RESEARCH

DISEASE-RELATED NEEDS OF BLACK PATIENTS WITH CERVICAL CANCER

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Abstract

The high incidence of cervical cancer amongst South African black women is complicated by late presentation for treatment as well as by misconceptions and ignorance which adversely affect the quality of their lives. The aim of the research was to determine the disease-related needs of patients suffering from cervical cancer which would serve as a basis for planning on providing for these needs.

Needs for the following were identified:

- *Education on early detection in the community.*
- *Education on nutrition and hygiene.*
- *Information on and assistance in obtaining financial relief by means of subsidised transport and disability pensions.*

Opsomming

Die hoë insidensie van servikale karsinoom onder swart vroue in Suid-Afrika word gekompliseer deur aanmelding vir mediese behandeling op 'n gevorderde stadium van die siekte sowel as deur wanopvattings en gebrekkige kennis wat die kwaliteit van hul lewens nadelig beïnvloed.

Die doel van die studie was om die behoeftes van servikale karsoom pasiënte te identifiseer sodat beplan kan word hoe om in die behoeftes te voorsien.

Behoefte aan die volgende is geïdentifiseer:

- *Inligting aan die gemeenskap oor die vroeë opsporing van karsinoom*
- *Inligting aan pasiënte na ontslag oor voeding en higiëne*
- *Inligting oor en steun in die verkryging van finansiële bystand in die vorm van ongeskiktheidspensioen en reistoelae.*

INTRODUCTION

Statistics kept by the oncology nurses at the Ga-Rankuwa Hospital revealed that cancer of the cervix comprised 30% of the total of 962 cancers treated at the hospital in 1986. This high incidence concurs with findings published in the 1986 Cancer Registry of South Africa according to which cervical cancer accounted for 43% of all specific incident cancers amongst a total of 2274 black women.

This high incidence is aggravated by the fact that blacks suffering from cervical cancer who seek help at a hospital often have cancer in an advanced and incurable stage with resultant poor survival rates. Such late presentation is very costly - not only in terms of human lives but also financially. These patients are hospitalised for five weeks to receive chemo- and radiotherapy. The hospitalisation costs alone amount to R4 130 per patient if calculated at a figure of R118 per day as quoted by a hospital administrator in 1988.

Oncology nurses from the Ga-Rankuwa Hospital reported to the researcher that apart from having a poor prognosis the diagnosed patients' suffering is often aggravated by ignorance and misconceptions which adversely affect the quality of their lives. This study was aimed at identifying these patients' needs for information on disease-related matters which could be provided by health professionals.

PROBLEM STATEMENT

The high prevalence of cervical cancer amongst black South African women is complicated by late presentation for treatment as well as by misconceptions and ignorance which adversely affect the quality of their lives.

AIM

The aim of the research was to determine the disease-related needs of hospitalised black patients suffering from cervical cancer which would serve as a basis for planning in order to meet these needs.

OBJECTIVES

To do a survey of hospitalised black patients suffering from cervical cancer in order to determine

- demographic data pertaining to the respondents
- the stage of their disease on admission
- the possible reasons for late presentation for treatment
- the physical problems experienced
- the beliefs about the sequelae of their disease
- support from other patients suffering from cervical cancer
- the input from health professionals regarding consultation and discussion of the disease

It was hoped that clarification of the above variables would allow recommendation of nursing measures to help meet needs thus identified.

LITERATURE STUDY

Cervical cancer is characterized by a long, asymptomatic premalignant phase, during which it can be detected only by means of cervical cytology. Early detection is desirable for reduction in the mortality rate since eradication of this pre-malignant lesion is associated with 100% curability. Cervical cancer can therefore be described as a

potentially preventable neoplasm (Kahn *et al.*, 1987:89).

The control of cervical cancer in many countries is impressive and the prevalence low. In the United Kingdom, for instance, cervical cancer comprises only 4.3% of all incident cancers (Butcher, 1987:7). The corresponding figure for black women in 1986 was an alarming 43% (Cancer registery of South Africa 1986). Presentation for treatment is also at a later stage than in whites, which results in poorer survival and cure rates (Kahn *et al.*, 1987:89).

Gordon Grant ascribes the fact that cervical carcinoma has been reduced to a minor problem in other countries to the mass screening of certain age groups and propaganda disseminated via the press, radio and television. Mass prophylaxis in South Africa poses a problem since free Papanicolaou (Pap) smears at state family planning clinics have been curbed since 1975 (Gordon Grant, 1982:821).

A study done amongst Johannesburg women on their knowledge of and attitudes toward cancer of the cervix revealed although only 27% of the black women had cervical smears taken, 83% indicated a willingness to have a free Pap smear done after the significance was explained to them. Although 72% of the black patients indicated a desire for further information only 33% had asked their doctors for information on their disease (Kahn *et al.*, 1987:91).

It is important to note that although the level of knowledge of a common cancer and its prevention was found to be markedly deficient amongst black women, they indicated a willingness and readiness to participate in preventive as well as therapeutic measures once they have been informed of the nature of the disease (Kahn *et al*, 1987:92). On the other hand they are reluctant to undergo hysterectomy since, according to black culture, a woman is considered to be less valuable in marriage, even divorcable, if she can no longer bear children (Kahn *et al*, 1987:92). Ill health concerning the reproductive system therefore strikes at the core of African lifestyles and beliefs. It has so many socio-cultural implications that the opportunity for early diagnosis and treatment is negated (Searle, 1986:7).

Traditional healers have an entrenched relationship with their community (Searle, 1986:6) and are usually the first to be consulted when health problems occur. Western doctors are the second choice and this phenomenon leads to patients seeking Western health care at a late stage and with a poor prognosis (Van Rensburg, 1981:42).

The psychological impact of cancer is often devastating and therefore treatment aimed at stress reduction and emotional support should be an integral part of the management of patients with cancer pain (Warfield, 1987:101). Most patients want to discuss their problems with not only health professionals but also with other patients who have undergone a similar experience (Ariel and Cleary, 1987:534).

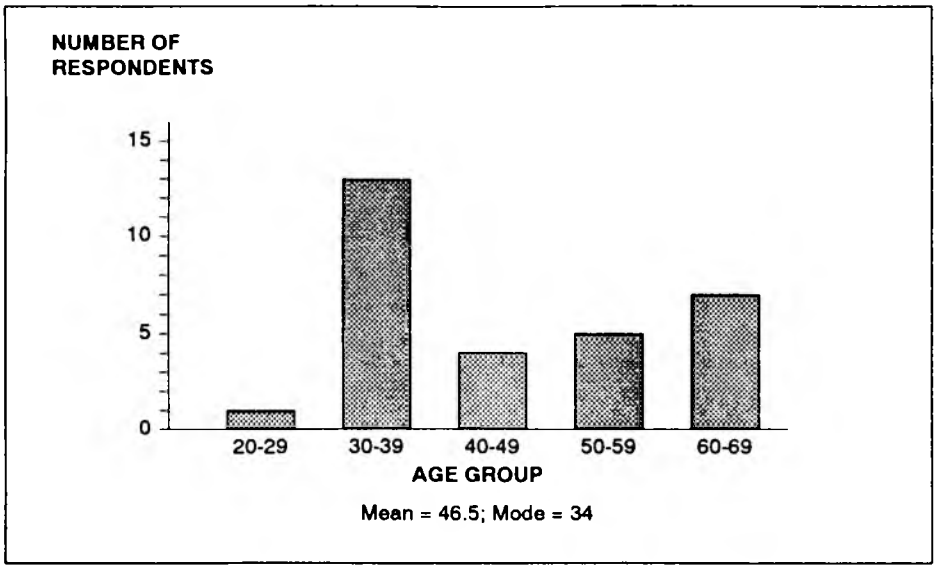

Figure 1
Age on Admission (n=30)

Findings therefore indicate a failure in primary health education as well as a need for more explanation to women attending clinics and to patients undergoing therapy (Kahn *et al.*, 1987:92).

METHOD

A questionnaire was compiled to obtain information on the respondent's stage of disease on admission, reasons for late presentation, physical problems, beliefs, support and input from health professionals. The instrument was tested for face validity and pilot tested by interviewing five patients.

In order to overcome language problems the questionnaires were completed by black professional nurses who had been briefed beforehand. These nurses were lecturers in the Nursing Science Department and a B Cur (I et A) student at Medunsa as well as an oncology nurse at the Ga-Rankuwa Hospital.

The convenience sample for this descriptive survey comprised thirty hospitalised patients suffering from cancer of the cervix. The respondents received radio- and chemotherapy and were in different stages of their five week hospitalisation period. Permission was obtained for each interview which lasted approximately twenty minutes. Due to the busy schedules of the fieldworkers, the patients selected were all those who were in the wards at times convenient for the fieldworkers. The study was carried out during the period December 1987 to March 1988.

Responses to the questionnaires were computer-analysed by the Department of Biostatistics of the Medical Research Council.

RESULTS

Demographic data

* The peak incidence of cervical carcinoma (Fig.1) was in the 30 to 39 year age group with a mean of 34 years. This is at least 10 years younger than findings of international studies (Angell & Riche, 1981:568).
* All the patients had children, the number ranging from 2 to 13. Although the mean number was 5,1 the majority (63%) of the sample had 2 to 4 children.
* The average annual income per family was low (R5 132).

Unfortunately the number of dependants per family is not known.

Stage of cancer on admission

It was found that the majority of the respondents (83,3%) had cancer in an advanced stage i.e. Stages 2 and 3 on admission (Fig. 2). Surgery was performed on only 6,7% of the respondents.

Possible reasons for late presentation for treatment

* The main reasons given for seeking medical help (Table 1) were vaginal discharge, bleeding and pain, the latter being a very late symptom. None of these patients had ever had a PAP smear taken as routine checkup.
* When asked to list the warning signs of cancer (Table 2) all the respondents obviously knew by then what vaginal bleeding and/or discharge meant. The second and third best-known signs were a lump in the breast and

TABLE 1
REASONS FOR SEEKING MEDICAL HELP (n=30)

REASONS	FREQUENCY	%
Vaginal discharge	25	83,3
Vaginal bleeding	23	76,7
Pain	15	50,0

TABLE 2
KNOWLEDGE OF WARNING SIGNS (n=30)

WARNING SIGNS	FREQUENCY	%
Unusual bleeding or discharge	30	100,0
Lump in breast or elsewhere	22	73,3
Indigestion or difficulty in swallowing	6	20,0
Nagging cough or hoarseness	3	10,0
Change in wart or mole	2	6,7
Change in bowel or bladder habits	1	3,3
A sore that does not heal	0	0

TABLE 3
RESPONDENTS' BELIEFS ABOUT THE SEQUELAE OF THEIR DISEASE

BELIEF	FREQUENCY	%
Coitus will be painful	19	63,3
Will bleed after coitus	16	53,3
Husband will reject her	15	50,0
Will not be able to have intercourse	13	43,3
Will loose sexuality	10	33,3
If menses stops, blood will go to head	3	10,0

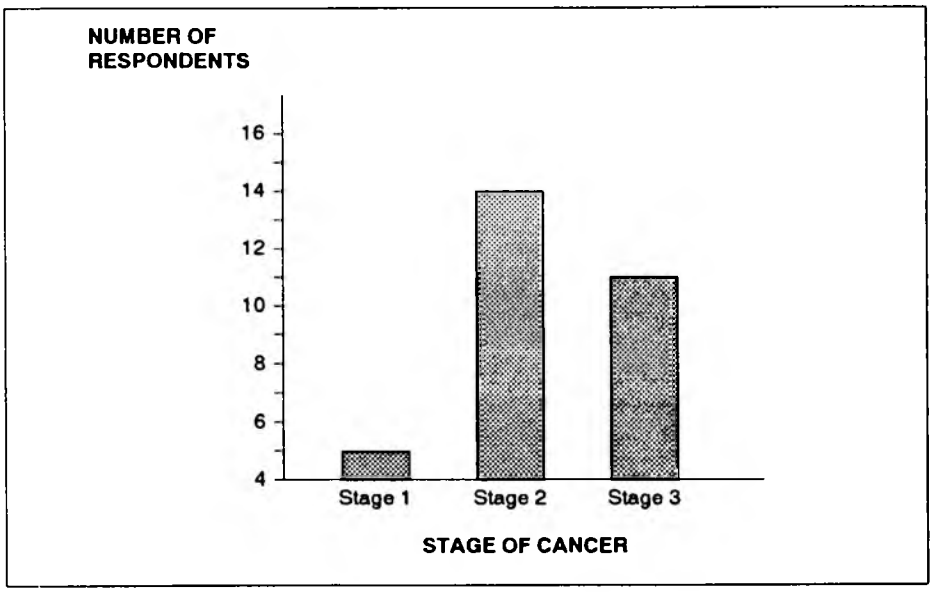

Figure 2
Stage of Cancer on Admission

indigestion/dysphagia. These three warning signs are indicative of the three most prevalent cancers seen at the Ga-Rankuwa hospital. Knowledge of the other warning signs was very poor.

Physical problems experienced

* Ineffective pain control was experienced by only one respondent. Paracetamol and/or Mist TC (Morphine mixture) was taken by the majority of respondents at an average frequency of 9 to 12 hourly.
* The main physical problems experienced (Fig.3) were associated with the gastro-intestinal tract namely constipation, weight loss, nausea, vomiting and anorexia. The occurence of these problems was at least 3 times more frequent than any other problem.
* Other problems included foul-smelling discharge (50%) and urinary tract infection (13%).

Beliefs about sequelae of disease

Most of these beliefs were centered around marital relations (Table 3).

Support groups

In hospital 30% of the patients were supported by others suffering from cervical cancer.

Input of health workers

A comparison of the availability and input of health care workers regarding consultation and discussion of the disease appear in Fig. 4:

* As can be expected the doctor had the greatest input.
* The clinic nurse, available to 90% of the respondents, was only consulted by 3% of the respondents before hospitalisation.
* Social workers made almost no input (6,7%) although they were available to 60% of the respondents.
* The traditional healer was available to 97% of the respondents.
* Although traditional healers discussed cancer with only 3% of the respondents (Fig. 4), 46,7% visited and took medicine prescribed by a traditional healer. The mean number of such visits was 1,3.

Media for health education

* Mass media are available to most respondents but seems to be underutilised (Fig.5):

  Seventy-seven percent of the respondents were literate but only 23% had seen literature in the form of brochures on cancer.

  All the respondents listen to the radio frequently but no regular cancer-education programmes on cancer are being broadcast.
* A telephone is available to all but 3,3% (Fig.6).

CONCLUSIONS

From the data analysis the following needs were identified:-

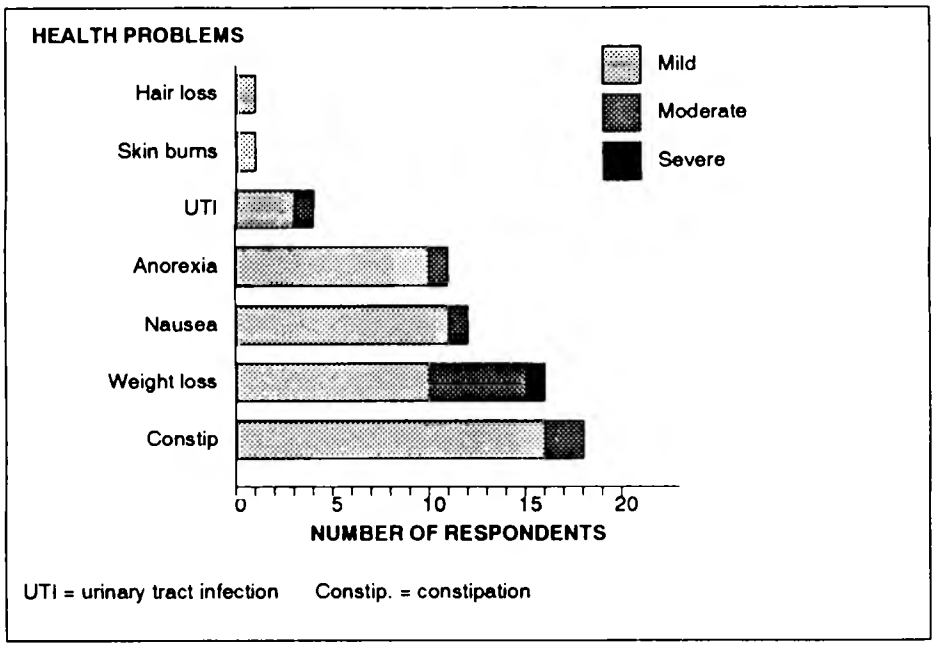

Figure 3
Health Problems

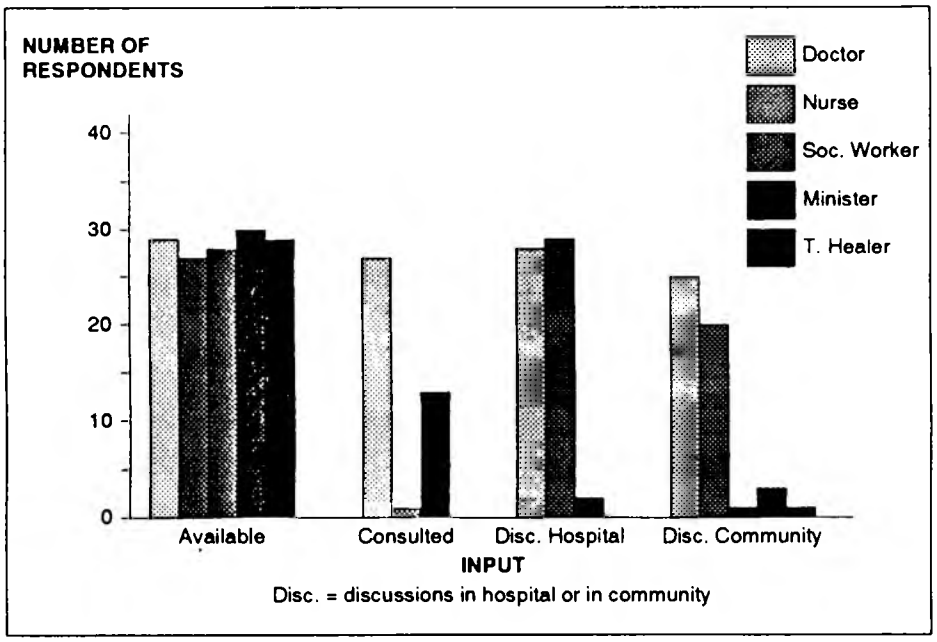

Figure 4
Input of Health Workers

- Health education to the public on early detection of cancer
- Motivation for regular checkups and PAP smears
- Education of patients suffering from cervical cancer on:

  – nutrition as the occurence of problems associated with the gastro-intestinal tract was at least 3 times more frequent than any other problem.

  – hygiene since it could alleviate the foul-smelling discharge and urinary tract infection experienced

  – pain control. Although 96% of respondents reported that their pain was effectively controlled one must bear in mind that black patients have a different perspective on pain and do not complain easily.
- Guidance by social workers to help alleviate the financial implications of the disease.
- Counselling and information on what to expect of marital relations since uncertainty gives rise to misconceptions and anxiety.
- The data revealed resources which could be utilised to meet the disease related needs:

  – the traditional healer still plays a major role in African culture and is readily available.

  – mass media are available to the majority of respondents but are underutilised for educational purposes.

  – a telephone is available to all but 3,3% which implies that counselling and referrals in some instances could be done without the inconvenience and cost of travelling.

RECOMMENDATIONS

In the light of the findings nurses could undertake the following actions to meet the identified needs of cervical cancer patients:-

Health education to the public

- The importance of early detection and treatment should be emphazised. Printed information on warning signs of cancer is available from the National Cancer Association. These are easily obtained and can be distributed and further explained at clinics.
- Education on cancer prevention and detection through the mass media should be encouraged since all the respondents listen to the radio and most (77%) are literate.
- Health education should not only be given but also critically evaluated by testing the comprehension of the public (McInerney, 1988:28).

Motivate women over the age of 25 years to have a Pap smear taken annually.

Unfortunately a national screening programme in South Africa does not exist although it has been advocated since 1982 as an urgent priority in order to reduce the enormous cost of treatment of an advanced malignant disease which potentially is preventable (Gordon Grant, 1982:821). Since the scope of nursing practice includes physical assessments and Pap smears the question arises as to reasons why existing clinic facilities cannot be extended to provide for cancer screening.

Nurses should be involved in the planning and implemention of such a programme (McInerney, 1988:29).

Education of patients

Patients who experience health problems as reported above should be guided on nutrition and hygiene. Patients may be counselled to rule out misconceptions about their disease.

Initiate support groups made up of women suffering from cervical cancer.

Patients can be referred to their nearest clinic after being discharged and group meetings/visits can be arranged or co-ordinated by the clinic sister or a contact person.

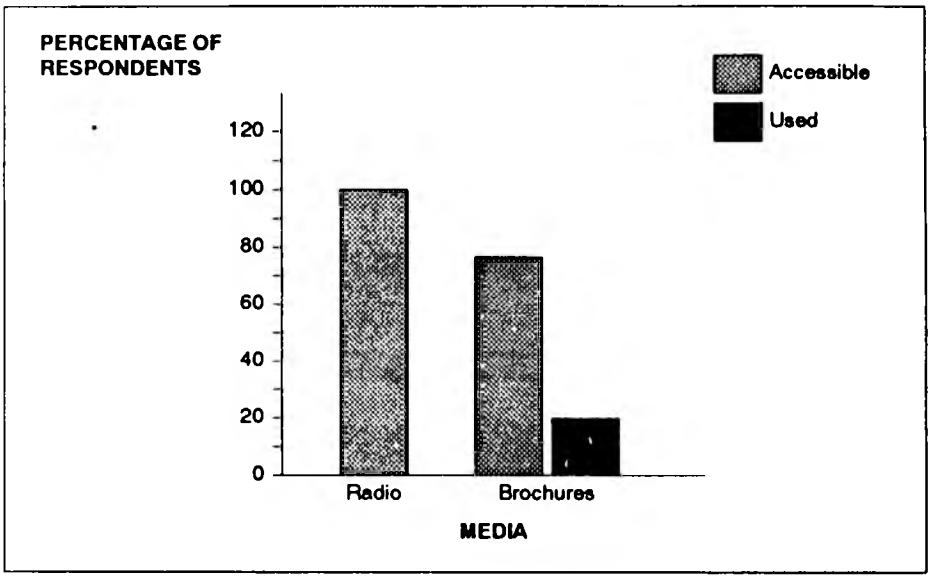

Figure 5
Mass Media for Health Education

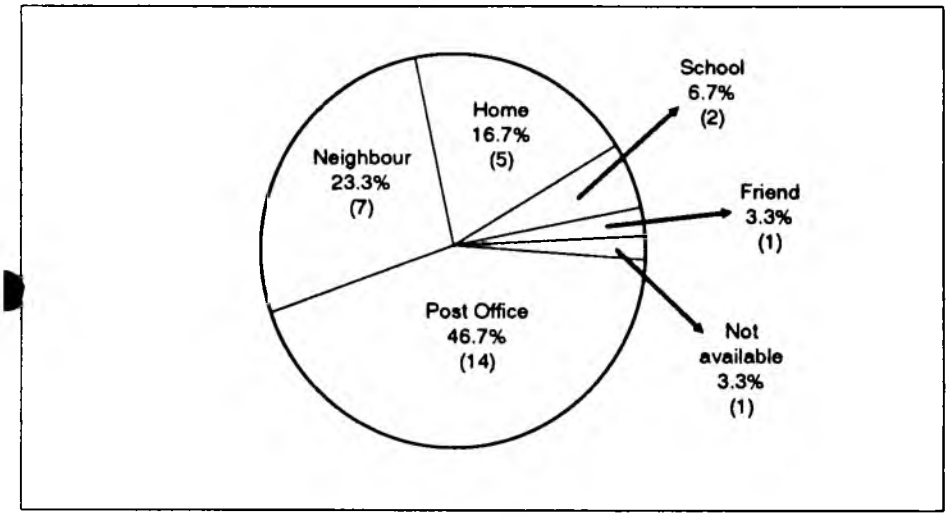

Figure 6
Availability of Telephone

Nurses have the responsibility to refer patients to social workers who are able to play an active role in alleviating social and financial problems related to travel subsidies and disability pensions.

Such advice may relieve the financial burden caused by the disease Nurses should verify whether patients are aware of and know how to apply for disability pensions and subsidised transport.

Co-operation with traditional healers might be obtained.

If they were given information on health education and cancer prevention they could serve as a valuable source of information to their clients.

Telephone Information Service.

A telephone information service should be initiated in order to counsel and refer patients which could in some instances prevent the inconvenience and cost of travelling.

BIBLIOGRAPHY

ANGELL, M.A. AND RIGHE, J.R. 1981. Basic Pathology. Toronto: W B Saunders.

ARIEL, I.M. AND CLEARY, J.B. 1987. Breast Cancer. New York: McGraw-Hill.

BUTCHER, J. (Ed.) 1987. Breaking the silence on cancer. London: BACUP

CANCER REGISTRY OF SOUTH AFRICA. 1986. Johannesburg: SAIMR

GORDON GRANT, M.C. 1982. Carcinoma of the cervix - a tragic disease in South Africa. *South African Medical Journal*, 61:819-822.

McINERNEY, P. 1988. Cervical intraepithelial neoplasia - its prevention and the role of the nurse. *Nursing RSA*, 3(2), 26-29.

KAHN, H., BERELOWITZ, L., BORODA, A., CHIMES, M., GARDNER, S., GORDON, B., MANOIM, T., MIRMAN, R., SMITH, R., AND LEIMAN, G. 1987. Knowledge of and attitudes toward cancer of the cervix in Johannesburg women. *The Southern African Journal of Epidemiology and Infection*. 3:89-92.

SEARLE, C. The problem of establishing early detection programmes in developing countries. *Nursing RSA*, 1(10). November 1986:4.

VAN RENSBURG, H.C.J. Die aard en die tradisionele, nie-Westerse of stammedisyne in Suid-Afrika. *Curationis*, 4(2), September 1981.

WARFIELD, C.A. Pharmacologic Treatment of Cancer Pain. *Hospital Practice*, October 1987:93.

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