Coping with cancer and adversity : Hospital ethnography in Kenya

Mulemi, B.A.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Ethnography inside and outside the hospital

Are you going to say in your report how badly we are doing? ... Are you investigating to report how efficient or inefficient we are? (Senior nurse)

In the fourth month of fieldwork, I had to reintroduce myself to a doctor in the cancer clinic. He asked me to explain my research again. After I did, I requested to observe the patient admission process. I attended the main admissions clinic every Monday as part of my fieldwork. I observed clinic events involving new patients and those who were due for subsequent hospitalisation. My presence in the clinic facilitated my rapport with patients and hospital staff, especially those I interacted with later in the ward. The doctor at the clinic hesitated and asked:

What exactly do you want to observe? That must be a very interesting research. … Okay, just sit there and observe …

Medical professionals and ethnographers apply the term ‘observation’ differently, and the doctor was not familiar with ethnographic observation in medical settings. Whereas I wanted to observe interactions and events in the hospital that would give clues about patients’ experiences of treatment and care, physicians and other healthcare professionals would take observation to mean looking out for objective signs and symptoms of patients’ experiences of illness and treatment. They are not used to studies in which a social scientist hangs around taking notes without structured research instruments. My fieldwork approach was indeed new, ‘interesting’, and strange to the hospital staff. Doctors asked university medical students and other trainees attached to the clinic and present during ward rounds to state the objectives of their observations each time. They occasionally
prompted students to ask questions “if they were to learn anything.” On occasion I asked questions for clarification or to hear an explanation of a particular issue, but my questions were different from those of the hospital apprentices, generally falling into the categories of either social work or community health. The hospital staff were curious about my fieldwork and unfamiliar research approach. They stopped asking me about the objectives of my observation of clinic and ward events as time went by. A pharmacist once asked me:

Are you doing your (medical) studies by correspondence? And how long is your course taking?

Many patients and staff wondered why I came to the hospital daily and spent so many hours there. Some staff thought I was evaluating their performance. During a ward round, a senior nurse-in-charge asked:

Are you going to say in your report how badly we are doing? People will say according to research done by so and so it was found that things are going in this manner ... Are you investigating to report how efficient or inefficient we are?

Other hospital staff members were curious to know what I was ‘writing all the time.’ I noticed that writing notes at times interfered with the natural flow of conversations and events. In such cases, I retreated to the staff room or a quiet place to record observations and conversations before I could forget. After the first few months, the cancer ward staff got used to my presence and research; nevertheless, I explained my research whenever there was the need for clarification. Low awareness of hospital ethnography or anthropology contributes to the constraints to anthropological studies in hospitals (Zaman 2005). Anthropological fieldwork is also a potential source of conflict, as healthcare professionals detest being under social scientists’ scrutiny (cf. Hensen 1991; Van der Geest 1989). This chapter describes the methodology of the present study, beginning with a brief definition of ethnography and a discussion of the field of hospital ethnography. Next I address the choice of my study site, my interaction with study participants and the scope of the ethnography. After this, I describe the process of my integration into the hospital setting, and issues in gaining access to the hospital as a site for anthropological fieldwork. Finally, I discuss my position in the hospital during the fieldwork, and explain the techniques I used in data collection and analysis.

Anthropology in medical settings

Ethnography is both a qualitative approach to data collection on cultural phenomena and a product of fieldwork. It entails direct description of the culture of specific communities or social groups drawing on observation and verbal communication as activities happen naturally. An important feature of ethnography is
the presence of the researcher in the field to observe and record ongoing human activities and interactions in their actual settings.

Numerous research sites are available to anthropologists for ethnography, the basic presupposition of ethnography being that human interactions in a defined setting generate a culture that anthropologists can study systematically and describe. The essential premise for hospital ethnography is that hospitals are not identical clones of a global biomedical model. That is, hospitals the world over take on different forms in different cultures and societies (Van der Geest & Finkler 2004). Healthcare services in different hospitals and wards focus on different goals for patient care and assumptions about the diseases being treated. This results in a variety of approaches to organizing and healthcare activities, as well as a broad range of staff attitudes, expectations and relationships with patients (Morgan 1986: 69). Hospital ethnography thus focuses on descriptions of the distinctive cultures of different hospitals. Interactions and practices in medical settings bring to view major societal values and beliefs that shape healthcare activities and patients’ experiences. In the 1950s and 1960s, social scientists focused on cultural studies of hospitals in developed countries due to the ubiquity and relative ease in accessing hospitals (Freidson 1963: ix-x). Sociologists gradually presumed that hospital practices in technologically developed countries took similar forms (Glacer 1963), and this reduced the interest in ethnographic studies of hospitals. Hospital ethnography was then abandoned due to the shift of social research toward quantitative surveys that marginalized cross-cultural investigation of variations in hospitals (Zussman 1993). In contemporary medical anthropology, the recognition that hospitals are social institutions with cultural variations which influence healthcare practices and outcomes has promoted interest in hospital ethnography.

The groups of people interacting in medical settings share norms, rules of behaviour and experiences amenable to ethnographic observation. Aspects such as social status and livelihood contexts of hospitalisation shape patients’ experiences. The present ethnographic study focuses on healthcare issues from patients’ perspectives during their on-going hospitalisation experiences. Ethnography is a highly effective approach to comprehensive description and analysis of how patients make sense of their physical suffering and parallel social and emotional adversity. Hospital ethnography serves as an important method for applied (medical) anthropology, or strategic ethnography (Spradley 1980). Hospital ethnography is ‘strategic’ research because it provides useful data for addressing gaps in medical services and initiatives for the improvement of patients’ quality of life. It is an appropriate approach for exploring the experiences and felt needs of patients as sufferers in medical settings. This is essential for the interpretation of healthcare issues and qualitative data that can strengthen conceptual frame-
works on coping with illness. Qualitative hospital study can also facilitate an in-
depth understanding of the needs of patients and their carers. This can also con-
tribute data for theoretical debates on illness experiences and patient satisfaction
and quality of life. Hospital ethnography also reveals realities about wider con-
texts of healthcare experiences within and beyond medical settings. Therefore,
ethnographic approach has important practical applications in health policy init-
avatives. Stepping back, it can thus also be said that this study entailed fieldwork in
a new and an unusual site for anthropological research; the community or village
has been the conventional fieldwork site for most anthropological studies before
the advent of ethnography in modern institutions.

Unusual fieldwork site
At the inception of the present project, I recalled my previous interest in studying
the experience of terminally ill patients. I had earlier envisaged the possibility of
doing a study among patients in institutional care, possibly a hospice. This partly
influenced my selection of the hospital as my fieldwork site for the present study.
The fieldwork I conducted towards my master’s degree in anthropology was in a
rural setting in western Kenya. The thesis was an ethnographic appraisal of a
community-based malaria control programme. After finishing the fieldwork in
1996, I became interested in collaborating with a sociologist friend at the Univer-
sity of Nairobi to conduct a qualitative study of patients’ experiences of illness
and care at a Nairobi hospice. Popular discourse and literature about the hospice
tended to emphasize its role in providing palliative care services to cancer pa-
tients and their families. The leaflets and other documents available at the hos-
pice also confirmed that most of the hospice clients at the time were cancer
patients. My friend and I eventually ended up dropping the idea of developing a
proposal for the study due to a lack of time and other resources. We nonetheless
still wished to do a collaborative project on patient care owing to our common
interest in social science perspectives of health and illness.

I completed my Master of Arts study and soon got an appointment as a part-
time lecturer in a local private university and two of its constituent colleges in
Nairobi. Apart from teaching introduction to anthropology to first year students, I
taught African Belief systems and thought, African ethnomedical systems, culture
and development studies and comparative ethnography, among others. The last
three course units interested me most. Following my full-time appointment to
teach at the university, I developed a PhD research proposal drawing on my
master thesis. I proposed to investigate the social and cultural construction of
malaria control at the district level in the same fieldwork site I visited for my
master’s degree. I submitted this proposal to the Medical Anthropology and
Sociology unit at the University of Amsterdam for consideration. The process of
communicating my research interests with one of my supervisors in the Netherlands exposed me to ideas about other opportunities for anthropological research. I found the idea of fieldwork in a hospital newer and more captivating than others I had been considering at the time. This reminded me of a popular example our research methods professor at the University of Nairobi often cited. This was the work of Rosenthal (1973), “On being sane in insane places”. Rosenthal’s research assistants stayed in a psychiatric ward for some time as pseudo-patients. This inspired me to formulate a project in which I would spend time in a hospital to observe patient care interactions and experiences of medical treatment.

My interest in the re-emerging but ‘less-trodden’ field of hospital ethnography was gradual. I considered this the best opportunity to pursue my earlier interest in an anthropological study of an institution for the terminally ill. I shifted my research focus to a proposal to study cancer management practices in a cancer ward in the national referral hospital in Nairobi, Kenya. This would grant me the opportunity not only to pursue my interest in medical anthropology, but also my earlier interest in patients’ experience of terminal illness and institutional care. The cancer ward and the Nairobi Hospice are less than a kilometre apart, and I assumed there would be collaborative interaction in patient care. Therefore, my selection of the national hospital and specifically the cancer ward for this study was strategic. The idea of ‘ethnography in non-village’ medical settings was also interesting to me after years of discussing comparative ethnography using secondary data from a macro-societal level; ethnography in a modern health care institution would be a novelty for me. Later I learned that the Nairobi Hospice is only a day-care centre, not an inpatient facility, and that it is semi-autonomous from the hospital. Based on this information, I decided that it was not an appropriate site for hospital ethnography.

On embracing the idea of a ‘new site’ for medical anthropology research, I settled for a single site, or ‘micro-ethnography’ (Zaman 2005; Spradley 1980). The main fieldwork site was the adult cancer ward, though; I collected complementary data from related units as I will explain later. The ward brought together patients from diverse Kenyan cultures and a range of ages. Despite these differences, they faced some of the same challenges related to their livelihoods, cancer illness distress and hospitalisation that produced some similarities in their responses. Since I was interested in patients’ responses to on-going hospitalisation, it was necessary to spend as much time in the hospital as possible. The usual approach to hospital treatment research focuses on patients’ views and experiences as they report them after having left the hospital. Other approaches to hospital studies involve short encounters between patients and researchers in wards, outpatient clinics or in treatment waiting areas. Longitudinal and in-depth, qualitative study in the hospital was therefore a new idea to the hospital staff and me.
The hospital Ethics and Research Clearance Committee found it strange as they had only a vague idea about social science, not to mention ethnography in medical settings. Anthropological research in Kenyan hospitals is new, and the present ethnography is the first of its kind. Most hospital staff as well as the research clearance committee initially perceived the hospital as an ‘unusual study site’ for anthropology. Establishing and maintaining the ethnographer position in the hospital posed various challenges. These constituted unique field entry constraints relative to the process of access to villages or open community sites for anthropological research.

Admission to the hospital as ethnographer

Available literature indicates that hospitals vary in the way they permit different kinds of research. Social scientists who have conducted hospital studies have experienced different degrees of difficulty in entering clinical settings. The relative ease with which social scientists accessed hospitals (compared to other organizations) in Western countries (Freidson 1963) gradually declined due to physicians’ reservations about external evaluation or regulation of their profession (Freidson 1970). Admission of social scientists into hospital settings for research takes at least two forms. First, both biomedical and social science researchers can access clinical settings through (informal) negotiation with hospital managers or unit supervisors (cf. Halford & Leonard 2003; Kirkpatrick 1980). Physicians and other hospital staff who do research in their own or other hospitals often use this approach to access clinical sites. Zaman (2005, 2008) for instance used his role as a physician to gain informal access to conduct an ethnographic study of a hospital ward in Bangladesh. The second mode of access to medical settings for research is through research and ethics clearance committees, which vary in their organization and rules among different hospitals and countries.

Formal procedures of approving researcher entry to hospitals vary in both developed and developing countries. In some cases, ethics committee approval is only necessary when the research involves patients (Halford & Leonard 2003). Some individual members of research clearance committees may use their power to restrict ‘outsiders’ from ‘using their patients’ or intruding in their research fields or disciplines. After I received approval, some hospital staff adopted a protective attitude regarding the ‘use’ of the hospital, medical unit, staff, patients and other caregivers. A medical professional for instance, turned down my request to talk to him. He argued that the only benefit he would anticipate from participating in my research was ‘co-authorship of articles’, yet this would not be possible as he was not part of my supervision team. He categorically retorted:
... Sorry ... you know when you are doing a study at a department ... one of us should be your supervisor. That is how it goes ... Now you are doing the study with other people ... How will the head of this department or I benefit from the study? It may be a PhD that you are doing, or whatever, but the only way one of us can benefit is through writing papers from the data. You are going to write papers, aren’t you? You are doing the study in our department and yet other people are supervising you ... This means you are using other people. How will I benefit? You are doing a study and we are the ones giving you the information ... That means that you are using us ... I am sorry, I have other things to do.

While a number of participants including patients seemed to understand the ultimate value of my research, others were interested in potential personal benefits. Some respondents expected material benefits from participating in this study. A number of patients’ suddenly lost interest in follow-up conversations. Others hoped that I could link them to organisations that give assistance to cancer patients and their families. Several patients expected financial handouts and information about educational assistance to family members. Access to some secondary data that would complement this study was not easy due to some hospital workers’ reluctance to facilitate this. An informant, for example told me that she could only ‘steal’ some documentation on the status of cancer treatment in the hospital because colleagues would not willingly share the information.

An important criterion for approval of a hospital research projects is the perceived usefulness and benefits to patient care (Poland 1985). Hospitals in both developed and developing countries could benefit enormously from input from ethnographic studies, but have yet to fully appreciate this. Many barriers can arise to block an anthropologist’s access to a hospital or clinic space and access cannot be taken for granted (cf. Long et al. 2008: 71). The hospital research clearance committees, for instance, are often unfamiliar with qualitative research and its significance to patient care. This may be a basic barrier to their acceptance of ethnography. My application for access to the hospital as an ethnographer entailed a negotiation process. This required finding a delicate balance between meeting the demands of the hospital research project protocol and respecting the principles of ethnography.

As an outsider to both the hospital setting and the medical fraternity, even official clearance to enter the hospital, cancer ward and radiotherapy clinic did not guarantee cooperation and access to daily events. Nurturing relationships with hospital actors was necessary long after the study’s clearance; rapport building is a continuous process, and it is essential for continuing access to daily events in the ward and related sites. I bargained continuously to be present in social and medical situations involving study participants. Negotiation for access in this sense goes beyond official sanction. Two types of challenges to accessing medical settings for ethnographic data collection emerged in this study. First, the procedure for physical admission to the ward and related sites was very rigorous. It required discretion in addressing questions about the ethnographic project
without compromising anthropological methodology. The clearance committee expected me to adapt my research proposal to meet guidelines that did not entirely suit an ethnographic approach, as the next section shows. The research proposal review process was scrupulous and it entailed a long waiting period. The ethics and clearance committee met to discuss hospital study proposals every six weeks. I received final approval for the fieldwork after two revisions of my proposal to comply with their standard format. The guidelines were entirely based on the tenets of quantitative research proposals. The second challenge in an ethnographer’s entry into the hospital concerns accessing participants’ social and subjective experiences. In order to access patients’ and other hospital actors’ perspectives, constant rapport building is necessary. I was conscious of the fact that my career and professional differences from hospital staff could influence my interaction with them. My ‘hanging around’ some medical personnel while they worked made them uneasy. A few of them either asked me to ‘give them a minute’ to finish their work or ignored my attempts to communicate with them. It proved easier to be with patients than the medical staff who were often busy and needed their work space to themselves. However, I considered study participants’ emotional disposition before proceeding with conversations with them; distressed patients, relatives and hospital staff could resent the presence of a researcher.

As an anthropologist by training, I was an outsider among hospital workers and could not participate in their professional activities. As a ‘native anthropologist’ however, I was an insider with regard to the patients’ and other participants’ general culture. This facilitated my social interaction with patients, their relatives and staff. Patients’ experience of disease and hospitalisation alter a patient’s lifeworld, which researchers may not easily access. Therefore, an ethnographer needs patience and tact in order to understand and interpret patients’ lived experiences from their perspectives. My daily and prolonged interaction with patients and their carers facilitated the data collection on the sufferers’ experiences. I sought basic cancer therapy information and literature from ward staff in order to understand essential aspects of the disease and general treatment discourse. Since most of the ward staff were aware that I was doing the research as a student, they readily explained some treatment and patient care issues. Nurses explained aspects of their work to me, while some physicians and the pharmacist in-charge gave me basic information about treatment. However, some medical workers seemed uneasy when I asked after things they considered ‘obvious’, or things that medical students discovered in due course. This raises a challenge many social scientists face when conducting research in medical settings: their own lack of basic medical training. Social scientists may need more skills for ‘speaking medicine’, ‘knowing biology’ and ‘taking care of patients’ (cf. Poland 1985: 61). Although current protocol for hospital study proposals already points out the
challenges of accessing the hospital and related events for ethnographic study, additional emphasis should be placed on how essential such medical knowledge and skills can be to facilitating admission to different clinical sites and for understanding essential patient care phenomena.

**Ethnographic study design versus Hospital Research Protocol**

The hospital’s Ethics and Research Clearance Committee had preset protocol for research project proposals, and their first recommendation for me was to revise my hospital ethnography proposal to make it consistent with their guidelines. It is important to note here that the research proposal structure and clearance forms reflect mainly the paradigm of quantitative biomedical research design; available guidelines did not include an option for ethnographic procedures or social science research. The hospital committee approved my proposal after three reviews that entailed significant modification of the initial ethnographic presentation. As an example, I had to include (working) hypotheses, sampling design and sets of questions (questionnaire) for the committee to endorse. I derived working hypotheses from the research questions outlined in Chapter 1 in order to make my application for clearance complete. The hypotheses reflected the general assumptions of the present ethnography in broad terms: First, that patients’ subjective experiences of their condition and treatment influence their satisfaction with hospitalisation. Second, that cancer patients’ narratives and observable events while they undergo current hospital treatment reflect an array of issues related to healthcare and the cancer crisis in Kenya. I also proposed that positions of different actors in the hospital’s social and professional hierarchy influence patient care interactions and communication in the cancer ward. The final hypothesis stated that hospitalisation due to cancer threatens the livelihood security of patients and their families.

In place of questionnaires, I offered conversation and observation guides that I drew from the study goals stated in Chapter 1. In the process of my proposal review it became clear that the Ethics and Research Clearance Committee would not readily approve a project of entirely ethnographic design. The absence of a social scientist on the clearance committee could arguably account for their reservations about ethnographic hospital study designs. As noted earlier hospital research protocol reflected the exclusively quantitative approaches that are familiar to medical settings. These approaches, as the proposal guidelines indicated, emphasized experimental designs with specified human and non-human samples. My reviewers initially expected me to provide details about sample designs typical of biomedical interventions. They later asked me to justify the absence of causal hypotheses with definite dependent and independent variables. Issues about quantification featured in most of the medical staff’s comments on
the present study during the initial phases of gaining access to the hospital and fieldwork. The hospital research clearance committee insisted on this and their minutes declared in part:

… you state that data from patients will be collected through observation, informal conversations and follow-up visits. You still need to show how you will quantify the parameters obtained… (Ethics and Research Clearance minutes, February 2, 2005)

For quantitatively-oriented physicians, facts must be demonstrated, while for anthropologists, meanings must be interpreted (von Merring 1985). In this sense, while medical scientists and quantitative researchers may make generalizations about a population based on study samples, ethnography contributes to the development of conceptual generalization. Despite the apparent complementary roles of qualitative and quantitative hospital research, however, methodological differences might restrict the application of both approaches together. After approval of my project, I still had to negotiate with some informants for the use of conversation guides as opposed to questionnaires. Most hospital staff expected short answer, open or close-ended questions. In fact, some of them said that they would have preferred to go through a questionnaire in advance of the conversation. The words of Dr. Koki below illustrate the unfamiliarity with ethnography in the study hospital. While he introduced me to his clinic during my orientation to the hospital, he said:

… this student wants only to observe and see how we talk and ask questions here. He wants to do this so that he can know how to ask and frame his questions when his turn comes. He does not have a questionnaire and he will have to rephrase the ‘hard core’ questions he has.

I used the orientation week to do some pilot fieldwork in the hospital. Throughout the orientation and actual fieldwork the responses of the hospital staff revealed their limited exposure to ethnographic studies. Usually hospital studies are predominantly quantitative surveys, so respondents’ expectation of survey-type questionnaires was not surprising. The Ethics and Research Clearance Committee had earlier remarked:

… include questionnaires, observation and conversation guides alone are not the way to do research … State the sample size and how it was derived. Clearly state the sampling plan and procedures …

Similarly, Dr. Martina insisted on seeing a questionnaire during a conversation session. I explained that my study was ethnographic and that my question and conversation guides were adequate. Before consenting to participate in the conversation, Dr. Martina said:

… You need to interview the head of department. I think he is the appropriate person with all the facts you might be looking for … Make a questionnaire for him. Even for me, you should have sent the questionnaire in advance so that I could prepare. … then you need to leave me with your questions so that I can prepare the answers accordingly.
The ethnographic approach values spontaneity of responses; questionnaires sent to respondents to ‘prepare answers in advance’ would negate the essence of the method. In view of possible professional disagreement or conflicts in studies and collaborative work in clinical settings Barnet (1985: 59) argues that:

… anthropologists in clinical settings have to ‘demystify methods’ because the potential contribution of ethnographic methods is not yet fully appreciated. Elaborating clearly on the ethnographic approaches can also diminish the misconception that the choice of ethnography is an escape from scientific rigor in research.

My application for clearance and the fieldwork process turned into advocacy for ethnography as a valid anthropological method. Hospital staff’s curiosity and criticisms of the ethnographic design indicated their enthusiasm for the ‘new research approach.’ Their later inquiries about the fieldwork process signified their commitment to the research and interest in its outcome. Some physicians and nurses were eager to understand ethnography and find out what contributions it would provide at the end of the project. Dr. Koki, for instance was interested in the psychological and social effects of cancer on patients. Although he insisted that I needed to have a questionnaire, he later showed appreciation of the ethnographic method. He concurred with the clearance committee and other staffs’ final positive reception of ethnography as a ‘new research approach’. He remarked:

In your approach, you have combined the “theme and saturation” method. You need to choose one. You will have to use the narrative method rather than any instruments that you may have developed in the Netherlands. They may not be applicable to our hospital. The experiences of our patients are unique …

The essence of the ethnographic method is observation and study of events as they occur naturally. Dr. Koki’s comment above concurs with the basic principle of ethnography; that is, questions emerge spontaneously as the fieldwork progresses. Ethnography does not rely on preset questions as in survey studies.

I provided the tentative sample sizes of my respondents as the hospital research protocol required, considering time, the nature of ethnography and other practical constraints in deciding the viability of sample sizes. Since, researchers cannot determine the exact number of human subjects that will be included in an entirely ethnographic project beforehand. I envisaged that by the end of the fieldwork I would include a purposive sample of 40 patients (20 men and 20 women) as main respondents. The other research participants would be: 40 family carers, five informal carers (three pastoral workers and two volunteers), 10 doctors linked to the cancer ward, 10 nurses, 10 policy makers in the ministry of health, five social workers and two administrators in the cancer treatment department. In compliance with the demand that my proposal should specify a definite sample size, I proposed to include a maximum of 132 respondents in total. However, I took note of the fact that the actual number of study participants
in a qualitative study depends on how soon saturation of information related to research themes is realized (Conrad 1990).

The minimal research design changes I made were useful and consistent with the methodological flexibility in ethnography. This forms a framework for professional and interdisciplinary dialogue between anthropologists and other scientists. The flexibility of the ethnographic method was handy in the actual selection of the study participants. Situational constraints and exclusion criteria shown in the next section were important in the choice of the main respondents. My methodology critics gradually became aware of the complimentary roles of ethnographic and quantitative approaches in health care studies. As the foregoing account shows, disciplinary firmness and an emphasis on methodological uniqueness of hospital ethnography can facilitate useful professional interaction between anthropologists and healthcare specialists. Ethnography increases chances for rapport building and data collection through informal talks. However, the hospital Ethics and Research Clearance Committee prefer questionnaires for the research approval procedures because of at least three reasons. First, the research instruments have to be approved as not being potential sources of antagonism in study reports. Second, the busy schedules of medical personnel necessitate preset questions, which can be available to them prior to conversations. Third, biomedical researchers focus on questions that easily meet conventional data coding and quantification techniques.

Participants

I selected patients who had been in the ward for at least one week as main respondents. Most of them were on the first to fifth courses of chemotherapy, or prolonged treatment. Apart from the long-term cases, patients were in the ward for either three or six days of chemotherapy treatment and observation. They took a maximum of six chemotherapy courses with intervals of three weeks before further treatment decisions. The hospital prescribed a minimum of eight, and a maximum of 30 radiotherapy sessions, often followed by chemotherapy. Combined treatment regimes of ‘radio-chemotherapy’ entailed relatively shorter duration chemotherapy and radiotherapy. Negative side effects, holiday and weekend breaks, the disease responding poorly, and the intermittent loss of patients to follow-up hospitalisation often interrupted treatment.

I excluded patients who were too sick or unwilling to participate in the study. Inclusion of very sick patients in a study can result in ethical and methodological difficulties (Jones & Lyons 2003). Very sick patients are not able to give informed consent, maintain emotional stability, or sustain conversation. I continued
conversations with willing patients if they could speak Kiswahili or English, as well as a few patients I talked with in both Luhyia and Kiswahili, transcribing the information in English. I asked those who had good knowledge of both English and Kiswahili to switch freely between these languages in case they had difficulty with expressions. (Doctors and other hospital staff also occasionally speak to patients in their common ethnic languages, and available ward staff will interpret when patients speak neither English nor Kiswahili.) I did neither pursue conversation with patients who spoke other languages nor used ward staff interpreters. It was cumbersome to do so for the informal conversation approach I used. However, most of the patients I approached and could not speak English had sufficient competence in Kiswahili. I explained my study to them in detail before asking them to participate. They consented either verbally or in writing, signing a written consent form of which they retained copies. I used a voice recorder only when respondents had agreed to it in their response to my request for their participation consent.

The final number of respondents at the end of the fieldwork was a convenient sample fitting the criteria described above. Over time, I included 42 patients as main respondents, and had in-depth conversations and interactions with them on multiple occasions. Their ages ranged from 18 to 73, with a mean of 42. Sixty-five per cent of the patients were male and 35 per cent female and they came from 10 different Kenyan ethnic groups. They had travelled to the study hospital from all parts of the country, from as far away as 600 kilometres. Thirty-two of the respondents either were married or had been married, while 10 of them were single. A few of the patients had formal employment, mainly as primary school-teachers, clerical officers, or technicians. All the patients depended on unpredictable subsistence farming, while a few of them also had small-scale cash crop farms. Appendix 1 summarises the characteristics of 27 patients whose verbatim excerpts appear frequently in this ethnography. I have used pseudonyms for all the respondents and key informants I refer to throughout the text.

I interacted with the main respondents for a minimum of two, and a maximum of six hospitalisations, which ranged from three to five days each. The interaction ended when respondents either died or did not return to the hospital before the end of the fieldwork. I endeavoured to maximize the information I collected during initial conversations with patients I identified for direct participation in the study. This controlled the effect of unexpected drop-out of respondents. I interacted with main respondents for most of their hospital treatment period. I sought the views of key informants to supplement data from patients. The key informants included 11 nurses, three doctors, a pharmacist, a nutritionist, two

---

1 Kiswahili is the national language while English is the official language in Kenya.
administrators, a physiotherapist, three radiographers, a clinic records officer, and two ward assistants. The study entailed observations and conversations with participants during various events in the ward and related places.

Family members constituted an important part of the ward and significantly shaped the inpatients’ experiences. I talked to the relatives of patients who participated either directly or indirectly in this study, and found they provided a good deal of information for the analysis of particular respondents’ experiences. In the instances where I followed patients to their home areas, I also had informal conversations with family members who joined in with the spouse or other close family carer to talk about cancer treatment experiences and clarify related issues. For the most part this was done in the patients’ presence, though on occasion relatives would continue to talk about their experience of caring for the cancer patient as they escorted me out of their houses or compounds.

Events and places

Observing the daily healthcare procedures and interactions between patients and relatives, hospital staff and patients, and the staff among themselves meant attending a variety of events at the hospital. I attended the weekly major and minor ward rounds conducted by a consultant and a ward physician, respectively, and also occasionally sat in on diet and general counselling sessions for patients and their relatives in the nutritionists’ office in the ward. On Mondays and Wednesdays I observed the weekly main admission and review clinics. Remaining conscious of timing and the appropriateness of my presence was crucial in determining which places to visit and which events to observe. The hospital for instance set aside the period between 12:30 pm and 2:00 pm as the official patients’ visiting time, and the ward staff tried as much as possible to keep out of patients’ way while they were interacting with their visitors. The cancer ward matron reminded me at the beginning of my fieldwork that visiting hours were the ‘patients’ time with their relatives.’ I was therefore to be cautious during these periods when patients needed time with their relatives and friends, or just to be alone. Some patients however did not mind having conversations until their visitors arrived, and some did not even mind my presence while they were with their visitors. I used my own discretion at times to let respondents be with their relatives when my presence seemed to constrain their interaction.

Considering hospital activity timetables in order to identify useful openings for observation and conversation, I made observations in all places that were accessible to me in the ward, its surroundings and the cancer treatment centre clinic, observing patient review clinics; admission, patient discharge and clearance activities; and events in radiotherapy rooms. While doing hospital ethnography, researchers must take precautions against disturbing vital tasks of the hos-
hospital staff and other carers (Andersen 2004). Some patient care events are routine, however, and researchers can plan when to be present. Nevertheless, both the researcher and hospital workers may not foresee and plan for other patient care events. In such cases, I made spontaneous choices to attend proceedings with discretion to avoid intruding in work spaces and social affairs, excusing myself whenever a patient or staff performing a procedure seemed uncomfortable with my presence.

Patients were eager to return home either at the end or before the completion of their treatment sessions. Being back in their home environment offered them a break from their individual experiences of hospital management of cancer. Each hospital discharge denoted the desirable, yet temporary retreat from the routine hospital life for both the in-patients. The temporary break was similarly a relief for me, the hospital ethnographer, when my arrangement to visit some discharged patients at home materialized. Neighbours and friends called frequently to either greet in-patients or talk to them briefly. Being at home facilitated less constrained interaction between patients and their social network than in the formal hospital setting. Friends, visitors and family members interacted freely at home, provided emotional support, and attempted to meet patients’ needs for a variety of foods and alternative therapies. However, there were moments when patients were virtually alone while their family members and others went about their chores. The homes I visited were within the accessible parts of the Nairobi metropolitan area, ranging from between five and 200 kilometres from the hospital. I made an effort to visit patients in both low and middle income Nairobi city neighbourhoods. While some of the patients were city residents, those from rural areas were often hosted by family or friends during the hospital treatment sessions. Those without such social support relied on accommodation from well-wishers. Patients with limited financial resources rented affordable tenements in low-income neighbourhoods. Congestion and inadequate food and sanitation often characterised such arrangements.

Some of the patients moved back and forth between the residences of at least two of their relatives in the city before and after their hospitalisation sessions. Mr. Ndege, for instance stayed with a cousin in the outskirts of the city when he had difficulties climbing the stairs of his brother’s apartment on the third floor of a flat about one and a half kilometres from the hospital. Mrs. Pakot and her husband went back and forth, staying some of the time in their rural home some 200 kilometres from the hospital some of the time at her sister’s house seven kilometres from the hospital, and, once discharged, in a guest room one mile from the hospital at Mr. Pakot’s cousin’s house, where well-wishers continued visiting Mrs. Pakot. Staying with kin in the city meant an extra burden for the hosts as
they had limited space and facilities to spare for patients and other carers, mostly living either in single rooms or at best two bedroom houses.

Some forty kilometres from the hospital were semi-rural areas where some of the participants lived. As in the slums of the city and rural areas, the peri-urban environments typically lacked essential infrastructure such as passable roads, especially during rainy seasons, adequate supply of piped water, and electricity. The home areas and the hospital constituted transitory contexts of cancer management with varying opportunities for improving patients’ well-being and quality of life. Different actors in these environments had different roles and engaged in a variety of activities that influenced patients’ recovery process.

My position
Researchers have conducted hospital studies in different roles, as either ‘outsiders’ or ‘insiders’. Biomedical staff working in hospitals have privileged access to patients and their families, making it easier for them to combine research with their work. Social scientists and other ‘outsiders’ in medical settings have often contemplated what roles to take for effective data collection. There are those who considered disguising their research roles and collected data under cover as either fake patients or medical staff. Rosenhan (1973), Goldman et al. (1970) and Caudill (1958) report on research in psychiatric hospitals where the researchers collected data in unnoticeable, fictitious patient roles. Van der Geest and Sarkodie (1998) attempted a similar approach to hospital research in an experiment in Ghana. The second author in this experiment sought admission and made research observations in hospital as a fake patient. Other researchers such as Coser (1962) preferred doing hospital studies disguised in hospital staff roles by taking up medical accoutrements, especially the lab coat. Initially I thought it would be appropriate to conceal my researcher identity by wearing a lab coat, but I soon dropped the idea, realizing that by wearing my own clothes, the hospital staff would not see me as usurping any of their roles. It would have been easier for me to disguise my identity by passing myself off as a medical social worker. However, hiding my identity as a researcher and taking on a double role in the hospital study would have posed ethical and practical challenges. Attempts by other ethnographers to conduct participant observation in medical settings, as either fictitious or real participants, have led to researcher role ambiguities and ethical dilemmas (Parker 2001; Goodwin et al. 2003).

I was a conspicuous ethnographer ‘outsider’ (cf. Roberts 1977; Måseide 1987) in the cancer ward and related spaces and the only person on all occasions without the hospital staff symbols, particularly the lab coat and a name tag. In conformity with the general etiquette of work environments in Nairobi I occasionally dressed formally. I explained my research position periodically, emphasizing that
I was an anthropologist interested in learning about life in the hospital. Several medical staff later understood my position as a social scientist rather than ‘anthropologist’ or ‘ethnographer.’ Whenever it was required, I always introduced myself as a social science researcher. As a neutral, visible observer, my participation in the ward was limited to general tasks and those discussions I could indulge in as any person taking ordinary social roles. I tried to empathize with patients and other informants, but not as a person possessing the skills of the hospital staff, nor as someone with a similar background to the patients’. I gradually became a familiar part of the cancer ward and clinic, and some staff even described me as being ‘one of them’. This facilitated my interaction with those I was meeting for the first time. Since I did not have any hospital attire or badge on, hospital staff who were meeting me for the first time needed assurance with regard to my presence among them. This did not interfere with my research role among patients, but instead facilitated their gradual recognition of my neutrality. I could easily shift my association with all the participants through informal social interactions.

I limited my activity among the patients to tasks and conversations that non-medical people can generally engage in. Taking a patient role, in contrast, might have entailed moral and emotional discomfort (Caudill 1958; Zaman 2005). On the other hand, the combination of research with actual or improvised hospital staff roles might have resulted in role ambiguity that could compromise the quality of ethnographic data. Patients, for instance, might find the dual role of health adviser and researcher confusing. They may not have been able to identify the end of the health adviser role and the beginning of the research role (cf. Parker 2001). Attempts to perform formal job duties simultaneously with research may also have affected concentration on the research activity. Most people in the hospital and cancer ward did not understand my role at the beginning. Some patients and nurses initially thought I was a medical student. Nurses were curious about the outcome of my ‘assessment’ after my supervisors visited during the fourth month of the fieldwork. The supervisors had been present during a ward round when they visited. Nurses and ward assistants asked if I had ‘passed the assessment.’ According to them, supervisors would not come unless it was time to examine a student. A nurse told me:

We knew you were being assessed, so we had to give you a chance for a good report. We were ready to support you and confirm that you were working well with us.

The visit by my local supervisors and one from the University of Amsterdam confirmed my introduction to the hospital and the ward as a PhD student. Although I had established my role in the hospital as a ‘student researcher’, it still took time for some hospital staff to understand the significance of an anthropological research in the hospital. Nurses who had enrolled for part-time diploma or
certificate courses in counselling or palliative care later observed that my research themes were somewhat similar to what they were learning. A few nurses, in fact approached me towards the end of my study for comments on the topics for their field projects. I clarified to the hospital staff that I was neither a medical student nor doctor. However, some still preferred to address me as daktari (doctor) either teasingly or as part of their effort to find a place for me among them. When I reminded a ward assistant that I am an anthropologist and not a medical doctor he remarked:

What is the difference any way? You are doing a doctorate degree and you will become a doctor. You will be daktari in your own way. That is why we have physiotherapists, nutritionists and social workers here. Patients see anyone who walks in the hospital corridors and speaks to patients daily as a doctor. Maybe if the person says he is a pastor, or she is a sister (nurse), that is different.

I took some time to explain my researcher role to curious patients. Although patients generally understood my role, some shared the ward assistant’s view above. Some took this attitude a step further in their apparent expectation that I could discuss and comment on their medical conditions. They also on occasion anticipated that I could mediate between them and hospital staff. I constantly reminded patients that I did not have a background in medical training, and advised those who sought to discuss specialist issues in cancer treatment with me to address their concerns to the physicians. I emphasized to patients that any comment I could make was limited to the general knowledge which some of them had. The expectation of specialized healthcare which I in fact could not offer reduced some of the respondents’ enthusiasm to participate in this study. An elderly woman for instance told me she would take part in a conversation with me on two conditions: she wanted me to tell her what ‘our research’ had found about the exact cause of her cancer, and she wanted to know if I had alternative medicine for her since the ‘other doctors’ medicines’ had not helped. I discreetly reduced my interactions with such patients who expected biomedical interventions from my interaction with them.

The nature of my research drew me closer to patients. Many of them readily confided in me about their experiences. I acquired the additional role of listener due to the informal approach of the fieldwork process. Those I had interacted with earlier readily invited me to chat with them further. Occasionally, I had to run errands such as calling a relative, bringing a newspaper, getting mobile phone air time cards, buying a snack or juice, moving a pillow or even calling a nurse for patients. As a social being in the ward, I occasionally consoled patients and some grieving relatives. Some ward staff commended the fieldwork process for offering patients an alternative audience and helping them to talk about their emotional issues. I empathized with patients and always offered to listen to their ‘extra stories’. They appreciated my presence since I spent much time with them.
talking about their experiences. They considered me an appropriate audience to hear some of their anxieties. My interaction with some patients also seemed to pave the way for nurses who wished to get more social and medical history from rather introverted or withdrawn patients. Other patients appreciated my company when they felt alone and bored by the monotony of the ward. Data collection was an ongoing process that began with accessing the hospital, culminating in the establishment of my role in the ward.

Data collection
I collected data for this study between August 2005 and July 2006. The main data collection techniques were direct non-participant observation and informal conversations. I participated in informal, brief, and focused, in-depth conversations with selected respondents and key informants on multiple occasions. I elicited more data from other actors’ indirect ‘passive participation’ owing to their presence and involvement in the research setting. I perused some of the patients’ files for more background information on their social and medical history. The first part of data collection involved observation and informal conversations with patients, relatives and hospital staff in the adult cancer ward and clinic. The second part entailed follow-up visits of ten patients at home to explore the socio-economic circumstances of ongoing hospital management of cancer.

Observation
This ethnography entailed direct non-participant observation as mentioned above; I did not participate or disguise myself as belonging to any of the categories of hospital actors (patients, ‘visitors’ or staff). My presence in the ward involved social rather than technical or medical professional participation. Non-participatory observation facilitates a relatively detached reporting of occurrences and subsequent impressions of the field. Since I was a visible ethnographer, direct non-participant observation was acceptable to the participants. This technique required only being present, watching activities, maintaining social interaction and occasionally asking for short explanations. Participatory observation requires competence in the skills, backgrounds and shared experiences of the groups being studied. Hospital work is too specialized and the information circulating is too complex and sensitive for an outsider to discuss or relay since he or she is not part of the team structure in which the information is generated and interpreted (Vermeulen 2004: 2072). In such setting, the clear role of a researcher described above befitted me as an ethnographer without a biomedical training background. Doing anthropological fieldwork in highly specialized medical settings renders the assumptions of participant observation inapplicable. Therefore, the most applicable mode of observation for the ethnographer in the hospital
or the clinic is social participation. This is what Wind (2008) proposes to label ‘negotiated interactive observation’. The success of observation depends on the ethnographer’s precision in observing, recording, and reporting what he or she sees (Kottak 1991). Although a combination of hospital staff roles may be possible for those with cross-disciplinary training, this compromises the research role as I have indicated earlier. Active participation can therefore inhibit the quality of observation. I strove to be flexible and position myself socially in the ward in order to build trust and join different situations and activities in the hospital as I collected the data (cf. Wind 2008: 82). I relied on the flexibility of direct observation to occasionally withdraw from interaction scenes in order to record observations without disrupting the natural flow of events.

I did not participate in the ‘work’, medical procedures and decision making of any of the places in the hospital. My participation in hospital centred on my ability to take general social life as a vantage point for observation and collection of data. In addition to observing some medical and patient care activities, I joined nurses in the staff/tea room and participated in their informal talks. Patient care issues came up spontaneously on many such occasions. As a non-participant observer, it took me longer time to be present at some medical events and discussions. Some hospital staff were cautious and uncomfortable about being observed. Direct observation was in contrast more comfortable with patients, their relatives, and the support staff; it was easier to be with them for informal talks while they performed their tasks than the medical and nursing personnel. Non-participant observation posed some limitation to accessing events with hospital workers I had not met before. I encountered this problem more at the clinic and in the radiotherapy waiting area than in the ward. On a few occasions when I tried to talk to respondents in the treatment waiting room, a radiotherapist asked for a hospital badge or my research clearance permit. Another challenge was the main ward round, which often had many participants; making mere observation was a problem for some consultants. From time to time, a ward round consultant would demand that ‘the students should ask questions’ instead of ‘just observing.’ He once asked me: “what are you learning by just looking at what I do?” I had to continuously negotiate access to observe and participate in informal conversations that facilitated the data collection process.

Informal conversations
I combined informal conversations with observation in the data collection process, which also involved listening to unsolicited talk and comments among different actors in the ward and related sites I visited. Often ward procedures, meal times, arrival of visitors, and patients’ experience of pain and exhaustion would interrupt conversations. The informal approach to data collection however
made it possible for me to resume conversations with different study participants when it was convenient, facilitating the flow of additional information from different study participants. Data collection through informal conversations was a continuous process. I sustained interaction with respondents as long as possible during their hospitalisation periods, talking with them on multiple occasions and paying attention to new information and emerging themes. Data collection from main respondents and key informants began as focused, in-depth conversations. Multiple encounters with them gave me the opportunity to gather more data and clarify issues at any time.

Information from informal talks was occasionally scanty. I tried to make sense of it by crosschecking recurrent the themes I observed. This provided the direction for follow-up on the research themes and questions in subsequent interactions. Since conversations can be so wide-ranging and sometimes lead to the loss of focus, I always motivated the participants to develop interest in the research issues. I pursued bits of information for clarification and elaboration in subsequent casual conversations. Informal conversation in longitudinal fieldwork provides an opportunity for continuous rapport-building and negotiation, as aforementioned. It also facilitates gradual access to the life worlds or lived experiences and social worlds of the participants.

Conversations ranged from daily chats to prolonged in-depth discussion through which I put together data fragments. Continuing conversations with main respondents and other participants were essential to cross-checking available information. This study benefited from the flexibility in ethnographic techniques, free selection of themes and combination of data collection procedures. A field notebook and the voice recorder were handy in the data collection process. I suspended either taking notes or using the voice recorder when these modes of data collection were interfering with the natural flow of conversation. In case I could not make notes, I used the voice recorder with participants’ consent to capture bits of conversations. Retreats to the ward staff room, my workroom or any other silent place were useful for organizing the data and making notes on issues I had not written in my note book or captured on voice recorder.

Beyond the hospital
Data collection in selected respondents’ homes was essential for an exploration of socio-economic contexts outside the hospital that shaped cancer in-patients’ experiences. I sought to explore how the experience of ongoing treatment was entwined with wider social and economic circumstances. Collection of data beyond the hospital highlighted the context of issues surrounding the affordability of treatment, appropriate diet and social support. Data beyond the hospital supported observation that transient hospital stay often conceals the actual con-
text of patients’ suffering. The plight of ‘socials’ which I return to briefly in Chapter 7 is a case in point. The term ‘social’ is often used in the ward to refer to interactions that are not official. Patients who are perceived as poor and lack adequate social support are also referred to as ‘socials’. Such patients are unable to pay bills and access extra food for their diet. They depend on the sympathy of ward staff for priority when there are drugs to spare or opportunities for admission on credit and other additional care services. When it is proven that they cannot clear their hospital bills, they are discharged after several days of being detained in the ward.

Some patients rarely had visitors and were unable to access extra food from outside the hospital to supplement their diets. They also had difficulty buying medicines that doctors recommended. The ward management kept such patients in the hospital until they could demonstrate beyond doubt that they were unable to clear pending bills. Information from patients’ home circumstances shed some light on the importance of making observations beyond medical settings. The observations provide additional data for an understanding of the livelihood struggles among cancer in-patients and their families. Placing blame on patients for delayed or interrupted treatment may often overlook their fragile social and livelihood contexts.

Existing hospital ethnographies have focused mainly on what happens to patients in medical settings. Recent ethnographies provide only impressionistic inferences about how what goes on in medical institutions reflect realities in wider society (Müller-Rockstroh 2007; Zaman 2005). There is little representation using ethnographic data of how social and economic circumstances beyond the medical setting shape patients’ experiences. Ethnographers may presume general knowledge of the contexts of hospitals and medical practice, but this does not sufficiently reflect patients’ actual personal experiences of coping with ongoing treatment and parallel socio-economic challenges. The present study takes hospital ethnography a step further to explore patients’ wider contexts in their treatment experiences. I observed conditions of patients out of the hospital through a purposive sample of 10 respondents, four of whom lived in rural areas outside the city of Nairobi, and three of whom were temporarily living in the city for the sake of treatment. Tarus, for instance, had relocated temporarily to a rented room in Nairobi. His wife and four children lived in their rural home about 450 kilometres from the hospital. Two other patients lived in the city, and one in an urban area approximately 200 kilometres from the hospital. I visited each of the selected respondents at home at least three times and talked with them and their relatives. I observed their general home conditions, which depicted their livelihoods (as described in Chapter 7). They filled expenditure diaries for at least two months of hospitalisation with the help of their spouses or adult family
members. We discussed the expenditure entries during subsequent home visits and on the telephone. The patients also clarified issues in their estimated expenditures when they returned to the hospital. The estimated income against expenditure during the hospitalisation period as described in Chapter 7 was the average of two months of self-reported expenses (see Appendix 5, Tables 1 & 2). Data on patients’ conditions outside the ward facilitate a holistic understanding of issues related to their quality of life in the medical setting (Conrad 1990). Home conditions affect patients’ hospital treatment and rehabilitation processes. Hospital researchers and medical practitioners may take this dimension of patients’ experience for granted.

Data processing and analysis

The fieldwork generated vast qualitative data on the study question and goals. The final descriptions in this dissertation are analytic summaries of what I saw or observed and heard from the respondents (cf. Becker 1998). Data analysis began in the field with continuous attempts to focus conversations and observations to address the research themes, identifying initial patterns of the data and sub-themes to pursue further. More ethnographic questions related to this study emerged as the project progressed, so I moved items in the conversation guides back and forth in order to refine data collection in relation to those emerging patterns. I relied on the flexibility of ethnography to refine data collection through probing, follow-up on new sub-themes and selective recording of information. Reflecting on the main research goals and my field experiences served as the basis of my ongoing analysis in the field. I took note of the common elements that gradually became apparent during transcription of observation notes and recorded conversations, keeping track of these developments in monthly reports to my supervisors on preliminary findings. I did not postpone all analyses to the end of the fieldwork.

I took note of the points of saturation in data related to recurrent and emerging themes during fieldwork. In the first four months, for instance, most patients highlighted their experience of delayed referral for proper treatment. They also highlighted common experiences of long ‘waiting on the queue’ for their first hospital treatment elsewhere or after admission in the study hospital. Transcribing recorded conversations, I identified the main themes in respondents’ experiences and also noted the significant aspects of the hospital and home environments that affected patients’ well-being and recovery processes. For further data processing I entered both the notebook and audio transcripts in a database for analysis using Maximum Qualitative Data Analysis (\textit{MAXQDA}) software, coding data under 10 different text groups. These groups represented conversations with patients, relatives, and other carers. The other text groups included general ob-
surveillance notes in the ward, review clinics, patient counselling, relatives in the ward, and notes from home visits and medical records.

The main codes in the texts denoted data categories that describe the study themes presented in this dissertation. I listed descriptive categories of patients’ perspectives and experiences which form the central focus of this ethnography. This facilitated further qualitative analysis and reflexive interpretation of the data. The dissertation draws on the most frequent notions of the study participants to describe coping with hospital treatment from patients’ perspectives. Drawing on conversations with 27 patients (Appendix 1), I use verbatim excerpts from some of the respondents and informants to illustrate and emphasize characteristic ideas about themes that emerged. These excerpts provide detailed information characteristic of the experiences of many other respondents. The present ethnography does not delve into in-depth analyses of biomedical aspects of patients’ experiences. Instead, I have attempted an interpretation of patients’ experiences of physical symptoms drawing on general knowledge. The basic working knowledge of medical care for cancer patients that I acquired along the way through literature and fieldwork complements my analysis and interpretation.

Summary and discussion

The constraints I faced in gaining access to the hospital to conduct an ethnographic study are linked to the low awareness hospital practitioners demonstrated regarding this venture. The medical staff and the Ethics and Research Clearance Committee initially expressed reservations about the study’s methodological reliability and practical relevance. I attribute the relative success of establishing my role as a social science researcher in the hospital to five factors: First the hospital Ethics and Research Clearance Committee developed an interest in my research. The committee eventually accepted the ethnographic project as innovative and relevant to patient care. The present study is the first ethnography in the study hospital, and the medical and nursing staff gradually demonstrated commitment to it and enthusiasm its results. Second, the endorsement of the project by the deputy director of clinical services after formal clearance paved the way for my formal entry to the hospital. Third, a formal, week-long introduction and orientation to the hospital by a staff member appointed by my hospital supervisor facilitated my familiarization with the hospital staff before the main study began. Fourth, most actors in the ward and the clinic accepted my presence among them as a ‘student researcher’. Several other medical or health science students did their internship rotations in the ward. My hospital supervisor also linked me to the postgraduate research group, which accorded me a recognized position as a student working with a member of staff. Finally, hospital staff interacted with
members of my PhD supervision team at the initial stages of my fieldwork. A formal introduction of my research and supervision team to the deputy director of clinical services reinforced a positive reception of this study.

Disciplinary and methodological firmness is an important principle to foster cooperation between ethnographers and medical scientists. This study partly entails a plea and advocacy for hospital ethnography. The present study shows that anthropologists (and social scientists in general) need to make themselves useful in clinical settings (Kleinman 1985). The ethnographic method that anthropologists apply can help in the realization of the link between biomedical and psychosocial paradigms. Collaboration between ethnographers and biomedical personnel in the hospital can promote incorporation of patients’ perspectives in hospital care. This is essential for patient satisfaction and identification of their needs. While quantitative and experimental research offer valuable results for biomedical practice, they may miss qualitative details that are essential for the well-being of patients during ongoing hospital treatment. The process of my entry into the hospital for this study shows the need for deliberate efforts to incorporate social science paradigms in hospital studies. Although medical practitioners gradually appreciated the ethnography, their critiques indicate subtle unease about fieldwork approaches from a different discipline. The views of some hospital practitioners and members of the Ethics and Research Clearance Committee reflected an attitude that Van der Geest (1995) calls ‘scientific ethnocentrism’. Little understanding or appreciation of the fields of social science field and theoretical approaches characterizes this attitude among biomedical scientists. Biomedical practitioners may resist social science studies in hospitals claiming that they lack objectivity and relevance (Mulemi 2006). However, hospital ethnography has the potential to reduce indifference to the patient’s and the community’s viewpoints. Unresponsiveness to the sufferers’ perspectives result from ethnocentrism in professional practice, and this has negative consequences for health care (Kleinman 1985). Anthropological approaches and particularly hospital ethnography in the present study provide data on individual patient and other hospital actor perspectives, which are essential to the enhancement of patient care. Quality improvement in this regard can be defined at the level of the patient and based on the patient experience. This study also incorporates holistic perspectives on cancer patients’ needs, and attempts an interpretation of in-patient care experiences based on the understanding of a wider context beyond the clinical setting.

My interactions with the hospital staff served as their learning process about ethnography. Their reception of this study paves the way for interdisciplinary collaboration with social scientists. Medical scientists in Kenya nonetheless need more exposure to social science in medical settings, and medical scientists have
yet to fully appreciate ethnography in medical settings. However, physicians’ critiques and methodological suggestions for this study indicated that they gradually received it favourably and were eager to see its results. Social scientists have observed that medical institutions worldwide are reluctant to grant non-medical researchers access to their sites (Martin 2009; Freidson 1963; Zaman 2008). Medical practitioners are often suspicious that social scientists will infringe on their autonomy and subject their profession to undue criticism (cf. Mathews 1987; Van der Geest 1995: 870). Similarly, ethnography as an aspect of collaboration in healthcare practice and research remains unnoticed in developing and some developed countries. Therefore this study is an important contribution to the use of ethnography as a method in hospital studies. The data described in this ethnography specifically contributes to the need for comprehensive understanding of cancer patients’ responses and experiences during ongoing hospital treatment. The ethnography depicts cancer patients’ experiences of hospitalisation in the context of their beliefs, social support systems and wider socio-economic circumstances.

My role as a neutral ‘outsider’ in the hospital guaranteed me flexibility to interact with different actors. For this reason, patients considered me a suitable audience for an array of their personal concerns. Respondents who wish to safeguard their relationships with people who offer essential care and support often hesitate to complain to and about them. They find a researcher, especially one who is an outsider to their context of care, as a safe audience for their complaints (cf. Van der Geest 2007b). The analysis in this study therefore includes patients’ expression of negative emotions and evaluations of their care. Expressing these sentiments was psychologically satisfying for patients as they sought an audience for grievances. Listening to patients’ and other hospital actors’ complaints may affect the research environment and participants. Therefore I maintained ethical neutrality while at the same time attempting to avoid appearing indifferent to the research participants’ plight. Anthropologists require discretion in their interaction with research subjects. They also need to take responsibility for the effects the research process can have on participants and their environments. This is particularly essential in ethnographic fieldwork because ethnography presents more opportunities for intimacy, disclosure, and feelings of familiarity between researchers and informants (Stacey 1988). This may increase suspicion about the presence of ‘an outsider’ in a medical setting. However, the opportunity that ethnography offers for interaction with patients demonstrates that carers need to empathize adequately with patients in order to successfully attend their emotional concerns. Healthcare providers may also need to tolerate what they may construe as negative evaluation in patients’ complaints. This ethnography therefore includes data that can facilitate giving voice to patients as partners in their own
healthcare, because patients’ perspectives reflect important aspects of their lived experience. These aspects are significant for healthcare concerns such as quality assurance and patient satisfaction (Press 1985). Situations inside and outside of the medical setting interact in shaping patients’ experience of current hospital care as the present study shows.