

# Living with the late effects of cervical cancer treatment: a descriptive qualitative study at an academic hospital in Gauteng

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## Abstract

**Objective:** The late effects of cervical cancer and its treatment are well known. However, qualitative research describing how women experience these effects seems to be unavailable. The purpose of our study was to describe how women experienced the late effects of cervical cancer treatment.

**Design:** A qualitative descriptive design was used.

**Subjects and setting:** Purposive sampling was employed to select the participants treated at an academic hospital in Gauteng. Sixteen in-depth interviews were conducted. Data saturation determined the sample size. Thematic analysis was used to analyse the data.

**Results:** The average age of the sample was 44.1 years, and half of the participants had stage IIB cancer. Most were treated with external beam radiation in combination with brachytherapy. Five themes arose from the data, namely experiencing the physical consequences of the treatment, struggling with the socio-economic implications of the treatment, living with the sexual consequences of the treatment, spiritual issues relating to cervical cancer and facing health system challenges.

**Conclusion:** The late effects deriving from cervical cancer treatment deprived women of the lives they lived before they were treated for cervical cancer. They were burdened with physical changes which aggravated their already difficult financial situation, and they had to live with unattended healthcare needs. Sexual dysfunction changed their intimate partner relationships, leading to anxiety about the possible loss of their life partners. Despite all this, they were positive about their future owing to their faith. Nurses should assess patients for the late effects of cervical cancer and implement interventions to meet their individual needs.

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## Introduction

According to the 2012 Globocan statistics,<sup>1</sup> cervical cancer, a preventable disease, is the fourth most common cancer in women. Approximately 85% of the global cervical cancer burden occurs in the less developed regions of the world, where most women present with advanced disease, too late to be cured.<sup>2</sup> In South Africa, cervical cancer is the second most common cancer in women, and the most common cancer in black women. The 2007 South African Cancer Registry<sup>3</sup> indicates that 30% of all black women newly

diagnosed with cancer were diagnosed with cervical cancer, compared to 7% of Asian and 3.92% of Caucasian women.

The International Atomic Energy Agency (IAEA)<sup>4</sup> guides the management of both early and late stages of cervical cancer in resource-restricted settings. The IAEA recommends that every patient without metastatic disease should be treated as aggressively, as far as can be tolerated, to improve the chances for cure. Patients with stage IIB-IVA cervical cancer are not candidates for surgery, but should receive the standard curative treatment, consisting of external beam

radiation plus brachytherapy, with or without concomitant chemotherapy.

Cervical cancer treatment causes both acute and late effects. Acute effects or complications are those experienced during and immediately after radiotherapy,<sup>5</sup> while late complications develop six months after completion of the treatment.<sup>4</sup> Physical effects include diarrhoea, constipation, lymphoedema, menopausal symptoms, poor body image, sexual and or vaginal dysfunction, and dyspareunia<sup>6</sup> and chronic fatigue.<sup>7</sup> All of these influence the emotional, psychosocial and sexual well-being of the patient.<sup>8,9</sup>

The significance of our study relates to the fact that the prevention and treatment of cervical cancer is emphasised in best practice guidance. Although the late effects of cervical treatment are well known, qualitative research reflecting the experiences of women living with these effects does not seem to be available. Our study addresses this knowledge gap by reflecting on these experiences.

## Method

### Sample

Our sample consisted of 16 women returning to the oncology clinic at an academic hospital in Gauteng for their routine assessment 12 months after completing curative treatment. The ages of the participants ranged from 27- 59 years, with an average of 44.1 years. Half of the participants had stage IIB cervical cancer, while three had stage IB, three stage IIIB, one stage IIA and one stage IVA cancer. Three participants were treated with external beam radiation, brachytherapy and chemotherapy; 11 received external beam radiation and brachytherapy; one received external beam radiation only; while one participant had surgery, external beam radiation and brachytherapy. Women had to be 18 years and older, treated curatively, and able to speak basic English to be included in the study.

### Design, sampling and data gathering

We selected a qualitative descriptive design<sup>10</sup> for our investigation. This design was suitable for our study as it allowed us to present a descriptive summary of how women experience the late effects of cervical cancer treatment. Purposive sampling was used to select the participants. Purposive sampling is usually employed in qualitative studies as it serves as a measure of improving the transferability of the findings.<sup>11</sup>

After ethical clearance (# M130344) was obtained, the first author, an oncology nurse, approached eligible women waiting to consult the oncologist, explained the study, invited them to participate and handed them an information leaflet. Participation was voluntary, and informed consent in writing was obtained before in-depth interviews were conducted in

English for an average of one hour. The initial question asked was: "Please tell me what problems you are experiencing at this stage which were caused by the treatment you received for the cancer?" The interviewer used deliberate prompts and member checks to ensure that she understood what the participants meant and to enhance the credibility of the findings.

The interviews were conducted in August and September 2013. Data gathering and concurrent data analysis continued until 16 interviews were conducted and potential themes were saturated. Field notes were written during and immediately after the interviews, and inserted at relevant points during the transcription of the data.

### Data analysis

Thematic analysis<sup>10</sup> was utilised to analyse the data. Thematic analysis is a flexible approach enabling researchers to identify, analyse and report patterns within the data.<sup>12</sup> Familiarisation with the data was achieved by reading and re-reading the verbatim transcribed interviews. Initial ideas were written in the margins and interesting features coded across the entire dataset, whereafter the codes were organised into potential themes. The emerging themes were checked against the dataset and named. Both authors analysed the data, and reflexivity was employed to create self-awareness with regard to how the authors current position and past experiences might affect the study findings.<sup>13,14</sup> Five themes arose from the data.

## Results

### *"I feel bad": experiencing the physical consequences of the treatment*

Participants experienced various physical problems, including chronic fatigue, chronic pain, vaginal, bladder and bowel problems, lymphoedema and menopausal symptoms. Chronic fatigue was a major problem, and had a negative influence on participants' daily lives as it limited their normal activities. One participant said: "During the day I feel dizzy. My heart pumps very fast as if something wrong is going to happen. When I am cleaning, cooking or fetching water, I feel something bad, I cannot go out of the house. I have to stay in".

Experiencing chronic pain, most commonly in the abdomen and lower back, made it impossible for participants to continue with the same lifestyle to which they were accustomed before they became ill: "Just that pain which comes and go in the back. When it comes, I feel like screaming. I feel like: 'Oh my God, why, why must this pain come now?' I must do this and this, but I can't because of the pain".

Participants experienced various vaginal problems, such as pain, stenosis, dryness and bleeding. One participant said: "I was feeling pain in my vagina. Aaaa! you can feel it deep in your vagina. Sometimes my vaginal became too dry". Vaginal stenosis was a major problem. Another said: "The vaginal is small. That's the main one (problem), that one. The bleeding small, not serious".

In addition to bowel and bladder complications, consisting of diarrhoea, constipation, urgency and urinary incontinence, some participants developed fistulae. It was explained: "I found out that the poo comes out through the vagina. It wasn't painful, but disgusting, because you can't just walk freely, because any time... It comes out a lot. I had to go for this colostomy, but now I have got the problem of urine. It's like I can't hold urine. I have to go to the toilet now. That's my problem".

***"Life is tough": struggling with the socio-economic implications of the treatment***

The physical problems that the participants experienced resulted in financial hardship, social problems and body image changes. Participants experienced financial difficulties as they were unable to take part in hard physical work or full-time paid work. One said: "I am not working right now, so life is tough. My children are suffering. They go to school. There's no transport and food. The money, it's not enough". Another explained: "I cannot work every day because I am getting pain in the hand. The money cannot get so much. I am paid according to work".

Financial hardship made it difficult for the participants to buy basic commodities, and to return to the hospital for follow-up visits. One said: "Sometimes I feel a lot of discharge. I am scared to be with people, like going into public. I have no money for pads". Another added: "They said I must come back for the blood, but I didn't have money to come. You know, if you are not working".

Participants' relationships with their life partners were of great concern to them as feared that their relationships would be affected by their illness. One participant said: "Eish, my husband, nay. He is not feeling alright with me. He has changed, complaining. He is saying (I) am sick". Participants were sometimes abandoned, leaving them with sole responsibility for their children: "These men are going away, and leave us with these children".

Incontinence changed participants' social lives as they were constantly concerned that they might soil themselves. One said: "I am worried. I have to check all the time. Maybe it's wet on the trousers, or on your skirt. That is my main worry. When you sit, maybe at home or in the taxi, you just have to... Eish! Maybe I am wet". Another added: "You see. Now I have to cover with a blanket here (pointing at the small blanket wrapped around her hips). And you see I wear two skirts. It's

a problem. You can't go to people's houses. You are worried: 'What if I wet the bed?' It's very bad to the people. Even at home, you must go fast because it will come out, and then what if you are in somebody's house? It's a big problem".

Participants were fully aware of the necessity of preventing vaginal stenosis by dilating their vaginas. However, their home and work environments did not afford them the opportunity of performing this procedure privately. One of the participants explained: "I am using, I don't want to lie to God, but not every day. My child is old now, so I do not have privacy. When they are at school, I am at work. At work time, it's only at break. There is only one toilet we share".

***"It is worrying me a lot": living with the sexual consequences of the treatment***

Participants experienced sexual problems. Some found that their partners were unable to cope with their altered sexuality and complained about these changes. One participant said: "My vagina was changing. My vagina was becoming short. It was hard because my husband was complaining that my vagina is not the same like he knows. It was paining when we meet". Another participant added: "Yeah, eish. This thing is affecting my life. The vagina. If you want to make love, sometimes my vagina is tight, tight, tight. He is complaining. It's worrying me a lot. He has to push and push and push".

The treatment had a devastating influence on the participants' sexual desire, and some engaged in sexual intercourse merely to please their partner. One participant said: "The feeling to have sex like a woman is not there. But I can't tell him that. If you are a woman, you have to sleep with your husband anytime that he wants, but he touches and there is nothing. It can be so bad. Yeah, if he wants something now, you must give him what he wants. If not, it might be a problem".

The complications women experienced influenced their own sexuality, and also seemed to have a negative effect on their partners: "My husband, he also has problems. It takes long to meet me to have sex, even if I ask him. He said that he is not feeling to have sex". Another added: "I think he doesn't enjoy sex anymore because I can see that. Aaaa! Not like before anymore. We don't sex like before. He takes long. I can see it he is just doing it to satisfy me. I am worried".

***"The only way to survive": spiritual issues relating to cervical cancer***

Most participants blamed themselves for their life situation. "Why?" was a question that participants often asked God. A participant said: "Last year, my sister passed away. Then, last year again, my granddaughter passed away. Yoooo! It's just like that, and am asking: 'Why? Why?'" In addition, experiencing the effects of the treatment confronted participants with their own mortality, and led to anxiety

about what would happen to their children should they die: "I am not feeling well in the body. I am thinking about my children. They are still young. I have no one who can look after them. I have no mother, no father. I am the only one to look after them. If I am dying, no one can take care of my children. So I am very, very worried about my life".

Prayer and faith in God served as a source of hope and strength. Believing in God helped them to have courage and confidence. One participant explained: "I believe in God, to move on yes. If you believe in God, nothing can happen to you. Cancer, it's not the end of the world. The time will come when everybody is going to die". Another added: "I only go to church to pray. I believe in God. Yeah! The only way to survive is God must give me strength, to give me power to overcome this situation. God is the only one who can save me, who can heal me".

#### ***"We are not treating cancer here": facing health system challenges***

The healthcare system added to participants' burden as they were denied health care at primary healthcare clinics. As soon as their status as a cancer patient was known, they were referred to the hospital where they were treated for cancer, which they could not afford. One participant explained: "When we go to the clinic, they said we are not treating cancer here. Will you please go to...I start at 04h00 to get here. I didn't have money and I am sick".

Participants were reluctant to tell the medical practitioners at the radiation oncology clinic about their health problems. Those who had back and abdominal pain reported it to the doctor, but those who experienced pain in other parts of their bodies were reluctant to mention it. A participant explained: "It's just pain here, and when I come to tell the doctors I have pain here and here (pointing at the arms and joints), the doctors said: 'No, I am working here for the cancer, not for the pain here and here'. I have other problems, but I can't tell them".

Participants reported an information deficit. Some were of the opinion that they "didn't know anything", and felt that they had received inadequate information about cervical cancer, the treatment and side-effects, and the importance of follow-up consultations. One participant explained: "Ahhhh! I don't know. Why we must keep here, why we must come to check every month, every year, every month, every year, check, check". Some were advised to use traditional medicine, but did not have the confidence to ask the healthcare professionals whether or not this was feasible: "The people say there are medicines that you must take, like herbal mixtures, and many other things. So I wanted to ask: 'Is it possible to use these things?'"

The late effects of cervical cancer treatment had a negative influence on the participants' lives. Their social lives

changed. They experienced financial difficulties and sexual dysfunction, and feared losing their partners. They had to live with unattended health problems and insufficient knowledge of their disease and treatment, and were confronted with their own mortality. However, their belief in God was their source of strength.

## Discussion

Living with the physical effects of cervical cancer treatment is not easy. The fatigue which participants experienced had a negative influence on their daily living activities. Pain aggravated their inability to engage in normal household activities, and even in paid work, thus adding to the financial hardship already experienced. Chan and Molassiotis,<sup>15</sup> who investigated fatigue in Chinese cancer patients, found a similar trend, and reported that fatigue had a negative influence on the daily routines, social life, work and role functioning of patients. Chinese patients experienced the same work disruption, which, similar to the women in our study, led to emotional distress about being able to care for their families. Our finding that the women still experienced pain was not new, and is supported by Brown, Ramirez and Farquhar-Smith,<sup>16</sup> who found that pain caused by cancer and its treatment has the potential to last many years, has a negative influence on people's ability to recover and regain the same functional levels as before the diagnosis, and a negative influence on their quality of life.

Participants' body image and social lives were negatively influenced by the bowel and bladder effects they experienced. Burns, Costello, Ryan-Woolley and Davidson<sup>17</sup> found that even persistent mild bladder symptoms influenced the daily lives of women treated for cervical cancer, while Brown et al<sup>18</sup> found that accidental bowel leakage changed women's social activities, led to feelings of frustration, and influenced the emotional health of women experiencing this problem. In addition, Peden-McAlpine, Bliss and Hill,<sup>19</sup> similar to the findings of the current study, found that anxiety about the risk of accidents in public places resulted in a sense of discomfort at being in a public place, and limited women's ability to engage in work outside the home.

Participants had to live with various vaginal complications, which led to sexual dysfunction and emotional distress. It was interesting to find that the socio-economic situation of having to share rooms with others, a reality for many South African families,<sup>20</sup> served as barrier to vaginal dilation. In contrast to the findings of Burns, Costello, Ryan-Woolley and Davidson,<sup>17</sup> the participants in this study reported that they experienced dyspareunia. This is evidence of the relationship between sexuality and the physical effects of treatment. In addition, having sexual intercourse only to satisfy or please their spouse, as well as experiencing loss of sexual desire,

had an adverse influence on intimate partner relationships. Unfortunately, sexual dysfunction places South African women at increased risk of losing their partner, something they cannot afford, considering their unfavourable economic position. This can force them to exchange sex, either formally or informally, for money.<sup>21,22</sup>

The study provided evidence that the women experienced signs of spiritual pain, apparent when they asked: "Why?" in connection with their illness, and the way in which they blamed themselves for their life situation.<sup>23,24</sup> According to Villagomez,<sup>25</sup> patients lose hope, question their belief system, or feel separated from their personal source of comfort and strength when experiencing spiritual pain. This did not apply to the women in our study. Although some experienced signs of spiritual pain, their belief in God gave them hope and strength to cope with their life situation, and allowed them to believe that they would be able to cope and survive.

The healthcare system added to their financial hardships by referring patients to the hospital for basic health care, where they had to incur additional costs which they could not afford. In addition, not having the confidence to tell the medical practitioners about their apparent non-cancer-related health concerns left them with unresolved health problems. Women with cervical cancer seem to be continuously let down, as studies<sup>26,27</sup> suggest that the healthcare system fails women in terms of early diagnosis. In addition, Goudge et al<sup>28</sup> found that barriers to providing health care to the chronically ill in South Africa included households not being able to pay the costs of seeking chronic care, as well as the clinical ineffectiveness when diagnosing and prescribing at the clinics. If a lack of knowledge on cervical cancer and its treatment and the reasons for follow-up consultations is added to these barriers, the potential for women to default and revert to traditional medicine is created.

This study provides evidence that participants experienced a knowledge deficit in terms of their disease, treatment, the side-effects of the treatment and the importance of follow-up consultations. This is not unique as Sanson-Fisher et al<sup>29</sup> found that Australian patients had high levels of unmet information needs. In addition, Burns, Costello, Ryan-Woolley and Davidson<sup>17</sup> reported a similar finding, and revealed that women treated for cervical cancer felt they were not adequately informed about the treatment effects. Lauer, Murphy and Powers<sup>30</sup> found that patients' information needs and nurses' perceptions of these needs were not necessarily the same, and it is quite possible that the patient education given to the participants was not individualised and did not emphasise what patients considered to be important.

There were some limitations to our study. This was a qualitative study, and no such study can reflect the only true meaning as there is more than one interpretation of the

narratives. All of the participants were black women treated at the same hospital, and therefore, it was not possible to conclude that all women treated for cervical cancer would share the experiences of the women included in our study. However, we believe that the themes that emerged from the data were authentic, and could be applicable to other women living with the late effects of cervical cancer as there are overlapping issues which might apply to all such women.

## Conclusion

The late effects deprived women of the lives that they had lived before they were treated for cervical cancer. They were burdened with physical changes which aggravated their already difficult financial situation. Sexual dysfunction changed their intimate partner relationships, leading to anxiety about the possible loss of their life partners and how to live with unattended healthcare needs. Despite this, their faith sustained them and gave them hope for the future.

Nurses practising in cancer care settings should assess patients for the late effects of cervical cancer and implement interventions to meet their individual needs. In addition, nurses practising in primary healthcare clinics should differentiate between non-cancer-related health care needs and cancer-related problems, and make referrals, if necessary. It is important that women living with cervical cancer should be able to access primary health care.

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## Declaration

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