

Reasons why unscreened patients with cervical cancer present with advanced stage disease

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Abstract

Objective: Cervical cancer is the most common gynaecological cancer in South Africa, and the vast majority of women present with an advanced stage of the disease. This can be attributed to the absence of an implemented screening programme, resulting in patients becoming symptomatic prior to diagnosis. There are little data on the health-seeking behaviour of these women. The objective was to investigate the circumstances of patients who present with cervical cancer, as well as examine their presenting symptoms and behaviour following the onset of symptoms.

Design: Descriptive study. Data were collected from patients who were diagnosed with cervical cancer by means interviews and a questionnaire.

Setting and subjects: Women diagnosed and managed with cervical cancer at the Gynaecological Oncology Unit, Kalafong Hospital, Pretoria.

Outcomes measured: Included demographic data, tumour characteristics, presenting symptoms, number of visits to and interventions performed at the primary healthcare contact.

Results: Eighty-five patients were recruited. Of these, 74% lived in rural areas, 81% had access to primary healthcare facilities and 83% lived close to a healthcare provider. Eight had early-stage disease. The most common presenting symptoms were vaginal bleeding, pain and vaginal discharge. After the onset of symptoms, 55% of patients visited their healthcare provider within four weeks. At the first visit, only 41% of patients had a gynaecological examination and only 15% were appropriately referred, compared to 23% at their second visit. Late presentation was significantly associated with no gynaecological examination (p -value < 0.01).

Conclusion: The lack of a cervical cancer screening programme, suboptimal management of symptomatic patients and low levels of literacy and knowledge about cervical cancer and screening are compounding the plight of these patients.

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Introduction

Cervical cancer is the most common cancer among South African women, affecting 1 in 41.¹ It is one of the few cancers where screening can identify precancerous lesions and where an association exists between screening and a decline in mortality.^{2,3} In countries with no or insufficient screening strategies, most cases are diagnosed when the disease is already advanced (stage IIB or more), with a corresponding poor prognosis.⁴⁻⁷

The South African National Department of Health has compiled a screening programme comprising three smears at 10-year intervals, commencing at the age of 30.⁸ However, this screening policy has not been

widely implemented and the majority of South African women are not screened at all.^{9,10}

The Gynaecological Oncology Unit at the Pretoria Academic and Kalafong Hospital Complex manages more than 300 newly diagnosed patients with cervical cancer every year. The majority of these patients are unscreened and have advanced-stage disease at the time of diagnosis. The objective of this study was to investigate the reasons why unscreened patients present with advanced-stage disease, as well as their presenting symptoms and behaviour following the onset of symptoms. We also wanted to establish what the course of events was once these patients made contact with the healthcare system.

Method

This was a descriptive study. Patients diagnosed with cervical cancer at Kalafong Hospital, which forms part of the Gynaecological Oncology Unit of the Pretoria Academic Complex, were eligible to be enrolled into the study. These patients are referred from local clinics situated in the western suburbs of Pretoria, as well as from Mpumalanga, a neighbouring province with a large rural population.

Patients with confirmed cervical cancer were approached to be part of the study, and written informed consent was obtained from those who agreed to take part. A questionnaire was used to interview participants. Interviews were conducted by the different registrars who rotated through the oncology unit. Ethics approval was obtained from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

SPSS® Version 14 for Windows was used for data analysis. Means and standard deviations were employed to describe the population in the case of continuous data, and frequencies and percentages in the case of categorical data.

Associations between independent variables and late presentation (patients with a disease stage of IIB or more) were examined using the chi-square test or Fischer's exact test for categorical data and Student's t-test for continuous data.

Results

Eighty-five eligible patients were recruited for the study. Seventy-seven patients (90%) were diagnosed with advanced-stage cervical cancer, of whom 13 (15%) were stage IIB, 2 (2.4%) stage IIIA, 48 (56.5%) stage IIIB, 9 (10.6%) stage IVA and 5 (5.9%) stage IVB. Eight patients (10%) were diagnosed with early cervical cancer, 1 (1.2%) with stage IA, 5 (5.9%) stage IB and 2 (2.4%) stage IIA (Figure 1). Demographic data are summarised in Table I.

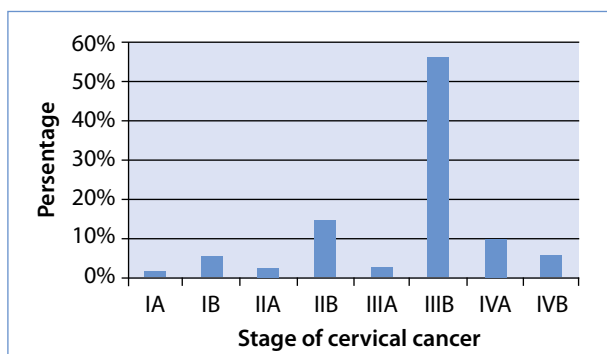


Figure 1: Distribution according to disease stage

Table I: Demographic data of the women in the study

| Mean age of patients | 53 years (SD 13.13) n | 26-83 years (%) |
|-------------------------------------|--------------------------|-----------------|
| Referred from | | |
| Rural areas | 63 | 74 |
| Cities or big towns | 22 | 26 |
| Marital status | | |
| Married | 32 | 37 |
| Single | 32 | 37 |
| Widowed | 17 | 20 |
| Divorced | 4 | 4 |
| Literacy levels | | |
| No or minimal | 66 | 77 |
| Secondary school | 18 | 21 |
| Tertiary education | 1 | 1 |
| Healthcare access | | |
| Primary care clinic | 69 | 81 |
| Hospital | 38 | 45 |
| General practitioner | 28 | 33 |
| Mobile clinic | 6 | 7 |
| Accessibility to health care | | |
| < 1 hour travel | 71 | 83 |
| 1-2 hours travel | 10 | 8 |
| > 2 hours travel | 4 | 4 |
| Mode of transport | | |
| Walk | 49 | 58 |
| Taxi | 27 | 32 |
| Own transport | 5 | 6 |
| Public transport | 4 | 4 |

Presenting symptoms that prompted a visit to the healthcare provider are shown in Figure 2. Sixty-three patients (74%) had vaginal bleeding (menorrhagia, intermenstrual bleeding or postmenopausal bleeding). Fifty-five patients (64%) had pain, while 28 patients (33%) complained of vaginal bleeding and pain. Only 22 patients (26%) had vaginal bleeding as the only complaint, while 9 patients (10%) had pain only as a presenting symptom. Nineteen patients (22%) had a vaginal discharge and 4 (4.7%) presented with urinary incontinence. Six patients (7%) presented with other symptoms. One patient had dysuria. Health-seeking behaviour, following the onset of symptoms, is shown in Table II.

Twenty-one patients (24.7%) knew what a Papanicolaou (Pap) smear was before they consulted their healthcare provider. Of these, 12 patients (57%) had previously had 1-2 smears, 7 (33%) 3-4 smears, and 2 patients (9%) more than six smears. The majority

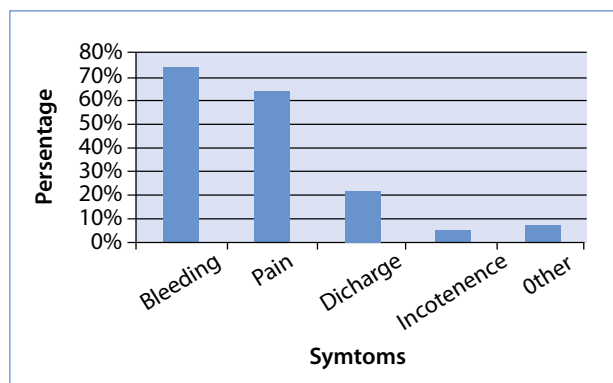


Figure 2: Most common presenting symptoms

Table II: Health-seeking behaviour of the women in the study

| | n | % |
|---|----|----|
| Entity visited after onset of symptoms | | |
| Primary healthcare facility | 43 | 52 |
| General practitioner | 22 | 26 |
| Hospital | 14 | 16 |
| Mobile clinic | 4 | 4 |
| Traditional healer | 1 | 1 |
| Time from symptom onset to visit | | |
| Within 1 month | 47 | 55 |
| 1-2 months | 12 | 14 |
| 3-6 months | 10 | 11 |
| 6 months+ | 16 | 18 |

of patients did not know when it was ideal to perform the first smear.

Thirty-five patients (41%) had a gynaecological examination at their clinic, which included a cervical smear. Nineteen of these patients (54%) were given a date to return for the results, while 4 (11%) had no return date. Only 2 patients (5%) returned on their own to obtain their results. No information was available for 12 patients (34%) with regard to feedback on their cervical smear results.

Only 13 patients (15%) had been referred on their first visit. Forty-seven patients (55%) returned to the same healthcare provider, while 23 (27%) went to another one. No information was available for 6 patients (9%). Of the patients who returned to the same healthcare provider, 13 (27%) were referred on their second visit; 7 (15%) on the third; 7 (15%) on the fourth; 2 (4%) on the fifth; 1 (2%) on the sixth and 9 (19%) after the sixth visit. No information was available for 2 patients (4%). Of the 23 patients who went to different healthcare providers, 12 (54%) visited their closest hospital, 2 (9%) another primary care clinic, 4 (18%) a general practitioner, and 2 (9%) relatives in Pretoria. No information was available

for two patients. Of these patients, 7 (30%) were referred on their first visit to a new healthcare provider; 5 (22%) on the second visit; 3 (13%) on the third visit; 2 (8%) on the fourth; 1 (4%) on the fifth and 2 (8%) on the sixth visit. No information was available for 2 patients (8%).

Fifty-eight patients (58%) presented at Kalafong Gynaecological Oncology Clinic within one month of referral. Sixteen patients (19%) were seen between 1-3 months after the initial referral. Fifteen patients (17%) were attended to four months after referral. No information was available for 5 patients (5%).

Although this study was not designed to investigate the differences between early- and late-stage disease, these data are shown in Table III. The omission of a gynaecological examination on presentation was the only statistically significant difference between the two groups.

Discussion

The majority of the patient population in this study presented with advanced-stage cervical cancer. Most of the patients had relatively easy access to primary healthcare facilities and lived within less than one hour's travel from them.

Cervical cancer knowledge and cervical smear awareness were problematic. Only 24% of the recruited patients had knowledge about the importance of cervical cancer screening, and only half of whom had heard about the Department of Health's screening policy. These figures are lower than previously reported rates of cervical cancer knowledge and screening among women in South Africa.¹¹⁻¹⁶

The most common presenting symptoms in this study included postmenopausal bleeding, pelvic pain and vaginal discharge. This is similar to data published in other African countries.^{7,17}

Most patients did not experience unnecessary delays between the onset of symptoms and their visit to the healthcare system. Nearly all patients consulted their healthcare provider within two months of the onset of symptoms. This is in contrast with the findings from other studies in Africa which have reported an average of six month's delay before presenting.^{7,17}

Low awareness of screening and of the disease itself further contributed to the problem of patients being diagnosed with advanced-stage disease. Minimal literacy and, in many patients, illiteracy, further aggravated the situation.^{7,17}

We found no relationship between the duration of symptoms and the International Federation of

Table III: Factors associated with late versus early presentation

| Variable | Late presentation n = 77, % | Early presentation n = 8, % | p-value |
|---|--------------------------------|--------------------------------|---------|
| Age (mean, standard deviation) | 53.1 (13.2) | 53.4 (13) | 0.9 |
| Marital status | | | |
| Married | 31 (40.3) | 1 (12.5) | 0.2 |
| Single | 46 (59.7) | 7 (87.5) | |
| Education | | | |
| Secondary and above | 17 (22.1) | 2 (25) | 0.9 |
| Primary and below | 60 (77.9) | 6 (75) | |
| Travelling time | | | |
| £ 1 hour | 63 (81.8) | 8 (100) | 0.3 |
| > 1 hour | 14 (18.2) | 0 (0) | |
| Transport | | | |
| Walking | 33 (42.9) | 4 (50) | 0.7 |
| Motor vehicle | 44 (57.1) | 4 (50) | |
| Healthcare site | | | |
| Private | 21 (23.3) | 2 (25) | 0.9 |
| Public | 56 (72.7) | 6 (75) | |
| Knowledge of Pap smear | | | |
| No knowledge | 57 (74) | 7 (87.5) | |
| Presenting symptoms | | | |
| Vaginal bleeding | 56 (72.7) | 7 (87.5) | 0.5 |
| Pain | 52 (67.5) | 3 (37.5) | 0.1 |
| Discharge | 17 (22.1) | 2 (25) | 0.9 |
| Incontinence | 4 (5.2) | 0 (0) | 0.9 |
| Time from symptoms to presentation | | | |
| < 3 months | 53 (68.8) | 6 (75) | 0.9 |
| ³ 3 months | 24 (31.2) | 2 (25) | |
| Gynaecological examination performed | 8 (36.8) | 27 (87.5) | 0.008 |
| Time from diagnosis to referral | | | |
| < 1 months | 29 (39.7) | 2 (28.6) | 0.7 |
| ³ 1month | 44 (60.3) | 5 (71.4) | |

Pap: Papanicolaou

Gynecology and Obstetrics (FIGO) stage of disease. This means that the majority of the patients, although of minimal literacy, realised when they had a serious health problem that required medical intervention.

Of concern is what happens to patients once they have visited a healthcare provider. On average, the patients who were surveyed in this study were 53 years old and presented with postmenopausal bleeding and pain, yet the majority of them did not undergo a gynaecological examination on their first visit to a primary healthcare facility. Only half of these patients had a follow-up appointment. According to the Department of Health, any woman with a gynaecological complaint should receive a gynaecological examination or smear. The

absence of a gynaecological examination was the only statistically significant finding between patients with early- and those with late-stage disease.

Many patients who presented with clinically evident advanced-stage disease received a screening test (a cervical smear) instead of a diagnostic test (a biopsy). This may add further to delays in the diagnosis and treatment of such women.

There was a delay in the diagnosis and referral of the majority of patients. Up to 13% of patients consulted their healthcare providers more than six times before they were referred to the Gynaecological Oncology Unit.

Conclusion

Although the majority of patients in this study group lived in rural areas and had minimal literacy, they consulted their healthcare providers who were in close proximity without unnecessary delay after the onset of symptoms.

From the collected data, it seems that the healthcare system, represented by the clinic, general practitioner or hospital, failed the majority of patients by not examining and referring them appropriately. In patients who were examined, crucial clinical observations were missed and inappropriate tests carried out, which might have contributed to further delays in diagnosis, referral and treatment. The lack of effective measures to inform patients of abnormal cervical smear results was also of concern, as it is the primary responsibility of the healthcare provider to inform patients of abnormal test results.

The absence of an effective cervical cancer screening programme in South Africa emphasises the important role that primary prevention will have in the future, in the form of a vaccination programme.

The majority of women with cervical cancer in South Africa do not undergo cervical cancer screening. This disadvantage is aggravated when the healthcare system seems to fail them a second time, when those who develop the disease present timeously to the system with symptoms.

In the absence of effective screening and vaccination programmes, every effort should be made by all healthcare providers to accurately and timeously examine, diagnose and refer patients with symptoms that are suggestive of cervical cancer, to prevent unnecessary delays in treatment.

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