minutes and 39 seconds, with the shortest interview being about 32 minutes and 17seconds and the longest interview being about 44 minutes and 3 seconds.

4.2 Demographic data

The demographic data of participants is shown in the table below:

Table 2:Demographic data of participants

STUDY NO	AGE	EMPLOYMENT	MARITAL STATUS	NUMBER OF CHILDREN
R001	62	Farmer	Divorced	4
R002	51	Teacher	Divorced	None
R003	36	Small scale b4.2usiness	Married	3
R004	32	Shop attendant	Married	4
R005	40	Farmer	Divorced	1
R006	54	Small scale business	Divorced	6
R007	55	Business	Married	5
R008	37	House maid	Single	2

4.3 Themes

Themes and sub-themes developed during the process of coding were presented and supported by important quotes from the semi-structured interviews that were conducted.

Four (4) themes emerged from the interviews and each theme has subthemes as shown in the table 3 below. The sub-themes are illustrated by direct quotes from the study participants.

THEME ONE: INTIMACY	**THEME TWO: EMOTIONAL SUPPORT**	**THEME THREE: BECOMING INFORMED**	**THEME FOUR: DRAWBACKS OF SUPPORT GROUP**
1.1 Impact of cancer on intimacy	**2.1 Emotional support**	**3.1 More informed about cancer**	**4.1 Risk of privacy violations**
1.1.1 Isolation 1.1.2 Stigma, 1.1.3 Low self-esteem	2.1.1 Sense of humour 2.1.2 Solidarity 2.1.3 Encouragement	3.1.1 Discussion about positive living	
1.4 Factors improving intimacy 1.2.1 Able to discuss issues of sexuality 1.2.2 Overcoming loneliness in intimate relationships 1.2.3 Alternatives to sexual intercourse	**2.2Emotional wellbeing** 2.2.1 Relaxed 2.2.2 Less anxiety	**3.2 Know about resources** 3.2.1 Symptom control 3.2.2 Improved quality of life	**4.2 Revisiting cancer** **4.3 Monopoly of some group members**

4.3.1 THEME ONE: INTIMACY

All the women indicated that cervical cancer diagnosis had an impact on their intimacy. However, through support group participation these negative impacts have been reduced. Under impact of cervical cancer on intimacy they reported below subthemes.

Impact of cervical cancer on intimacy

Isolation

Some respondents mentioned that being diagnosed with cervical cancer, they end up being isolated or there had feelings of self-isolation which mostly affect their intimate relationships.

"The time I was told I had cancer, I felt the pain which I could not explain, I could not listen to whatever the nurse was saying thereafter, I was really down, my resolution was to stay alone at home and never socialize with anyone else including my partner and this affected my intimate relationship…." (R008)

"At first my husband usually says, I cannot stay here with you, after all you are leaking foul smell. It was indeed an intimate lonely life which is so frustrating……….. (R007)

Stigma

Some women indicated that at first, it was either they had self-stigma or their loved ones stigmatized them because of symptoms they had like leaking of urine and bad odour.

"Before joining support group I thought that it was not necessary to be closer to my husband for all what he could smell from me was the bad odour and I could notice the intimate loneliness…….." (R004)

"My partner was treating me badly, harshly and he did not even want to be near me, but after explaining to him that anyone can be diagnosed with cancer, he has changed. Our intimate relationships have been restored." (R008)

Low self esteem

Some women indicated that before support group participation, they had lost their confidence as being a woman. They felt no longer admirable by partners, friends and communities.

“My body has changed completely, I was having pain and foul smelling vaginal discharge, my self-esteem was disturbed, I could not take care of myself because of pain, everything has changed……but now I have learnt how I can maintain my self -esteem”.(R001)

“At first I was thinking that I was no longer attractive to my husband, but now I know that this is not the case. I have learnt that it is possible to make myself attractive to my husband despite all these symptoms.” (R003)

Factors improving intimacy

Factors Improving intimacy is another subtheme which was said by many women. Below are subthemes emerged under this.

Able to discuss issues of sexuality

Most women indicated that sexuality problems are common in women with cervical cancer and its discussion is done with reservation because culturally it is not accepted to discuss it freely. Contrary to this, during support group meetings this topic was discussed freely without any restriction. It was a privilege to have this type of forum.

“ ... I was very happy to note that during support group meetings and participation sexuality issues were discussed.” R003

“During support group meetings we had a chance of discussing everything even issues of sexuality which is culturally sensitive.” (R007)

Overcoming loneliness in intimate relationships

Some women indicated that before support group meetings, they were not loved by their loved ones.

"……Although this was the case, I still needed a loving and caring man in my life. My main desire was to be loved and treated like a human being. Now my husband knows my wish and treats me as his wife…." (R004)

"At first I was telling myself that much as I wish to have a husband and being loved in my life but no one can fall in love with a sick woman like me? But now I can find someone who can show me love (she laughed) '' (R002)

Alternatives to sexual intercourse

Some women indicated that it was good to be in a support group because there were different ways of sexual satisfaction which were explored.

"During support group discussion we explored ways of sexual satisfaction without intercourse like oral intercourse and gentle massaging on sensitive body parts." (R003)

"I did not know that even being close to sexual partner can have a sexual satisfaction" (R007)

4.3.2 THEME TWO: EMOTIONAL SUPPORT

Getting emotional support

Most women indicated that support group meetings and attendance were helpful because they got emotional support.

Sense of humour

During support group meeting some women indicated that they had time to share funny stories and they could laugh.

"...I liked the way we laughed during support group meeting up to the extent of forgetting what we were passing though....... "(R006)

"The way we shared funny stories it was interesting, I wish I could be coming here every week…." (R002)

Solidarity

It was reported that the fact that every member was given a chance in contributing on best strategies on each topic, this was an advantage to every group member.

"The agreement on the topic of discussion during next support group meeting empowered most members for active participation. Every group member felt that was part of the group." (R008)

"During support group meetings and participation there was so much support that when you are down fellow women uplift your mood. I liked the way group members supported each other." (R004)

Encouragement

Most respondents mentioned that the encouragement they got from support group meetings positively impacted their lives.

"The encouragement I got from the support group members has positive impact towards my life, I know you cannot understand what am talking about…" (R002)

"…Our group supported and encouraged each other, we advised each other never to think about problems that come due to cancer." (R008)

Emotional well-being

Most women indicated that support group participation helped them on emotional well-being.

Relaxed

Some women explained that the environment at support group meetings was conducive for relaxation.

"The environment created during support group meetings was conducive for relaxation." (R003)

"I was able to express my feelings freely because I knew that what I was passing through most members understand them." (R001)

Less anxiety

Some respondents mentioned that their anxiety has reduced since they joined support group.

"When I was diagnosed with cancer it was not easy, I thought I would die any time sooner, thanks to my fellow women with same cancer, we had time to talk about it freely, my anxiety was reduced." (R006)

"My anxiety had reduced, before joining support group, I had much of it… (R001)

4.3.3 THEME THREE: BECOMING INFORMED

During support group meetings most participants were fully informed about cancer. Subthemes that emerged under this theme are as follows.

Informed about cancer

Most respondents said that they had time to learn more about cancer. Facilitators talked about cancer in details.

"In our communities, there are lots of misconceptions about cancer, people tell lies about it but now through support group sessions I am able to tell others the truth about cancer. (R004)

"I was scared to ask my doctor on certain questions, but through the group I had the opportunity to ask as many questions as I had. Now I know the truth about cancer." (R001)

Discussion about positive living

Most women indicated that during support group meeting they had chance of sharing ways of health, normal and productive life.

"During support group meetings we discussed ways of making our lives move on positively ……..." (R007)

'During support group meetings we give each other hope that so long as we follow instructions from health workers, quality of our lives will be improved." (R002)

Know about resources

Most women explained that being in support group, it was easy of being connected to resources that improve their quality of lives.

"During support group meetings, we were referred to other stakeholders where they offer other services other than medical care." (R007)

"I was happy to learn that in cancer cases local resources like use of charcoal can be used to eliminate foul smell in foul smelly discharges." (R003)

Symptom control

Women indicated that because the group was meeting at the health facility it was easy to get drugs for symptom control.

"At the end of each support group meeting, the nurse asked us if anyone needs drug refill or needs to be reviewed before going home." (R001)

"We got adequate drugs every time we come for support group meetings, I think the nurse appreciates the need for us to be symptom free so that we attend the meeting effectively." (R003)

Improved quality of life

Women reported that during support group meetings they discussed ways of improving their quality of lives.

"At first, I was distancing myself from my husband because of the uncontrolled per vagina smell, but now through support group meetings I have learnt how I can eliminate this smell and my whole quality of life has improved…." (R007)

"My husband could not touch me because he thought am very sick but after sharing what we discussed during support group meetings, he is now free with me and this improved my quality of life." (R007)

THEME FOUR: DRAWBACKS OF SUPPORT GROUP

Some women expressed that although support group may be effective in supporting women with cervical cancer, it has its own drawbacks. Below are some of the subthemes.

Risk of privacy violation

All the women expressed fear that privacy was somehow compromised when discussing issues in a group.

"During support group meetings there is risk privacy violation because we gather and talk as a group….." (R004)

"In support group we discussed issues as a group not one to one, there is no privacy there, although we agreed that confidentiality should be maintained but we have different characters …." (R001)

Revisiting cancer

Some women indicated that when you keep on talking about cancer you remember the pains you passed through the time you were just diagnosed.

"In reality cancer diagnosis is bad news that comes with bad experiences, sometimes you are not happy talking it anymore." (R002)

"If I remember how my husband abandoned me due to this cancer, sometimes I hate topics to do with cervical cancer and intimacy." (R006)

Monopoly of some group members

It was a concern that some women had introvert and others extrovert personality type. This affected how introvert ones participated.

"Some group members are too talkative, they want to be leaders always, but I decided to accept them it is their personality." (R004)

"In our group we had few women who had difficulties in opening up." (R001)

Summary

In summary, during this study of exploring the impact of support group intervention at Tiyanjane clinic for palliative care; Four (4) themes emerged which were: intimacy, emotional support, becoming informed and drawbacks of support groups. Each theme has its own subthemes that came out from patients quotes.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This chapter is interpreting results of the study and integrate them with current knowledge. Most cervical cancer women expressed that support group intervention is key to comprehensive and holistic care because these women are affected holistically.

5.2 Demographic data

Four (4) women representing half of the total women interviewed were divorced during the course of their illness, three (3) were married and one (1) woman was single. Therefore this study reveals that divorce in cervical cancer women is common, and that is why Perrin et al. found that cervical cancer women also reported limited disclosure of their diagnosis to their husbands because of fear of being stigmatized because of the nature of their disease which will eventually lead to divorce (Perrin et al., 2016: 93-100).

Out of the eight (8) women interviewed four (4) women representing half of the total women interviewed were in their reproductive age that is 15 to 45 years of age. Then this study concurs with Ferlay et al. who state that most cases of cervical cancer are diagnosed in their reproductive years (15-45years) (Ferlay et al., 2010: 2893-2917).

Under employment, two (2) women interviewed were farmers and six (6) were employed; this might be being employed by someone else, a certain company or self-employment. This may be so due to the location of the study which was in the city of Blantyre, which is Tiyanjane Clinic for palliative care which maintains most patients from the city.

5.3 Intimacy

5.3.1 Impact of cervical cancer on intimacy

In a study conducted on African women diagnosed with cervical cancer in South Africa by Maboko & Mavundla (2006:27-28) reveal that when women are diagnosed with cervical cancer there is feeling of isolation hence negative impact on intimacy.

Again, a considerable number of women which was seven (7) out of eight (8) indicated that stigma was another challenge faced by cervical cancer women. In a qualitative research conducted with cervical cancer survivors reveals their concerns about being stigmatized(Dyer, 2010:321-330) by people surrounding them including partners or spouses, family members and communities.

Furthermore, the research found that four (4) women interviewed reported that self-stigma was an issue. These women would not want to be closer to the loved ones especially partners. Some of the reasons mentioned were the presence of distressing symptoms and how the cervical cancer is spread.

Although these are international studies, in Malawi it is a similar case as revealed by most cervical cancer women interviewed, they further indicated that, when one is diagnosed with any condition in relation to unprotected sex, people think that that person is or was a prostitute and prostitution is socially unacceptable. Some cervical cancer women indicated that even their husbands at first were side-lining them when making decision. This might be because they thought the woman would die soon. Therefore, stigma or self-stigma negatively impact women’s and their spouse’s intimacy.

In this study, it was noted that all the eight (8) women interviewed indicated that cervical cancer affects their self-confidence as women.

According to Arrossi et al., the mother who is the home manager may be frail and bed ridden or may be away from home to seek medical treatment and care. This affects the general wellbeing of the children as well as the self-confidence and pride any woman has (Arrossi et al., 2015: 32). This might be due to progression of the disease which comes with many distressing and complex symptoms which affect both general well-being and genitals which has an impact on sexual well-being. Therefore, it is concluded that low self-esteem negatively impacts on intimacy.

5.3.2 Factors improving intimacy

Although it is well known that in Malawian culture, sexuality issues are sensitive and are not discussed freely (Msyamboza et al., 2010:3). This study supported the study conducted by Lyndsey et al. which indicated that women with cervical cancer discuss their sexuality issues freely when they are in a group (Lyndsey et al., 2013:302).

This is evidenced by five (5) women out of eight interviewed who indicated that although sexuality issues are sensitive, private and never discussed at hospital or community setting but during support group meetings, women were able to discuss it freely.

Central to the study by Atara which reveals that there is disrupted intimate love among women diagnosed with cervical cancer. They further indicated that when someone has disrupted intimate love, there is nothing exciting including intimate excitement (Atara, 2011:43). However, women interviewed revealed that there is improved intimate love when attending support group meetings where intimate loneliness is reduced. Therefore, they found support group meetings as one way of improving intimate love with their partners.

Three (3) women indicated that they were excited to learn that although sexual intercourse cannot be possible, there are other ways of fulfilling sexual desire with their partners. These ways included; being close to partner and gentle caressing the partner.

Again, according to these women support group meetings and attendance changed positively to husbands' and community views on nature and prognosis of cervical cancer. This was because these women had a role to play in changing mind-set of their spouses by explaining to them the truth of cervical cancer diagnosis hence improvement on intimacy.

In a study conducted by Sanchez, it was described that cancer of the cervix and its treatment make patients lose interest and have pain when having sex (Sanchez, 2013:327). Although this is the case, partners of women with cervical cancer feel they have responsibilities of meeting sexual needs of their sexual partners.

5.4 Emotional support

5.4.1 Getting emotional support

It was noted that all the eight women interviewed indicated that support group meeting is a place where they were able to laugh and feel accepted. They further say having time for laughing has a positive impact on psychological distress which these women mostly have. This is in support of the findings of Harman Foundation which indicates that support groups offer a friendly, safe, social environment for patients to come together and share their experiences in confidence (Harman Foundation, 2019:3). Although some research studies indicate the impact of the illness on spiritual issues, the study participants did not comment on spiritual or religious concerns or support (Ashing-Giwa et al., 2011:13; Khazee-Poo et al 2018:8))

Six (6 women out of eight (8) indicated that support group intervention strengthened solidarity. This confirms a study conducted by Demjen which found that humour generally has multiple functions, potentially contributing to interpersonal and psychological effects such as group bonding and solidarity (Demjen, 2016:20).

The findings from this study indicated that the agreement between group members and their support they offer to each other was positive to them.

Again, in this study six (6) women out of eight (8) expressed that they got encouragement during support group meetings. They could get support and hope from fellow women who are facing the same problems. Mayo Clinic staff reveals that support group meetings bring together people who are going through or have gone through similar experiences hence the feeling of encouragement (Mayo Clinic staff, 2018: 3).

Furthermore, the findings of this study support Mayo Clinic staff findings that state that a support group can help participants feel less lonely, less isolated or less judged, gaining a sense of empowerment and control; improving coping skills, sense of adjustment, talking openly and honestly about feelings hence reducing psychological distress (Mayo Clinic staff, 2018: 3).

5.4.2 Emotional wellbeing

A study conducted by Lyons found that women are relaxed and calm in the support group setting, only if they get comprehensive package of care that includes psychosocial support (Lyons, 2004:23). Therefore, this study supports the formation of support group as one strategy to overcome complex psychosocial problems faced by cervical cancer women.

Again, globally when women are diagnosed with cervical cancer, they develop complex psychosocial problems and these include anxiety, depression and sadness (WHO, 2005: 38).

In this study, it was found that all the cervical cancer women interviewed reported anxiety soon after confirmed diagnosis of cervical cancer. This is because of fear of the prognosis and eventually premature death. They then all indicated the reduction of anxiety after support group participation.

5.5 Becoming informed

5.5.1 Informed about cancer

In a study conducted by Zabalegui, indicates that diagnosis with cervical cancer seems to be more distressing than with other cancers because of its nature, beliefs around causality and the treatment modalities involved and these worsen the psychological distress (Zabalegui et.al, 2015:23). In this study, the research found that it is through support group meetings that cervical cancer women can ask as many questions as they could. Six women out of eight interviewed reported that in support group meetings, cervical cancer women were free to ask any questions related to cancer.

The study by Zabalegui indicated that women diagnosed with cervical cancer may lose ability to think positively and that previous coping mechanism may be affected (Zabalegui et.al, 2015:23). In the current study, it was found that when these women take part in support group meetings their thinking change completely. They share ways of healthy, normal and productive life because despite them being sick or diagnosed with cervical cancer their lives need to continue hence positive living. This was reported by seven women out of eight who were interviewed.

5.5.2 Know about resources

In a study conducted by Faneli and Moyo, it indicates that women diagnosed with cervical cancer have complex symptoms which include fatigue, pain and incontinence and these affect how cervical cancer women feel about themselves and they function (Fanelli and Moyo 2018: 7). From the researcher's study, four women out of eight interviewed indicated that during support group meetings, health workers present during the meetings also focus on physical problems control.

Indeed, for individuals to effectively take part in support group meetings, pain and other symptoms have to be controlled first. Again, WHO findings reported that women with cervical cancer face many challenges including irregular supply of drugs (WHO, 2005: 37). From this study it was noted that when women living with cervical cancer are in support group meetings, they are able to get regular medication for their physical problems. Furthermore, two out of eight women interviewed reported that during support group meetings, they get professional care.

This was so because their facilitator was a health professional. In most PLWHA support groups' facilitators are group members who are not professionals which is contrary to this support group. They further revealed that the meeting place was also strategic because it was at the hospital setting. According to Harman Foundation (2019:3) which indicated that peer support sessions have successful outcome because referrals to professional health care are available for necessary support. The research findings supported the fact that support groups have an advantage of getting professional care easily especially when its venue is at a health facility.

In Malawi, cervical cancer is usually diagnosed in advanced stage. Late presentations usually affect the quality of life because of the complex symptoms that come with advanced cervical cancer. This supported a study which states that as with all cancers in most developing countries, cervical cancer is usually diagnosed at an advanced stage (Ali et al., 2016:2). Four women out of eight interviewed indicated that they were happy to learn that if cancer is diagnosed in early stage cure is possible hence improvement on their quality of lives. They further requested for cancer information to reach a lot of women to avoid late presentation.

The research results support the findings of Harman Foundation, which indicates that members in a support group are eager to learn more about their condition and invite specialists to talk about their condition and this in turn improve their quality of life (Harman Foundation, 2019:3).

5.6 Drawbacks of support group

5.6.1 Risk of privacy violation

In support of Transverse Myelitis Association which revealed that members fear that other members will violate the members' right to privacy by revealing to others what is known about them (Transverse Myelitis Association, 2012:35). The research findings noted that two women out of eight who were interviewed were worried about the issues of privacy. People in the group have different personalities therefore even if they agree not share any information to anyone else who is not in a group, there is risk of privacy violation. They further indicated that this may be dealt with by putting in place norms and values of the group and emphasise the importance of following them.

5.6.2 Revisiting cancer

Again, two women out eight interviewed said despite the positives that come with support group discussion, there is a possibility that they remember the hardships they met when they just diagnosed with cancer. This is in line with the study by Schechter which states that in support group discussion you remember painful experience you faced long time ago (Schechter (2012: 36).

5.6.3 Monopoly of some group members

One woman out of eight who was interviewed did not like the talkativeness and control of some members over the other. There was an indication that the facilitator tried to control this, but others are born with this character and it becomes difficult to teach them acceptable ways of being in the group. This is in support with study by Schechter which indicates that sometimes a group member may dominate the discussion (Schechter, 2012: 36).

The learning point is that though support group intervention has positive impact on psychosocial needs in women with cervical cancer, it has some drawbacks. However, these drawbacks do not surpass the advantages.

Summary

This research study has brought new knowledge in Malawi and possibly other countries in Africa. Previously, support group intervention was common in PLWHA and not in cervical cancer patients, and it may be proved to produce positive results on complex psychosocial distress. The majority of the participants in this research study indicated that support group participation improves psychological and emotional distress of patients with cervical cancer. The participants in this research study appreciated the need for support group participation because it is one way of getting emotional support from the peers.

In addition, generally, women are able to discuss sexuality issues freely which is mostly taken as sensitive issue. The results of this study provide evidence that most cervical cancer women found support group attendance as maybe a good strategy of relieving their complex psychosocial distress, intimacy and other problems though has some few drawbacks and yet it is not prioritized in Malawi.

Area of further research

It may be important to conduct a quantitative study of finding out whether support group intervention can be ideal for cervical cancer conditions in Malawi because cancer diagnosis comes with complex psychosocial distress. The generalization which comes with quantitative results may help in policy adjustment when it comes to cervical cancer management.

Study limitations

The research findings cannot be generalized, but for the findings to be generalized, a large quantitative study should be done involving different palliative care sites in Malawi.

Although thematic saturation reached after conducting interviews in eight (8) participants it was still a small number.

During the research, the researcher discovered that the research assistant lacked probing skills in some areas where participants could have been assisted to open up about areas that were of concern to them. For example, challenges faced during support group meetings were directly mentioned by two participants only, in other participants, challenges were mentioned indirectly, but it was the duty of the research assistant to probe more to uncover participants' views or concerns regarding this.

The design of the questionnaire included few demographic questions. The form for demographics could have be longer and would have been separate from the interview questions. There were additional questions that could have been included to address most of the issues found in the literature review, in particular questions about spirituality and the impact of the illness on spirituality..

There was no triangulation of data in this study. However, if this study is done again there is need to consider methodological triangulation using different sources of data in the study.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This research aimed at exploring the impact of support group intervention among women with cancer of the cervix, to explore the psychosocial impact of support group intervention among women with cervical cancer, to explore the impact support group intervention on cervical cancer women's experience on intimacy and to evaluate the outcomes of attending the support groups among women with cervical cancer.

This research has shown that women with cancer of cervix experience complex psychosocial and emotional distress which affects them holistically.

Most women revealed that support group participation improved intimacy with their partners because women could discuss issues of sexuality and physical symptoms associated with cervical cancer. This gave them confidence to discuss these issues with their husbands and to try other ways to achieve intimacy if sexual intercourse was not possible because of the physical effects of the cancer.

Cancer information provided during support group meetings help in emotional support and in emotional well-being; participants become informed about cancer and know about resources. However, though support group intervention seemed to have many advantages it had its own drawbacks. Few women were concerned that support group discussion risks privacy violation, during discussion they revisited their cancer experience and monopoly of some group members. Fortunately, the general conclusion is that the advantages surpass the drawbacks.

6.2 Recommendations

Women with cervical cancer experience complex psychosocial and intimacy distress which has proved to affect them holistically. There may be a need to incorporate support group interventions in managing women with cancer of the cervix. Support group interventions may be regarded as valuable part of psychosocial and intimacy treatment if holistic treatment has to be achieved.

Being in an environment where they can discuss anything in relation to cervical cancer freely help cervical cancer women overcome their complex challenges.

Although the results cannot be generalized, there is recommendation to national and international organisations to fund for a large quantitative research on impact of support group intervention so that the results can be generalized hence influence policy adjustment towards essential interventions in women with cervical cancer. This is because support group intervention is found to reduce complex psychosocial and intimacy distress associated with cervical cancer diagnosis, and hence leads to improved quality of life of these women and their families.

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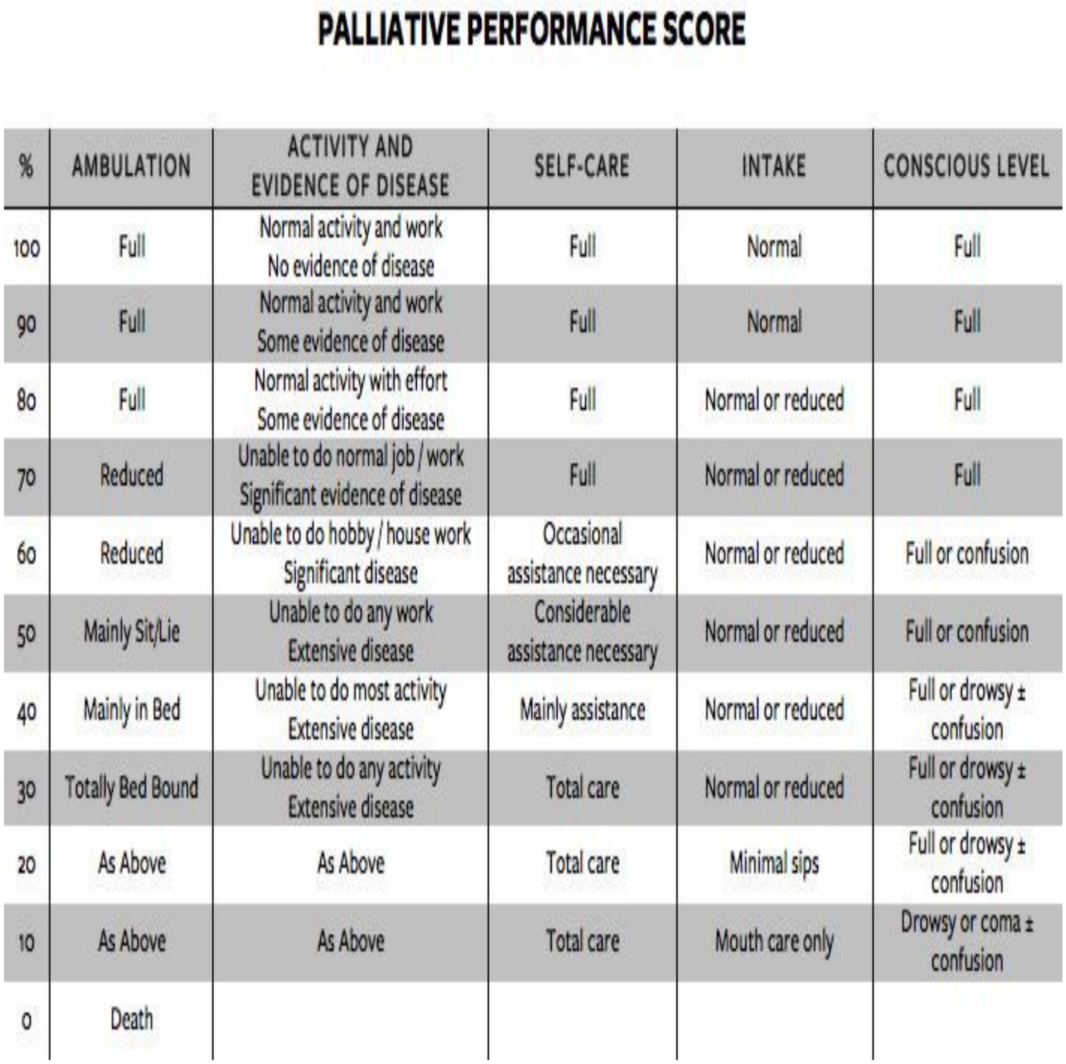
APPENDICES

APPENDIX 1: Information of the data base used

Search Terms	**Data Base**	**Number of Hits**	**Date**
WHO+cervical cancer	Google scholar	132	28-02-18
Cancer of cervix+ epidemiology + malawi	Pubmed	11	20-07-18
Cancer of cervix+ BMJ 2018	Hinari	114	23-07-19
Sexuality+cancer of cervix+Africa+2012 to recent	Google scholar	978	25-07-19
Sexuality+cancer of cervix+Malawi+2012 to recent	Google scholar	1,132	25-07-19
Magnitude+sexuality+cancer of cervix	Pubmed	349	23-12-19
Cervical cancer+disclosure+spouses	Pubmed	288	1-2-20
Cancer+supportgroup+benefits	Google scholar	12	1-2-20
Malawi+healthfacility+mapping	Google scholar	6	4-9-20
Malawi+health+transportation	Google scholar	23	4-9-20
Qualitative research+rigour+assess+criteria	Pubmed	422	5-9-20

APPENDIX 2: Palliative Performance Score



PALLIATIVE PERFORMANCE SCORE

%	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100	Full	Normal activity and work No evidence of disease	Full	Normal	Full
90	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal job / work Significant evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby / house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance necessary	Normal or reduced	Full or confusion
40	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy ± confusion
30	Totally Bed Bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy ± confusion
20	As Above	As Above	Total care	Minimal sips	Full or drowsy ± confusion
10	As Above	As Above	Total care	Mouth care only	Drowsy or coma ± confusion
0	Death				

APPENDIX 3 : Interview guide (English version): A study to explore support group interventions in women with cancer of cervix at Tiyanjane Clinic

Demographic data

ID: Age: Employment:

Marital status: No of children:

1. What do you understand about your illness?
2. How can you explain the support you get from
   - Family members
   - Community members
   - Partner
3. What difficulties do you experience because of the cancer?

   Prompts: physical problems, problems fulfilling the role of mother, of wife?
4. One of the areas of difficulty women sometimes experience when they have cervical cancer is in the relationship with their husband. How has cervical cancer affected your relationship? How has it changed your experience of intimacy?

   Prompt: how has it affected your sexual relationship?
5. Why did you accept to join support group?
6. What kept you coming back?
7. What have you gained from attending support group?
8. What are the challenges of attending the support group?

Thank you for your active participation

APPENDIX 4: Interview guide (Chichewa version)**:**Kafukufukuwofufuzamomwesupotigulupuingathandizileamayiomwealindikhansayakho molachibelekeloku Tiyanjane clinic

Zokhudzaodwala

Namabalaya ID: Zaka: Ntchito:

Zokhudzaukwati: Nambalayaana

1. Mukudziwazotanizokhudzamatendaanu?
2. Mumalandirachithandizochotanikuchokerakwa:
    - ➢ Achibale?
    - ➢ Anthuakumudziko?
    - ➢ Wokondedwawanu?
3. Mumakumanandimavutoanjichifukwa cha khansayimongakuthupi, komasokukwanilitsaudindowanungatimayi?
4. Chimodzimwamavutoomweazimayi a khansayakhomolachibelekeroamakumananawondiubalendiamunaawo, Inuyozilibwanjipankhaniimeneyi. Nanga kumbaliyokhaliralimodzingatibanjazilibwanjiso?
5. Chinakupangitsanikuvomelakukhalanawo mu supotigulupundichiyani?
6. Chimakupangitsanikubwelabekusupotigulupundichiyani?
7. Supotigulupuyakupinduliranibwanjimmoyowanu?
8. Ndimavutoanjimumakumananawopokhala mu supotigulupu,

Zikomokwambirichifukwachotenganawombalipoyankhamafuso

APPENDIX 5: Information sheet (English version)

AN EXPLORATION OF SUPPORT GROUP INTERVENTION AMONG WOMEN WITH CANCER OF THE CERVIX: A CASE OF AT TIYANJANE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE: MALAWI

Dear participant,

Thank you for giving your time to hear about this study. This information sheet tells you about a study that you may wish to take part in. The information sheet is for you to keep. I will go through the information with you and if you may have questions to help you decide whether you want to take part, please ask them. I will be happy to answer them and explain the study further. Please note that participation in this study is voluntary, meaning that you are not forced to take part. Please take your time to make a decision.

What is the purpose of the study?

This study looks at support group intervention among women with cancer of the cervix to gain some understanding of how to best help women with this cancer.

Do I have to take part?

No, you don’t have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, your care will not be affected in any way. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

What will happen if I take part?

You will be included in a support group which will meet twice a month for a maximum of three months. After being in the support group for 3 months, a researcher who is also a staff member at this clinic will conduct invite you to take part in an interview about the support group. It will take about forty five minutes to conduct the face to face interview which will be audio recorded.

Benefits of the study

The anticipated benefit is affording a therapeutic opportunity and safe space for you to share your concerns and experiences as well as your views about the support group and whether this may help other women with cervical cancer.

What are the risks of the study?

Answering some questions might cause an emotional response. A palliative care counsellor will be available to help you if you feel distressed. In the event that there is emotional response, the researcher will stop the interview and appointed counsellors will attend to emotional needs of the interviewee.

Will my taking part in this study be kept confidential?

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. No-one outside the study will have access to the information you give us.

How will I know about the results of the study?

At the end of the research, we will send you a report and the report will also be presented to the palliative care clinic.

Who is organizing the research?

If you have any questions about the study, you can contact the following people.

Researcher*:*Mwandida Nkhoma, Palliative Care Support Trust, Cell No: 0999374881

Dr. Cornelius Huwa, Palliative Care Support Trust, Cell No: 0999 374 103

Supervisor: Dr Liz Gwyther, University of Cape Town, Cell No: + 27 21 6501475

Co-supervisor*:* Dr. Jane Bates, Malawi College of Medicine, Cell No: 0999 208 193

If you have any questions about your human rights or any ethical issues about the study, please contact:

UCT Research Ethics Committee: **Mrs LameesEmjedi**, Human Research Ethics Committee, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338

APPENDIX 6: Information sheet (Chichewa version)

KAFUKUFUKU WOFUNA KUDZIWA MOMWE SUPOTI GULUPU INGATHANDIZILE AMAYI ODWALA KHANSA YA KHOMO LACHIBELEKERO KU TIYANJANE CLINIC KU BLANTYRE, MALAWI

Zikomochifukwa cha nthawiyonseyomwemutamvetselezokhudzakafukufukuyu. Chikalatachichikufotokozazokhudzakafukufukuamenemungafunekutenganawombali. Chikalatachindichotichikhalechanu. Tichiwelengeralimodzibwinobwinondipongatipalimafunsoenandinuololedwakufunsandicholinga chotimupangechiganizochotenganawombalikapenaayi. Ndiliokondwakukuyankhanikomasokulongosolamonvekabwinongatizilizoyenerakutelo. Dziwanikutikutenganawombalipakafukufuyisitikukakamiza. Chondekhalanindinthawindithukutimupangechiganizochotenganawombalikapenaayi.

Cholinga cha kafukufukuyindichiyani?

Mu kafukufukuyi, tikufunakudziwangatisupotigulupuingathandizeamayiodwalakhansayakhomolachibelekelo. Tikufunakudziwansokutiamayiodwalakhansayakhomolachibelekeroamakumanandimavutoanjiokhudzanapokhaliranakomasommaganizo. Zotsatilazakafukufukuyizizathandiza a kuundunawazaumoyokudziwakutisupotigulupuimathandizabwanjikwaamayiodwalakhansayakhomolachibelekelo. Izizidzathandizirakakonzedwekandondomekoyabomapakathandizidwekwaamayiodwalakhansayakhomolachibelekelo.

Ngatimungalolekutenganawombalimukafukuyindekutimudzayenelakumakumananawo mu gulupuyaamayiomwealindivutongatilomweli. Kukumanakondikawilipamwezikwamiyeziitatu.

Kodindikuyenerakutengambalimukafukufukuyi?

Ayisikutimukuyenerakutengambalikomaaliyensealindiufuluosankhakutenganawombalikapenaayi.

Mukalorakutenganawombalimuliololedwakusiyakafukufukuyimosakakamizidwakupelekachifukwa. Mupitilizabekulandirachisamalirochakunokuchipatalangakhalemutalora kaya kukanakutenganawombali.

Mukakhalakutimwalorakutenganawombalitikupemphanikutimutisayinilefomuyachilolezo.

Ndinuololedwakukhalakayendinthawiyoganizirakutenganawombalikapenaayai.

Muthakukakambilanandibanjalanuzakutenganawombalikapenaayi.

Zikhalabwanjindikavomelakutenganawombali?

MmodzimwaanthuopangitsanawokafukufuyuKambilananananuzakafukufuyuamenealiokhudzazachithandizochomwesapotigulupuingapelekekwaamayiodwalakhansayakhomolachibelekero.

Mukambilananawokwamphindifotefiyifi. Pakhalakugwilitsantchitochimtapamawu.

Malipirondiphindu?

Sipadzakhalamalipiroenaaliwonsechifukwachotengapombalimuzokambiranazi.

Zomwetizapezemukafukufukuyizidzakhalazofunikirakwambirikupangiramfundozachithandizochoyenerakupelekedwakwaamayiodwalakhansayakhomolachibelekelo.

Palibendalamailiyonseyomwemudzaononge,

komanthawiyanundiimeneidzatayikechifukwamudzatenganawombarikwanthawiyapafupifupimp hindimakumiatatu. Palichiopsezokumbariyakutimwinamatendankukulatiri mu zokambirana. Dziwanikutititizakhalandiadokotala, a nesindi a soshopafupinthawiyonseyazokambiranaameneazathandizangatipazafunikakutero.

KomansodziwanikutimulioloLedwakusiyazokambirananthawiiliyonsemwafunakutero. Kafukufukuyisazasinthachithandizochanu cha kuchipatala.

Palichiopsezochanji

Kuyankhamafunsoenaomwemungafunsidwezithakukukumbutsanizazowawawazinazomwemunak umananazommoyowanuwu. Pakhalawinawachipatalawotiathekuthandizapankhaniimeneyingatizingachitikemotero. Ndipongatinkoyenerakusiyakayezokambilanazikhalachonchondithu.

Chinsinsi

Mayinaanuadzasungidwamwachinsinsikwaanthuenaonsechifukwazikalatazanusipazakhalamayin akomamanambalaokhaomwetizagwiritsentchitozomwezidzadziwikendiotsogolerakafukufukuyi (Mwandida Nkhoma) yekhabasi. Kafukufukuyiakazatha, zikalata zones zizasungidwamchipindachokhoma. Zotsatirazokha, zidzapelekedwamosatchuladzina la winaaliyense, ku u ndunaowonazaumoyom’boma lino ndikulikulu la u ndunawuku Lilongwe, ndimabungweenaamenealindichidwi pa nkhaniyokhudzaamayiodwalakhansayakhomalachibelekelo.

Zotsatirazakafukufukuyindizadziwabwanji?

Kumapetokwazonsezotsatirazakafukufukuyizidzapelekedwakulikululachipatala chino, ku Tiyanjane clinic komasokwaonseomweatenganawombalindipoamafunakudziwazotsatirazi.

Akuyendetsadongosolo la kafukufukuyundindani?

Ngatimulindimafusomukhozakufunsaineyokapenaanthuawa pa manambalaawa:

Researcher: Mwandida Nkhoma, Palliative Care Support Trust, Cell No: 0999374881

Dr. Cornelius Huwa, Palliative Care Support Trust, Cell No: 0999 374 103

Supervisor: Dr Liz Gywther, University of Cape Town, Cell No: + 27 21 6501475

Co-supervisor*:* Dr. Jane Bates, Malawi College of Medicine, Cell No: 0999 208 193

Ngatimulindimafunsookhudzanandizaufuluwachibadidwewamunthufunsaniuku: UCT Research Ethics Committee: **Mrs Lamees Emjedi**, Human Research Ethics Committee, E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Telephone: 00 27 21 406 6338

APPENDIX 7: Consent form (English version)

AN EXPLORATION OF SUPPORT GROUP INTERVENTION AMONG WOMEN WITH CANCER OF THE CERVIX: A CASE OF AT TIYANJANE CLINIC, QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE: MALAWI

1. I have read and explained about the study.
2. I have understood and any questions and concerns were attended to.
3. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
4. I understand that if I decide to withdraw from the study this will not in any way affect my care which I receive from this hospital.
5. I agree to audiotaping of the interview
6. Participants signature:____________________Researcher signature:__________________

(Full name) (Full name)

____________________________________ ____________________________________

Date: Date:

APPENDIX 8: Consent form (Chichewa version)

KAFUKUFUKU WOFUNA KUDZIWA MOMWE SUPOTI GULUPU INGATHANDIZILE AMAYI ODWALA KHANSA YA KHOMO LACHIBELEKERO KU TIYANJANE CLINIC KU BLANTYRE, MALAWI

7. Inendawerenga / ndafotokozeledwazakafukufukuyu.
8. Ndamvetsetsa zones ndipomafunsoangaayankhidwabwino.
9. Ndamvetsetsakutindikhozakusinthamaganizoangapanthawiiliyonsekapenakukanakuyankhafunsolililonse.
10. Ngatindingasinthemaganizokutindisiyekutenganawombalimukafukufulu, izisizidzapangitsakusokonekerangwilizanowangapakati pa inendiameneakupangitsakafukufuku
11. Ndavomerezakutenganawombalimuzokambiranazamagulu

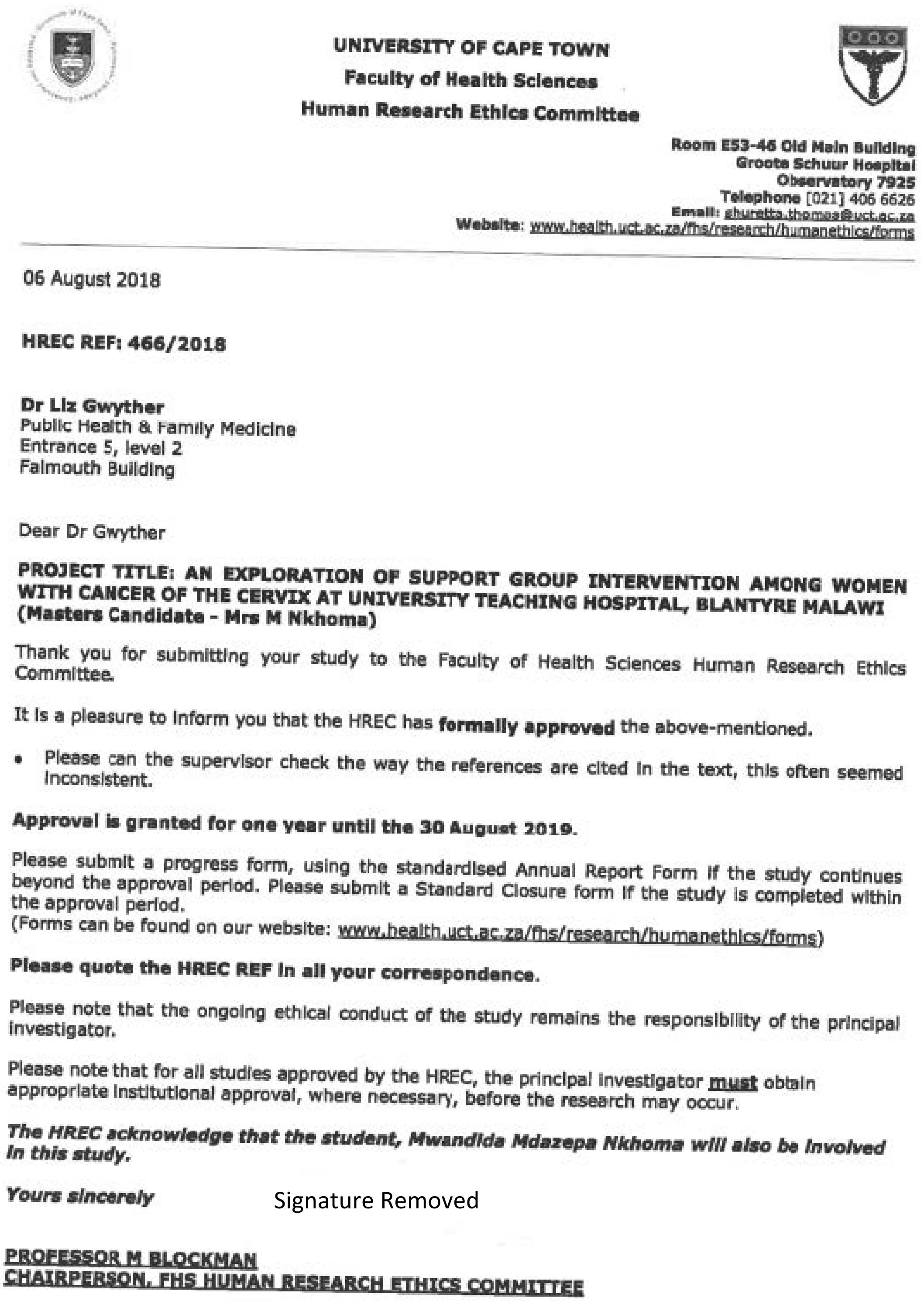
Wotenganawombali: ____________________ Wochititsakafukufuku: __________________

(Lembanidzinamowonekabwino) (Lembanidzinamowonekabwino)

____________________________________ ____________________________________

Tsiku: Tsiku:

APPENDIX 9: Ethical Approval letter from UCT HREC



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

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: ghuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

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06 August 2018

HREC REF: 466/2018

Dr Liz Gwyther
Public Health & Family Medicine
Entrance 5, level 2
Falmouth Building

Dear Dr Gwyther

PROJECT TITLE: AN EXPLORATION OF SUPPORT GROUP INTERVENTION AMONG WOMEN WITH CANCER OF THE CERVIX AT UNIVERSITY TEACHING HOSPITAL, BLANTYRE MALAWI (Masters Candidate - Mrs M Nkhoma)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

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

- Please can the supervisor check the way the references are cited in the text, this often seemed inconsistent.

Approval is granted for one year until the 30 August 2019.

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

Please quote the HREC REF in all your correspondence.

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

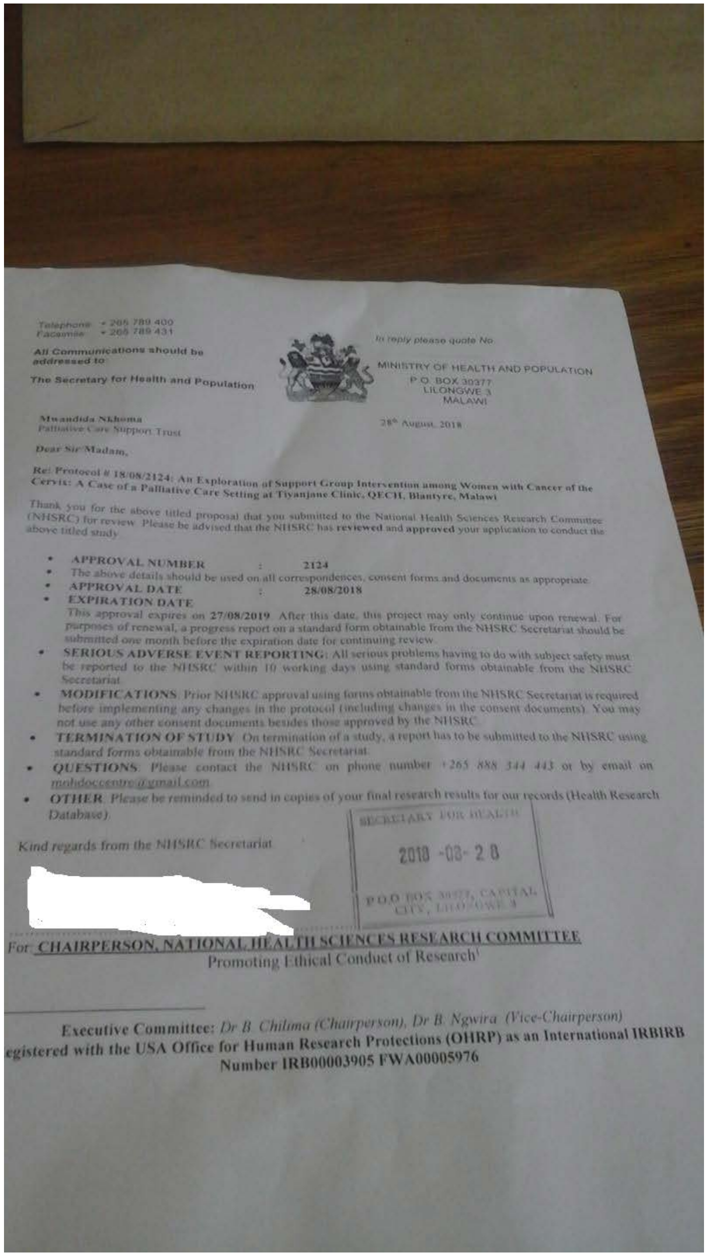
Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Mwandida Mdazepa Nkhoma will also be involved in this study.

Yours sincerely Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

APPENDIX 10: Ethical Approval letter from NHSRC



Telephone + 265 789 400
Facsimile + 265 789 431

All Communications should be addressed to:

The Secretary for Health and Population

In reply please quote No

MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

28th August, 2018

Mwandida Nkhoma
Palliative Care Support Trust

Dear Sir/Madam,

Re: Protocol # 18/08/2124: An Exploration of Support Group Intervention among Women with Cancer of the Cervix: A Case of a Palliative Care Setting at Tiyanjane Clinic, QECH, Blantyre, Malawi

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER : 2124**
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE : 28/08/2018**
- **EXPIRATION DATE**
  This approval expires on **27/08/2019**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on phone number +265 888 344 443 or by email on mohdoccentre@gmail.com.
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat

SECRETARY FOR HEALTH
2018 -08- 28
P.O. BOX 30377, CAPITAL CITY, LILONGWE 3

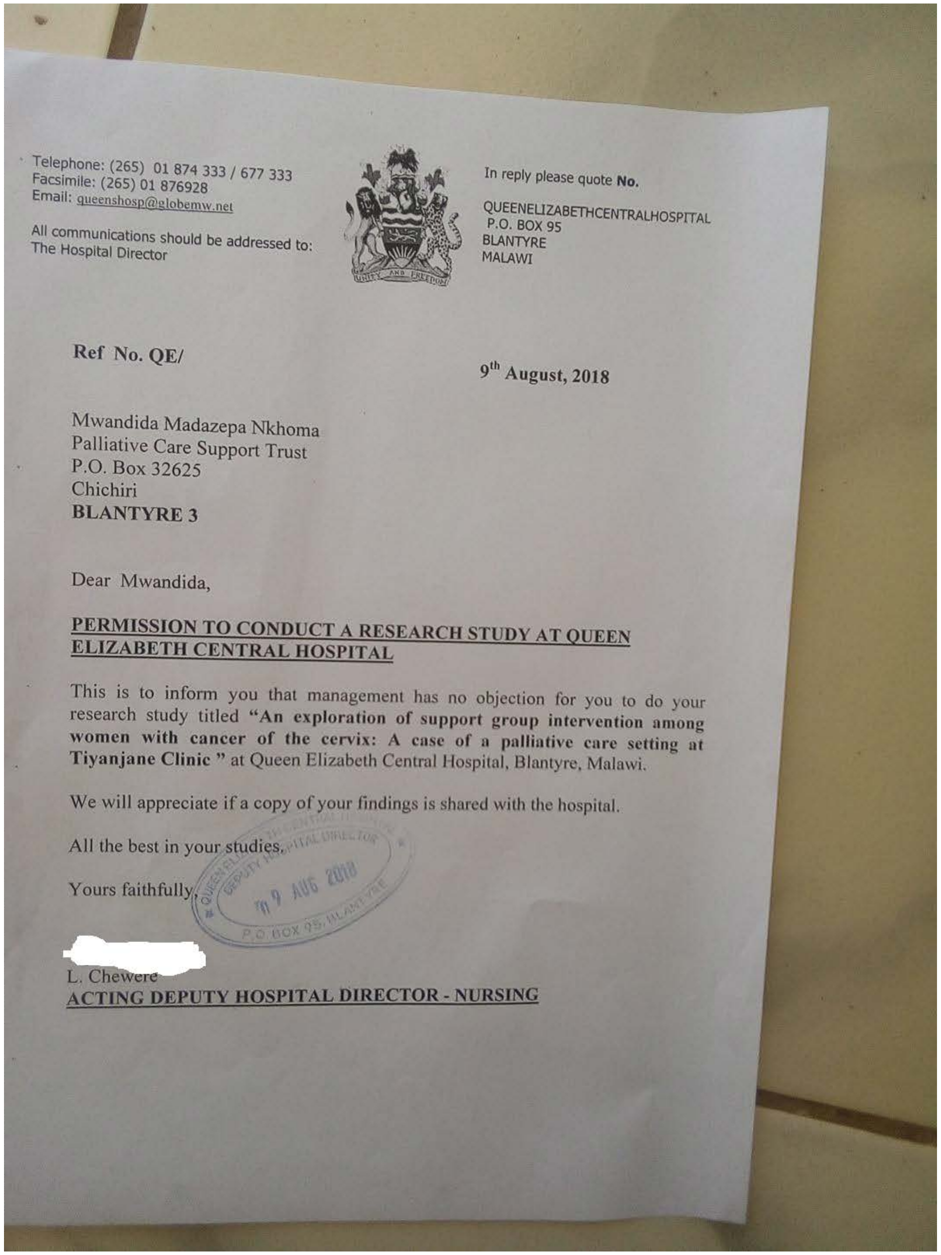
[redacted]

For **CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE**
'Promoting Ethical Conduct of Research'

Executive Committee: *Dr B. Chilima (Chairperson), Dr B. Ngwira (Vice-Chairperson)*
egistered with the USA Office for Human Research Protections (OHRP) as an International IRBIRB Number IRB00003905 FWA00005976

Signature Removed

APPENDIX 11: ETHICAL APPROVAL FROM THE HOSPITAL DIRECTOR



Telephone: (265) 01 874 333 / 677 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net

All communications should be addressed to:
The Hospital Director

In reply please quote **No.**

QUEENELIZABETHCENTRALHOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

Ref No. QE/

9th August, 2018

Mwandida Madazepa Nkhoma
Palliative Care Support Trust
P.O. Box 32625
Chichiri
BLANTYRE 3

Dear Mwandida,

PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN ELIZABETH CENTRAL HOSPITAL

This is to inform you that management has no objection for you to do your research study titled **"An exploration of support group intervention among women with cancer of the cervix: A case of a palliative care setting at Tiyanjane Clinic "** at Queen Elizabeth Central Hospital, Blantyre, Malawi.

We will appreciate if a copy of your findings is shared with the hospital.

All the best in your studies.

Yours faithfully,

QUEEN ELIZABETH CENTRAL HOSPITAL
DEPUTY HOSPITAL DIRECTOR
09 AUG 2018
P.O. BOX 95, BLANTYRE

L. Chewere
ACTING DEPUTY HOSPITAL DIRECTOR - NURSING

Signature Removed

APPENDIX 12: APPROVAL LETTER FROM HEAD OF DEPARTMENT –TIYANJANE CLINIC

palliative
care
support

Queen Elizabeth Central Hospital
PO Box 32625
Blantyre 3
Malawi
Tel: 0111 919 595
E-mail: pcst@medcol.mw
Web: www.pcst.org.mw

6th August, 2018

Mrs M. Nkhoma
PCST
P.O. Box 32625
Chichiri, Blantyre 3

Dear Madam

RE: REQUEST FOR PERMISSION CONDUCT A RESEARCH AT TIYANJANE PALLIATIVE CARE UNIT

This is to acknowledge receipt of your letter dated 3rd August, 2018 with the above subject. I am happy to grant you permission to conduct research at Tiyanjane Palliative Care Clinic. You will be working hand in hand with the team leader of Tiyanjane clinic, Mr Mark Howard who will be more than willing to provide you with more information as you may need. If there is anything that my office could do to assist you, you will let me know through my email,chuwa@medcol.mworchuwa1982@gmail.com

Yours Faithfully

Signature Removed

Dr Cornelius Huwa
Medical Director – PCST

APPENDIX 13: Distress protocol (English version)

This distress protocol is for the research study titled: An exploration of support group intervention among women with cancer of the cervix: A case of Tiyanjane Clinic, Blantyre, Malawi. All research participants will be fully informed about the nature of the topic to be covered in the interview. All patients will have the opportunity to stop the interview at any time if they experience distress of any kind. Patients will be allowed freedom and a choice to either terminate or restart the interview if they wish so, at a time convenient to the participant. Arrangements have been made with hospital social worker who will offer support, counsel and debrief patients in the event that a patient becomes distressed.

APPENDIX 14: Distress protocol (Chichewa version)

Ndondomekoyakapelekedwekauphungu mu kamukafukufukuwotchedwa: **Kufufuzangatisapotigulupuingathandizeamayiodwalakhansayakhomolachibelekelo.** Anthuonseofunakudzalowanawo mu kafukufukuadzawuzidwazamtunduwamutuwakafukufukuumeneudzakambidwemwachimvekere. Odwalaonseadzakhalandimwayiwoyimitsazokambirananthawiiliyonseimeneiwoadzawonekutisangathekupitilizazokambiranazochikukwaaliokhudzidwakwambirindimtunduwazokambiranazo. Odwalaadzakhalandiufulundichisankhochopitilirizazokambiranazokapenaayimolinganandikufunakwawo. Chikonzerochakhazikitsidwandimkuluwasoshopachipatala chino ndipochilorezochapelekedwakuchokerakwaiwo, chodzalandianthuawiriodzathandizakupelekachilimbitso, uphungu, ndiponsokumasulaodwalakuzokambiranazoadzakapezekakutiakhumudwandizokambiranazo.

APPENDIX 15: Dissemination strategy checklist

PLANNEDDISSEMINATION STRATEGIES CHECKLIST		
	Yes	No
Conference presentation		
Media coverage in newspaper		
Poster publication		
Organizational website		
Journal article		
Any other strategy (please specify)		