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# “Just live with it”: Having to live with breast cancer related lymphedema

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## ABSTRACT

An exploratory qualitative research approach was selected for this study aiming to explore how people living with breast cancer related lymphedema experience this complication. Unstructured interviews were conducted with nine purposively selected participants. Living with breast cancer related lymphedema was not easy. Participants were not informed of the possibility of developing lymphedema and felt let down by the medical professionals they consulted. They had to face the physical, psychological and practical consequences without the continuous support of a knowledgeable therapist. Managing the lymphedema was a challenge as they could not afford the necessary treatment and the self-care items. In addition, treatment failure resulted in them feeling exploited and using various treatment options. Nurses should maintain a high level of suspicion of breast cancer related lymphedema, assess patients for lymphedema and refer them to a therapist specifically trained in the management of this debilitating condition.

Hierdie studie ondersoek die belewenis van mense met borskanker verwante limfedem. 'n Kwalitatiewe eksploratiewe navorsingsontwerp is gekies en ongestruktureerde onderhoude is met nege doelgerig gekose persone gevoer. Limfedem kompliseer die lewe en die proefpersone het die nie maklik gevind om daarmee saam te leef nie. Hulle is nie ingelig oor die moonlikheid om limfedem te ontwikkel nie en was van mening dat hulle deur die medici wat hulle behandel het in die steek gelaat is. Die proefpersone moes die fisiese, psigologiese en praktiese gevolge van limfedem sonder die bystand van 'n kundige terapeut te bowe kom. Die hantering van die limfedem was 'n uitdaging aangesien hulle nie die behandeling en self-sorg artikels kon bekostig nie. Die slegte resultate van behandeling het tot gevolg gehad dat die proefpersone uitgebuit gevoel het en ook verskillende behandelingsopsies gevolg het. Verpleegkundiges moet 'n hoë vlak van bewustheid ten opsigte van limfedem handhaaf, pasiënte hiervoor beraam en na 'n terapeut wat in limfedem spesialiseer verwys.

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## 1. Introduction

### 1.1. Key focus of the study

Lymphedema is one of the most distressing debilitating complications of breast cancer (Norman et al., 2009:390) and the problems created by lymphedema is poorly understood (Norton School of Lymphatic Therapy 2007:104). Breast cancer is the most common cancer in women worldwide and the most common cause of cancer death in women in less developed regions (International Agency for Research on Cancer and World Health Organization, 2014). However, the world focuses on controlling the spread of major killers in the developing world such as HIV, tuberculosis and malaria (Lingwood et al., 2008:398) whilst African governments focus on infant and child mortality, maternal mortality and communicable diseases (Parkin et al., 2008:683). This means the prevention, early detection and treatment of cancer is grossly neglected (Lingwood et al. 2008:398). In addition, it seems as if health care professionals in South Africa regard lymphedema as a normal result of cancer and should a woman develop breast cancer related lymphedema, she is expected to merely accept and live with this condition (Maree, 2011). It is true that lymphedema cannot be cured, but without adequate treatment it tends to progress and brutally impairs quality of life (Földi & Földi, 2006:231).

### 1.2. Background

Lymphedema is defined in various ways. According to Kocak and Overgaard (2000:389), lymphedema occurs during functional overload of the lymphatic system in which the lymph volume exceeds the transport capabilities. Zuther (2009:48) and the Norton School of Lymphatic Therapy (2008:90) define lymphedema as an abnormal accumulation of protein-rich fluid in the interstitium, which causes chronic inflammation and reactive fibrosis of the affected tissues leading to the swelling of a body part, often the extremities. Lymphedema is classified as primary or secondary. Primary lymphedema is caused by a defect in the development of the lymph vessels and/or lymph nodes and not yet fully understood (Földi & Földi, 2006:231) but is less common than secondary lymphedema (Norton School of Lymphatic Therapy, 2008:92). Secondary lymphedema is the result of mechanical insufficiency and caused by surgery, radiotherapy, trauma, infection, tumoural blockage, immobility, chronic venous insufficiency and tourniquet effects (Lawenda, Mondry, & Johnstone, 2009:9).

It is unclear how many people live with lymphedema, however in 1984, the World Health Organization (Norton School of Lymphatic Therapy, 2008:104) estimated that 110 million people worldwide suffered from it. In 2006, Földi and Földi (2006:231) reported the number of people suffering from lymphedema worldwide could range between 140 and 250 million. Breast cancer related lymphedema is the second most common cause of lymphedema after parasites and according to the World Health Organization (Norton School of Lymphatic Therapy, 2008:104), it affected approximately 20 million people in 1984. According to Clark, Sitzia, and Harlow

(2005:343), the incidence of breast cancer related lymphedema ranges between 6% and 83%, whilst DiSipio, Rye, Newman, and Hayes (2013:500) found more than one in five women surviving breast cancer would develop lymphedema. Unfortunately lymphedema is largely under-diagnosed due to the focus on acute treatment, lack of uniform diagnostic criteria and the complexities related to reliable and valid limb measurements (Armer, Radina, Porock, & Culbertson, 2003:371).

Lymphedema is one of the most distressing debilitating complications of breast cancer and its degree of swelling, time course and symptoms are not well understood (Norman et al., 2009:390). It appears most women develop lymphedema two to three years after breast cancer treatment, as Norman et al. (2009:394) found that 80% of affected women developed this complication in the first two years of diagnosis whilst 89% developed it in the first three years. The development of arm lymphedema is associated with various risk factors including extensive surgery, adjuvant therapy, high body mass index and low physical activity (DiSipio et al., 2013:501). Changes in sensation might be the first indicator of possible lymphedema and patients reporting such changes should be carefully observed (Armer et al. 2003:377).

Lymphedema is staged according to various criteria. In the latency stage, oedema is not detectable and the patient might have subjective complaints. In Stage I, there is a build-up of protein-rich fluid in the interstitium, which is spontaneously reversible when the affected limb is elevated. In Stage II, pitting becomes increasingly more difficult, the lymphedema is no longer spontaneously reversible and fibrosis is also present. Stage III lymphedema is characterized by severe fibrosis and sclerosis, skin changes and lymphostatic elephantiasis (Norton School of Lymphatic Therapy, 2008:94). Without adequate treatment, the disease will advance from stage to stage (Földi & Földi, 2006:244) as lymphedema, unlike all other oedemas, is not a symptom but a disease with no possible cure (Norton School of Lymphatic Therapy, 2008:95).

### 1.3. Trends from the research literature

Breast cancer related lymphedema has been the topic of investigation in both the nursing and medical literature and studies originate primarily from countries like the US, Canada, Australia and the UK. The incidence and risk factors of this condition have been explored by various researchers (Clark et al. 2005; Morrell et al., 2005; Norman et al. 2009; Petrek & Heelan, 1998; ) whilst Armer et al. (2003) investigated the impact and measurement issues. The management of this condition was also investigated and include studies by Andersen, Højris, Erlandsen, and Andersen (2000); Vignes, Porcher, Arrault, and Dupuy (2007); Tsai, Hung, Yang, Huang, and Tsao (2009) and a South African study of Maree (2011). Velanovich and Szymanski (1999) and Ridner (2005) explored the quality of life whilst the lived experiences of women suffering from breast cancer related lymphedema was explored by Carter (1997) and Thomas-MacLean, Miedema, and Tatemichi (2005). Carter (1997) found that the women in her study felt abandoned by medicine, lived interrupted lives and had to conceal their imperfect body image. These findings differ from three of the themes identified by Thomas-MacLean et al. (2005) who described the experience of lack of

information about lymphedema, variations in triggers and symptoms relating to the lymphedema and lack of access to health care. Both studies highlighted the influence lymphedema had on the everyday lives of the participants in their studies.

#### 1.4. Objectives

Every year, an estimated 8000 South African women are diagnosed with breast cancer and about 1600 (20.0%) will die from this disease (Bateman, 2009:780). It is not known how many women in South Africa develop breast cancer related lymphedema as no statistics are available. Similarly in the rest of the world, lymphedema seems to be under-diagnosed and under-recognised in terms of its prevalence and impact on the lives of people suffering from this condition (Armer et al. 2003:371). Trained lymphedema therapists in South Africa are scarce and primarily render services to people with health insurance. Most South Africans (80%) however depend on public health care services (SouthAfrica.info, 2012), being unable to afford private health care, leaving them with untreated lymphedema. It is not known how people living in South Africa experience breast cancer related lymphedema, as no literature investigating this experience could be found. The objective of the study was therefore to explore how people living with breast cancer related lymphedema experience this complication.

#### 1.5. Ethical considerations

The study was approved by the Ethics Committee at a University of Technology and the ethical principles guided by Brink, Van der Walt, and Van Rensburg (2006) were followed. Informed consent was obtained from participants and all persons meeting the inclusion criteria of 18 years and older and living with breast cancer related lymphedema treated at the University, were approached to participate in the study. Interviews were conducted in a private room with only the participant and second author present. The transcribed interviews were numbered sequentially and the recordings were erased after the transcription. Pseudonyms protected anonymity.

#### 1.6. Theoretical framework

The Roy Adaptation Model of Nursing (Roy, 1970:42–45) was used as the theoretical framework for this study. Roy regards people as biopsychosocial beings who need to adapt to environmental stimuli (Tulman & Fawcett, 1990:96). Adaptation, a process in which feeling and thinking persons or groups use choice and conscious awareness to create human and environmental integration, is considered to take place in one biological and three psychosocial modes. The psychosocial modes include self-concept, role function and interdependence. The biological mode of adaptation is concerned with the basic needs of a human being. The self-concept mode pertains to people's conceptions of their physical and personal self, including components of body image and body sensation and the moral-ethical-spiritual self. The role function adaptive mode deals with the primary, secondary and tertiary roles

based on the person's position in society whilst the interdependence adaptive mode is concerned with development and maintenance of satisfying affectionate relationships with significant others (Philipps, 2010:310–312; Tulman & Fawcett, 1990:96). The Roy Adaptation Model of Nursing was selected for this study as the researchers are of the opinion that the dimensions of the biological as well of the three psychosocial modes change when a person is confronted with breast cancer related lymphedema.

#### 1.7. Significance of the study

The significance of the study is related to the fact that little is known about the experiences of people living with cancer related lymphedema in South Africa and will therefore add to the body of knowledge pertaining to this phenomenon. Existing studies investigating lymphedema originate primarily from the developed world, which does not face the same challenges, in terms of access to health care, as that of the developing world.

## 2. Methods

### 2.1. The study

An exploratory qualitative research approach (Grove, Burns, & Gray, 2013:266) was selected for the study, as it allowed the researchers to discover the essence of the phenomenon, breast cancer related lymphedema. According to Begley (2008:15) exploratory studies are usually qualitative and are conducted when researchers are not aware of any other studies in this field which can be applied to the current study.

The researchers used reflexivity (Burns & Grove, 2009:545) to become aware of personal experiences and feelings which could influence the study. Reflexivity was a continuous process and took place whenever the researchers met to discuss the study, which included meetings during the development of the research proposal, during the data gathering and analysis process and discussions of the findings.

### 2.2. The participants

Purposive sampling, a recognised method in qualitative research (McCarthy & O'Sullivan, 2008:113–123) selected the sample and data were gathered until saturated. Nine people suffering from breast cancer related lymphedema and treated at a lymphedema initiative at a university of technology, between May 2009 and December 2010, participated in the study; eight were female and one male. The average age of the participants was 61; the youngest was 43 years old and the oldest was 78 years. Participants were primarily Afrikaans first language speakers (7 of 9), one was Greek and one Tswana first language speakers. Six of the participants had Stage II, one had Stage II to III and two had Stage III lymphedema. The anti-cancer treatment the participants had received varied and included a modified radical mastectomy, lumpectomy, radiotherapy and chemotherapy. The time between surgery and becoming aware of the arm swelling varied between two and 60 months and the oedema volume of

the participants' affected arms ranged between 766 ml and 3841 ml, with an average of 1765 ml. One participant reported her lymphedema resulted in her having a poor quality of life, five were of the opinion they had a reasonable quality of life and one indicated that she had a good quality of life despite the lymphedema.

### 2.3. Data gathering and analyses

An unstructured interview technique was used to gather the data which, being more free-flowing, was applicable to the qualitative nature of the study (Brink, 1999:158). An opening question "Please tell me what it is like for you to live with lymphedema" was asked and probes and prompting questions (Polit & Beck, 2010:341) were used to encourage participants to expand on their experiences. The interviews, lasting approximately 1 h, were conducted in either Afrikaans or English, according to the preference of the participant and were audiotaped. The data gathered during each interview were summarized and verified with the participants to be true and correctly understood.

Data gathering and analysis were done concurrently to determine data saturation. Tesch's open coding process (Creswell, 1994) analyzed the data, as this approach allowed the researchers to generate a systematic and complete synopsis of data gathered. Interviews were transcribed verbatim and those conducted in Afrikaans translated into English. The transcripts were read and re-read to get a sense of the whole; thoughts and topics were written in the margins. The topics were listed; similar topics were clustered together and preliminary categories identified. This preliminary organizing scheme was compared to the raw data to see whether new topics and categories emerged. Once this process was completed the categories were grouped into themes. Both researchers were involved in the analyses of the data and the categories and themes were discussed, debated and reduced until consensus was reached.

### 2.4. Trustworthiness

Trustworthiness was established according to the strategies promoted by Lincoln and Guba (1985). To enhance credibility a well-established research method was adopted and the research proposal was submitted for peer scrutiny. In addition, frequent debriefing sessions between the lead researcher and the first author, who supervised this enquiry, took place. The researchers upheld the principles of prolonged engagement with participants and member checking to ensure the accuracy of the data (Shenton, 2004:68). Transferability was enhanced by means of a dense description of the data, as well as by describing the sampling and design details (Bothma, Greeff, Mulaudzi, & Wright, 2010:13). Dependability was established by describing the processes within the study in detail. Lastly, confirmability was achieved by means of an audit trail and detailed methodological description (Shenton, 2004:72).

## 3. Findings and discussion

### 3.1. Findings

Four themes emerged from the data: lymphedema the unknown and unspeakable, living with the physical consequences of lymphedema, living with an altered body and coping with the lymphedema.

#### Theme 1: "Just live with it": Lymphedema the unknown and unspeakable

Most participants were not informed about the possibility of developing lymphedema and those who were, were not told what to do or whom to contact should this happen. Developing the swelling was a traumatic experience and some participants did not understand what was happening. Charlene described her experience of developing lymphedema as:

*"...it felt like bread dough rising ...when it was rising I felt it because I had to go to the toilet often... It was painful, I could not make a fist. At first it didn't worry me, I just accepted it, but when it kept on rising and rising I thought this is going to kill me now, because something might not be pumping and go to my heart and the poor heart will just stop pumping... I didn't know what was in my arm, water or blood? When I feel the pain here I think, oh, it is going to burst!"*

Suzie said: "I could see the difference... I did not know what was going on, not at all because I was not prepared for it..."

Participants felt let down by the medical professionals they informed about the swelling, as they were neither listened to nor guided in terms of treatment. Participants were saddened by and angry with the responses they received which included "so what?" and "just live with it." Diana voiced her anger as follows:

*"I visited the doctor once a month and each time I told him there is something is wrong, but he just said 'it will go away'...nobody listens! I hate it when they say it will go away!"*

Paula added: "I had to phone my daughter in America to help me find somebody in South Africa who could assist me...oncologists know about cancer but nothing about lymphedema...said there is nothing that could be done to the lymphedema, I just have to live with it..."

In contrast to the health care professionals, family members supported the participants. Their families maintained a high level of awareness of the lymphedema, assisted them with activities of daily living and even massaged their arms according to instructions found on the internet. Charlene explained how her husband supported her:

*"I am so lucky, my husband does the meals for us and I am making the cookies...he is good for me because he mixes the*



*margarine and he put it in the oven and takes it out... Even when I am on my way back from town I phone him and he comes and helps me, because I only have the one arm... Sometimes he hooks up my bra. He is so supportive of me..."*

Suzie added: *"My family is very aware of my lymphedema... maybe it is because I had to go to hospital when I had the infection... when I want to do something not allowed my children would say 'Mom, don't do that!'..."*

The participants felt uninformed about breast cancer related lymphedema - not only the risk of developing this complication but also what to do should they develop it. They felt let down by the medical practitioners who treated them as they did not acknowledge the importance of the lymphedema. The medical practitioners did not support participants with information about treatment and expected from them to merely live with this complication. In contrast, their families provided emotional and instrumental support. Suffering from lymphedema led to various physical consequences.

## **Theme 2: "My arm is painful": Living with the physical consequences of lymphedema**

The participants experienced various physical problems related to the lymphedema including pain and numbness, sleep disturbance, infections and changes in posture. Pain described as "pressure", "tightness", "heaviness" and "cramps" was a daily experience for some. Pain was not only experienced in the affected arm, hand and fingers but also in the shoulder and chest on the affected side. Pain became worse with the increase in volume of the lymphedema and was also associated with a busy day and a change in the weather. Alecia said:

*"Many times, my arm hurts... especially the upper part [in] cold weather and if it rains too. It also affected my chest and shoulder. I could not bend my arm..."*

Hannah added: *"My arm is painful especially when it is cold and raining. I get cramps at night when I was busy during the day."*

Experiencing pain reminded participants of how their lives had changed as they were acutely aware of their inability to perform tasks as before. Some even had to lie down until the pain subsided.

Elsa said *"I cannot do what I used to do"* and Mary reported *"When it's painful I have to lie down, I can't do anything..."*

Numbness was experienced in parts of the lymphedema-affected arm and hand and caused severe discomfort. Hannah said: *"Parts of my arm feel numb"*, Elsa complained: *"I don't have grip in my hand."*

Most of the participants had infections in the affected arm and described them as a "traumatic" and "painful" experience. Some even had to be hospitalized. Suzie said:

*"I was admitted in hospital with infection twice. It was really bad! It made me so ill. I started with a high temperature and*

*landed in hospital with a drip. The last time in hospital my arm had red spots on. It was very traumatic and I was very ill."*

Participants reported major sleep disturbances and some were not rested when they woke in the mornings. Having a lymphedemous arm resulted in the inability to sleep in a comfortable position and waking up numerous times during the night. Mary said: *"I do not sleep well. When I turn on this arm, I wake up. I really have a problem with sleep and wake up often. I don't rest at night!"*

Hannah added: *"I have to sleep in a different position than what I was used to because I cannot sleep on the lymphedema-affected arm... when I had a busy day I tend to get cramps at night which also disturb my sleep..."*

Living with a lymphedemous arm was responsible for great frustration, unhappiness and depression as it hindered some participants in performing their routine household chores. Not only did it take up more time, but both hands had to be used to prevent objects from falling from their hands. Elsa said: *"If I take a cup of tea, it must be with two hands otherwise it falls from my hand. It's involuntary..."*

Diana added: *"In my home I can't do anything anymore! I am so depressed! Nothing is the same in my house! This thing overpowers everything! It feels like I had an amputation!"*

The participants had to live with chronic pain and numbness which had a negative influence on their daily activities and even influenced their sleep. Not being able to perform normal household chores led to great unhappiness, frustration and feelings of disempowerment. The infections participants developed as a result of the lymphedema added to their suffering. In addition to the physical complications of the lymphedema, participants also had to live with their altered body.

## **3.2. "You cannot hide it": living with an altered body**

Living with a lymphedemous arm had negative influences on the emotional wellbeing of the participants; they were self-conscious about the enlarged arm, "you cannot hide it" (Mary) from curious onlookers and some were of the opinion their lymphedema scared others. Some felt they had to explain why their arms were swollen and the innocent comments people made about their lymphedema negatively affected their self-confidence. Mary explained: *"My upper arm is so big and it's here in my neck. In winter it is a little better, I can hide it, but in summer it is very bad ... There's an emotional thing. You know it's not so nice when people see it. It feels to me if people talk to me, they immediately look at my arm and neck. People do not understand it! I try to explain to them, later I lock myself up in my room, because I am too tired of explaining."*

Suzie added: *"When I am in a gathering with people and I put my arm on the table, I see my arm and I remove it. It is a big emotional problem to me. The arm is horrible! When we take photos I will always hide the arm."*

Elsa explained: *"I did voluntary work...but I stopped because the poor women were so frightened when they saw my swollen arm..."*

Living with a lymphedemous arm also resulted in posture changes. These changes caused emotional distress as it was experienced as "disfigurement" and lead to self-consciousness. Mary said: *"My posture is also affected...on the x-rays you can see how this side is completely disfigured. It feels to me when people talk to me they immediately look to my neck and my wrist watch. People do not understand..."*

Suzie said: *"My daughter who is a physiotherapist was the first one who told me my posture was different and that when I walk I slant towards the side of my affected arm."*

Finding suitable clothes to fit the enlarged arm was a great challenge; some of the women had to "cut them" in order to make the sleeves fit, whilst others had to change the style of clothes they preferred and used to wear – changes that frustrated them, reminded them of the cancer and how different they looked before cancer was diagnosed. Female participants experienced loss of femininity and not being able to wear a watch or jewelry added to feeling unfeminine. The male participant also experienced emotional distress due to the fact he "cannot wear long sleeve shirts anymore, only short sleeve shirts."

Mary said *"Do you know how hard it is to buy clothes?... each time it ends in tears...I like wearing nice clothes, now I wear these oversized clothes to hide it... it was not my style before I became ill..."*

Hanna said: *"I have a cupboard full of blouses, but I can only wear three! I cannot wear a watch or any jewelry at all. At first it was bad but now I am used to it...It was a big issue for me, because I like jewelry and nice things..."*

Living with a swollen arm was not easy. Participants were unable to hide their arms from themselves and other people. They were reminded of their altered body when they were unable to find clothes that would fit over their enlarged arms and had to change the way they preferred to dress. Despite the emotional distress they experienced, they coped with their lymphedema by being grateful.

### Theme 3: "I am grateful": Coping with the lymphedema

Participants experienced finding effective, affordable, sustainable treatment a great challenge. Some participants did not have medical insurance and could not afford private treatment and were either not treated, or paid for treatment with money they did not really have. Charlene said: *"Everything was money, even the bandage. The first time I paid R549. The therapists were asking R300 per hour. They said to me if it is too much I must tell them. I said it will be too much for me, because I am a pensioner and I am looking after my son's daughter. With my pension and the money from the cookies I bake, I have to survive. So they felt sorry for me and cut it with another R50. So they asked me R250."*

Even participants with medical insurance found it difficult to afford the treatment as the insurance did not cover the cost of bandages and the compression garments. Some participants did not continue with the same therapist and treatment and had to revert to other treatment options. Suzie said: *"I had massages at the hospice, I have been to a physiotherapist who specializes in lymphedema, I had good results but the travelling distance became a problem. I did everything...I did the exercises another therapist gave me... but that was only a money making racket. I went to a physician and she said we must try water pills. That was one of the most sustainable things. When I do not use it for a few days I can see the difference. Yes that is my story, I use water pills, because it works for me at this stage..."*

Elsa explained: *"I tried everything! I have been to the physiotherapist...she did massage and bandaged my hand and arm. It helped but I could not afford it. The school raised money to help me to buy a machine to help with the lymph drainage. It was R35000 but it does not help much!"*

Despite the disfigurement and negative influence the lymphedema had on the quality of life of the participants, they were grateful to have survived the cancer and therefore felt they "just have to live with the lymphedema." Believing in God, praying and being prayed for provided them with comfort and hope as they believed God healed them.

Alecia said: *"I believe that the Lord has healed me from the cancer. The lymphedema is now a secondary thing, but I believe He can heal it also."*

Elsa added: *"I am grateful, the Lord was good...He healed me from cancer, now I just have to live with the lymphedema."*

The participants had difficulty in accessing effective, affordable treatment. Not being able to afford effective treatment and not experiencing the results they expected of certain treatments resulted in feelings of hopelessness. Yet, despite all their struggles and suffering they were grateful to be alive and trusted God to heal them.

Living with breast cancer related lymphedema posed various challenges to the participants. They were confronted by the lymphedema without knowing of the risk to develop this complication or what to do when their arms started swelling. They did not receive the necessary support from the doctors who treated them as they disregarded the lymphedema and expected of them to simply live with this complication. Participants were unable to hide their enlarged arms and had to live with chronic pain and numbness and posture changes. They are unable to access affordable effective treatment. The enlarged arm resulted in not being able to find suitable clothes reminding them of how their lives changed since their diagnosis of breast cancer. Yet, they were grateful to have survived and trusted God to heal them.

### 3.3. Discussion

The study supports the statement of [Farncombe, Daniels, and Cross \(1994:269\)](#), who 20 years ago called lymphedema the "seemingly forgotten complication." As evident by "I did not

know what is going on...” participants were not informed about the possibility of developing lymphedema, a trend also found in a Canadian study (Thomas-MacLean et al., 2005:247). It might be contended that lymphedema is an uncommon result of breast cancer and controlling the cancer is of greater importance, yet being confronted with this “cruel surprise” (Cohen, Payne, & Tunkel, 2001:985) is inexcusable, as the development of lymphedema is associated with significant psychological distress (Cohen et al. 2001:985), pain and other physical consequences as evident from the current study.

The best time to give patient education is unclear and ranges from before surgery (Cohen et al. 2001:986) to after the diagnosis and treatment (Towers, Carnevale, & Baker, 2008:141), thus placing this responsibility on different health care professionals involved in the continuing care of the patient. It was interesting to find the participants felt let down by the medical professionals they consulted and did not ascribe their lack of knowledge to the inadequate delivery of nursing care. The Scope of Practice of a nurse registered to practice in South Africa (South African Nursing Council, 1984) specifically refers to the “prevention of disease and promotion of health by teaching to and counseling with individuals and groups of persons.” In addition, Getz, in 1985 (1985:183), stated it was the responsibility of the oncology nurse to ensure that each patient undergoing a mastectomy has received effective patient education on the prevention, early signs and symptoms and appropriate treatment options in order to reduce the incidence and impact of lymphedema. It seems as if these nursing responsibilities, for some unknown reason, were neglected.

Whether the insensitive responses such as “so what?” and “just live with it” or the lack of referral for treatment medical practitioners bequeathed participants were due to insufficient knowledge of lymphedema is unknown. However, Ridner, Bonner, Deng, and Sinclair (2012) in their study conducted in the US, found participants reported that the medical community lacked knowledge about lymphedema and varied in their approaches to its management. Not only does this shortcoming leave participants feeling marginalized but leads to failure in the management of and worsening of the lymphedema. Similarly McWayne and Heiney (2005: 462), reported that insensitive remarks by physicians, their lack of knowledge about lymphedema and inconsistent treatment recommendations were experienced as sources of distress. Towers et al. (2008:140) adds other health care practitioners to the list of those lacking knowledge of lymphedema by finding health care providers also have inadequate knowledge of this condition. Cho (2002:1052) found Korean nurses lacked knowledge of lymphedema and told patients to accept this condition as God’s will without giving them any information relating to care, which left them feeling abandoned.

This study provides evidence that the families of the participants provided a positive social support system to them. Family members assisted with activities of daily living “sometimes he hooks up my bra...”, guarded against risky behavior “Mom, don’t do that...” and supported with information about possible treatment. Ridner et al. (2012), found spouses, family members, friends and co-workers were the most common providers of encouragement, direct care and comfort. Towers et al. (2008:140) found spouses, peer support

groups and exercise groups, organized by the local lymphedema clinic, provided support to their study participants.

Pain described as “many times my arm hurts...” is a known problem of people living with lymphedema. Cohen et al. (2001:980) stated that lymphedema was much more than a cosmetic problem, as the stretching of the soft tissues can be painful especially during the onset and phases of acute exacerbation. When reviewing the psychological and social consequences of lymphedema, McWayne and Heiney (2005:462) acknowledged pain as a significant predictor of social and psychological morbidity. In addition, the participants found living with the lymphedematous arm resulted in sleep disturbance which caused them to feel unrested. Ridner (2009) reported a similar finding and stated that sleep disturbances may contribute to psychological distress. It might be quite reasonable to conclude that participants in the current study experienced psychological distress. Ridner (2009) described various manifestations of psychological distress found the current study. These manifestations include feeling unheard evidenced by “nobody listens...”, depressive symptoms “I am so depressed...”, sadness “it ends in tears...” and undesirable lifestyle changes “nothing is the same...”.

Living with an altered body was not easy. As supported by McWayne and Heiney (2005:462) and Ridner (2009), participants became self-conscious, lost self-confidence and some felt they had to hide their “horrible” arms from others. Some withdrew from people, as evidenced by “I lock myself up in my room...” and “I stopped (voluntary work),” because they were of the opinion that people did not understand what was wrong with them and were frightened by their disfigured arms. Towers et al. (2008:134) supported this finding by reporting women in their study were of the opinion that society lacked awareness of lymphedema. Ridner et al. (2012) were also of the opinion that family, friends and the community lacked understanding, as they believed all should be well because the cancer had not returned. Additionally, McWayne and Heiney (2005:462) found women were subjected to increased social isolation due to the insensitive comments of others. Being forced to change wardrobes not only led to a practical problem of finding suitable clothes, but to feeling less feminine. Finding it hard to obtain clothing to accommodate the swollen arm was not limited to women in this study, but also applicable to women living in developed countries too as Thomas-MacLean et al. (2005) and Ridner (2009) reported a similar challenge.

It seemed as if lymphedema was not only forgotten in terms of being a chronic condition but also in terms of reimbursement by private health care insurance companies. Having private health care insurance did not assist participants in the current study who found themselves in the same position as those dependent on public health care – not being able to afford long term treatment and the necessary self-care items. In addition, as supported by “it felt like a money making racket to me...” treatment failure lead to participants feeling exploited. Thomas-MacLean et al. (2005) found women in their study were not supported in terms of acquiring a compression garment despite having a prescription for one. Ridner et al. (2012) found health insurance would either not cover, or only partially cover the expenses for physical therapy and the

compression garment, which added to the repeated disappointment of people living with lymphedema.

Spirituality and religion can have a significant influence on how people cope with life-threatening illness and religious beliefs, can play a substantial role in how women living with breast cancer cope with the disease (Choumanova, Wanat, Barrett, & Koopman, 2006:351), even when experiencing negative symptoms (Weaver & Flannelly, 2004:1212). Spirituality resulted in participants believing they were “cured” and “healed” and they expressed gratitude for surviving breast cancer. The statement “...He healed me from cancer, now I just have to live with the lymphedema...” illustrated how religion softened the blow of the lymphedema. Ridner et al. (2012) found religion facilitated acceptance for the difficult, non-reversible realities of living with breast cancer and provided psychological comfort.

#### 4. Conclusion and recommendation

The objective of the study was to explore how people living with breast cancer related lymphedema experience this complication. This study contributes to the body of knowledge of this under researched area.

Living with this complication of breast cancer was not easy. Participants were not informed of the possibility of developing lymphedema and felt let down by the medical professionals they consulted. In addition, they had to face the physical, psychological and practical consequences without the continuous support of a knowledgeable therapist. Managing the lymphedema was another challenge as they could not afford the necessary treatment and the self-care items. In addition, treatment failure resulted in them feeling exploited and using various treatment modalities. Family members were their primary support system and only religious beliefs made it possible for them to live with the lymphedema.

When applying the Roy Adaptation Model of Nursing (Roy, 1970) to the findings, it was evident that breast cancer related lymphedema changed the dimension of the biological and psychosocial modes. The swelling and pain supported the change in the biological mode whilst the enlarged arm, posture changes and challenges with finding suitable clothes support a change in the self-concept mode. The role function adaptive mode changed as participants were not able to continue normal household tasks and voluntary work. It also seemed as if the interdependence adaptive mode changed with partners and children having to support participants with normal activities of daily living and watch over them to protect their already compromised arm from harm. The Roy Adaptation Model of Nursing served as an appropriate model to describe the experiences of people living with breast cancer related lymphedema.

##### 4.1. Recommendations

Many factors could have resulted in nurses not educating the participants about breast cancer related lymphedema. The nursing management of patients with cancer requires specialist knowledge which the nurses caring for the participants might not have had. Therefore, nurses involved with the

management of patients with breast cancer at any stage of the disease should reflect on their level of knowledge and consider specialist courses in oncology nursing to ensure they are competent to educate patients on the prevention, identification and management of lymphedema. In addition, nurses should maintain a high level of suspicion, assess patients for lymphedema and refer them to a therapist specifically trained in the management of this debilitating condition.

Additionally, it might be beneficial to investigate the level of knowledge registered nurses involved in the care of patients with breast cancer have about lymphedema. This would give researchers and clinicians the opportunity to develop and evaluate educational interventions focused on the identified knowledge deficits and lead to improved patient outcomes.

##### 4.2. Limitations

A once off study including primarily participants who had access to private health care might not be sufficient to gain an understanding of what people living with breast cancer related lymphedema experience. Further research focusing on this phenomenon is needed to attain a deeper understanding.

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