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### Coping with cancer and adversity : Hospital ethnography in Kenya

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**Publication date**  
2010

[Link to publication](#)

#### **Citation for published version (APA):**

Mulemi, B. A. (2010). *Coping with cancer and adversity : Hospital ethnography in Kenya*. African Studies Centre.

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## Treatment and persistent struggle scene

Mr. Misaka Masseyi,<sup>1</sup> 55 years of age, was admitted to the cancer ward towards the end of the second month of my fieldwork. Chronic illness had compelled him to seek early retirement at the age of 54 from the parastatal housing corporation where he had been a clerk. With official retirement age for public servants like him set at 55 years, he had already exhausted his retirement benefits. His narrative of help-seeking for his illness exemplifies the experience of most of the patients who participated in this study.

At the time of our conversations, Misaka was in the ward to treat a recurrence of breast cancer. We would chat for various lengths of time, before or after ward visiting hours, as long as he was not in pain or resting. Through these informal conversations I was able to reconstruct the narrative of his experience of cancer and treatment. Misaka had been semi-conscious when his relatives brought him to the ward. The ward physician and nurses fed him intravenously for about one and a half months. They were also treating him for head injuries because he had fallen out of bed. This accident occurred as he was trying to get up and attempted to support himself on a curtain screen. After he regained consciousness, he told me that he had mistaken the screen for a wall at the time he fell.

Misaka said that he had experienced illness symptoms for six months before receiving the diagnosis in a district hospital that he was suffering from breast

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<sup>1</sup> I use pseudonyms and not the real names of respondents in this study. In Appendix 1, I have presented brief descriptions of the characteristics of respondents whose experiences appear more frequently in this dissertation.

cancer. The diagnosis was in 2003, over two and a half years before the present study. He remarked:

When this disease started, I even did not know that I was sick. I did not know it was cancer until it was nearly in the advanced stage. I went to the district hospital and they told me, “you are sick” ... They removed the swelling (*uvimbe*), but by then it had spread, nearly the whole chest. We noticed this from ‘outside’ and it was as if I had a (female) breast.

Misaka started seeking help when the pain and swelling increased. He began by visiting various public and private health facilities in his home area. A physician later referred him to a district hospital where he underwent mastectomy. Another physician at the district hospital referred him to the present ward for chemotherapy. He said that severe pain subsided after the second course of chemotherapy. He often wanted to talk about the agony of the disease, treatment and being in the hospital. As he relived the agony that chemotherapy caused, he noted:

It was something hard ... they inject the medicine into my vein and it is very painful ... The treatment is extremely painful. You cannot eat because you vomit a lot ... You feel weak and you cannot do anything else afterwards, especially in the last two days of chemotherapy. You can only start eating, bit by bit during the third and the fourth (chemotherapy) courses ...

Many respondents described treatment and cancer as trying phenomena. Pain and difficulty eating due both to the disease and the treatment were the main drivers of the patients’ experience of the hospital as an unpleasant place to be. It was a place where they continuously relived the difficulties of daily life brought on by cancer. As Misaka observes in the excerpt, pain and physical discomfort seemed to defy available remedies. The recurrence of the disease after enduring a mastectomy and first-line chemotherapy mystified him. He recalled how happy he was at the end of his previous hospital session. His family were relieved too, and they all celebrated the “successful cure”. The treatment had restored his physical functions reasonably well; the pain had dissipated, and he could wake up, sit, walk and eat well without assistance. These were the main components of a basic measure of a successful hospital stay. Each discharge from the hospital in such good condition delighted Misaka and other patients alike. Unfortunately, this did not symbolise the end of the “fight for life”; discharged cancer patients dreaded subsequent hospital appointments, as these reminded them that the “fight was not yet over.” Hospitalisation meant not only an uncomfortable relocation to an unfamiliar hospital and city environment, but also material and emotional hardships. Misaka expressed the anxiety and uncertainty that most patients associated with the hospital when he noted:

I sometimes fear...if I am going to the city ... who is going to take care of me? Where I am I going to stay? That is another problem. Maybe you do not have the funds for accommodation in the ward ... How do you stay in Nairobi? You need money to pay for the ward. Like now I really feel lonely ... I feel happy when those boys of mine come because they live

within Nairobi. Imagine if they were coming from the “reserve” (rural home). How much would they have wasted by now? It would be a lot! The disease has given me so many problems. However, I cannot think so much about those problems because now that I am with my family I cannot cry so much about the problems.

Many patients travelled from far-off rural areas. Distance from family and social networks shaped their experience of social and emotional support in the hospital. Those who had relatives in the city could make arrangements to go through radiotherapy or chemotherapy as outpatients. Relatives and friends in the city offered transit to and from the hospital. However, hospitalisation soon threatened the livelihood of both the rural and urban households on which patients depended for support. Misaka was worried that his frequent trips to the hospital, including the economic implications, would have a long-term impact on his family. He was afraid that his two children who were still in school would experience the burden of his hospitalisation more than the others. Of his eight children who were out of school, none had secured formal employment. He had already spent most of his retirement benefits on his hospital treatment and related expenses. Similarly, cancer and the hospital were isolating him and his family. Protracted hospital treatment exhausted and disrupted existing networks of social support and reciprocity. Misaka regretfully observed:

I share the cost only with my family. If you take this problem to other people, they will think you are joking with them. Relatives also tend to relax and withdraw when it takes long. Relationships with friends also weaken and even end when you are no longer employed. The sufferer does not sever the relationship with friends ... however; it is not possible to force this relationship to continue even though you wish that it would. Life is never the same when you fall ill for an extended amount of time. Friendships break up in life and it is not easy to restore. A friend advised me to bear with my situation ... He said I should be patient and not worry. Those are the most important words for me. People may be alone, but with God, they succeed, when there are miracles.

Doctors approved Misaka’s discharge on Tuesday, 1 December 2005 after two months of hospitalisation. Although the discharge was due a week earlier, they did not release him because of a hospital bill in arrears to the amount of 50,000 shillings. His son, a student in a Bible school outside the city, went through the clearance process. He told me that he was very happy that he finally managed to pay off the hospital bill. Close kin had contributed money to clear the balance. He thanked me for having ‘kept his father busy’ while his relatives were away. Some nurses and nutritionists also appreciated my presence on the ward noting that I helped in “keeping patients busy” and helped them “open up”. A nurse happily confirmed to Misaka’s son that his family had been the most cooperative relatives. They had resolved the dispute in which Misaka’s family members blamed nurses for not preventing his accident, the fall mentioned earlier. They argued that the accident contributed to Misaka’s slow recovery and extended his hospital stay. Misaka happily announced his successful conclusion of the hospital

session. He went to all the five rooms in the cancer ward to bid farewell to fellow patients and ward staff. He told me that he would come back to the clinic to begin regular reviews from February the following year (2006). His relatives were visibly delighted with his recovery and discharge.

According to the nutrition staff and internship dieticians, Misaka was a success case in the application of diet guidelines for cancer management. They commended his relatives for bringing appropriate kinds of food and drink to the patient. The fact that he could walk without assistance was an important indicator of recovery for the nutritionists, too. At Misaka's previous discharge, the staff had considered him a hopeless case. However, both nurses and patients resorted to their religious faith to cope with circumstances that seemed hopeless. Faith and belief in miracles, as Misaka noted above, were central in the expression of hope among patients and their caregivers. One nurse remarked:

This is an interesting case. At one point the patient was so confused and pulled the waterproof seal drainage tube we inserted in his chest. He was in such a critical condition ... He even one time fell from the bed. You know; when you see a patient recovering so well after such a condition, look to God. People talk about treatment, but forget it is God who cures.

Restoration and sustenance of cancer patients' well-being are often uncertain. Hospital staff often held subtle reservations about the possibility of sustained positive outcome of medical intervention. Patients and hospital staff alike drew on their religious beliefs to sustain their hope and resilience. Misaka's case reminded nurses of another that had appeared to be a success story in the ward. As they talked about this later in the staff room, they referred to a female patient whose improvement seemed unusually drastic. She gained weight rapidly after a prolonged experience of pain and the inability to eat. A nurse commented:

When patients begin putting on weight like this, I get worried because it shows they will go (die) sooner than later ...

I walked with Misaka and his son up to the door. The son talked about his experience during his father's hospital stay. He also attributed his father's recent recovery to their trust in God. Misaka's son, patients and fellow relatives struggled constantly with growing disillusion with hospital care. Contrary to their expectations, the limitations of healthcare facilities and medical knowledge of cancer rendered both medical scientists and lay people helpless. In such instances, maxims drawing on religious belief provided solace and strengthened their determination. In relation to this, Misaka's son noted:

The doctor told me my father's condition was very critical. He said that they could not do anything more for him. I went to the hospital chapel to call a priest to administer the sacraments for the sick in the presence of my family members. This helped to revive my father and now he can walk on his own ... The priest asked my family members to believe that he would be well ... Now he can eat and walk without assistance.

Misaka's son expressed concern over the patients' inability to eat well without assistance and encouragement. He observed that patients would probably eat better if nurses had time to assist them. Misaka's son also recalled a time when a nurse stopped him from cleaning his father. Since he was "a visitor" like other relatives and non-hospital staff, the nurse did not take kindly to his attempts to usurp nursing roles; this caused tension between him and the nurses for some time. He acknowledged the assistance Misaka received from other patients, particularly after his accident and when he was bed-ridden.

Misaka's family agreed that he should rest for some time at his nephew's before proceeding to his rural home. Then, in January 2006, a month before Misaka's scheduled appointment, a relative brought him back to the hospital for an emergency clinic review. He subsequently attended the scheduled clinics in February and March. By the end of March 2006, he needed urgent supportive care and was discharged after a week. Supportive care generally entails palliative care, intravenous feeding and drainage of fluids accumulating in the body.

On Tuesday, 11 April 2006 the ward doctor's ward round ended before eleven o'clock. The doctor prepared chemotherapy medicines in the treatment room as nurses went about their routine procedures, such as making beds and preparing patients for treatment. At the entrance of the ward, relatives were bringing in Mr. Misaka. He looked quite sick and exhausted on a stretcher. He (M) told me (B) about his clinic appointments in a short conversation a few days later.

M: I came back in January, but February was the most appropriate time ... I was supposed to come on February 2<sup>nd</sup>. How have you been all this time? In fact I asked about you when it was the third...

B: Clinic?

M: Yes, the third appointment ... I came here on 9 January (2006), and on 2 February.

During the last clinic, there was not much done...because they wanted to have results for these tests ... other X-rays ... CT (Computerised Tomography) Scans and my blood tests.

Requests for numerous diagnostic tests and examinations often coincided with prolonged hospital stays. They also characterised pauses in active treatment to address the patients' physical needs. This may also have been a way in which the medical staff coped with the challenge of conditions that did not respond to treatment. Awaiting diagnostic results in such desperate situations often kept patients, nurses and medical staff in the air as to the next course of action. Friday, 21 April 2006, a week after Misaka's re-hospitalisation, was a national holiday. Public holidays and weekends affected key hospital procedures such as admissions, radiotherapy and ward rounds; as it was, the consultant round during which essential decisions about patient care in the cancer ward took place on Fridays. On the day before the holiday, a nurse had expressed concern about Misaka's condition. The pleural effusion tube needed to be removed because it was due to be changed. In my conversation with a nurse, he noted:

We have everything assembled ... We are only missing one device: the thoracic catheter. It is not available and we are waiting ... (He shrugged and sighed).

How much does the device cost?

Three thousand (Kenya Shillings); we are waiting ...

Misaka was a victim of delayed help in the hospital due to inadequate stock of medical supplies. On occasion, patients had to wait until the end of a holiday or weekend for the delivery of required therapy equipment from the hospital's supplies store. Alternatively, they would wait for a ward doctor or consultant to recommend items for relatives to buy that were not available in the hospital. I arrived at 10:00AM from the admissions clinic the following Monday. A nutritionist informed me of Misaka's death:

He died on Saturday, and the next day he was in the (daily news) papers. This means these people (family and relatives) had money ...

A patient who had been in the bed adjacent to Misaka's said Misaka had given him his relative's mobile telephone number because "he knew that he was going (to die)". The patient said that when he realised at night that Misaka had died, he called the relatives. After the final clearance with the ward, Misaka's son told me:

They say that he knew he was dying. There were X-ray films he did not show us ... He said, 'how can I live without lungs? I have no lungs ...' So he died. He knew he would die. Everybody was there and he said he did not have lungs ... Therefore, he decided that the positive thing to do was to bid us farewell. That is the way for all of us ...

Misaka's experience provides a glimpse at the cancer patient care scene in the study ward. It presents the hospital as a place for the patients' persistent struggle for life. Their search for restoration of well-being is apparently endless as they are shuttled between the hospital and their homes. The hospital scene portrays only a small fraction of the experience of patients and their families; the role of wider social and economic circumstances that shape patients' overall experiences often remain invisible in the medical setting. However, current experience in the hospital ward reflects untold physical and social suffering related to treatment delays prior to and during current hospitalisation. Both formal and informal carers in the hospital struggle to help suffering patients restore their well-being and improve the quality of their lives. The hospital presents a place for the continuity of the struggle against disease and concurrent daily life adversity. Current hospitalisations embody the climax of such struggles, some of which have longer histories and trails of suffering.

## Study question and goals

Hospitalisation focuses on patients as subjects of socio-medical activity. However, cancer patients' subjective experiences of hospital treatment in varied so-

cio-economic contexts are inadequately documented. Social scientists have conducted few qualitative studies on experiences and perspectives of patients seeking help in medical settings (Bennet 1999; Kauffert 1999; Mullin *et al.* 1998; Eisenbruch 1990). Moreover, most of the literature on social, cultural and individual aspects of cancer treatment in hospitals focuses on experiences in America, Europe and Australia. There is thus a paucity of ethnographic studies on hospital management of cancer in developing countries, and especially those in Africa. Patients' responses to cancer and their narratives of help-seeking can highlight an array of issues that are relevant to initiatives for improvement of their well-being and quality of life. An understanding of sufferers' experiences is essential for attempts to address patients' needs and those of their carers. This perspective can also facilitate identification of healthcare issues in an entire national healthcare system. Conventional hospital treatment processes often impose the role of passive consumers of healthcare on patients. Health professionals tend to focus more attention to the technical than subjective aspects of healthcare. This is likely to undervalue the relevance patients' experiential responses to understanding their needs.

The central question for this ethnography is: How do life and experiences of cancer in-patients in a Kenyan referral hospital relate to their needs, and what elements characterise their hospitalisation? In order to explore this question it was necessary to find out and describe how patients felt about and make sense of their conditions. This included a focus on how they assessed their well-being in relation to current hospital treatment. The study further investigated health care issues that were apparent in patients' narratives of their experiences and events that were observable in the ward. The hospital is often presented as an arena of social relations that have consequences for patient well-being. This study therefore attempts to address the question as to how different actors in the study hospital enacted partnership in cancer patient care. This includes a description of in-patients' roles among other actors in the hospital. The study also explores of how wider conditions beyond the medical setting shape the experience of hospital treatment of cancer. In other words, what are the implications of parallel social and livelihood adversities for hospital treatment, and how do patients and their families attempt to cope with these problems?

The primary goal of this study is to contribute to hospital ethnography, specifically in developing countries. It attempts to show how hospital and family circumstances in Kenya shape patients' experiences of cancer treatment. This will facilitate an understanding of issues in comprehensive cancer management. Through this study I hope to make a contribution to the qualitative literature on the experience of illness and hospital life in developing countries. Most hospital ethnography has been undertaken in Western, developed countries, as opposed to

non-Western countries (Foster & Anderson 1978; Van der Geest & Sarkodie 1999; Zussman 1993). There is still a scarcity of in-depth ethnographic studies on the social meanings and dimensions of health, and therapeutic practices in modern hospitals; the present study is a contribution towards filling that gap. It adds qualitative data and analysis that are relevant to local assessment of patients' needs in relation to managing the cancer problem in Kenya. Ethnography of this kind is useful for assessment of the needs of chronically ill patients in developing countries with similar social, cultural and economic backgrounds. Qualitative data on in-patients' experiences are important for highlighting gaps in existing frameworks of cancer management. A distinct contribution of this research to hospital studies derives from its exploration of ongoing hospitalisation and management of chronic illness with reference to the wider social and economic context. It also highlights the reciprocal impacts of cancer management and livelihood vulnerability on the well-being of victims. I hope to provide a feel for in-patients' daily lives as they live with protracted illness and treatment efforts in the hospital and at home. Conrad (1990) underscored the importance of observing patients' experiences beyond medical settings as a way of understanding a broader context of healthcare issues. Patients' observable and articulated responses during hospital treatment portray their illnesses and treatments as part of their lived experiences. Although patients are recipients of medical care and as a consequence the lowest in the hierarchies in medical settings, their individual experiences constitute an important component in the analysis of healthcare issues.

### Personal experiences and healthcare issues

Biomedical practice varies globally with social, cultural, economic and political contexts. Differences in patient care and assumptions about disease influence healthcare staff attitudes, expectations, and relationships with patients and organization of activities in hospitals. A ward might share most of the cultural discourse, meanings, norms and practices of the entire hospital and society, but it remains a distinctive patient care setting. Unique patient, family and staff experiences, for instance, distinguish one cancer ward from another. The focus of hospitalisation is the patient, yet hospitals do not adequately incorporate patients' experiences and participation in healthcare processes. Following a classical model of hospitals and ward organization, health providers view patients as passive recipients of medical care. They expect patients to cooperate with hospital staff in order to expedite the curative process (Morgan 1986). However, patients have the potential to participate in improving their quality of life through negotiation and expression of their lived experiences of suffering. Their low positions in the social and professional structure of biomedical settings constrain their participation. In addition, hospital staffs pursue different professional goals and

interests within the framework of institutional rules and procedures. This influences patient care interaction among healthcare professionals and their communication with patients.

The wider circumstances that shape an in-patient's experience are often less visible, as Misaka's case above shows. Cancer patients are victims of progressive disease and daily life struggles that shape their experiences prior to and during hospitalisation. Delayed intervention and concurrent livelihood struggles entwine with their in-patient experience in a profound way. Circumstances in the hospital, family and national healthcare system interact in shaping treatment efforts. Patients and specialists grapple with the consequences of uneven healthcare coverage which current hospital care discourse may not adequately pronounce. Delayed diagnosis and referral of patients, for instance, can necessitate major treatment that patients have to endure (Onyango & Macharia 2006). This results in more social, financial and emotional burden to patients. Admission to the referral hospital for most cancer patients in Kenya is usually a continuity of previous and arduous help-seeking trajectories. Therefore, patients' personal experiences offer an ample reference point for issues in healthcare, especially in resource-poor countries like Kenya. This ethnography therefore takes patients' experiences as the starting point for understanding patients' needs and healthcare issues related to hospital management of cancer in Kenya.

The experiences of sufferers are significant in the analysis of healthcare issues in at least three ways. First, a focus on the experience of the sufferers, that is, cancer patients, in this study, highlights their potential for mutual participation with medical staff in efforts to maximise their levels of functioning. Second, subjective experiences of pain and therapy can inform interventions for the improvement of patients' well-being or quality of life. Finally, the experiences which patients articulate or researchers and health professionals observe give clues to how to improve essential partnerships in helping patients and their families to cope with severe illness. My theoretical assumption is that each participant in a medical setting contributes important resources to healthcare in terms of knowledge, skills, expertise and relationships that influence treatment outcome. I draw on the Critical Medical Anthropology paradigm (CMA) (Baer 1997a, 1997b; Baer *et al.* 1986, 2003; Singer 1989, 1990; Singer *et al.* 1990) to analyse in-patients' experiences of cancer and treatment in the Kenyan hospital. CMA goes beyond the general critical perspective in anthropology, which limits analysis of health issues to lower community, and individual levels, disregarding the influence of the wider political economy of health. Instead, in-patients' experiences with cancer and treatment efforts should be viewed in its context of national healthcare systems, social and professional interactions in the hospital and the wider social, economic and cultural environments. Some proponents of

CMA paradigm have seen it as a strategy for health activism (Baer 1997b) since it focuses on sufferers in society. This has also been the perspective in conventional development anthropology in its focus on speaking for categories of downtrodden people. Conversely, I have adopted the Critical Medical Anthropology perspective as a framework for broad description and analysis of issues in the care of cancer patients in a resource-poor country. I describe the experience of patients in the cancer ward in light of the larger socio-economic conditions that pattern interpersonal relationships, shape behaviour, generate social meanings, and condition collective responses to disease in a medical setting. This can facilitate an understanding of the multifaceted constraints to patient care within and outside a developing country hospital.

Patients' daily life in the hospital and experiences of disease display their socio-economic backgrounds. In the Kenyan situation, the poor have limited access to health services (Kimalu *et al.* 2004). This implies that the hospital may not play a significant role in addressing their physical and quality of life needs. The poverty situation in Kenya particularly limits the role of the hospital in meeting the needs of patients and families struggling with life-threatening conditions such as cancer. Due to high levels of poverty, 40 percent of the rural population has no access to health services and 25 percent of total households in the country are located more than eight kilometres from any health facility (Government of Kenya 2000). In addition, inadequate financial support for human resources and medical facilities constrain treatment and patient care in the public health facilities. The hospital may thus be a place where both patients and health-care providers relive and endure daily life misfortunes linked to a wider economic and political context. The hospital is a microcosm of the larger society (Van der Geest & Finkler 2004; Zaman 2005). In this sense a hospital may reflect the wider society values and collective responses to suffering manifested in the experience of individual members. Therefore, patients' lives in a ward depicts more than their present physical suffering; their daily life struggles beyond the hospital also shape their care expectations. The hospital is thus a setting of medical activities and social relations influenced by the wider contexts of healthcare. Individual patient experiences and expressed needs encompass both subjective and objective issues that affect entire healthcare systems. The issues can be analysed at the individual, micro-social, or intermediate levels that Baer *et al.* (1986: 96; 2003: 39-50) proposed. This ethnography takes the individual patient's level of analysis as this sheds some light on other levels of healthcare issues.

### Individual level

Patients are at the centre of any medical activity. They derive meanings of hospital stay and treatment experiences from social and medical interactions. The

interactions shape their responses to and evaluation of hospital care. In addition, patients come to the hospital with their own knowledge, skills, beliefs and notions which influence their expectations and well-being. However, hospital professionals often limit patients' participation to the sick role. In this sense, medical settings subjugate them and repress their voices in treatment activities and decisions. Patients may restrain their active participation and expression of concern, but negotiate discreetly in order to minimise conflict with health professionals. Inadequate information and medical knowledge, severity of illness and feelings of stress and powerlessness further constrain patients' negotiation in healthcare interactions (Morgan 1986). A deliberate focus on the sufferer's experiences can create awareness of both medical and non-medical needs that victims of chronic illness crave to satisfy. Patients' subjective experiences are critical in efforts to realise comprehensive initiatives to meet their needs. These include the subjective content of physical symptoms that may increase emotional and existential suffering. Healthcare providers often overlook patients' subjective experiences of pain, and other forms of suffering through attempts to medicalise such experiences (Scheper-Hughes 1990). This entails the tendency by medical professionals to separate disease from personal experiences. Such an approach does not address patients' existential and emotional suffering adequately. While medical care in the hospital may be an important resource to patients in times of distress and pain, it may also constrain their search for the deeper meaning of experience (Bury 1982). Patients' perspectives of hospitalisation do not separate their experiences of disease and medical treatment from their material contexts. This can facilitate an understanding of the place of social relationships and livelihood conditions in cancer patients' help-seeking struggles. This highlights the need to balance objective treatment and attempts towards restoration of all aspects of life which cancer and hospitalisation may disrupt.

### Micro-social level

The micro-social level of analysing healthcare issues encompasses therapeutic and care relationships. This includes an assessment of physician-patient relationships and the patient's network of social support. It provides a framework for describing interactions between patients and formal and informal carers. Treatment efforts within and beyond medical settings bring together individuals and groups with conflicting interests and unequal abilities to mobilise power to meet their own needs (Singer 1990). The encounter between medical providers and patients in particular involve unequal power relations. Health providers' use of professional and social power influence their communication, patients' satisfaction and healthcare outcomes. The Critical Medical Anthropology perspective also goes beyond the analysis of patient satisfaction, compliance and tensions in

the clinical encounter to include issues of provider-patient communication (cf. Singer & Baer 1995: 71). This is a departure from the usual medical anthropological perspective, which does not include a wider context of therapeutic experiences that influence healthcare outcomes. A wide range of social relations shapes provider-patient and patient-carer interactions, and these are not always directly visible in the medical setting (Singer 1989). This perspective is crucial in attempts to describe and analyse patients' responses in the present study. Owing to the power relations between patients and healthcare providers, for instance, it is important to delineate behaviours that constitute compliance, resistance, and strategies for eliciting favourable treatment. Social and medical hierarchy may constrain patients' negotiation for care and upfront expression of their concerns. Therefore, a patient's informal carers, especially kin, may provide important social, emotional and informational support when formal interactions do not meet these needs.

### Intermediate level

The intermediate level of the health care system encompasses the hierarchical relations among health providers. Professional hierarchy and differentiation form an important component of the description of interdependence (or lack of it) in patient care interactions. However, the interpretation of hierarchy from a CMA perspective (cf. Baer *et al.* 2003) does not fit neatly in the characterisation hospital staff relations in developing countries. Class, ethnic and gender hierarchy, for instance, are not articulated in public hospitals in Kenya. Hierarchy among healthcare providers in Kenya emphasises professional achievement, seniority and specialisation differentiations more than class. Doctors derive their power and professional status from their qualifications and levels of expertise. Healthcare workers at lower levels of the hierarchy, such as nurses, execute policies and decisions that higher-level staff make. In this regard, the hospital and its wards are sites in which professionals may play out power relations at the expense of patients' physical and emotional needs. Hierarchy and inherent power relations may be apparent in case discussions and patient care decision-making.

### Macro-social level

This level of analysis of health-related issues represents the broad social and economic context. It focuses on the national situation in relation to the international economic system (Baer *et al.* 2003; Elling 1981). As an example, public hospital management in Kenya is linked to the state, which in turn seeks services of other national and international corporate actors. Some of these actors, such as international pharmaceutical companies, have an interest in the healthcare sector that is

geared towards financial profit. At this level, through the government and hospital establishment, the business procedures of drug firms, medical technology producers and suppliers can have far-reaching consequences for patients' well-being. Constraints of drug and equipment procurement procedures in which the government has to negotiate with large corporations often cause treatment delays and drug shortages. Therefore, wider political and economic circumstances that influence healthcare delivery also shape patients conditions and corresponding daily life circumstances (cf. Baer *et al.* 2003: 45; Singer 1990: 184). This forms the context of the struggles of individual patients, families and hospitals in resource-poor countries such as Kenya to improve well-being and quality of life.

Unequal distribution and stringent procurement rules limit access to essential drugs. Regulations of institutions such as the World Health Organisation and the World Bank may also define local interaction with world systems, and these influence local healthcare delivery. The World Bank's blueprints for restructuring the healthcare sector in Kenya, for example, had some negative consequences for poor patients. The World Bank's cost sharing policy and recommendation for a reduction of wards at the study hospital restricted access to healthcare for poor families. In addition, the international economic system tends to favour the curative model of patient care over preventive and palliative care. In the face of perennial livelihood struggles, lack of health insurance and inadequate government subsidies for hospital treatment of chronic disease causes further impoverishment in developing countries. The hospital as a corporate actor depends on the political will of the government to improve cancer care facilities. It also looks to the government for sources of external support in healthcare improvement. Patients' experiences may reflect a hospital's ability or inability to source support through the government in order to address patients' needs comprehensively.

## The hospital

The fieldwork site was the adult cancer ward in Kenyatta National Hospital (KNH) in Nairobi, the capital city of Kenya. KNH is the main public hospital in the Nairobi district and it is Kenya's major referral centre. It is the pioneer and main teaching hospital and the public see it as the most important source of health services. The hospital takes a bigger share of the Ministry of Health's budget compared to other public hospitals. The government allocates more funds to this hospital to facilitate its efforts to handle the healthcare needs of the ever-increasing population of Nairobi. KNH also deals with enormous referral cases from government and private hospitals all over the country. Some of the key challenges to the role of the hospital in improving the health and life of patients over the years include overcrowding, low quality of care, and shortages of equipment, supplies and committed, well-trained staff (Collins *et al.* 1999, 1996;

Kenyatta National Hospital 2005). Popular views in common discourse about the quality of care in the hospital often describe material and technical aspects of healthcare. This perspective overlooks the qualitative aspects of patient care.

Patients in the cancer ward reported that the hospital had recovered from negative publicity. The climax of negative reports about the hospital followed reports of corruption in the institution a couple of years earlier. Commenting on what patients perceived as an improvement in the hospital, a patient said:

I was expecting to find Kenyatta Hospital still in a very bad condition. When I entered here, I found that it had changed since the last time I was a patient here. That time it was very bad and dirty. Compared to that time I can see remarkable changes because every patient has her own bed. Previously, two patients and even three shared a bed. This time I have always received my treatment on time. (Ms. Nadia)

According to most of the patients in this study, people believed that the hospital was “still filthy” and did not have good services. This was contrary to their experience in the cancer ward. They perceived services and nursing care in this ward to be an indicator of relatively improved hospital conditions. Cancer patients view the hospital as their ultimate source of relief to their physical suffering. Having gone through other public and peripheral private hospitals without success, admission to the national hospital revived their optimism. The government had salvaged the image of the hospital through changes in its administration. It changed its status from a department in the Ministry of Health to a state corporation in 1987. Before this, it relied heavily on the Ministry of Health for its daily management. Bureaucracy resulted in delays in decision-making and implementation of programs and activities. In this regard, the hospital received severe criticism from every corner of Kenyan society, especially from ordinary citizens who depended on it for their everyday medical needs. The hospital’s report stated in part:

The deteriorating conditions of the hospital hit the local daily newspapers with headlines such as ‘Hospital of Shame’; ‘massive shortages strangling KNH’ ... Run down equipment, massive shortage of essential drugs and medicines, lack of basic items, congestion, squalid and stinking wards, corruption and demoralised staff were some of the problems that made KNH a ghost hospital. (These) problems that faced the Hospital were aggravated by the general deteriorating standards in the country’s public health facilities. (Kenyatta National Hospital 2001: 23-24)

There was variation in the general condition of different units of the hospital during this study. Patients in the cancer ward, for instance, did not share beds as in some general wards. In other wards, some patients still slept on the floor due to congestion and a shortage of beds. Wards in the ‘private wing’ were cleaner, less congested and better organised than the rest.

The hospital was established in 1901 as the *Native Civil Hospital*, which served a population of about 6000 people who lived in Nairobi. At its inception, it had only forty-five beds (Collins *et al.* 1999, 1996). The hospital relocated its

in-patient services from the initial site near the central police station in 1922 to the present grounds of the Kenya Medical Training College. With this change, the bed capacity increased to 423 to cater for Africans and 41 beds for Asians. The colonial government initiated an expansion of the hospital's facilities under the rubric of *Nairobi Hospital Group* at the current site. The expansion meant including Europeans among the nationalities served by the hospital. This was followed by extensions in 1939, 1951, and 1953 with the bed capacity increasing to 600. The hospital was renamed King George VI in 1951 (Kenyatta National Hospital 2001), and in 1952, an exclusive wing called Rahimtullah was constructed to serve Asians. This is suggestive of the development of differential access to services in Kenya depending on patients' racial, ethnic and socio-economic backgrounds. The idea of the 'private wing' or amenity ward in the study hospital is probably a continuity of this historical phenomenon.

The hospital was given its current name – Kenyatta National Hospital – in 1964, one year after Kenya's independence in honour of the first president of the republic of Kenya. The government then gave it the mandate of a teaching hospital, affiliated with the University of Nairobi. The hospital launched its radiotherapy department in 1968. This coincided with an expansion of the hospital to accommodate the main hospital, medical school including dormitories, clinical science and hospital service blocks (Collins *et al.* 1996, Abdullah *et al.* 1985). In 1981, the KNH expansion programme was completed with a new ward tower building, bringing the bed capacity to 1928 (REACH 1989). The number of beds has risen to about 2000 today. There has also been an increase in specialised services. The hospital's specialised services relevant to cancer management are radiotherapy, medical oncology and haematology, surgical oncology, pathology and palliative care. The total annual inpatient and outpatient attendance at the hospital today is estimated at 89,000 and 500,000 respectively. On average, the hospital attends to about 2,000 patients daily and a large fraction of them suffer from advanced cancers.

Most of the people served by the hospital are poor and can barely afford specialised treatment. Up to forty percent of the poor people in Kenya do not seek medical care when they are sick because of their inability to meet costs, while about three percent of them have limited physical access to health facilities. As the first government hospital in a cosmopolitan setting, KNH has a long history of providing healthcare to people of different socio-economic backgrounds in a multicultural setting. The hospital still serves people from diverse ethnic and social backgrounds from all over the country, including some referrals from neighbouring countries, and non-Kenyan nationals living and working in Kenya. The 'Private Wing' of the hospital has about 225 beds and provides a private healthcare facility within a public hospital. The hospital relies on the private

wing for more revenue, offering improved quality of services to patients who are able to pay more. Both the staff and the general public view the quality of services in the private wing wards as a replica of what some leading private hospitals in the country offer.

As noted in *The Kenyatta National Hospital Strategic Plan 2005-2010* the hospital has twenty outpatient clinics, twenty-four theatres and an accident and emergency department at present. There are fifty wards classified as paediatric, medical (general), orthopaedic, surgical, emergency, and oncology wards. The hospital's specialised services including radiotherapy, important technology in cancer treatment, are the only ones widely accessible to the public. Similar services including chemotherapy are available in the Nairobi and Aga Khan Hospitals, which are privately run and are not financially accessible to a majority of Kenyans. With regard to cervical cancer, there are three treatment centres in Kenya. These include cervical cancer treatment services accessible to the majority of the public at the study hospital and the Nyanza General Hospital in western Kenya, as well as the services available at Nairobi Hospital, which is privately run and inaccessible to poor patients. The cancer specialists who serve at KNH also serve in the private hospitals as part-time consultants.

Due to a lack of qualified staff and adequate equipment in the western Kenya hospital, KNH remains the only national cervical cancer treatment centre (Gichangi *et al.* 2002). There are two main cancer wards at the hospital: the paediatric and the adult wards. The paediatric oncology ward caters to patients usually referred by the haematology clinic, and other general paediatric wards. The children's ward was established in 1986 and has a bed capacity of 30, admitting patients between three and twelve years of age. (The hospital has been planning to establish separate cancer wards for adolescents between 13 and 18 years of age since they are currently admitted in the adults' ward.) In the early 1990s, KNH donated space for the Nairobi Hospice, which provides day care services for some terminally ill patients. A few other patients are served by three hospices located in the central, eastern and Rift Valley provinces of Kenya. The number of patients seeking hospital intervention for cancer is increasing to more than the chemotherapy and radiotherapy services at KNH can handle, yet it remains the only public health facility which many Kenyans can just about manage to afford.

New and re-emerging communicable diseases such as cholera, typhoid and dysentery worsen the healthcare experience in Kenya. There is also a rise in non-communicable diseases, particularly cancer, diabetes and cardiac diseases, which health providers once believed to be "diseases of the Western world" or "diseases of civilization" (Iliffe 1998: 177). The spread of HIV/AIDS has complicated further the disease burden in Kenya and this affects the treatment of other ail-

ments at the study hospital. More than 60% of the patients in the medical wards in the hospital are HIV positive (Kenyatta National Hospital 2005).

Providers of healthcare in Kenya include the government, non-governmental organizations, mission hospitals and the private sector. The public sector serves most of the population at several levels of health services, and some cancer patients go through virtually all the levels in multiple referrals. The basic tier of healthcare at the community level is comprised of ill-equipped health centres, clinics and maternity homes, some of which are run by individual proprietors. The primary hospitals, also referred to as district or sub-district hospitals, form the next level of relatively affordable public health services. The facilities that follow this level are secondary or provincial hospitals. They cover wider areas compared to the primary hospitals.

### Cancer crisis and research in Kenya

The incidence of cancer in Kenya is rapidly increasing. The five most common types of cancer, in order of incidence, among men in Kenya, are oesophagus, prostate, non-Hodgkin lymphoma, liver, and stomach cancer (Sansom & Mutuma 2002). Cervical and breast cancers are the most common among women, with an incidence rate of about 19% and 10% respectively. Ovarian, non-Hodgkin and stomach cancers have an incidence rate of about 4.5% each (Sansom & Mutuma 2002; Mutuma & Ruggut-Korir 2006). The figures at the cancer treatment centre indicate that new cancer cases have doubled, yet treatment facilities in the National Hospital are still limited. At the time of the present study, only four out of the eight provinces in Kenya had hospitals with cancer care services. A total of eight hospitals provided cancer care in the country: two of the hospitals were in the Rift Valley province, two in Nyanza, three in Nairobi and one in Coast provinces. However, key medical technology, especially radiotherapy machines, is found only in the national referral hospital and one private hospital in Nairobi. Due to the change of political leadership in Kenya in 1997, the Ministry of Health neglected the national cancer control programme it had established in 1994. The national cancer control initiative in Kenya failed to take off fully afterward due to an array of reasons including lack of funds. In addition, the cancer problem is not on the Ministry of Health's list of priorities; the public health plan prioritises HIV/AIDS, reproductive health, maternal & child health, malaria control, environmental health, sexually transmitted infections, Tuberculosis control, and an expanded program for immunization.

Kenyatta National Hospital began treatment of cancer through chemotherapy in the 1960s, but the first full-scale cancer research study was conducted about ten years later in 1979 (Ilife 1998). This and subsequent studies reiterate the effect of late presentation for medical treatment and socio-economic background

on efforts to save the lives of cancer patients. There is a scarcity of comprehensive accounts of the patients' subjective experience of the disease and treatment process. Available studies also give little attention to the limitations of hospital budgetary expenditure in controlling the cancer crisis in Kenya. An important feature in the suffering of cancer patients that a few studies highlight relates to the difficulty of nursing terminal patients in Kenyan homes and the inadequacy of regional hospitals in helping these patients (Kasili 1979; Onyango & Macharia 2006). Short supply of effective analgesics in regional health facilities and the national hospital worsen the experience of terminally ill patients. Scarcity of pain remedies and medical supplies often render both physicians and families helpless during their cancer management struggles.

Existing studies underscore the fact that the fight against cancer in Kenya has been secondary to other important public health priorities. This is the scenario in spite of cancer's rank as the third leading cause of death after infections (including HIV) and cardiovascular diseases (Mutuma & Ruggut-Korir 2006). During the time of this study, there was no clear policy of prevention of the disease and comprehensive management. Funding for cancer research, registration of incidence and surveillance systems has remained insufficient in spite of the emerging burden of cancer on individual and household livelihoods. Most of the existing studies on cancer and its management in Kenya are quantitative. These studies exclude qualitative data that can complement efforts to improve the quality of care and life of the victims. Healthcare research in Kenyatta National Hospital reflects the predominant biomedical and quantitative orientation of the hospital staff, and collaborating institutions such as the Kenya Medical Research Institute. While it is true that the research department of the hospital encourages interdisciplinary research, such input is still scarce. The least represented disciplines in cancer and hospital studies in Kenya are the social sciences, and especially hospital ethnography.

Studies of cancer management in Kenya have focused on epidemiological and psychological aspects of the disease (e.g. Kamau *et al.* 2007; Mwanda *et al.* 2004). Most of these studies emphasise biomedical dimensions of coping with cancer using survey tools. These studies involve either post-discharge victims or outpatients and may miss important data on their lived experiences of hospital treatment. Researchers are aware that situational and psychological responses and social factors influence cancer patients' quality of life. Ethnographic approaches are better placed to elicit and document data related to these aspects and patients' experiences of ongoing hospitalisation. Those studies that exist do not address qualitative aspects of patients' experiences of the impact of cancer management on their social support and livelihood. Similarly, recent studies on cancer care at Kenyatta National Hospital (Othieno-Abinya *et al.* 2002; Waihenya & Muingai

2004; Onyango *et al.* 2004; Gichangi *et al.* 2002; Onyango & Macharia 2006) did not pursue the in-depth, qualitative issues related to patients' experiences of the disease and hospital treatment. These studies highlight the prevalence of cancer, age and ethnic distribution of victims and quantitative measures of quality of life. In addition, quality of life research studies among patients in developed countries pay more attention to quantitative measurements, which exclude in-depth descriptions of patients' lived experiences. The present study pays attention to cancer in-patients' views and subjective experiences of the disease and hospital treatment. It explores how the circumstances within and outside the hospital shape patients' experiences.

## Dissertation outline

I organised the chapters of this dissertation around a description of the reality of the cancer ward from patients' experiences and perspectives. I refer to other participants in the ward in order to show how social and medical relations influence patients' well-being. The dissertation describes experiences of multiple hospitalisations and patient care interactions. A brief summary and discussion of the findings conclude each chapter.

*Chapter 1* has dealt with an introduction to the ethnography and presented the study question and goals. I have also explained the conceptual framework of the study and indicated its background. This includes an overview of the hospital, the cancer problem in Kenya and the nature of previous cancer research in Kenya.

*Chapter 2* describes the ethnographic methodology in this study, including the choice and scope of the hospital ethnography. This chapter also highlights and explores issues in the entrée process, data collection, and addresses my role in the ward as an ethnographer. This chapter also considers the methodological challenges in the ethnographic hospital study.

*Chapter 3* describes the study site – the cancer ward, the physical and emotional space of the patients in the hospital. It highlights patients' expectations and the significance of the ward to them. The chapter describes the staff's understated perceptions of the status of the ward as a contrast with patients' expectations. A description of the physical layout of the ward and the human and non-human resources available to patients follow. The second part of the chapter deals with patients' experiences of treatment in the present ward circumstances. It points out patients' determination to focus their minds on treatment in spite of a potentially stressful treatment environment.

*Chapter 4* describes and analyses patient care relations and interactions in the ward. It further describes patients' daily life experiences in the context of social and medical interactions. The chapter also points out issues in social and medical hierarchy and their implications for patient care interaction and communication.

This chapter further explores and examines the network of healthcare relations in the cancer ward.

*Chapter 5* is about the patients' experience of the physical symptoms of suffering. The chapter describes and analyses patients' experience of pain and eating constraints. The first part of the chapter describes patients' communication regarding pain. It further describes the responses of ward staff to patients' explicit or implicit communications of pain, and interprets the hospital carers' responses to patients' physical needs in the context of insufficient hospital resources. The first part of the chapter ends with a description of patients' disillusionment considering their unmet needs. The second part describes patients' perceived eating difficulties and ward personnel's responses. The chapter concludes with a description of patients' discreet recourse to alternative aetiologies as part of their desperate attempts to understand their suffering and supplement hospital interventions.

*Chapter 6* describes patients' emotional and social concerns that arise from having cancer and hospitalisation, addressing patients' worries about social support, experiences of stigma, and moral ideas about cancer. This chapter considers how subjective feelings about physical symptoms and disease progression can shape sufferers' existential and emotional concerns.

*Chapter 7* explores the wider social, economic and livelihood realities manifested in the patients' experience in the ward. This chapter examines how patients experienced treatment and hospitalisation in relation to their livelihood circumstances, describing the social and economic realities that inform their experiences, and examining the implications of individual and family coping strategies for livelihood organization and security. The chapter also explores and describes access to formal and informal sources of support among the study's cancer in-patients.

*Chapter 8* presents the study conclusions and recommendations. The chapter emphasises the relevance of hospital ethnography to comprehensive patient-centered hospital care. The conclusions and practical implications of the ethnography further problematize the role of the hospital in offering solutions to cancer patients' physical and emotional adversity.