

An investigation into the causes of absconding among black African breast cancer patients

Sonya Vivien Wright

Objective. To discuss the complexities facing the researcher in attempting to determine reasons for the high rate of absconding from biomedical treatments by black African women diagnosed with breast cancer.

Design. Qualitative study based on in-depth interviews and participant observations of the informants, to ascertain attitudes, beliefs and practices of black African breast cancer patients with regard to the choice of healer.

Participants. 10 black breast cancer patients, 4 African indigenous healers, 4 black lay persons, and 8 Groote Schuur Hospital members.

Setting. Radiation Oncology Department, Groote Schuur Hospital, Cape Town.

Results. The study revealed that various determinants affect black women's decision to abscond from biomedical breast cancer treatments. These determinants were based on social and cultural peculiarities. However, these findings did not explain the difference in absconding rates between black cervical (30%) and breast cancer (80%) patients. Although the two patient groups shared social, economic, and cultural backgrounds, their decisions with regard to biomedical treatments of cancer were remarkably different.

Conclusions. The methods chosen for the research project provided a framework for a qualitative study of one ethnic group of breast cancer patients. However, the research framework failed to allow comparisons between breast and cervical cancer patients from the same ethnic backgrounds. Therefore, although the research findings revealed determinants affecting black breast cancer treatments, they do not explain the discrepancy between absconding rates of black cervical and breast cancer patients.

S Afr Med J 1997; **87**: 1540-1543.

Late presentation is a major problem in the treatment of breast cancer. In South Africa this problem is particularly pronounced among black African women, and has resulted in a poor prognosis for these patients.¹ The additional problem of absconding — failure to return to hospital to

complete treatment — has been noted at Groote Schuur Hospital and deemed worthy of further investigation.

For the period 1991 - 1995, the comparative absconding rates for the three main categories of breast cancer patients at the Radiation Oncology Department of Groote Schuur Hospital revealed significant differences.

It should be emphasised that, as far as could be ascertained from hospital records and staff, the majority of the 'white' and 'coloured' patients who 'abscond' from Groote Schuur Hospital are usually opting for further biomedical treatment in the private sector. By contrast, the vast majority of black patients generally lack the resources to continue biomedical treatment unless they remain at Groote Schuur Hospital. The information collected in this study further supports the hypothesis that absconding by black breast cancer patients seems to represent a preference for alternative (indigenous African) healing options.

South African state hospitals currently routinely collect patients' 'race' classification (following the standard Population Registration Act of 1950's categorisations²). This paper adheres to the above categorisation because it highlights a major difference within the population of the patients. As a generalisation, the population under discussion can be typified as for the most part Xhosa-speaking, working class or unemployed, poor, having significant ties with the rural areas, with limited years of formal schooling, and with some understanding of traditional African health systems.³

This description applies to the black women interviewed for this study and therefore does not necessarily apply to all other black breast cancer patients at Groote Schuur Hospital.

Methods

A qualitative research approach was adopted. This primarily involved in-depth interviews with patients and health workers, and participant observations of patient/healer interactions, the hospital setting and the patients' home settings. A primary intention of the interviews was to explore the meanings that govern various patients' attitudes, beliefs and practices regarding a specific illness.⁴

Interviews were semi-structured and open-ended. Care was taken to encourage informants to discuss their understanding of disease, especially breast cancer and associated treatments, as well as to elicit their own understanding of the phenomenon of absconding.

Participant observation sought to elicit insight into the content of various hospital staff/patient interactions, and to note the patients' concerns that arose during these interactions.

A brief analysis of the hospital's medical files of breast cancer patients, for the years 1991 - 1995, was also conducted, in order to note any obvious demographic differences between those black African patients who absconded and those who did not.

A major research problem occurred in trying to locate absconding black African breast cancer patients. This difficulty was primarily due to the small number of such patients seen each year at Groote Schuur Hospital, the fluid nature of many black women's lives, and the reluctance of

101 Second Avenue, Claremont, Cape Town

Sonya Vivien Wright, MA (Social Anthropology)

family members to reveal a patient's place of residence. (An average of 30 black women per annum are seen at the Radiation Oncology Department of Groote Schuur Hospital (Table I)). However, the informants were eventually located through actual contact at the hospital and through word-of-mouth referrals. By the end of the research period, a total of 10 black breast cancer patients had been accessed. (This figure represents approximately 32% of all black breast cancer patients diagnosed annually at Groote Schuur Hospital.)

Table I. Black African breast cancer patients diagnosed at Groote Schuur Hospital, 1991 - 1995

Year	Complied	Presumed dead	Absconded	Total
1991	2	10	20	32
1992	1	6	22	29
1993	2	3	25	30
1994	0	0	29	29
1995	5	2	37	44
Totals	10	21	133	164

*Presumed dead' is a category extrapolated from the medical files and therefore does not represent exact figures of patients who have died.

The bulk of the research effort focused on conducting interviews with: (i) 4 black breast cancer patients who had absconded, 3 who were complying with biomedical treatments (2 of these had used some form of indigenous medicines as well), and 3 recently diagnosed patients who said they would be accepting biomedical treatments; (ii) 4 indigenous black African healers; (iii) 4 black African laypersons; and (iv) 6 biomedical cancer professionals.

The empirical research took place between July 1995 and January 1996. The interviews were conducted at Groote Schuur Hospital or in the homes of the informants. All but one of the interviews were conducted in English. (In this case a young woman served as a translator for her mother.)

In order to minimise possible communication obstacles between the interviewer and interviewee (there were differences in language and culture), the interviewee chose meeting venues, times, who was to attend, the frequency of such meetings and the language in which she responded to questions. Despite such measures being taken by the researcher, certain limitations in discussion topics did arise, such as issues pertaining to sexuality and femininity, and the impact breast cancer had on these dimensions of the interviewee's lifestyle and treatment options.

Research

The results of the research suggest that the patients' decisions about their choice of breast cancer treatment are complex and multifaceted. Their decisions rest on the weighing up of the costs and benefits of each option, and are premised on answers to questions such as the following:

What are my chances of being cured by biomedical/indigenous African treatments? Do I know of people who have been cured of cancer by biomedical/indigenous African treatments? Does the biomedical/African healer's understanding of breast cancer make sense to me? How will the treatments affect my body and how will those effects

impact on my relationship with my partner? Will my decision be supported by significant others? Who will take care of me when I am ill? Who will take care of my children should I die?

In the light of such questions, the following factors were identified as reasons for most of the black breast cancer patients' absconding from biomedical treatments in favour of indigenous African treatments:

Black informants' understanding of breast cancer.

Although there were differences in the details provided by various informants, there was remarkable consistency in the absconding patients', indigenous healers' and black lay persons' understanding of the causes and treatments of breast cancer. It was explained that cancer patients are believed to have been 'sent' cancer by an angry or jealous person. This enemy commissioned an 'evil sangoma' (sorcerer) to poison the patient with the cancer, by putting it in her food, taking it to her while she slept, or leaving it on the ground for the patient to walk over. Once the poison entered the body it moved to a specific area (in this case the breast). Unless the cancer is drawn from the body through special *imbizas* (indigenous African medicines), it eventually kills the patient. In anthropological literature an 'evil sangoma' is referred to as a sorcerer. Sorcerers are defined as those people who use secret combinations of certain physical substances, such as herbs and animal parts, to cause mischief. In the present example of the causes of breast cancer, anthropologists therefore interpret the black African informants' description of an 'evil sangoma' to be that of a sorcerer.⁵

The patients and indigenous healers explained that black healers provided the patient with *imbiza* to drink. The consumption of these medicines continued until the cancer began to 'come out' of the body — in the form of an open and painful wound on the breast. The wound is believed to signify the final healing stages of the cancer. The *imbizas* 'push' the cancer out and the topically applied medicines treat the cancer from the outside by 'pulling' or drawing the poison out of the body. The combination of 'pushing' and 'pulling' medicines are continued until the wound has expelled all the poison (in the form of blood and pus) and the wound begins to heal and close. In many cases these treatments are accompanied by strict 'dry diets'. These diets are prescribed by the indigenous healers and forbid the consumption of meat, fats, alcohol and other 'wet' foods. Therefore, only 'dry' foodstuffs, such as *stywe mielie pap* (stiff maize porridge) were allowed. In some cases patients were allowed to drink only *imbiza* while being treated by the indigenous healer.

The indigenous healer was seen as the only legitimate and successful healer of cancer because of his/her expert knowledge of the causes and cures of cancer. In contrast, the biomedical approaches to cancer treatment were viewed with suspicion, because they were believed to be based on an unsound knowledge of cancer. This unsound knowledge resulted in the doctors' administering inappropriate and harmful treatments to cancer patients. These 'inappropriate treatments' referred primarily to surgery and radiotherapy. Surgery was believed to cause the cancer to spread throughout the body, while radiotherapy scars the cancer, thereby rendering it impenetrable to *imbizas*.

The informants said that cancer was associated with social stigma because it was seen to represent the

unspoken social conflict and disturbances within the patient's community. They further argued that people remained secretive about the identity of cancer patients because of this stigma and because they wished to avoid drawing further attention to the social tensions that resulted in the poisoning of the cancer patient.

Two of the 3 black patients who had complied with biomedical treatments disputed the notion that cancer is 'sent' to one by evil sangomas. They agreed that those people who believed in such notions were superstitious; however, both admitted that they had used some form of indigenous treatments for their cancers. They explained that they felt desperate and therefore sought 'the best of both worlds'. Neither woman had a clear perspective on the causation and both argued that their cancers had been inherited. The third woman's understanding of cancer was similar to that of the group which had absconded. She explained that, although she was accepting chemotherapy from the hospital, she was not certain that she would continue the sessions. She was very sceptical of the usefulness of any form of surgery and said that she would continue to visit the hospital until her indigenous healer advised her to cease.

The final group, whose intention it was to undergo biomedical treatment, expressed scepticism about the competence of indigenous healers. Two of the women explained that their churches had actively discouraged them from seeking indigenous treatments, telling them instead to rely on the hospital and prayers to help cure them. The third woman from this group said that her aunt had died of breast cancer after consulting an indigenous healer and that she therefore did not trust their treatments.

The role of the therapy management group. Several of the black African informants explained that the breast cancer patient is not necessarily the key decision-maker with regard to therapy choices. The decision-making process is a collaborative one involving various family members. It was clear from the interviews that this therapy management group comprised kin, usually elder family members, who meet with the patient to discuss treatment options. This support group, which has been reported in many black African communities, is a coping mechanism whereby members provide mutual economic and emotional support.⁶ Although the urban-based groups are small (on average 5 - 10 members), the members rely heavily on the social ties that are created and carefully maintained through such groupings. Therefore, although the group's role is to advise the patient, there is generally implicit pressure to heed its advice, given the risk of severing the carefully maintained social and economic ties between the patient and the group. This pressure relates to the economic and emotional support that the group is equipped to provide for the patient. (This support is particularly necessary for breast cancer patients, who are likely to become unable to support their dependants in the terminal stages of the disease.) Furthermore, the important role played by older family members, who were conservative in their attitudes towards cancer treatments, meant that there was pressure on patients to seek treatment from indigenous healers and to avoid all biomedical treatments.

The therapy management groups of the 10 women interviewed were not identical in their composition. However, this alone did not account for the difference in the treatment

choices of each support group. Previous experiences with cancer in the family, the influence of church members, and the geographical distance of kin all contributed to the varying decisions taken by the therapy management groups.

Seven of the 10 women interviewed (4 women who had absconded, 2 who were complying with biomedical treatments, and 1 of the women who intended continuing with biomedical treatments) said that their groups comprised at least two older relatives (either a parent, uncle or aunt), siblings and cousins of a similar age to the patient and, in two cases, a daughter of the patient. Two of the 10 women (both of whom were intending to continue biomedical treatments) said that their support groups also comprised church members and leaders. These women said that their churches had implicitly advised them against seeking help from indigenous healers. One of the women, who was complying with the hospital treatments, said that she had not informed her family as they would expect her to return to Transkei for treatment. She had therefore decided to keep the diagnosis to herself and attempt to treat the cancer in Cape Town.

Two of the women who were complying with biomedical treatments said that their therapy management groups had decided that they should continue the treatments (chemotherapy and radiotherapy); however, there was dissent in the group regarding the usefulness of surgery. The third woman in this group — the one whose aunt had died 'because of the healer's *imbizas*' — said that her family supported her decision to accept the hospital's treatments because they were sceptical of indigenous healers' ability to cure cancer.

Patients' experiences of the hospital setting and biomedical treatments. Seven of the women interviewed (those who had absconded and the compliant group), as well as the indigenous healers, and black lay persons, expressed various fears of biomedical institutions. The women who had absconded, indigenous healers and black lay persons argued that biomedical cancer treatments, such as surgery, are harmful practices and cause the cancer to spread throughout the body, eventually killing the patient. Interference with the cancer, in some cases even a needle biopsy, was believed seriously to hinder the efficacy of indigenous remedies. They also expressed fear of radiotherapy which was believed to scar and 'cover' the cancer so that indigenous medicines were unable to enter the cancer and thus rendered ineffective. However, some of the informants (including two of the indigenous healers) argued that chemotherapy was an acceptable procedure because it 'cooled down the poison and made it smaller' before traditional treatments were used to draw the cancer out of the body.

Two of the patients cited unpleasant incidents with junior and technical staff members as further reasons for absconding. Three of the black lay persons offered unpleasant experiences at the hospital as reasons for patients' absconding. In general, these incidents were not specific to the Radiation Oncology Department, but occurred in various areas of the hospital. Informants reported that some staff members were patronising and were curt to patients who failed to understand instructions or questions by such staff. One reported episode involved a technician who attempted to frighten a patient by telling her of the harmful experiments that the doctors were intending

to perform on her body. None of the patients who described such incidents during the research had reported them to senior hospital staff.

The patient/doctor interactions observed by the researcher were amicable. As a rule the doctors took care to try to explain their understandings of cancer to the patients and to be sensitive to patients' needs and concerns. However, some were unavoidably hindered by the mutual misunderstandings arising from the participants' opposing cancer models and from language problems. For instance, despite the hospital staff's explanations, many of the black patients did not see a link between a painless breast lump and a potentially life-threatening disease. The participants' opposing cancer models resulted in further misunderstandings because of the language problems. Therefore, in many cases, neither of the participants was able to communicate clearly to the other their beliefs about breast lumps and the treatments thereof.

Adopting the 'sick role'. All of the women interviewed mentioned the economic and social expense of adopting the sick role. They explained that the impetus to adopt the sick role was frequently hindered by a reluctance to lose working hours, to pay for child-minders and public transport, to be labelled an invalid and to risk social stigmatisation. Many of the informants admitted that they had initially chosen to hide their cancer rather than experience the above difficulties associated with becoming a 'breast cancer patient'. The hospital staff argued that many black breast cancer patients only consulted a healer once the initially painless lump began to interfere with daily living, e.g. it became painful, partners noticed and commented on the lump, or there was pressure from family to seek help. This tendency to ignore the lump for long periods of time results in the familiar phenomenon of late presentation of black patients to biomedical institutions.⁷

The costs mentioned by women included both social and economic expenses. The social costs are difficult to define but were related primarily to the social stigma and loss of independence that accompanied public knowledge of the diagnosis of breast cancer. The economic costs included transport fares, loss of work hours and child-minding payments. The black lay persons and the interviewees who had absconded said that visiting a biomedical cancer clinic was a public occasion, whereas a visit to an indigenous African healer did not necessarily reveal the patient's diagnosis to others. They argued that the loss of privacy associated with biomedical institutions was often a motivating factor in a breast cancer patient's decision not to attend a public hospital's cancer ward.

Discussion

The findings of the research project indicate that several factors contribute to the fact that over 80% of black breast cancer patients decide to abscond from biomedical treatments. These factors serve to demonstrate the complexity of the problem of absconding and also to illustrate the logic of black breast cancer patients' decision to abscond. Many of the patients' models of breast cancer differ fundamentally from those of the biomedical practitioners, which are perceived by patients as both

unfamiliar and harmful. The pressure from some patients' generally conservative therapy management groups to accept only indigenous treatments is further strengthened by many of the patients' dependence on family for both economic and emotional support.

Notwithstanding these pressures, it has to be acknowledged that some black cancer patients (Table I) do choose to comply with biomedical treatments. This highlights the dangers of assuming that all black women are locked into a 'traditional' or 'superstitious' framework. However, even the 6% compliance rate of black breast cancer patients (Table II) needs to be viewed in relation to a larger sample of other black cancer patients who comply with biomedical treatments. Such comparison would facilitate further insight into black patients' treatment decisions about particular types of cancer.

Table II. Groote Schuur Hospital's breast cancer patients who accepted hospital treatment (complied), 1991 - 1995 (%)

Population category	Complied	Absconded or private	Presumed dead
Black	6	81	12.8
Coloured	41.9	36	21.9
White	44.5	39	12

The research results presented here do not adequately account for black women who accept biomedical treatments, or for the fact that breast cancer in particular has such remarkably high absconding rates compared with other cancers. The research sample was limited by the small number of black breast cancer patients who attend Groote Schuur Hospital's Radiation Oncology Department, and by the researcher's specific focus on breast cancer patients. Therefore the results arising from this research need to be corroborated by a bigger sample involving cancer units from other South African hospitals.

Further research also needs to be conducted into the specifics of breast cancer in order to explain the differences of absconding rates across different cancers. Such research should focus on the specifics of breast cancer treatments, e.g. the types of treatments most frequently recommended to breast cancer patients, the patients' experience of these treatments, and how breast cancer relates to black women's notions of femininity and sexuality.

I would like to acknowledge the invaluable role that the staff of Groote Schuur Hospital's Radiation Oncology Department played in facilitating this research. I also thank Emile Boonzaier for his guidance in the formulation of this manuscript.

REFERENCES

- Hacking A, Gudgeon A, Lubelwana K. Breast cancer in Xhosa women — a management challenge. *CME* 1988; 6: 57-62.
- West M. Confusing categories: Population groups, national states and citizenship. In: Boonzaier E, Sharp J, eds. *South African Keywords: The Uses and Abuses of Political Concepts*. Cape Town: David Philip, 1988: 100-110.
- Hammond-Tooke D. African worldview and its relevance for psychiatry. *Psychologica Africana* 1975; 16: 25-32.
- Helman C. *Culture, Health and Illness: An Introduction for Health Professionals*. Oxford: Butterworth-Heinemann, 1994.
- Mair L. *Witchcraft*. London: World University Library, 1969: 7-32.
- Janzen JM. *The Quest for Therapy: Medical Pluralisms in Lower Zaire*. California: University of California Press, 1982.
- Du Toit JP. Carcinoma of the cervix in South Africa. *Nursing RSA* 1987; 2: 43-45.

Accepted 2 Feb 1997.