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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 Tsauo (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

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