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An exploration into the level and characteristics of pain experienced by South African women treated for cervical cancer

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ABSTRACT

Despite the high incidence of cervical cancer in Africa, little is known about pain management in women treated for this disease as best practices primarily focus on the prevention of cervical cancer. The study aimed at describing pain in women diagnosed with cervical cancer who received radiotherapy with/without concurrent chemotherapy, before treatment and at six and 12 months after the completion of the treatment. A cross sectional design and calculated sample size were used to recruit 168 women (n = 168), 58 (n = 56) in each treatment group. Structured interviews were used to collect the data and the Brief Pain Inventory (BPI) served as the data collecting instrument. Descriptive statistics were used to analyse the data and the Kruskal-Wallis H Test determined statistical significant differences between the groups ($p = 0.05$). The majority of the respondents (78.0% n = 131) experienced disease related pain and most (73.9%; n = 85) experienced pain at the time of data collection. However, pain, on average, decreased after treatment and was at its lowest level six months after treatment but increased during the following six months. Pain influenced all the domains of function before treatment but improved after six months. There was a misfit between the level of pain and the type of analgesia used. In addition, most participants (58.3%; n = 67) took their pain medication only when needed. Our study highlighted the complexity of pain control, suggesting failure of both the healthcare professionals and the patients in achieving the ultimate goal of being pain free.

1. Background

Cervical cancer is the fourth most prevalent cancer in women worldwide and second in Africa's women (International Agency for Research on Cancer, 2014). In South Africa, cervical cancer is one of the biggest health problems in women (Snyman, 2012). It is the second most prevalent female cancer but the most common cancer in Black women, responsible for 29.3% of all cancers found in this population group (National Health Laboratory Service., 2016). Cervical cancer is caused by persistent infection with one or more of the oncogenic types of HPV, most commonly types 16 and 18, which are responsible for up to 70% of all cervical cancers. Cervical cancer has a long natural history as it takes 10–20 years for mild dysplasia to progress to carcinoma (World Health Organization, 2006). Women living with HIV and AIDS, have an increased risk of developing cervical cancer with the disease occurring up to 10 years earlier compared to women who are not HIV positive (Snyman, 2012).

Cervical cancer is preventable and various screening methods, including Pap smears and direct visual inspection, are used in African countries with screening programmes. South Africa has a cervical cancer screening policy awarding asymptomatic women, 30 years and older, the opportunity to have three Pap smears free of charge, at a 10 year interval, at primary health clinics that are nurse led. Unfortunately this screening policy has not been widely implemented. Factors such as lack of knowledge of cervical cancer and the importance of screening play an additional role resulting in screening coverage as low as 13% (Snyman, 2012; Snyman & Herbst, 2013).

Similar to the rest of Africa, the majority of South African women present with advanced disease (Anorlu, 2008; du Toit & Kidd, 2015). Snyman and Herbst (2013), in a study conducted at a large South African hospital found more than 50% women presented with Stage IIIB cervical cancer, which means the cancer has spread to the pelvic wall and/or caused hydronephrosis, or a non-functioning kidney (World Health Organization, 2006). Treatment for cervical cancer depends on the stage of the disease. According to the International Atomic Energy guidelines for the management of cervical cancer in limited resource centres (International Atomic Energy Agency, 2012), women with Stages IIB to IVA disease are not candidates for surgery and should receive standard treatment consisting of external beam radiation and brachytherapy, with or without concomitant chemotherapy. Five

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weekly doses of cisplatin are usually given during external beam radiation.

It is well known that pain is synonymous with cancer and the majority (70–90%) of patients living with cancer or advanced cancer experience pain caused by either the cancer itself and/or its treatment (Payne, 2016; The British Pain Society., 2010; Van den Beuken-van Everdingen et al., 2007). According to Glare et al. (2014), cancer survivors also have chronic pain which interferes with their daily function, especially in the first few years after treatment. According to the The British Pain Society (2010), cancer pain involves mechanisms of inflammation, compression and ischemia causing a combination of nociceptive and neuropathic symptoms. However, Schmidt (2014), when describing the neurobiology of cancer pain, differs from opinion and states the cause of cancer pain is unknown. According to Schmidt (2014), cancer pain exhibits different mechanisms than those of inflammatory and neuropathic pain and it is most possible that the interaction between the cancer and the sensory nerves surrounding the cancer contributes to pain. In addition, the histologic type of the cancer, the anatomical site involved and whether the site is needed for musculoskeletal function, also influence the patient's pain experience.

Untreated and undertreated pain are common in cancer patients. Although this has been known for an extended time, there is little evidence of recent improvements in the management of cancer pain (Goodwin, Bruera, & Stockler, 2014). This is not justifiable, as more than 80% of cancer pain can be controlled with inexpensive oral drugs providing a proper pain assessment is performed and analgesics are chosen in an orderly fashion (Payne, 2016). Unfortunately developing countries such as South Africa have additional challenges because of the restricted availability of opiates at, for instance, primary healthcare level (Maree, Wright, & Makua, 2013) and limited prescription rights. In addition, Ntinga and Maree (2015) found women treated for cervical cancer also face health system challenges. Their healthcare needs are not necessarily addressed at primary healthcare level as they are referred to the hospital where they were treated for cancer – a situation that complicates pain control as most women cannot afford the additional journey to the hospital.

Little is known about the lives of women treated for cervical cancer in Africa, as best practices primarily focus on the prevention of this disease. It does not appear as if Africa's nurses have investigated pain in women treated for cervical cancer despite the high incidence on this continent (Maree, Herbert, & Huiskamp, 2017; Maree & Schmollgruber, 2014). We know pain is one of the most common symptoms cancer patients living in sub-Saharan Africa present with because of late presentation (Anorlu, 2008) and chronic pain is significantly more prevalent in women treated for cervical cancer than women in the general population (Vistad, Cvancarova, Kristensen, & Fosså, 2011). In addition, it is known that cervical cancer survivors struggle with lower abdominal pain and lower back pain twelve months after completing radiotherapy (Ntinga & Maree, 2015). However, the severity, characteristics, management and its outcomes and patterns of the pain seem to be unknown. In an attempt to provide base line data and initiate investigations addressing the identified knowledge gap, the Brief Pain Inventory was used (with permission), to describe the pain women treated for cervical cancer at an academic hospital in Gauteng Province, South Africa, experienced. The study aimed at describing pain in women diagnosed with cervical cancer who received radiotherapy with/without concurrent chemotherapy, before treatment and at six and twelve months after the completion of the treatment.

2. Materials and methods

2.1. Research setting

The setting for this study was an academic hospital in Gauteng Province, South Africa, a specialist hospital part of the public healthcare services. The cost of services is supported by a National Tertiary Service Grant and funds allocated to the province and is rendered free of cost to patients. The hospital hosts 1088 beds, various out-patient units and serves as a specialist referral hospital for regional hospitals and neighbouring provinces, as well as a clinical learning platform for nurses, medical practitioners and other healthcare professionals (Gauteng Province, S.A.). The adult oncology units are recognised as centres of excellence and approximately 3500 patients are treated at the Department of Radiation Oncology, the largest oncology unit in the country, annually (SAnews.gov.za, 2014). The department has a chemotherapy room to accommodate patients receiving concomitant chemotherapy and a resting room for patients who need bed rest as they wait to be treated. Most of the patients treated with radiotherapy receive treatment as out-patients, but those who are too ill to travel are admitted to the ward designated for radiotherapy patients. Between 662 and 721 women are treated for cervical cancer annually and about 360 are reviewed each month after completing treatment (Dzaka & Maree, 2016; Msadabwe, 2009). Patients treated for cervical cancer are reviewed six weeks after completion of treatment, thereafter every three months for two years, then every six months for two years and then yearly for the rest of their lives.

2.2. Research design and respondents

A cross-sectional design was chosen for the study as it allows researchers to select respondents in various phases of treatment and describe changes across the phases (Grove, Burns, & Gray, 2013). All women 18 years and older, diagnosed with cervical cancer, who were either referred for or treated with curative intent and were in the before treatment phase and six months and twelve months after treatment were eligible for the study. A calculated sample size was used in consultation with a statistician. The formula $\eta = (Z\alpha/\Delta)^2$ where η is the sample size, Z the desired level of statistical significance (normally 1.96).

α the standard deviation of the outcome variables (from previous studies, in this case 3.3) and Δ the margin of error (0.5) applied. Thus:

$$\eta = (Z\alpha/\Delta)^2$$

$$\eta = 1.96 \times 3.3/0.5$$

$\eta = 167.34$ rounded off to 168 to include 56 (n = 56) respondents in each of the three groups. Convenience sampling was used to select the sample. Women were recruited after their first consultation at the gynaecology clinic and those scheduled for a follow up consultation six and twelve months after completing treatment. Recruitment started in the first week of June 2015 and continued until the sample size was reached in July 2015. All the women approached, agreed to participate in the study.

2.3. Data collection, instrument and analyses

Structured interviews (Grove et al., 2013) were used to collect the data as this approach enables researchers to include women of all literacy levels, answer questions and explain and rephrase the questions if necessary. The English version of the Brief Pain Inventory (BPI), reliable and valid across various cultures and languages, served as the data collection instrument. The BPI asks 32 questions and measures both the intensity of pain and how pain interferes with the patient's life (Cleeland & Ryan, 1994). The instrument uses open and closed ended questions, numerical scales and a body chart to collect the data. The first six questions collect general information, whilst questions 7–10 investigate whether the patients experienced pain relating to their current disease. Question 10 poses three questions and only respondents who answered "yes" to any of the three are eligible to answer the rest of the questions. This question focuses on experiencing pain other than everyday kinds of pain, taking pain medication in the past seven days and needing pain medication every day. Question 11 asks