THE PROBLEM OF NON-COMPLIANCE AMONGST BREAST CANCER PATIENTS:
A study of the high rate of absconding by African women diagnosed as having breast cancer

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ABSTRACT

"Ill people make choices...between diagnoses and advice that make sense to them and those that do not. In the latter case the result may be 'non-compliance', or a shift to another part of the therapeutic network"

(Helman, 1994: 85)

In South Africa at present, one in 32 women develop breast cancer during their lives. Breast cancer is the second most common cancer among females. The biomedical prognosis for breast cancer patients is good provided that the cancer is detected early and that patients comply to biomedical treatments. However, over 80% of African breast cancer patients abscond from the Oncology and Radiotherapy Departments at Groote Schuur Hospital each year. These patients are usually only seen again in the terminal stages, when they seek pain control from the hospital.

The biomedical literature refers to this phenomenon of absconding but does not explore the cultural and social factors that may determine African women's decision to abscond. This study looks at the variables effecting absconding, by focusing on the cultural, social and economic contexts, in which African breast cancer patients choose to abscond from biomedical treatments.

The research was conducted within the methodological framework of social anthropology. The methods used were primarily qualitative in nature and included participant observation and in-depth interviews. These methods produced information on the meanings that govern the informants' perceptions of, and reaction to, incidence, such as the diagnosis of breast cancer. The methods also produced information about the decision-making processes of African breast cancer patients. The Oncology and Radiotherapy Departments' files were analysed to generate some quantitative data regarding the rates of absconding.

The main findings of the research* were that an African breast cancer patient's decision, regarding absconding from Groote Schuur Hospital, was almost always determined by her therapy-management group. The patient's heeding of their decisions rested on her
social and economic commitments to the members. It also rested on the patient's economic ability to adopt the sick role.

It was found that African breast cancer patients' explanatory models of cancer saw traditional healers as the most appropriate cancer 'treaters', whereas the hospital was considered useful only for certain functions. Thus the pluralist approach of therapy-seeking behaviour resulted in patients' absconding from hospital treatments that they did not consider safe in terms of their explanatory cancer models. The patients' mistrust of biomedical cancer treatments was further exacerbated by their frustration with the communication difficulties experienced during doctor / patient consultations.

This report will provide the Oncology and Radiotherapy Departments at Groote Schuur Hospital with further understanding of the social and cultural contexts, in which African breast cancer patients chose to abscond. The report will also provide recommendations for changes in the biomedical practitioners' approach to, and treatment of, African breast cancer patients.

*note: these findings are based exclusively on the interviews and contacts with specific informants that occurred during the period of this research project. The findings are thus not necessarily generalisable to other individuals or groups, outside of the researcher's specified informant group.*
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CONSIDERATIONS AND REFLECTIONS ON "BEING THERE":
A discussion paper on the experiences of medical anthropological fieldwork
CHAPTER ONE: THE INTRODUCTION

1.1. The brief

The brief for this project, formulated by the Oncology and Radiotherapy Departments at Groote Schuur Hospital, was to investigate why most African patients diagnosed with breast cancer failed to return to the hospital for treatment (see Appendix 1).

1.2. The problem

Patients' failure to return to the hospital for treatment (hereafter referred to as "absconding") is reported to be a common problem in many of the hospital's departments, but it is particularly pronounced amongst breast cancer patients.

Further, the problem of absconding breast cancer patients is associated with African* patients in particular. Absconding in this context refers exclusively to patients who reject biomedical treatment from the hospital, and instead chose to consult traditional healers. These patients may initially accept some forms of medical treatments but are primarily treated by non-biomedical healers. The incidence of such absconding by "coloured" and "white" breast cancer patients is negligible. It is generally assumed that the patients from these two groups who do seek treatment outside of the hospital, invariably choose to consult private biomedical practitioners.

*Groote Schuur Hospital categorise their patients according to three racial groupings: "black", "coloured" and "white". This reflects the categories documented in the Population Registration Act of 1950, as amended (West, 1989). The distinction of the three groups enables the hospital to engage in comparative research studies and examinations of diseases. Therefore, for the purpose of this research project, the researcher has chosen to use the established categories. The researcher, however, has chosen to use the term "African" instead of "black", as this denotes more accurately the group that is being studied (see Wilson and Ramphele, 1989). These choices do not reflect the researcher's acceptance or condonement of the categorisation of people on supposed racial divisions.
Over 80% of African breast cancer patients abscond from the Oncology and Radiotherapy Departments. Comparative figures show that the absconding rate for African patients is almost three times higher than for the two other population groups. It is noted that amongst the other two groups, the patients who are recorded as turning down treatment from the hospital, have chosen instead to consult private biomedical practitioners, thereby remaining in the biomedical therapy field (see tables 1-6).

1.3. **Possible causes of absconding**

The following suggestions were mooted by the Oncology and Radiotherapy Departments as possible causes of absconding of African breast cancer patients:

i) Many African patients are afraid of hospitals and do not understand the biomedical treatments these institutes offer them.

ii) African patients therefore tend to chose to consult traditional healers because they are familiar with their practices.

iii) African patients return to the Transkei for treatment when they are sick or dying.
1.4. **Research objectives**

To fulfil the requirements of the brief, the following research objectives were identified:

1.4.1. Conduct qualitative research to generate information on the knowledge, attitudes and perceptions of the African informants, focusing on:

1.4.1.1. *Traditional healers'*:
   i) explanations of breast cancer
   ii) treatments of breast cancer
   iii) attitudes to Groote Schuur Hospital's biomedical approach to breast cancer

1.4.1.2. *Lay persons'*:
   i) perceptions and understandings of breast cancer
   ii) attitudes towards both the biomedical treatments and the traditional healers' treatments.

1.4.2. Investigate the cultural and social factors that cause African breast cancer patients to abscond from hospital treatment:

   i) African patients' pluralist approach to seeking treatments from various practitioners, including biomedical and non-biomedical healers.

1.4.3. Provide the Oncology and Radiotherapy Departments with recommendations regarding their approach to African breast cancer patients.
1.5. Literature review

The undertaking of this empirical research project required an understanding of both the biomedical and the cultural contexts in which the phenomenon of absconding occurs*. The following section highlights:

i) the current concerns within the biomedical field regarding the provision of treatment appropriate to African breast cancer patients, and

ii) the need for further research into the cultural and social factors resulting in the absconding of most African breast cancer patients.

1.5.1. Biomedical literature on cancer

1.5.1.1. Biological issues: there is much biomedical literature on breast cancer which deals predominantly with the biological indicators and implications of breast cancer (see D'orsi and Wilson, 1983; Hacking, 1994; Harris, 1991; Stoll, 1986).

1.5.1.2. Psychological issues: there is also literature that focuses on the emotional and psychological effects of breast cancer, on both patients and their families, these works focus on European and American case studies (see Forsen, 1989; and Gyllenskold, 1982).

* note: the use of generalisations about African beliefs in many of the works discussed in this section, have been noted and considered by the researcher. However, for the purposes of providing the reader with a broad overview of African cultural and social contexts, the researcher has deemed it useful to include such works. The reader is requested to view the section in light of the above.
1.5.1.3. **Sociological issues:** some of the current literature does acknowledge that cultural and social peculiarities play a determining role in the rate of absconding of certain population groups (see Blumberg et al., 1991; Hacking et al., 1988; and Mahoko, 1993). As Shapero (1980: xi) notes:

"Breast cancer is not necessarily the same disease in each patient...
Therefore, the same treatment is not necessarily best for each patient"

Gifford (1991) argues that biomedical practitioners need to realise that patients have knowledge about illnesses and that their breast cancer is bounded within their particular cultural and social framework. This framework provides a logic within which the patient can understand and treat her disease. Gifford argues that once biomedical practitioners are made more aware of the peculiarities of the patient's cultural understandings and explanations of breast cancer, they will be better equipped to offer their patients more culturally and socially appropriate treatments. This awareness would result from research into the cultural and social concepts of the breast cancer patients.

Although the above works do not explore the cultural and social dimensions influencing African breast cancer patients' decisions to abscond, they do highlight the need for further research into these issues. This report will provide such information by discussing some of the variables that direct patients' decisions to abscond from biomedical cancer treatments.

The discussion of such cultural, social and economic variables needs first to be contextualised by explaining the terms and concepts that underlie and structure the informants' responses. An overview of anthropological literature will provide information into such concepts.
1.5.2. Cultural understandings of cancer

This research project is concerned with African breast cancer patients' cultural and social perceptions of their disease. In order to understand such perceptions, one needs to have some knowledge of the terms and cultural notions that underpin the informants' models of cancer.

1.5.2.1. Witchcraft

Many anthropologists have conducted research into the belief in witchcraft by African people (see Evans-Pritchard, 1950; Mair, 1969 and Turner, 1964). The generally held view is that witchcraft is a means by which ill fortune, both in the form of daily crises and unexpected disasters, is explained (Mair, 1969). It is through the belief in witchcraft that theories of causation are possible, thus enabling the victim of the misfortune to make sense of his/her situation. As Pradelles de Latour (1995: 608) explains:

"The victim projects the origin of this misfortune onto somebody else, whose identity is not yet known"

The basic belief in witchcraft and its ability to disrupt one's life is further evident in the belief that evil sangomas (sangomas are people vested with the skills to communicate with dead ancestors for advice and guidance) can cause one to fall ill due to poisoning with "bad medicine" (see Waldram, 1989).

In order to escape or reverse the "bad medicine" the victim needs to consult a sangoma who is capable of revealing the identity of the evil doer and sometimes offers treatment for the illness. In many cases, patients consult sangomas to find out the cause of their illness and then consult a traditional healer, who treats them with medicines made from closely guarded ingredients.
Although breast cancer is a biomedically defined disease, it is perceived differently by patients due predominantly to their specific cultural beliefs (Charez et al., 1995). Anthropologists would argue that although many women have breast cancer, they experience their illness differently depending on their explanatory models of illness, cancer, death and so forth. It is through these specific cultural models that the women create a logic regarding their status as cancer patients.

Therefore, if one hopes to understand African breast cancer patients' reactions to their diagnosis, one needs to view or at least be aware of, the cultural and social factors that shape the patient's experience of breast cancer (Singer, 1995).

1.5.2.2. Purgation: the need to draw out the illness

Numerous anthropological studies have documented the central role that purging plays in the healing processes of native patients (see Cavender and Beck, 1995; Janes, 1989; and Pigg, 1995). The practise of purging the body of the disease is a popular one and is based on the understanding that many illnesses are poisons inflicted upon the patient by a evil person. Therefore by vomiting, diarrhoea, poultices and so forth, the poison is physically extracted from the body. These extractions play a crucial role in many of the treatments administered by traditional healers and the physical expulsion of the poisons are viewed as the beginning stages of the recovery process of the patient.

This pre-occupation with purgation is often based on strong notions of pollution - in the case of breast cancer the pollution of the body and the soul by an external force (Beidelman, 1970). Amongst many African groups there are strictly enforced pollution taboos and cleansing rituals. These taboos are seen to protect members of the group from disruptive forces and actions that might threaten the security of the entire group. In the case of cancer, the cancer is seen as a pollutant that threatens to disrupt and even end the patient's life.
Helman argues that cancer is often associated with disturbed social relations and therefore represents social disorder. The cancer thus needs to be managed in a manner that will restore the equilibrium of the body and the society. Helman explains that cancer is widely perceived to be an evil poison that needs to be drawn out of the body.

This fear of an evil pollution, and the need to rid oneself of such a state, often guides the therapy-seeking behaviour of patients to consult healers who claim to be able to rid the body, in a safe and acceptable manner, of the pollutant or poison.

1.5.2.3. Medical pluralism

Many medical anthropologists discuss the frequency with which African people, and other native groups, engage in medical pluralism (see Cavender and Beck, 1995; DeSantis, 1989; and Pigg, 1995). Medical pluralism refers to the practice in which patients choose to consult several healers. These healers may be from biomedical or non-biomedical fields. The term "medical pluralism" usually refers to patients who accept treatments from both biomedical and non-biomedical healers in their quest for therapy. This notion of biomedical or healer pluralism, defies some researchers' wish to divide African patients into two neat groups: those who ascribe to biomedical practitioners' treatments and those who ascribe to traditional healers' treatments - and never the two shall meet. In reality African patients move between healers, seeking specific treatments for specific diseases and often combining the treatments of two or more healers (Saunders, 1975). Each type of healer is seen to have specialised knowledge in certain fields. These fields are often divided into those diseases that need special analysis by a sangoma and / or traditional healer, and those that are seen to be merely biological in nature and require a biomedical doctor's treatments.
African patients therefore consult many types of healers depending on the disease and the perceived efficacy of the treatments. Patients in the urban centres have a wide range of therapeutic options which they can manipulate according to their illness, their faith in the treatment options, their economic abilities, social pressures, and so forth (Boonzaier, 1983).

1.5.3. Social dimensions of illness

1.5.3.1. Group versus individual decision making processes

The notion of the individual is one that is peculiar to Western notions of identity and self. Many other cultural groups perceive identity to be chiefly about one's relationships and interactions with others, as the old African adage says "A man is a man through others". It is useful to understand this "communal" concept of identity when discussing breast cancer patients' decision-making processes. These women are seldom making decisions alone and instead are consulting with a group of kin to consider various treatment options.

The notion of the "therapy-management group" has been discussed by medical anthropologists attempting to explain the decision-making models used by many native patients (see Janzen, 1982; Helman, 1994, and DeSantis, 1989). DeSantis defines therapy-management groups, as consisting of:

"...individuals who become involved with and 'take charge' of the sick individual during an illness episode, participate in the diagnosis, selection and evaluation of the treatment regimen, and provide support to the sick individual"

DeSantis, 1989: 84.
DeSantis warns biomedical professionals that confining explanations and advice to the patient alone is often futile because s/he is only one component of the decision-making group. She suggests that a means to getting round this problem is for the biomedical professionals to include members of the therapy group in consultations and also to consider themselves as *a part* of the therapy-management group, and not *the* therapy-management group. DeSantis argues that by adopting this participatory approach, biomedical practitioners will be able to increase their effectiveness by making themselves more approachable to and integrated with the therapy groups.

Janzen (1982: 140) represents a typical therapy-management group's functioning in the following diagram:

```
    c
   /|
  a-|b
   | 
  
   d
```

*a* = patient  
*b* = therapy-management group  
*c* = biomedical practitioner  
*d* = traditional healer

He notes that there is no contact between the therapy group and the doctor, and the doctor and the traditional healer. He further argues that, although patients are working within a medically plural context, they are not engaged equally with the healers. Therefore he argues that biomedical practitioners need to actively involve themselves in the therapy-seeking behaviour of the group. This can be achieved by encouraging members of the therapy group to consult with the biomedical practitioner and by the practitioner
seeking further contact and dialogue with the appropriate traditional healer (Jansen, 1982: 140)

Janzen also argues that biomedical practitioners need to view their position as healers as only one aspect or consideration of the therapy group's quest for healing. He argues that by accepting that patients choose to consult and move between several rather than one healing model, the biomedical practitioner can modulate his/her approach accordingly, thereby providing more accessible treatments and therapy options. He explains that in order for the biomedical practitioners to continue / begin to play a significant role in the healing process, they need to attempt to understand and act upon the cultural and social theories that underpin peoples decision makings (Jansen, 1982: 223)
CHAPTER TWO: METHODS

In order to fulfil the brief's requirements the researcher needed to implement research methods that would produce qualitative data on African patients' understandings of and reactions to the diagnosis of breast cancer. The research was based on anthropological mores of fieldwork methods and thus sought to focus on qualitatively produced results (see Appendix 1 for a discussion on qualitatively generated research findings). An examination of the biomedical files and records was also used to generate the smaller amount of quantitative data collected during the research.

It was recognised that the research would not produce one or two definitive answers to the reasons for, and alleviation of, the high rate of absconding. Instead the research was intended to investigate and highlight the many different, yet frequently overlapping, cultural and social dimensions that create the 'culture of absconding' that the Oncology and Radiotherapy Departments are experiencing with over 80% of the African breast cancer patients. By exploring issues, such as, decision-making processes, the African patients' explanatory model of cancer, traditional healers' treatments of breast cancer, the pluralist model of therapy-seeking behaviour, and so forth, the researcher would be better equipped to present recommendations and suggestions that sought to highlight, and not hide, the complexities that make up the phenomenon of absconding.

To operationalise the above research objectives, the researcher engaged in participant observation, conducted in-depth interviews, and analysed breast cancer patients' medical files.

2.1. The rationale for the choice of methods

The discipline of social anthropology is based on the premise that, before one is able to understand others' behaviours, there first needs to be a comprehension of the meanings of, and the context in which, such behaviours
occur (Wood, 1995). It is the use of qualitative methods that provide the researcher with an opportunity to understand the cultural viewpoints of informants. These viewpoints are based on both the meanings that informants give to certain behaviours, and the position that the informants hold in the relevant context. Thus, it is qualitative methodologies that enable the researcher to explore the cultural relationship between observable behaviours and unobservable meanings (Helman, 1994).

2.2. The research methods

2.2.1. Participant observation

The empirical research period began at Groote Schuur Hospital. The researcher was granted permission to observe the various consultation sessions between the patients and hospital staff, and also those amongst the hospital staff members (these observation periods were primarily conducted during the Breast Clinic and the Combined Breast Clinic days).

Time was spent observing the interactions within the various areas where breast cancer patients are consulted or consulted about. These sites of observation included the passages in the Breast Clinics, the consultation rooms and the examination rooms. These periods of observation afforded the researcher the opportunity to familiarise herself with the hospital procedures that breast cancer patients are involved in. It also enabled her to interact freely with both patients and staff members in a space outside of the self-conscious interviewing context.

The researcher also attended meetings of a cancer information group that meets monthly and includes doctors, psychologists, social workers and St. Luke's Hospice volunteers.
2.2.2. In-depth interviews

The intention to investigate the many variables of absconding resulted in the researcher choosing to interview people from a broad selection of fields and with various experiences of breast cancer. This selection process enabled the researcher to explore themes from contrasting viewpoints and resulted thus, in a collection of data that is sourced not only from the patients themselves.

The researcher focused on three categories of African informants to interview about the phenomenon of absconding. The categories were African breast cancer patients, African lay persons who do not have breast cancer, and traditional healers. Staff members of the Oncology and Radiotherapy Departments were also interviewed. These informants included social workers, volunteers, nurses and doctors.

The majority of the interviews followed the format of semi-structured open-ended interviews which were based on a comprehensive checklist. By adopting this interview technique the collection of certain standardised data was ensured. However, this interviewing approach simultaneously alleviated the problems of inappropriate questioning and technique confinement, that strictly structured questionnaires often produce. This approach is useful when dealing with a sensitive topic, such as cancer, for it enables the interviewee to expand on issues that are particularly significant to him/her. It also boosted the interviewee's confidence in discussing issues that s/he felt were important to the research topic. The raising and discussion of such unforeseen issues frequently made valuable contributions to the research findings.

Some of the interviews did not take the above format. Such interviews were unstructured and informal, and were conducted with some of the Departments' personnel. These interviews frequently involved more than one informant and most often occurred during periods of participant observation.

The areas that the researcher sought to draw information on during the interviews, included the informant's notion of the causation of cancer, the
possibility of a cure, the choice of healer and his/her methods of healing, the informant's own or others' experiences (accounts) of breast cancer, their social or culturally determined taboos and attitudes towards breast cancer, their attitude to the hospital's approach to breast cancer, and so forth.

2.2.2.1. Informant profile

The African breast cancer informants were interviewed in their homes or at the hospital. The breast cancer patients were accessed through meeting them at the hospital during observation periods or via other informants. Except for one informant, whose daughter translated for her, the other informants were prepared to conduct the interviews in English (for further information regarding demographics and experiences of these informants, see the chapter on Findings).

A further lot of interviews with four African lay-persons were also conducted. These informants (one man and three women) had never been diagnosed with cancer and their views were based on experiences with, or stories of, cancer patients. The researcher had personal ties with these informants and the interviews were informal and open-ended. These interviews served to support the emerging themes that the semi-structured interviews with the breast cancer patients were producing.

Three traditional healers and one sangoma were also interviewed, as well as six members of the relevant Departments' hospital staff including volunteers (yellow ladies), social workers and nurses. Several informal discussions were held with the doctors during the research period at the hospital.

2.2.3. Analysis of the medical files

Although the research was primarily qualitatively oriented, time was also spent surveying the data in the files and records of all three of the patient groupings (1991 - 1995). These analyses were intended to elicit information on
the different demographic and behavioural patterns of the three patient groupings. It was felt that such differences between the three groups, and also between members of the same group, would indicate particular factors that could be determining the differing levels of absconding amongst the three patient groupings. Tables depicting figures and percentages generated by these analyses are recorded in the Tables 3 - 6.

2.3. Problems experienced in the implementation of the methods

2.3.1. Finding informants

The major problem experienced by the researcher was the difficulties associated with finding the absconded breast cancer patients. The hospital staff had also expressed their frustration in attempting to make contact with the African women who absconded.

The first factor that contributed to the difficulty was the small number of African breast cancer patients that Groote Schuur sees each year. On average, the Breast Clinics diagnose 30 African women a year (see Table 5). Thus the initial group from which informants could be sourced was limited.

The second factor that hindered accessing absconded breast cancer patients was the inadequate record of permanent addresses. Many of these women live transient lifestyles and are thus constantly changing location. Although the hospital files record patients' addresses, these are invariably not the permanent residencies of the African women.

The third factor is that many of these women keep their disease a secret from others. Thus access via word of mouth, is not necessarily a successful way to find such informants.
Despite these problems of access, the researcher conducted in-depth interviews with ten African breast cancer patients (this sample group is approximately 32% of the total number of African breast cancer patients that Groote Schuur Hospital sees annually, see Table 5). Four of these women had absconded, three were recently diagnosed and said they would be complying with hospital treatments, one was still undergoing treatment at the hospital, and two said they were combining hospital and traditional treatments. These women were sourced through a combination of referrals by mutual acquaintances, and via the contacts made between the researcher and patient at the hospital.

2.3.2. Analysing the medical files

The analysis of the medical files was intended to produce comparative information on the women who absconded and those who did not. However, due to the nature of the files such information was not readily available and so the researcher needed to surmise the patterns underlying some of the data.

Patients' booking date and last date of consultation at the hospital were recorded in the files, however these dates did not reveal the reasons for a patient who DNAs ("do not return" to the hospital for a booked consultation). Thus exact figures (especially with regard to the "coloured" and "white" patients) on the absconding rates, the rejection of hospital treatment in favour of private biomedical practitioners, and deaths, were not readily available. This resulted in tables (see Tables 3 - 6) that cannot claim to reflect exact percentages and statistical breakdowns.
CHAPTER THREE: FINDINGS

3.1. Introduction

Research into social behaviour does not focus on identifying a single cause for the behaviours under study. Instead, such research seeks to generate a range of variables, that can be shown to impact on the decisions that determine the social behaviour. Such variables include social and cultural elements and apply to the majority of the research population. However, they should not be seen to represent the attitude and perceptions of the entire grouping. The findings generated by this qualitative research reflect only those informants interviewed, and are not generalisable to all African breast cancer patients and traditional healers.

The biomedical staff of the Oncology and Radiotherapy Departments, mentioned several factors that they felt caused African breast cancer patients to abscond. The factors were the following: decision-making processes regarding cancer treatments, African women's' explanatory model of cancer, traditional healers' perceptions of cancer, and the breast cancer patient's attitude towards hospitals. These factors were later again echoed by other informants, and so, the researcher chose to use these points as the framework in which to discuss and explain the cultural and social factors that inform patients' decisions to abscond. The research revealed that factors frequently overlap, and in many cases it is a combination of the factors that results in patients' absconding.

The researcher ranked the themes in order of the frequency and weighting that both the patients and healers (biomedical and traditional) gave them. Close observation of patients' interactions with both their families and the hospital staff, confirmed the importance that patients and their kin ascribed to these dominant themes.
The recommendations, presented at the end of the report, are based on the issues that these findings highlighted. These recommendations are divided into two sections:

- recommendations for changes in the Oncology and Radiotherapy Departments' approach to African breast cancer patients
- areas and issues recommended for further research.

3.2. **Decision making: the individual and group**

"We will call a meeting to discuss treatments with her. We, her family, will decide for our mother"

Patricia*, daughter of breast cancer patient

This theme is one of the most useful to acknowledge and understand if one wants to get insight into how, why and when the African informants made decisions concerning the treatment of breast cancer. In brief, cancer was never simply represented as a disease affecting an individual patient. All the interviewed patients agreed that family meetings and consultations were regarded as an integral dimension of their decision-making processes. They said that in the case of illness, it is common (perhaps automatic) for a patient and her family to meet to discuss possible treatment options. These meetings usually included adult family members who were close to the patient both emotionally and geographically.

*note: all names referred to in the report are pseudonyms. The informants were assured of complete confidentiality and thus no record of their full names, addresses or other identifiable data has been recorded in this or any other document pertaining to this research.*
Such meetings may be called before the patient consults for diagnosis (whether that be at a biomedical institution or a traditional healer) but they were more frequently held once the patient had been diagnosed and needed to consider treatment options.

3.2.1. The social and cultural dynamics of decision making

Many of the African informants' families had strict age hierarchies that came into play particularly in moments of crisis, such as when the informant was diagnosed with breast cancer. When this occurred the elder members of the family asserted that it was both their right and responsibility to decide on the best treatment for the patient. The informants explained that these decisions were based on their explanatory models of illness which include fixed ideas of causation, treatment and the outcome of cancer. In these models cancer is caused by an enemy who pays an evil sangoma to poison one with the cancer (see section 3.3.: Traditional understandings and treatments of cancer). It was from this premise of understanding, that cancer is caused by malicious interfering, that traditional healers and/or sangomas were consulted for their expert knowledge in determining the identity of the perpetrator and ridding the patient of the poison. The followers of this model (the four women who absconded from hospital treatment) did not believe that a biomedical doctor is capable of healing the patient because s/he does not have sufficient knowledge of the causes and appropriate means by which to cure cancer.

The family meetings, in the form of therapy management groups, served to advise the patient on what treatments she should seek. Although the informants described them as ostensibly advisory in nature, there noted that there were frequently external factors which impacted on a patient's decision to heed the advice offered at such gatherings. These external factors usually rest on the economic circumstances of the patient. If the patient was economically
dependent on others (husband, partner, mother, uncle and so forth) then it was in her interest to agree to their suggestions, as she will invariably need both their economic and emotional support during her illness. One of the primary considerations that determined women's acceptance of other's advice, was whether or not she had dependent children, who would need caring for should she become very ill or die.

This composite decision-making was not practised exclusively with young patients, it was also a means of discussing treatment options for older patients. An example, is the case of 65 year old Thembisa, whose family (two daughters, son and an uncle) met to discuss treatment options with her (see the quote by her daughter at the beginning of this chapter). They decided that due to their previous experiences with biomedical treatments* they would not continue to consult the hospital. Instead they chose to consult a traditional healer who was reputed to be skilled at curing cancer. Thus, one can see that there was a great amount of responsibility placed on Thembisa's therapy-management group, for should the chosen treatment not cure or aid Thembisa, then the blame would be placed on the inappropriate decision-making of her kin members.

The exceptional case of Victoria however, indicates that not all the informants choose to inform their family of their cancer. Victoria, a well educated woman (she has two UNISA diplomas), living in the former Transkei, chose not to tell her family about her breast cancer.

* note: Patricia explained that two older members of her family had died of cancer because their therapy-management groups' had decided that the patients should undergo surgery at a hospital. She explained that there was much animosity between those decision makers and other members of the family who blamed the decision-makers, saying that they had "sent their parents to be killed by the surgery". Patricia said that she was worried that she and her family may make the wrong choice of treatment for her mother. She therefore felt that the choice of consulting a traditional healer was "safer" than engaging exclusively in biomedical treatments, from which people often died.
She explained that they would have insisted on rallying round her and being part of her decision-making. Victoria said that her family would have expected her to consult a traditional healer for treatments because that was the accepted practice at their home in the Transkei. However, Victoria said that she was not convinced of the efficacy of traditional healers' medicines and instead decided that she wanted biomedical treatment as soon as possible:

"I have to get rid of the poison. It's like a scorpion on you, just waiting to strike and you feel almost mad with wanting to get it off you...I wish I could just cut it out myself. I keep thinking of it there, multiplying and growing inside of me."

Victoria, due to her unique economic and educational position, was able to make a decision alone without fear of retribution. She explained that her family was not well educated and that they were still caught in the "old, suspicious traditional ways". Victoria said that she did not fear reprisal for she intended to live for many years and prove to them that the hospital medicines had cured her.

The African patients observed during their consultations with the doctors at Groote Schuur were frequently reluctant to make any decisions until they had consulted with relevant family members. The outcomes of these consultations often resulted in the hospital staff's frustration over a patient's apparent willingness at one consultation to return for treatment or further tests, and then later experiencing her non-arrival.

3.2.2. The patient's need for social and emotional support

The desire for approval and support from family members was one frequently expressed by the informants. As mentioned above, when a woman
was diagnosed with cancer she began to make decisions that were based on her new status as a cancer patient or, depending on the advancement of the cancer, her status as a dying woman. Her pre-illness priorities may shift and she becomes increasingly focused on ensuring that her dependants will be cared for should she become incapable of providing for them. This planning for the future did not only include securing economic resources for her dependants. The woman also attempted to keep and even re-establish strong social relations with kin and friends so that such persons would be obliged to provide for her children once she is unable to do so.

In order to achieve such relations with others it is important that the woman is seen to abide by such persons' advice regarding treatment options. If the woman ignores her family's suggestions then her family members may be less inclined to commit themselves to her dependants should she die or become very sick, because she purposefully ignored their advice.

Dorris, a thirty year old woman, explained that she had wanted to accept some of the hospital treatments, such as radiotherapy and hormone pills, however, her mother was adamant that she should consult a traditional healer instead. Dorris consented to drink the traditional healer's imbiza but continued to argue with her mother about accepting some form of hospital treatment. She argued that she wanted to increase her chances of being cured by combining several treatments simultaneously. However, Dorris explained that she knew that she would eventually heed to her mother's wishes because her mother supported her and her young child. Dorris felt that she could not afford to break ties with her mother because she feared for the future of her child should she die from the cancer (Dorris managed to combine biomedical and traditional treatments for a while before her mother decided that the biomedical treatments were dangerous for Dorris and she was forced to cease accepting them).
3.2.3. The fear of rejection by partners

Many African women are either unemployed or earn very little each month and so rely on others for economic resources. In some cases, a man will not support his partner but will agree to provide for the children, thereby rendering the woman dependent on her partner for provisions for her children. Some of the lay person informants (two of the women who do not have cancer) said that women, who are diagnosed with breast cancer, fear that their partners will leave them for a healthy woman. They argued that was the reason that some women chose not to inform their family members of the cancer. They further argued that, a woman, who hides her cancer from family members, is unlikely to accept hospital treatment because it is believed to produce 'visible' signs of cancer, such as hair loss, operation scars, loss of breast and so forth.

3.3 Traditional understandings and treatment of cancer

"It's a poison - it needs to be drawn out of you or it spreads and you die"

Joseph, a traditional healer

The African informants from this research could be divided roughly into two groupings based on their definitions of cancer. The first group saw cancer as something that grows in one and needs to be taken out of you, preferably by a biomedical surgeon. They had no formalised notion of the causes of the cancer and did not view such causation as originating from a sinister source. This group of informants was the smaller of the two and included four of the patients who were either undergoing or had completed treatment at Groote Schuur.

The second group, including the three traditional healers, a sangoma, and five of the breast cancer patients, saw cancer as a poison that needed to be drawn out of the body with special medicines. They explained that cancer was
given to you by an enemy, either by one walking over the carefully planted poison, by having it placed in your food or via a tokolosh (a small man intent on evil doings) who visited the victim during the night. In either of the three cases the victim could not avoid being poisoned. All of these informants argued that the poisoning was the result of discord in social relations. Such a discord resulted in the victim's enemy wishing to harm or punish the patient.

The second group felt that one could be cured of cancer if the poison was removed from the body without allowing it to spread to the rest of the body. However, they all argued that any form of cutting into the cancer would result in death.

3.3.1. The traditional healers' "explanatory model" of cancer

Joseph and Alice are traditional healers. Gladys described herself as a sangoma but said that she was trained in, and still practices, traditional healing methods. David is a sangoma and is involved in identifying the causes and reasons for a person getting cancer (he refers such patients to a traditional healer). All four informants' knowledge and approach to breast cancer were very similar and so in this section it is their joint views, unless otherwise stated, that are expressed and described.

3.3.1.1. Causes and acquisition of cancer

The informants explained that cancer is a disease that people get via "an evil magical poison" that is purposefully given to persons who have enemies. The enemies may either be those who feel angry or jealous of the victim for a specific reason or action, or they may merely be malicious persons, intent on evil-doings. These people pay evil sangomas to concoct a poison which is then administered to the victim.
The informants explained that the poison (cancer) was obtained in four ways. Firstly, by walking over poison (cancer) that has been specifically set for the patient. There are often blades and nails put into the poisoned heap so that the foot is pierced to allow for easy access for the poison and other germs. Alice said that the person experiences the sensations of intense heat or pain (like walking on broken glass) when s/he steps on the poison.

The second means of getting cancer was for someone to put the poison into one's food. The poison is thus ingested and spread within the body. The third means of getting cancer involves the tokolosh taking the cancer to the sleeping victim during the night.

The fourth way of getting cancer was mentioned only by Alice, who said that if any wound is neither cleaned nor bandaged then it can turn into cancer.

Princess, a forty year old domestic worker, had never been diagnosed with cancer, however she described her understandings of cancer as those of many Xhosas in South Africa. Princess said that many Africans feel that cancer has changed over the past decades. She argued that, although the explanations of the causes and acquisition of cancer had remained the same, the "type of cancer" had changed. Princess' belief that cancer had changed was echoed by Gladys, a traditional healer, in a later interview.

Both these informants said that the cancer of fifteen or twenty years ago was a "slow-killing cancer". They explained that in the past people diagnosed with cancer lived for many years with the disease. However, in the present decade, people were dying from cancer soon after diagnosis. Both women argued that the cancer had become "stronger", as Princess noted:

"In the past people would carry on living with cancer for many years. But that has changed. Nowadays everyone with cancer dies - people know that and everyone is afraid of it. It has become a big killer"
Both informants stated that biomedical practitioners could not cure this "stronger" cancer. They argued that only traditional healers could successfully treat cancer because their medicines could be adapted to the peculiarities of each person's disease. They further argued that African people felt that biomedical treatments were increasingly failing to help cancer patients and that "dabbling" too deeply into hospital therapies served only to hinder the efficacy of traditional treatments (both informants felt that diagnosis and pain control were the only legitimate or "safe" procedures offered by the hospital).

3.3.1.2. Traditional treatments of cancer

The four informants (three healers and the sangoma) explained that only traditional healers (and occasionally) sangomas could heal people of cancer. However, they stressed that not all traditional healers were equipped to cure cancer and that it was only the cancer specialists (Joseph claims to be one) who have the medicines to cure.

They agreed that although the hospital was useful, for the initial diagnosis of the cancer, patients should subsequently seek help from a reputed 'cancer curer', i.e. a traditional healer. All four argued that a consultation with a sangoma was valuable because s/he could explain the reasons for, and the perpetrator of, the cancer. Once the patient's mind is at ease about the cause of the cancer then she could consult a traditional healer for treatments.

The traditional treatment is comprised chiefly of the intake of large amounts of imbiza by the patient. Imbiza refers to the bottle that the liquid medicines are stored in. The intake of such medicines serves to prepare the body, from the inside, for an attack on the cancer and to generally strengthen the body to fight the cancer. During or after the consumption of various amounts of imbiza the healer attempts to draw the poison out of the body. This is either
done through the skin or is initiated once the cancer has come out of the skin, in
the form of a large open wound.

The liquids that are released from the wound (pus, blood etc.) are seen to
be the cancer that is escaping from the body by being pulled out by the topical
medicines and pushed out by the imbiza. The body releases the cancer in this
form for varying periods of time, usually a couple of months. Once the breast
has purged itself of the poison then the wound begins to heal and finally dries up
completely leaving only a scar along the breast.

Alice and Joseph said that breast cancer could also be cured by drinking
imbiza (all four were very secretive about the ingredients of their treatments) and
by placing medicines on the unbroken skin. They argued that this method cured
the cancer from within the body.

Many of the informants said they had heard of traditional healers who
could cure people of cancer, however they had never personally seen the cured
patient. They also said that, although traditional healers claim to have cured
others, they refuse to reveal the identity of such patients, explaining that "it
[patient's identity] is not something that I can just tell. It is the private affair of
those people [patients]."

However, despite this initial inability, to find any people who claim to have
been cured of their cancer, the researcher eventually met two informants who
told of their experiences with a particular traditional healer, Leonora, who lives in
the Ciskei and cures people of cancer. Beauty and Lydia are women who had
breast cancer, from which they claim to have been cured. Their accounts of the
healing process are very similar.

Leonora has a large settlement in the Ciskei. Her land is divided into
three sections where the patients stay depending on their state of health. The
land is also divided into male and female sections. On arrival patients are seen
by Leonora and told how and why they get their cancer - the patient may not
choose to know the identity of her perpetrator. The course of healing takes
place over several months during which the patient drinks much *imbiza*, adheres to a stringent diet and is bathed daily with special medicines that draw the poison from the breast. This bathing also includes scrubbing of the cancer and results in large and deep wounds forming. Once the wound begins to heal the patient is sent home with a course of *imbiza*.

Beauty and Lydia said that they were cured of their cancer and felt healthy again. They believe that Leonora is the only person in South Africa who can cure people of cancer.

Norma also claims to be in the process of being cured of her breast cancer by a traditional healer in Cape Town. Norma explained that her treatment is progressing slowly because she originally went to a hospital where she was diagnosed and underwent various tests. Her traditional healer explained that, because of these early interactions with medical procedures, his medicines would take longer to work. Dorris believes that the healer will eventually cure her:

"What can I do now but wait for the cure? The hospital isn't right for me. I don't think their medicines work, everyone dies who is worked on by them [undergoes surgery or radiotherapy]. But I am tired now of waiting."

### 3.3.2. Faith in traditional healers

In almost all of the conversations and interviews undertaken with informants, both lay- and professional persons, the issue of traditional healers and their role in treating cancer patients emerged as crucial to understanding the phenomenon of absconding. The basis of the argument presented by most informants was that African women abscond from hospitals and biomedical treatments because they choose to seek help from traditional healers. However, as yet no-one has explored the attraction that the traditional healer holds over
that of the biomedical doctor for African breast cancer patients. It is important at this point to draw attention to the term "attract", for the researcher's argument is that the factors that cause women to leave or reject hospital treatment, are due more often to what they perceive to be positive pull factors than to negative push ones. So, the positive pull factors, as noted by the informants in this study, are:

1. The African woman's understanding of, and familiarity with, traditional healers' explanatory models of illness, especially cancer.

2. The social acceptance that consulting such persons affords the African woman (this is particularly important if she is already experiencing some form of social stigma associated with having cancer).

3. The belief that, as only traditional healers truly understand what causes cancer, only they can successfully cure one of cancer.

4. Most African patients and their families see cancer as a death sentence, therefore they choose rather to seek help from a source with reputed successes in curing cancer, than one from which no-one is cured and painful and unsightly treatments are recommended (i.e. hospitals).

5. The non-invasive, painless and scar-free treatments that the traditional procedures are seen to ascribe to. This is especially attractive to patients who generally do not associate a painless lump with a serious condition for which surgery is recommended.

6. The holistic and individual attention that the patient obtains from the traditional healer.
3.3.3. The cut and burn taboo

The 'cut and burn taboo' are at the crux of which hospital treatments African breast cancer patients will accept. The belief of the four traditional healers and the four absconded informants, was that, by engaging in certain interferences with the cancer, one decreases the efficacy of the traditional treatments.

A commonly expressed view by some of those interviewed (including the traditional healers, the African lay persons and some of the patients) was that cutting the cancer resulted in the death of the patient. These informants explained that, because cancer is seen to be a poison, it is believed that if you "open" the poison it will rapidly spread via the blood stream into the rest of the body, resulting in the premature death of the patient. Therefore the cancer or poison needs to be treated in its contained state, e.g. the breast. This belief formed the basis of the traditional healer's practice of drawing the poison out of the body without cutting into the cancerous area.

A further taboo was that of burning the cancer. Radiotherapy is therefore also seen to interfere with the cancer by burning it which renders it impenetrable to traditional medicines.

Thus if a patient is considering consulting a traditional healer, she will not be eager to accept surgery or radiotherapy because of the detrimental effect that they will have on the effectiveness of the traditional medicines. Chemotherapy and hormone pills however, are sometimes viewed as acceptable treatments because they are not seen to effect the traditional medicines' efficacy. Joseph argued that chemotherapy was sometimes beneficial to both the patient and the traditional healer because it "cooled down the cancer" - meaning that it diminished the cancer, therefore making it easier for the healer to treat with his/her drawing medicines.

Several informants said that some African people fear having to go to a hospital because of the possibility that surgery may be recommended. They
believe that if surgery (rather than pills or a more "passive" treatment) is suggested then the cancer is very advanced and the patient is soon to die from it.

3.4. **African patients' fear and mistrust of hospitals**

"I knew that if I took their treatments then I would surely die"

Lydia, a breast cancer patient

The vast majority of the African informants interviewed (including some of those women undergoing hospital treatment) expressed dissatisfaction with, or mistrust of, the hospital's approach to cancer and cancer patients. They sited examples of hospital staff treating them like children and not informing them fully about their condition or possible treatments. Some of the breast cancer patients interviewed described upsetting incidents at the hands of hospital staff.

Victoria said that while she was undergoing various tests at Groote Schuur Hospital she encountered a junior staff member who said to her in Xhosa: (so that other staff members around could not understand)

"The white doctors are just using your body for their experiments. None of this is going to help you or the cancer at all. You're only their puppet to do experiments on."

Victoria said that she was very upset but told him to shut up and leave the room. She felt that had she not been sure about wanting hospital treatments she would have lost her nerve and been scared off by the man. Victoria expressed concern that other less sure women would heed such rumours and reason that;
"...if one of our own people, who is actually working in the hospital, think such things are happening, then it must have at least some truth to it".

Beauty and Lydia said that African people always complain about how they are treated in the hospital. They argued that African patients feel that they are not informed about their illnesses or the types of treatments that they require. Lydia said that she often felt like a child when a doctor spoke to her because s/he did not approach her as an adult capable of understanding illnesses. She said the problem with African patients is that they seldom complain and remain quiet about their unhappinesses but then just do not return for further treatments or visits.

All the African informants agreed that many African people equated hospital treatments with death. The informants who rejected biomedical treatments said that they did not believe that hospital treatments could cure a cancer patient - they argued that they had never met anyone who had been cured of their cancer by a Western doctor. The same informants however, all claimed to have met people who had been cured of cancer by traditional healers.

3.4.1. Avoidance of hospital treatments

The three traditional healers and sangoma agreed that hospitals do not use appropriate drugs for cancer, although Joseph and David felt that chemotherapy was often useful to "cool down the poison and make it smaller, before it can be drawn out of the body". Alice and Gladys said they were not sure about the usefulness of such a treatment.

They said that in some cases even a biopsy can negatively effect the efficacy of traditional medicines (Alice said that any woman, who suspects that she may have cancer, should consult a traditional healer straight away and only if the healer is unable to cure her, then may she accept hospital treatments, such
as pain-killers). Although Joseph and David felt that some combining of traditional and biomedical treatments were acceptable, they stressed that the patient needed to be careful that she did not accept any treatment that could interfere with the workings of the traditional medicines.

Joseph, David and Gladys felt that there was no problem in combining hospital and traditional treatments as long as the hospital procedures did not include any cutting or interference with the actual poison (cancer). All four saw the hospital being particularly useful for diagnosis and pain control.

They also agreed that the African women often left the hospital because they did not want to undergo surgery and because they knew that the doctors could not cure them of the cancer. They argued that such women often consulted the hospital doctors for diagnosis only and then went to traditional healers to be treated, although sometimes they combined chemotherapy or hormone pills with the traditional medicines (a practice that they claim most traditional healers do not condemn). Joseph and David said that there was a stigma attached to going to the hospital and this was especially so if the woman got very sick or died - then the family or community would blame her for her condition and would not be as sympathetic to her plight. They said this stigma was particularly true in cases where therapy management groups had suggested that the woman visits a traditional healer and not to take advice from the hospital doctors. In contrast, Gladys and Alice argued fiercely that although patients often feel ashamed of having cancer, and may even attempt to hide it from their families, (the reasoning being that they blame themselves for creating an enemy who would wish to harm them), families and friends do not shun the sick.
3.4.3. The African lay person's rumours about cancer

Most of the African informants said that they knew about biomedical treatments of breast cancer from friends and relatives. They said that such rumours were usually in the form of horror stories, citing various examples of people who had died as a direct result of their contact with hospitals.

The four lay people informants believed that African breast cancer patients are vulnerable to rumours about cancer because of their situation and so they often believe the rumours that circulate their homes, social circles and even the hospital. One of the female informants said a nurse friend had informed her that breast cancer patients often frighten each other with horror tales during their visits to the hospital. She explained that the more conservative patients told of Africans' breast cancer experiences with biomedical practitioners, attempting to dissuade any new patients from considering accepting hospital treatments.

3.5. The consultation: patient / doctor interactions

Some of the informants, particularly those who absconded from the hospital, expressed dissatisfaction with the doctor / patient consultation. They cited the following complaints: the long waits for consultations, the limited time allowed for each consultation, the clashes of different sickness or explanatory models of the doctor and patient, the power dynamics between the lay-person and the medical professional, the language differences, and so forth. It seems that these issues result in many of the misunderstandings that occur between doctor and patient, and result in non-compliance and absconding.

In a state hospital, such as Groote Schuur, there are both time and staff shortages. However, despite these limitations, observations of the doctor / patient interactions indicate that the former are accommodating and friendly to the breast cancer patients. Such observations reveal that the problems
experienced in the breast clinic are due mainly to the language and "explanatory models' differences between the staff and the African patients.

The consultations observed lasted on average 15 minutes, during which the doctor explains to the patient that:

i) she has cancer that requires certain medical treatments

ii) she needs to agree to use the birth control injection to avoid falling pregnant while she is being treated for the cancer

iii) she must return the following week for further consultation by other doctors

The patients however, are more concerned with the answers to questions such as: why did I get cancer? where did it come from? why do I need surgery if the lump is so small? will the treatments cure me of the cancer forever?, and so on. The language differences were highlighted at such times, as the doctor and patient attempted to understand each others' concerns.

During the observed doctor / patient interactions the researcher noted that, although the majority of the African patients spoke English, not many of them possessed the vocabulary to fully understand explanations of treatment options and other medical terminology used by the doctors. The difference in the medical and traditional models of illness sometimes resulted in doctors and patients talking at cross purposes, often misunderstanding the reason behind certain lines of questioning.

During one observed consultation, a patient asked how she got the cancer. The doctor truthfully answers that s/he did not know, "it is a disease that some people just seem to get". However, the patient was not satisfied with that answer and seemed disinterested in the remainder of the consultation
The following conversation occurred during an observed consultation between a doctor (D) and an African woman (P) just diagnosed with breast cancer.

P1: How big is the lump?
D2: It is not very big at all, we can remove it fairly easily.
P3: But I have had it since February. Hasn't it got bigger by now?
D4: It is a slow growing tumour so it hasn't spread everywhere in your body.
P5: But then why do you say I need an operation? Can't I just take pills? I have heard that if you cut it then it will spread everywhere in your body.
D6: Yes, I have heard people say that but an operation will help prevent it from spreading because we take the cancer out.
P7: If I have an operation will that cure it?
D8: We hope so. But it may come back and we will put you on other treatment after the operation.
P9: If I agree to the cutting then I won't need more treatment?
D10: No, you may need more.
P11: If I take the other treatments will that cure it?
D12: No, we can never be totally certain that it won't come back again one day.

This conversation is a good example of one in which the doctor and patient, unwittingly, are talking at cross purposes. In P1 the patient attempted to ascertain the seriousness of the disease, she later reasoned in P5, that if the tumour had not grown bigger then it could not be dangerous. The doctor, unwittingly, reinforced this perception by trying to reassure the patient by emphasising that the lump was still small.

Thus, in P3 and P5 the patient expressed puzzlement at the doctor's suggestion that the lump be removed despite its smallness. The patient believed that a recommendation by a doctor for surgery indicates a serious
condition and could not reconcile her beliefs that small, non-invasive, painless lumps are not dangerous, with the doctor's wish to perform surgery that may not even cure her.

The patient felt that she was receiving conflicting reports from the doctor, the cancer was small and not spreading, however it required surgery that may not cure her of the cancer (D8).

This example demonstrates the difficulties that doctors face when trying to understand the African patient's (unspoken) concerns about the cancer. It also highlights the fact that, although the patient spoke English, the cultural nuances (of differing explanatory models of cancer) were not obvious to the conversants. Therefore, although a doctor may feel that the patient understands his/her medical explanations, it is frequently the unspoken words that reflect the real misunderstandings of the consultation.

3.6. Medical pluralism: cure seeking behaviours

The majority of the all the African informants said that, when sick, they consulted both biomedical and non-biomedical healers. They explained that each sector is perceived to be equipped for treating specific problems, for example; the medical sector is better equipped for diagnosis and pain-control of cancer patients. Similarly, the traditional healer is considered by many (those who reject the hospital treatments) to be skilled in the on-going treatment and curing of cancer. Six of the interviewed African breast cancer patients and four other African lay persons, said that they used both the biomedical and non-biomedical services according to their reputed fields of expertise.

All, but one, of the breast cancer patients said that she had consulted a hospital for the original diagnosis of cancer. Of those informants who chose to accept traditional treatments, all but two continued to undergo some form of
biomedical therapy (several tests, hormone pills or chemotherapy). These informants explained that they felt it was beneficial to participate in some biomedical treatments because:

i) the tests would provide their traditional healer with more information about the cancer

ii) the pills and chemotherapy would help to diminish the cancer so that the traditional healer could cure it more easily

iii) it is sensible to combine cancer treatments, "two must be better than one"

The patients who absconded ceased using any form of biomedical therapy once their treatments with the traditional healers began in earnest. Those who refused to continue biomedical treatments, beyond the point of initial diagnosis, argued that their therapy-management groups had told them that it hindered the efficacy of the traditional therapies. These patients said that they did not want to risk ruining their chances for a cure by consulting biomedical practitioners.

The two informants who admitted to using both biomedical and non-biomedical treatments, either consecutively or in combination, argued that they were reducing the risk of not being cured. As Dorris explains:

"I know the doctors can't cure me of my cancer but they are good at telling you where it is [spread] and the pills can make it smaller. Anyway I know that they can't hurt. My healer said that I should stop the pills now because he's got medicines for me. I know I have done all I can now"
The claim to have "done all I can to fight the cancer", was repeated by many informants (from the absconded and the compliant groups). These informants frequently emphasised that they had used all the treatments that they felt were both safe and beneficial to them. Some described their feelings of desperateness, as they sought treatment after treatment in the hope of a cure for the cancer. Those informants using traditional therapies exclusively or in combination divided the biomedical and non-biomedical treatments according to their short- and long-term benefits. The biomedical treatments were seen to provide immediate answers, such as diagnosis, pain-control, and the temporary reduction of the lump size. The non-biomedical treatments were described with reference to their long-term efficacy, such as eradicating the breast cancer and preventing other cancers from appearing (there was a belief amongst the traditional healers that once you have been cured of cancer no-one can give you / send you cancer again).

3.7. Adopting the sick role: the economic considerations

"It's expensive to be sick, especially of you're poor already"

Anne, one of the hospital volunteers

The majority of the African breast cancer informants had 3 or more children. In most of these cases the children are still dependants for whom the patient needs to provide.

During this research it became increasingly apparent that the health problems of the poor in the Western Cape are not merely ones stemming from unhygienic living conditions, malnutrition and so forth. One of the factors that hinders the effectiveness of public health services is the relative expense of being sick.
Many of the informants, both patients and lay persons, spoke about the enormous stresses that are placed on African women in the urban centre. They explained that the increase in the economic burden that sickness induces, is one of the reasons that women decide not to undergo hospital treatment - they simply cannot afford the time, social and monetary resources that the sick role demands.

Informants working with the issues of social welfare and breast cancer patients explained that, unless illness symptoms are impacting on a woman's ability to continue her daily activities, she will choose to ignore the disease and avoid visiting a hospital.

Therefore, the impetus to adopt the sick role does not merely rest on the physical manifestation of cancer. Although a patient experiences symptoms of cancer, such as a lump in her breast, she may choose to delay visiting a healer until it is economically and socially 'too expensive' not to. Therefore, it is often only when the cancer begins to threaten the woman's access to scarce monetary and social resources, that she will seek therapy treatment.

Anne, one of the hospital's volunteer workers, argued that if a patient chooses to accept the hospital treatments she can expect to lose at least ten days of work within the first month or two of diagnosis. Visits for diagnosis, tests, combined clinic, radiotherapy (at least three days a week for at least one week) or chemotherapy (at least three days of feeling very ill), and so forth. She said that it is not only the loss of income that costs the patient but also the payment for child minders, taxi fares and so on.

If one compares this economic cost to that of the cost of consulting a traditional healer, the traditional healer, although more expensive than the hospital cost, is frequently a more cost effective treatment. The traditional healers can charge up to R500 for a cure / a treatment for cancer. There is usually an up front payment and then one later (either at time of revisit or cure). However, these costs are usually the total cost to the patient. In most cases the
patient lives closer to the healer than to the hospital which cuts down/out the transport fare, the visit is shorter than the long waits at the hospital so less or no child minding payment is necessary and no or less work hours on forfeited.

Clearly a cancer patient's choice of healer is not based simply upon economic considerations however, one can not deny the practical implications and consequences that the woman faces in choosing which healer to consult for treating her cancer.

Anne also spoke about the change in the patient's pre-sickness social role once she is proclaimed to be sick. Anne noted that the woman's standing in her family and society changes dramatically once she is diagnosed with breast cancer. This change is invariably perceived by the patient to be a negative one, as it focuses on reducing the patient's responsibilities on which her social status is based. Anne argued that a further reason for breast cancer patient's choosing to consult traditional healers was the relative secrecy that such visits could afford the woman. Hospital visits are too disruptive to remain secret and the patient constantly fears that during such a visit an acquaintance will see her on the cancer floor.

Thus, the expense of adopting the sick role in the breast cancer patient's case, also includes the social and emotional expense of losing previous social roles and standings in the eyes of others. Such "expenses" are more easily avoided if the patient chooses a more 'discreet' type of therapy treatment, in the form of a traditional healer.*

*note: an estimated 30% of Groote Schuur Hospital's African cervical cancer patients abscond. This rate compares to the 80% absconding rate of the African breast cancer patients. One of the reasons put forth by the researcher and the hospital biomedical practitioners and social workers, is that symptoms of cervical cancer affect a woman's lifestyle. The second suggested reason is that, due to the nature of the disease, surgery is not offered as often to cervical patients. So, unlike cervical patients who suffer from bleeding and pain, the breast cancer patient presents with a painless lump for which surgery is usually recommended - which is rejected by most of the African patients in the form of absconding.
CHAPTER FOUR: CONCLUSION

The findings presented in the previous chapter demonstrate that firstly, the phenomenon of absconding rests on both cultural and social factors and thus, cannot merely be explained in terms of "the African culture". Secondly, the numerous factors should never be seen in isolation from each other or from the political-economic context in which the African breast cancer patients live.

Any attempt to reduce complex human behaviour to a few simple variables is a dangerous pursuit. Such variables as one might identify are never absolute determinants but rather, should be seen as those factors that influence behaviour in complex and highly situationalised contexts. These variables have a joint effect and are all present to a greater or lesser extent.

In the end, the choice of healing treatments comes down to making decisions based on the individual's logic (the course of action taken, given one's particular interpretation at the time), as Helman (1994: 85) explains:

"Ill people make choices...between diagnoses and advice that make sense to them and those that do not. In the latter case the result may be "non-compliance", or a shift to another part of the therapeutic network."

Thus, the aim of any research into behaviours should be to investigate the common sense of the informants - that is the beliefs and meanings with which they perceive the world and act upon it. An understanding of people's meanings and beliefs enables one to better comprehend and analyse their actions.

It became apparent during the research, that many of the African breast cancer informants chose, for varying periods of time, to accept both biomedical and non-biomedical therapies. This sheds new light on the phenomenon of absconding, for it demonstrates that many patients, prior to
diagnosis, had already decided or been advised to consult both sectors of healers for specific treatments.

Therefore, these patients attend the breast clinics with pre-set notions of the uses and advantages of the biomedical treatments. The act of absconding is thus a pre-determined part of a larger therapy-seeking model.

In can thus be seen that the phenomenon of absconding, by African breast cancer patients, is not simply a matter of African women being afraid of biomedical treatments, it is more complex than that. An African woman, pressured by therapy-management groups, attempts to reconcile two vastly different healing models (the biomedical and the traditional) in an attempt to ensure herself of the best possible chance of being cured of the cancer. However, because the two models are at fundamental loggerheads she is unable to combine them fully. Thus, she is ultimately forced to chose one above the other. The choice is invariably that of the traditional healer. This either/or choice is further swayed by factors such as, the patient's explanatory cancer models, social and economic pressures, the role of the oft conservative therapy-management group, and the fear of some of biomedicine's treatments.

In the following chapter, recommendations are made as to ways of addressing absconding, by discussing possibilities of overcoming the either/or therapy choice. This is achievable by seeking to accommodate patients' traditional models of cancer, and by furthering communications with traditional healers, thereby narrowing the present chasm between the two healing models.
CHAPTER FIVE: RECOMMENDATIONS

The following suggestions and recommendations are based on the findings of the empirical research. These recommendations identify issues requiring consideration by the Oncology and Radiotherapy Departments regarding the phenomenon of absconding by African breast cancer patients.

5.1. Working within African patients' pluralist model

In general African patients use the pluralist model in seeking health treatments from various sources. In the case of the breast cancer patient however, the two health models used most frequently, are inherently contradictory.

Firstly, many breast cancer patients do not believe that biomedical treatments can cure cancer. They view a few of the hospital treatments as useful but not curative. Therefore, they expressed little interest in initiating or continuing biomedical treatments.

Secondly, the African breast cancer patients expressed a great fear of surgery which they described as a dangerous and harmful practice. They further argued that surgery was the treatment most preferred by biomedical practitioners.

The biomedical and traditional models' of acquisition, causation and treatment differ so radically, that the patient is eventually forced to make an either/or decision regarding treatment options.

It is therefore crucial, that biomedical practitioners and traditional healers create forums wherein cross-model links and collaborations are sought. Such meetings should facilitate communications between the two health systems.
5.2. **Including the therapy-management group in consultations**

The issue of decision-making processes was discussed in the *Findings* chapter. It was argued that women do not usually make treatment decisions alone. Instead they have therapy-management groups who advice / or coerce them on appropriate treatments. It is thus recommended that the patient's therapy-management group be incorporated into the doctor / patient consultations.

The information that is communicated to the patient needs to be communicated to the therapy-management group too, for they are frequently the ultimate decision-makers. If the hospital hopes to change Africans' perception of biomedical cancer treatments, then doctors need to inform the actual decision-makers (who are not necessarily the patients) on the treatment options and outcomes of biomedical procedures.

5.3. **Africans' perceptions of biomedical cancer treatments**

The Oncology and Radiotherapy Departments need to emphasise that the hospital offers a *range* of treatments, of which surgery is only one. At present African patients equate biomedical cancer treatment with surgery.

Patients' consultations with the social workers (and doctors) could concentrate on the good prognosis that early detection affords breast cancer patients. The counsellors need to emphasise that, although the patient is offered several treatments, she is not obliged to accept any of them and that, should she choose to return for another appointment, no treatment will be forced upon her. This approach will enable the power dynamics to shift in the conversation, so that the patient and / or her therapy-management group discuss what treatments *she* is interested in. Therefore, the opportunity is created whereby, should the patient not want to accept the doctors' recommended treatment, absconding is
not her only form of resistance. She can, for example, refuse the surgery but accept chemotherapy instead.

Thus, the consultation is premised on the understanding that the patient has breast cancer, she (or her therapy-management group) will decide what treatment to accept and the hospital staff will inform but not coerce her.

5.4. Encouraging the adoption of the sick role

The stigma associated with cancer is a common problem and is not peculiar to any population group in South Africa. That issue is being addressed by the ongoing national campaign on cancer education. The other two issues, the economic and social interruption of adopting the sick role, are addressable by the hospital.

The hospital does provide transport fare for those patients who need the assistance, however African patients need to be made more aware of this facility. The hospital does issue absentee letters for employers, however it is recommended that the hospital staff, with the patient's permission, inform such employers directly. Such an approach will serve to sensitise the employer of the circumstances related to the absenteeism, thereby facilitating greater employer awareness of the patient's condition. This increased awareness will result in

i) the patient feeling confident in requesting sick leave for hospital appointments

ii) the employer more readily granting such leave because s/he understands the patient's medical situation

The second interruption caused by adopting the sick role, is associated with the childminder/mother role of the patient. This inconvenience could be improved by allowing the patient to chose the time for return visits, for example
the Combine Breast Clinics are held in the afternoon, which is not usually a convenient time for mothers because their children are home for school and need minding. A morning clinic may suit such patients better and reduce possible obstacles to their not returning for booked consultations.

A further recommendation is that a crèche for patients' children be established at Groote Schuur Hospital. This would enable women to take their dependants to the hospital with them, thereby reducing the cost of hiring a childminder and simultaneously serving to ease the woman's concerns about leaving her children.

5.5. Creating a breast cancer support group

There are breast cancer support groups in Cape Town, however these are generally privately formed and are thus not encountered by African patients. It is recommended that the hospital establish such a group consisting of women who accepted biomedical treatments and are presently well, and those who are beginning or continuing hospital treatments.

Such a group/s should not be exclusive to African patients. It should consist of women who are willing to meet other breast cancer patients to discuss their problems and concerns, as well as providing each other with support.

It is further recommended that African members of the support group spend time in the passages and waiting areas of the Oncology and Radiotherapy Departments. This is recommended in response to the claims that some African women (patients or family members) scare off breast cancer patients with horror stories of biomedical treatments while they are at the hospital. The support group members would act as a foil to the rumours that abound in the waiting areas of the two Departments.
5.6. **Education programme for hospital staff members**

The doctor / patient interactions that were witnessed during the research period were amicable and polite. However, a few of the African breast cancer informants said that some of the junior hospital staff's behaviour upset them (see section 3.4. *African patients' fear and mistrust of hospitals*). These incidents were not investigated by the researcher however, they could require attention by the senior staff members of the Oncology and Radiotherapy Departments.

It is therefore recommended that a carefully planned information programme be implemented in the Oncology and Radiotherapy Departments, primarily for the African nurse aides, nurses and medical technicians. This programme should seek to inform the participants of the reasoning for the hospitals' approach and treatment of cancer. The programme should aim to explain that staffs' attitude to breast cancer patients is a crucial element of the success of the Departments. It should also explain that the staffs' commitment to, and belief in, the departments' treatments is fundamental to the smooth workings of the departments.

The programme should aim to, through providing information and instilling importance in the participants' roles in the Departments, create a sense of job satisfaction and unity amongst the various levels of the departments.
5.7. Areas requiring further research

5.7.1. Detailed analysis of the medical files

At present, statistical and comparative information, both within and between population groupings of breast cancer patients, is not in a readily accessible format.

It is therefore recommended that comparative research be conducted across the three patient groupings. Such research should attempt to collect data that allows meaningful comparisons and cross-comparisons to be made between the groups regarding patterns of absconding. This research would provide a historical perspective of the phenomenon of absconding.

5.7.2. Therapy-management groups' interactions

Qualitative research into the meetings and actions of African therapy management groups would provide insight into the functioning of such decision-makers. Such research would produce information on the variables on which the therapy management groups base their decisions. Thereby providing medical practitioners with an in-depth comprehension of further determinants that result in African breast cancer patients absconding from treatment.

5.7.3. The cervical / breast cancer patient enigma

My findings on the phenomenon of absconding focused on what makes African patients different from the other breast cancer patients. Several variable emerged such as the decision-making processes, explanatory models of cancer, the adoption of the sick role, the doctor / patient interaction, and so forth. These social and cultural variables differentiated African from the "coloured" and "white" patients. It was therefore argued that a combination of social and cultural
peculiarities resulted in the phenomenon of absconding. It is from this premise that one would suppose that all African female patients, suffering from cancers, would have similar rates of absconding.

However, this does not hold true. The rates of absconding of African cervical patients is roughly 30% compared to the over 80% of breast cancer patients. The social, cultural and economic variables of the women are the same, so why the discrepancy? The following suggestions by hospital staff were put forward:

i) treatments, that usually exclude surgery, are offered to African cervical cancer patients

ii) advanced cervical cancer symptoms (bleeding and pain) negatively effect the woman’s lifestyle and so she seeks treatment

There is clearly a need for comparative material regarding the discrepancy. It is thus recommended that research into differences between the non-compliant rates of two seemingly identical population groups be initiated. The research would identify further variables influencing the behaviour of absconding by African cancer patients.


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APPENDIX 1

THE UNIVERSITY OF CAPE TOWN
DEPARTMENT OF SOCIAL ANTHROPOLOGY

MASTERS THESIS PROPOSAL:
The problem of non-compliance amongst breast cancer patients: a study of the high rate of absconding by African women diagnosed as having breast cancer.

MASTERS STUDENT: SONYA VIVIEN WRIGHT
SUPERVISOR: EMILE BOONZAIER
DATE: 30 JUNE 1995
TITLE: The problem of non-compliance amongst breast cancer patients: a study of the high rate of absconding by African women diagnosed as having breast cancer

THE PROBLEM: The Oncology and Radiotherapy Departments at Groote Schuur Hospital of Cape Town, have requested research into the reasons for African women's non-compliance. A high percentage of African women, who are diagnosed as having breast cancer, are failing to comply with the Departments' recommended treatment procedures. This non-compliance denotes various behaviours but the Oncology and Radiotherapy Departments' primary concern at present is that of the absconding - failure of African women to return to the hospital for further treatment of breast cancer - which adversely effects their biomedical prognosis.

OBJECTIVE: To identify and examine factors determining the decision of African women, who have been diagnosed with breast cancer, to abscond from the Oncology and Radiotherapy Departments and/or further treatment at Groote Schuur Hospital, Cape Town.

CONTRIBUTION: This research will contribute to South African biomedical practitioners' current concern with the avoidably high mortality rate amongst African women with breast cancer. The research and findings will identify the factors which help to shape some African women's perceptions and understandings of breast cancer, such as the women's perceptions of their bodies, of being a woman, of cancer, of having cancer, of the treatment of cancer, of hospital procedures, and so forth. Thus, the research's findings will provide data and knowledge on which the Oncology and Radiotherapy
Departments can draw in order to evaluate current, and structure future, approaches and treatments for African women with breast cancer. The research will also contribute to the academic debate on lay person's perceptions of illness and disease by discussing the interaction between patient's and biomedicine's models of illness.

**LITERATURE:** There is much biomedical literature on breast cancer which deals predominantly with the biological indicators and implications of breast cancer. This literature is generally set in the European or American context and is frequently concerned with debates and cases from the 1980's (see D'orsi and Wilson 1983, Margolese 1983, and Stoll 1986). Despite the large amount of biological literature there is a small amount of current information on breast cancer focuses primarily on the role that cultural and social factors play with regard to breast cancer and women's response to diagnosis (see Blumberg et al. 1991, Hucking et al. 1988 and Mahoko 1993). These works are valuable in assessing South Africa's breast cancer situation by examining social and cultural issues, they do not however, focus on the unique context and environment in which South African oncologists and radiotherapists, and African women interact. This research will therefore contribute to the gap in the literature by providing information on African women's perceptions of breast cancer, and how various factors relate to the non-compliance, specifically the absconding, of African women.

**METHODS:** The fieldwork component of the research will be conducted primarily during the second half of 1995. The research will take place in the Western Cape only.
Research methods:

(1) Analysis of the breast cancer medical files: this will provide demographic information, such as economic and marital status, on the African women who abscond after having being diagnosed with breast cancer. This background information will be useful in formulating a broad socio-economic context in which individual women's experiences can be studied.

(2) Make contact with African women in the Breast Clinics: this will take the form of interviewing the African women who are attending the cancer clinic. This early point of contact will facilitate illness histories of some of the women, noting their responses to the diagnosis, their decision to return to the hospital or not, what and how they chose to relay the information to their families and their attitude to their illness.

(3) Interview the Oncology and Radiotherapy Departments' staff: the staff are a valuable data source due to their experience-based knowledge and their personal contact with the absconding women. The interviews and surveys among the staff will aid in complementing and contextualising some of the information gathered during the home visits.

(4) Home visits with absconded women: the time limit for this research will not permit in-depth contact with more than six women. During the home visits in-depth interviews, life histories and illness histories will be conducted to ascertain and explore the factors determining the women's decision to discontinue treatment of their breast cancer. These visits will also enable observation of the social and cultural environments in which the women deal with their cancer. However, due to the time limit, the researcher's focus during these home visits will be on interviews with the women.
FINAL REPORT: The final report will consist of two separate documents. The first will be a report on the research, the findings, suggestions and practical comments focused at the Oncology and Radiotherapy Departments. The second report will be handed into the Social Anthropology Department and will focus on the process through which the research was conducted, the difficulties, issues and dilemmas that the researcher experienced during the fieldwork period. This latter document is a reflective piece of material in which the researcher discusses the experience of undertaking practical medical anthropological research projects.
BIBLIOGRAPHY


APPENDIX 2:

A discussion of anthropological research methods

The research methods used in this study are described in anthropological literature as the "ethnographic approach" (Helman, 1994: 6). This approach best served the objectives of the study, namely; to discover the informants' meanings of, and attitude towards breast cancer and the treatment thereof.

The "ethnographic approach" is concerned with meanings and perceptions of people. The approach enables the researcher to understand the meanings that people attach to certain behaviours and the cultural significance that such meanings and actions hold for that particular society. These meanings need to be contextualised if the researcher is to fully appreciate their role in society, therefore the researcher seeks to include social, economic and political contexts when discussing meanings. An awareness of the importance of context serves to remind the researcher to avoid generalisations of similar seeming peoples. The results of a study are therefore an interpretative representation of the informants, however such anthropological research hypothesises that other actors will have similar attitudes and beliefs (Wood, 1995).

Medical anthropology focuses on the cultural and social beliefs and related practices, that influence people's perceptions of behaviours regarding ill-health (Foster and Anderson, 1978). Central to this study is the theoretical premise that such attitudes, behaviours and practices are determined by the particular culture of the people. Thus, as Helman states (1994: 8):

"It is...important, when studying how individuals in a particular society perceive and react to ill-health, and types of health care they turn to, to know something about both the cultural and social attributes of the society in which they live"
### Table 1: Most common cancers for females for all populations in South Africa (1989)
*(Cancer Association for South Africa)*

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<tr>
<th>SITE</th>
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<td>Breast</td>
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<tr>
<td>Oesophagus</td>
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<tr>
<td>Uterus</td>
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<tr>
<td>Lung</td>
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</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
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### Table 2: Most common cancers for African females in South Africa (1989)
*(Cancer Association for South Africa)*

<table>
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<td>Other</td>
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<td><strong>Total</strong></td>
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*note: the figures for the years since 1989 are not yet available for analysis*
### Table 3: "White" breast cancer patients diagnosed at Groote Schuur Hospital (1991 - 1995)

<table>
<thead>
<tr>
<th>YEAR</th>
<th>COMPLY</th>
<th>DIED</th>
<th>PRESUMED DEAD</th>
<th>PRESUMED PRIVATE</th>
<th>TOTAL</th>
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53 cases with missing data are not included in the calculations *

### Table 4: "Coloured" breast cancer patients diagnosed at Groote Schuur Hospital (1991 - 1995)

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<th>YEAR</th>
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<th>DIED</th>
<th>PRESUMED DEAD</th>
<th>PRESUMED PRIVATE</th>
<th>TOTAL</th>
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76 cases with missing data are not included in the calculations *
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<td>Totals</td>
<td>10</td>
<td>21</td>
<td>133</td>
<td>164</td>
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Table 5: African breast cancer patients diagnosed at Groote Schuur Hospital (1991-1995)

<table>
<thead>
<tr>
<th>RACE GROUP</th>
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<td>44.5%</td>
<td>*39%</td>
<td>12%</td>
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<td>Coloured</td>
<td>41.9%</td>
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<tr>
<td>Black</td>
<td>6%</td>
<td>^81%</td>
<td>12.8%</td>
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</table>

Table 6: Percentages of Groote Schuur Hospital's breast cancer patients who accepted treatment (comply) at the hospital (1991 - 1995).

*note:
"comply" refers to patients who are receiving treatment from Groote Schuur Hospital
"died" refers to patients who received treatment from the hospital before dying
"presumed dead" and "presumed private" are categories extrapolated by the researcher from the files and therefore are not presented as exact numbers
"private" refers to patients who chose to consult a private biomedical doctor
"abscond" refers to patients who chose to consult a non-biomedical healer
CONSIDERATIONS AND REFLECTIONS ON "BEING THERE":

A discussion paper on the experiences of medical anthropological fieldwork
1. INTRODUCTION

The biomedical profession has become increasingly aware of the need for a holistic approach to the treatment of patients (see Helman, 1994 and Scheper-Hughes, 1990). This global trend towards an inclusive health model is particularly relevant to South African biomedical practitioners who are faced with patients and sicknesses from different cultural and social contexts. The South African biomedical practitioner, unlike her international contemporaries, cannot afford to concentrate only on restructuring the age-old Cartesian mind/body dualism of Western medicine. Instead, limited by her specific biomedical training, she is still expected to provide treatments that are culturally, socially and economically appropriate to patients from numerous social groupings.

Many biomedical professionals see this demand for socially appropriate treatment, as a challenge that requires an open-minded and accommodating attitude. However, despite the acknowledgement for such an attitude, South African biomedical practitioners are not equipped, with the expertise or the resources, to conduct the research needed to inform on providing appropriate biomedical treatments. Therefore, the responsibility has fallen on social scientists, particularly social anthropologists as the "culture experts", to conduct research that will generate qualitative information (Helman, 1994).

Although anthropologists, namely medical anthropologists, have taken up the challenge, they frequently experience difficulties working within, and for, the biomedical profession (Singer, 1995). This paper explores some of those difficulties using the author's recent research experience in Groote Schuur Hospital's Oncology and Radiotherapy Departments, as the ethnographic context (see attached report).
2. ANTHROPOLOGIST AS CULTURE EXPERT

During our initial meetings regarding the brief and my internship in the Oncology and Radiotherapy Departments, the doctors expressed their frustration with the high rate of absconding of the African breast cancer patients. They explained that as an anthropologist I was expected to investigate the cultural peculiarities that resulted in the women's persistent non-compliance. They further explained that they saw the problem as one resting on cultural dimensions, and that, unless they had greater insight into why, and how, the African culture prevented the women from accepting biomedical treatment, they would not be able to successfully tackle the problem.

As the "culture expert" I was expected to fulfil a prescribed role. Early into the research a doctor approached me, was introduced and informed of my role, and commented "Well, of course the problem is, that you'll probably launder your results and tell us it's all about bus fare". This comment reflects the doctor's view that culture was at the heart of the absconding problem. However, he presumed that I, as an anthropologist, would try and down-play the cultural aspect and concentrate on social and economic factors instead.

This remark needs be seen in light of South African anthropologists' past. During the Apartheid era (1948 - to the early 1990's) anthropologists, at many of South Africa's tertiary institutions, were concerned by the Nationalist government's appropriation of the term "culture" into a political commodity. The government sought to present race and culture as synonymous concepts and based their Apartheid ideology on the inherent dissimilarity of cultures (Thornton, 1988). They argued that, unless "cultures" were separated, not only would the unique differences between them be lost, but these differences would result in violence and mayhem amongst "opposing" cultural factions.
The anthropologists of the time (of whom Harriet Ngubane (1977) and David Hammond-Tooke's (1975) works are appropriate examples) argued in direct response to this political ideology, that:

i) culture is learnt behaviour and beliefs, it is not something with which people are predisposed thus, one is not born with a natural propensity to be a Zulu, Xhosa, Afrikaner, etc.

ii) culture is one of many differentiating factors between people and generally it is the social, economic and political variables that more effectively determine people's behaviours.

The doctor's remark therefore, should be seen to be premised on the particular reactive stance that social anthropologists took during the Apartheid era. This stance saw anthropologists actively trying to disguise or down-play the differentiating role that culture played between groups of people.

The Oncology and Radiotherapy Departments' decision to chose an anthropologist to conduct the research, indicates that the majority of those doctors believe that anthropologists can uncover the cultural peculiarities underlying the phenomenon of absconding. As Pletto and Pletto (1990: 275) note: "...medical anthropologists are thought to be the methodological experts in the study of cultural factors".

This attitude indicates that the doctors felt that "the answer" to the problem rested on something of which they were ignorant, some cultural belief or practice that prevents African women from complying with biomedical breast cancer treatments. This ignorance simultaneously absolves the doctors of any guilt, that it is their approaches and their biomedical culture, that drive the women away.
3. THE ANTHROPOLOGIST'S PERSPECTIVE: WORKING IN THE BIOMEDICAL FIELD

It quickly became apparent that the doctors expected cultural answers and explanations to the problem of absconding. The cultural bias, previously presented in terms of race, results in the belief that culture is the most important differentiating factor amongst people and population groups. Culture is thus perceived to be the sole reason for differences in behaviours, values, beliefs and attitudes. Culture also becomes the explanation for seemingly inexplicable and non-sensical behaviours (such as absconding). As Chrisman and Johnson (1990: 102) argue:

"...the clinicians' focus on the culture of patients may be a red herring...not all problems of ethnic patients are the result of cultural background"

Therefore, as cultural proprietor and merchant, I was expected not only to conform to, but also to perpetuate, the cultural bias of biomedical institutions.

I was aware that although culture may well play an integral part in the reasons for African women absconding, I needed to emphasise the importance of considering social and economic factors, and the dangers of viewing any human behaviour in a context vacuum. I also wanted to highlight the problems that viewing behaviours as purely culturally determined can cause; the ease in which the need for further research is dismissed, because 'the answer' has been found, or the reluctance to seek further understanding of an issue, once it is neatly labelled as a "cultural phenomenon". Pletto and Pletto (1990: 274) argue that, in anthropology:
"Culture and cultural differences have come to be seen as one major cluster of variables among complex networks of factors that account for, or explain peoples' actual behaviours" (italics mine)

4. A DISCUSSION OF THE DIFFICULTIES EXPERIENCED DURING THE FIELDWORK

4.1. Finding absconded African breast cancer patients

I had initially intended to gain access to absconded African breast cancer patients through the hospital files. However, the addresses given were frequently either false or the residents claimed that the patient had moved to an unknown location. I attempted to gain further information and access to patients by contacting the head sister, Sister L, at Philani Cancer Unit in Langa. The unit provides cancer education programmes to the surrounding townships and is involved in basic examinations and check-ups. The unit also has a few fieldworkers who do home visits to cancer patients who are not, or can not, consult the hospitals.

My attempts however, at gaining access to absconded patients through Philani, were met with considerable resistance by Sister L. She gave me various reasons for her inability to help me, such as, she was too busy with her own commitments, she would have to get authorisation from higher authorities, she was not sure that her fieldworkers would be willing to help me, and so forth. This fruitless search for absconded patients forced me to rely on word-by-mouth referrals and on meeting potential abscondees at the hospital.

I argue that the secrecy that African informants attached to cancer played the primary role in my struggle to find absconded patients. Eventually,
I conducted interviews with four absconded breast cancer patients and six other breast cancer patients. Although this sample group may appear small, it represents approximately 32% of the total number of African patients seen each year by the Oncology and Radiotherapy Departments (see Report for future details).

4.2. **The cervical / breast cancer enigma**

During the research, several variables were identified as being valuable for consideration regarding the phenomenon of absconding. These variables were presented in various combinations by the African informants as being the primary reasons for absconding (see Chapter 3 on *Findings* in the report). However, towards the end of the research period, I saw figures of cervical cancer patients and the absconding rate for African cervical cancer patients was only 30% (in contrast to the over 80% figure of breast cancer patients).

The discrepancy between the two cancer groups is remarkable. The social, cultural and economic variables, identified as the determining factors of absconding by African breast cancer patients, are identical for the cervical patients. Why should there be such a noteworthy difference between absconding rates of members of the same group?

One of the differentiating issues that comes to mind is the symbol of the breast. Some authors have argued that breast cancer is most traumatic for women because it frequently involves the physical loss of a symbol of their sexuality. During my research I was surprised by the dismissive attitude that African women expressed when questioned about the symbol of the breast. Many of the women dismissed the questions, explaining that, for example: "It isn't such an important thing for us. It is for breastfeeding but we don't worry about showing them off".
I do not suggest that my research experience is indicative of all African women's attitude to their breasts, indeed my informants may simply not have wished to discuss sexuality with someone on the basis of only one or two interviews.

It was not possible due to time limits for me to explore the cervical / breast puzzle further. However, my suggestions (which were echoed by a doctor and social worker) are that:

i) unlike the African breast cancer patients, most African women presenting with cervical cancer at Groote Schuur Hospital, have "life-affecting" symptoms, such as bleeding and pain. The cancer is thus hindering their daily lives and so biomedical treatment is more readily regarded by the women as a necessary priority

ii) surgery is not recommended to the cervical cancer patients as often it is to the breast cancer patients

iii) although I did not come across it in my research, I argue that may be much symbolism and meaning attached to the breast by African women.

It is with the benefit of hindsight, that I would now reformulate and expand on my research to include comparative research across cancers affecting African women. I focused on the differences between women with breast cancer to ascertain the variables that determine the high rate of absconding by African patients. However, having completed that pilot project it is now possible to explore the cross-cancer dynamics that the recent cervical / breast differences have highlighted.
4.3. **Formulating "do-able" recommendations**

The formulation of the recommendation chapter was a challenging one because of the nature of the findings. The Oncology and Radiotherapy Departments expected answers to their problem of absconding African women. As Singer (1995: 99) so aptly warns, there is danger of "imposing externally generated 'solutions' to externally determined health problems".

Throughout the research period, the doctors expressed the belief, that I would "find things" that would lend themselves to recommendations that could solve the current compliance problem. They also requested several times that I publish a paper based on my findings because they argued that there is a great need for such information in South Africa.

It seemed that the "things" that I was expected to find, would enable the Department to work at changing the African cultural peculiarity that caused absconding. As Singer (1989: 1195) argues, I felt that I was:

"Trapped in a restricted role as the translator of cultural knowledge to health care providers, [and are] appointed the task of discovering 'how to get patients and laymen to do things that medical practitioners consider good for them'"

By understanding the cause they would be able to combat it, by being prepared for the tell-tale signs they would be able to "nip it in the bud". I was uneasy about this attitude and thus my recommendations were intended to change the ways and approaches of the doctors into accepting the patients' explanatory model and working *within* and not against that framework.
5. **Issues Arising From the Research**

There were several issues that emerged from the fieldwork and which need to be considered from the reflective position of hindsight. These issues were not necessarily apparent to me during the research period, however having taken the time to reflect on my experiences, I have become more sensitive to them. This section therefore, facilitates my consideration of the impact of these issues on the research experience.

5.1. **The Position of the Researcher**

Many anthropologists have debated the impact that the researcher’s physical presence has on her work. (see Bernard, 1994 and Burgess, 1991). The generally accepted view is that the presence of the researcher directly effects the research environment, primarily by creating self-awareness amongst the researched.

5.1.1. **Broaching Sensitive Topics**

During fieldwork, there is always the possibility, cynics would say the likelihood, that informants will consciously or unconsciously withhold information from one. The act of withholding information is due to several factors, some of which, are that:

i) the informant does not realise that s/he is withholding information that the researcher desires,

ii) the informant decides to withhold information because this gives him/her a perceived or real power advantage over the researcher,
iii) the informant does not feel confident in explaining certain pieces of information in a language other than his/her mother-tongue,

iv) the informant feels uneasy about discussing certain sensitive issues with the researcher.

During my research into the absconding of African breast cancer patients, the research methods of participant observation and in-depth interviews were used to gather information. The informants were willing to speak to me and no-one openly refused to discuss any of the issues that were raised. Occasionally informants would dismiss questions, saying for example, "That isn't really important" or "I don't know". These dismissals were accepted by me and the interview would simply continue. However, having encountered the cervical / breast puzzle, I have needed to reconsider such dismissals and other factors that could have prevented me from accessing certain information. I argue that, my breast cancer informants' withholding of information, fell into points (iii) and (iv) of the above four points.

As a young, unmarried woman who has no children, and does not speak Xhosa, I was clearly different to the breast cancer informants. In their eyes I held the social position of daughter (Beauty, one of the breast cancer patients, jokingly commented that I should call her "mama", because I was the same age as her youngest child). For the most part, however, the social differences between myself and the informants were not problematic. However, the differences in our social status, did hamper the discussion of certain topics that were considered to be reserved to adult conversation, such as; female sexuality, the symbolism and meaning of breasts, and so forth.

One of factors suggested, as a reason for the difference in the African breast / cervical cancer absconding figures, is the symbolism and meaning of breasts for African women. Many authors have written about the breast as
symbolising sexuality and womanhood for women. They have also discussed the trauma that breast cancer patients' experience with the loss of a breast (see Berger, 1990 and Gyllenskold, 1982).

The argument is that a higher rate of breast cancer patients abscond because they fear that they will lose their breast/s if they accept hospital treatment. The problem is that the informants only described their fear of cutting and did not mention their fear of losing a breast (see Chapter 3 on Findings in the report).

I argue that the informants were reluctant to discuss their fear of losing their breasts because:

i) breasts and female sexuality are not topics that are discussed openly within many of the African women's social contexts, and

ii) they considered me as holding a "daughter-status" and they would not discuss their sexuality with their daughters, or any woman much younger than themselves.

I further suggest that, although the breast cancer informants did not verbalise their perceptions of breasts and sexuality, they used their fear of cutting to represent their fear of losing a breast. The informants frequently spoke about the dangers of surgery, saying that cutting the cancer causes death. I suggest that this fear not only represented a fear of physical death, but also one of social death, in the form of the rejection by partners, of women who undergo mastectomies.

I interviewed three traditional healers and one sangoma. None of these informants mentioned African women's perceptions or symbolic attachment to their breasts. Their reaction to my social status, as a young English speaking girl, may have discouraged them from talking to me about
older women's sexual issues and concerns. They may have felt that it was inappropriate for them to discuss such issues with me - an obvious outsider.

5.2. **The scope and limitations of the fieldwork**

The research objective was to identify factors that caused the high rate of absconding by African breast cancer patients. However, it was clearly not possible for me to observe the act of absconding, neither was it possible, due to my time limitations, to observe the decision-makings of the patient and her therapy-management group. This meant that I needed to rely on interviews and participant observations of other interactions, in order to gain insight into the patients' decision to abscond.

The fieldwork's time frame did not allow for a long period of immersing myself-in the field. Although, many anthropologists argue that the researcher needs to immerse herself in the field in order to truly understand it, such immersion is not possible in all cases. Medical anthropology is a case in point. Invariably the applied medical anthropologists have limited fieldwork periods in which to research a particular subject. The clients (hospital staff or medical research organisations) want quick fixes, and two to three years in the field do not fit into such a schedule.

It would not have been possible for me to immerse - what would I have immersed myself into? There is no "absconding community" that I can live with and research on. Instead, I was concerned with observing individual incidence, the individual explanations of absconding. Such isolated events did not form a continuum but they did provide further insight into the absconding of African breast cancer patients. Therefore, although my research component consisted of regarding individual experiences, I was ultimately required to present findings on a "whole" shared experience - on a "cultural" phenomenon that the client wanted insight into. Therefore, throughout the report, in reaction to the biomedics' expectations of the
research, I consciously cautioned against seeking to generalise individual experiences into one group experience.

6. REVISITING THE FIELDWORK

In this section I briefly discuss how I would alter my research methods and approaches, if the same research topic was constituting a Masters Degree, through dissertation alone. This discussion is premised on my recent fieldwork experiences. The time frame would be between two to three years and there would be financial support available.

One of the difficulties I experienced implementing the methods, was my inability to communicate with the African informants in their mother-tongue. I have previously argued that there were no obvious problems of misunderstanding or confusion in the interviews. However, had I been fluent in Xhosa, the informants would have been able to express themselves better and I would have been aware of the nuances and meanings that only a first language speaker can identify.

Using the above introductory description as the scene-set, I would implement the following changes in the fieldwork component. I would employ two Xhosa speaking middle-aged women to translate and to conduct group interviews with informants. Such women would ideally be breast cancer patients too. Thus, the research assistances would be sympathetic to the informants' positions and would, because of their social status, be more readily accepted by the informants. The implementation of group discussions is an important one, because it would allow women to discuss points of common interest in a "safe" environment (an environment away from dominating family members and biomedical practitioners).
The participant observation of therapy-management groups' discussions would provide me with invaluable information into the factors and reasons for their treatment choices. It would also reveal the degree to which the breast cancer patient is actively involved in the discussions.

Comparative work would be undertaken between African cervical and breast cancer patients. Individual interviews, as well as group discussions, would be conducted with the cervical patients. This comparative approach would facilitate insight into African informants' different perceptions of cervical and breast cancers. Such insight would help to explain the huge difference in the absconding rates of the two cancer groups.

7. **CO-OPERATION BETWEEN TRADITIONAL AND BIOMEDICAL HEALERS: THE ANSWER TO ABSCONDING?**

7.1. **The biomedical and traditional healers' perceptions of collaboration**

Throughout South Africa biomedical practitioners are beginning to acknowledge the unique approaches and knowledge of the traditional African healers (see Abdool Karim et al., 1994 and Freeman and Motsei, 1991)). Indeed, there is a current concern within many of the biomedical health departments, that attempts be made to integrate the biomedical and traditional health models into a more inclusive healing system. However, the Oncology and Radiotherapy Departments have expressed doubts about the usefulness of such a merging in their field.

They acknowledge that the traditional healers have important social and cultural roles to play with regards to treating African breast cancer patients. However, the biomedics argue that when the traditional healers' encourage breast cancer patients to abscond from biomedical treatment, they
are doing them a great disservice. They argue that the traditional remedies neither cure nor control the cancer and that they are thus, preventing the women from receiving effective physiological based treatment from the hospital.

It would therefore, seem that the biomedics are arguing for an integrated model, where the women are counselled and their symptoms are attended to by the traditional healers, but where the control and possible cure of the cancer, is facilitated exclusively by the hospital staff.

The traditional healers, with whom I spoke, said that, in principle, they were willing to consider integration with the biomedical health model. However, they were suspicious about the motives of the biomedics and feared that they were merely after the recipes of their secret medicines and imbizas. They said that should such an integration occur, the biomedics would be useful for certain areas, including the following: providing diagnoses, conducting initial testing and specific treatments (such as chemotherapy and pills), and pain control.

The traditional healers were adamant that surgery and radiotherapy as treatments for breast cancer, would not be allowed. The healers felt that their role would be to counsel the "whole person", thereby providing emotional and physical healing. They argued that they would treat the cancer with their medicines only.

The biomedical practitioners stated that, although they had previously attempted to incorporate traditional healers into the hospital, most of the healers have not been willing to enter into any such form of dialogue. The doctors felt that this disinterest indicated the unwillingness of the healers to forfeit the power and financial benefits that being a traditional healer affords one.

The experiences I had with both healing groups demonstrated that neither is willing at present to compromise their position of power. The
traditional healers argued that biomedical practitioners only wanted to steal their medicines from them, and the biomedical practitioners felt that the traditional healers would continue to distrust their treatments. Their mutual assertions that their health model should dominate any co-operative venture, indicates that there is much work to be done, before the two groups can begin to discuss possible collaboration. Initial contact and communications will need to be the first step in this process.

7.2. Is collaboration the answer to absconding?

The Oncology and Radiotherapy Departments have argued that, by incorporating the traditional healers into their cancer treatment procedures, they will encourage African women to comply to biomedical treatments. However, the traditional healers’ notions of medical collaboration do not include their encouraging breast cancer patients to undergo surgery.

As Chavez et al (1995: 70) note "Women with radically different views of...cancer [compared to biomedical practitioners] are not necessarily presenting random, idiosyncratic misconceptions". Thus, the African breast cancer patients are unlikely to suddenly change their 'logic' or their explanatory models of breast cancer, and accept surgery. However, they may be more willing to accept other forms of biomedical treatments, once they realise that cancer treatment it is not an either / or choice (between biomedical and non-biomedical healers, and also between surgery or no hospital treatments).

Therefore, I argue that it is the ridding of the African breast cancer patient and her therapy-management group’s perception of an either / or treatment option, that will ultimately enable traditional and biomedical healers to create a successful collaboration. A collaboration that patients trust and consult. By removing the either / or pressure, the patient may be more inclined to comply with some form of biomedical cancer treatment for longer.
8. CONCLUSION

The phenomenon of absconding is a complex one that demands research attention, for not only is it comprised of social, cultural and economic factors but it also has far wider implications for medical anthropologists. The phenomenon is not a new one and is certainly not exclusive to African breast cancer patients. An exploration, into the practice of absconding, raises some pertinent questions for the medical anthropologist, such as:

i) is absconding simply a matter of African breast cancer patients rejecting biomedical treatments in favour of traditional therapies?

ii) is absconding a problem 'solvable' by a medical anthropologist? if not, then of what use is the medical anthropologist, as researcher, to the biomedical practitioners?

iii) can research, into the phenomenon of absconding, provide insights into the incipient relationship between traditional and biomedical healers, and also offer suggestions for the future scope of such interactions?

In response to the above questions, I argue that absconding should not be viewed as a simple rejection of biomedical treatments. The act of not returning to Groote Schuur Hospital for treatment, is based upon the social, cultural and economic compositions of African breast cancer patients' lives. Therefore, it is the patient's 'logic' that determines her decision to abscond.

This logic enables the woman to decide to adhere to or reject her therapy-management group's recommendations. In deciding whether to listen to her therapy group's advice, the patient needs to play their pressures to abscond against her position regarding; the viability of her adopting the sick
role, her belief in the efficacy of biomedical and traditional treatments, her response to the potential loss of a breast, and so forth.

Therefore, although the decision to abscond is made by a patient's therapy-management group, the decision to adhere to that ruling is made by the woman herself. However, the two invariably concur and thus, the breast cancer patient is supported in her choice to consult a traditional healer.

The biomedics view absconding as a problem that, given enough research and understanding, can be addressed. The implementation of this 'addressing' is presented in rather vague terms by the biomedical practitioners, suffice to say, that they see absconding as a practice founded on ignorance, and perpetuated by the traditional healers.

As a medical anthropologist, I do not perceive absconding, or any other form of non-compliance, as an easily solvable biomedical problem. I argue that the act of absconding constitutes many social and cultural peculiarities, that biomedics can not simply 'fix'. As Scheper-Hughes explains (1990: 194), many patients:

"...continue to hold out for an explanation and a therapy capable of linking their symptoms with their experiences, their lives. One attraction of [alternative health models] is that these provide...a satisfying interpretation of...the infliction, and they do so by explicitly locating disorders in their wider social context"

Thus, the phenomenon of absconding will continue, until biomedical approaches to breast cancer fall within the terms of the patients' explanatory models. It seems unlikely, however, that biomedics will ever adopt such an approach, for it would be diametrically opposed to the biomedical model of disease. Therefore, a compromise on the side of the hospital is required, a compromise in which biomedics offer more appropriate treatments to the
African breast cancer patient and her therapy-management group (see the chapters Conclusion and Recommendations in the report, for further discussion of this compromise).

As a medical anthropologist and researcher, I argue that my contribution to the absconding debate, is to highlight the multi-layered contexts in which decisions to abscond are made. As Scheper-Hughes (1990: 194) argues:

"...if medical anthropology does not begin to raise the possibility of other realities, other practices with respect to healing the...body, who can we expect to do so?"

Therefore, I need to inform biomedical practitioners that absconding is not an easily solvable problem. It is a phenomenon that is based in, and arises from, the tension between the biomedical and the African breast cancer patient's explanatory models. Therefore, I recommend that the biomedics seek to bridge the immense gap between traditional and biomedical approaches to cancer treatment, by initiating communications with traditional healers and therapy-management groups.

I argued in the Conclusion chapter in the report, that the phenomenon of absconding arises primarily out of the inherent contradictions between the traditional and biomedical models of cancer. As I explain (page 44 of the report):

"However, because the two models [traditional and biomedical] are at fundamental loggerheads, she is unable to combine them fully. Thus, she is ultimately forced to chose one above the other".
In researching the factors determining absconding, I spoke to several biomedical and traditional healers about their perceptions of the other's approach to treating cancer. Both sides expressed doubts about the efficacy and safety of the other's methods. Although, they indicated an interest in participating in future collaborations, they expressed reserve about committing to any particular working-model that such a collaboration would entail. However, both felt that their treatments should be given priority in such a model.

The report aims to highlight the complexities that biomedical practitioners need to consider in attempting to better understand the phenomenon of absconding. Provided with such insights, the Oncology and Radiotherapy Departments will be able to initiate communications with traditional healers to reduce the tensions that currently exist between these two groups. It is hoped that such a collaboration will ultimately serve to offer African breast cancer patients treatments that are culturally and socially acceptable to them.
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