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Coping with cancer and adversity: hospital ethnography in Kenya
Mulemi, B.A.

Citation

Mulemi, B. A. (2010). *Coping with cancer and adversity: hospital ethnography in Kenya*.
Leiden: African Studies Centre. Retrieved from <https://hdl.handle.net/1887/15029>

Version: Not Applicable (or Unknown)

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Coping with cancer and adversity

African Studies Centre
African Studies Collection, vol. 22

Coping with cancer
and adversity
Hospital ethnography in Kenya

Benson A. Mulemi

Published by:
African Studies Centre
P.O. Box 9555
2300 RB Leiden
The Netherlands
asc@ascleiden.nl
www.ascleiden.nl

Cover design: Heike Slingerland
Cover photo: Benson A. Mulemi

Printed by Ipskamp Drukkers, Enschede

ISSN: 1876-018X
ISBN: 978-90-5448-092-1

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Dedication

To the cancer patients, their families and the staff in the cancer treatment centre and ward at Kenyatta National Hospital, Nairobi.

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Preface

This monograph is the result of an ethnographic study in a cancer ward in Kenya. I carried out the fieldwork in Kenyatta National Hospital between August 2005 and July 2006. The study sets out to examine the experiences of cancer in-patients and suggests ways to improve their condition. It explores how cancer patients feel about and make sense of their conditions and treatment, and describing and analysing healthcare issues that emerge from patients' narratives and experiences. The description situates these experiences in the context of healthcare interactions among actors in the ward, and highlights the role of patients in negotiating their own care. The study also draws attention to patients' circumstances outside the hospital in order to describe the wider social and economic implications of their hospitalisation. My work is a contribution to hospital ethnography as a research approach in low-income societies, in particular in Kenya.

The analysis is patient-centred and focuses on sufferer experiences of disease and hospital treatment. It differs from the usual 'hospital study': gauging patient satisfaction, for instance, based on data collected outside the hospital or through post-discharge interviews. The present study contextualises patients' distress, dissatisfaction and satisfaction in the realities of the ward and their socio-economic backgrounds.

Cancer patients, their relatives and staff members at Kenyatta National Hospital were consistently supportive during my research. I am indebted to all the patients and their relatives who participated directly in this study through either brief or in-depth conversations with me. The patients who participated in this study fought bravely to cope with cancer and arduous hospital treatment. Only a few pulled through to the end of my fieldwork and the conclusion of this book. May God rest the souls of those who passed on to eternal peace.

I wish to express my special gratitude to the hospital's Ethics and Research Clearance Committee for approving this study. Special thanks go to the then Deputy Director, Clinical Services Dr. Jotham N. Micheni who confirmed approval of the ethnography in the adult cancer ward. He welcomed my supervision team and me at the beginning of the study, which further legitimised and facilitated my position in the hospital and ward as a social science researcher. I am grateful to the ward and Radiotherapy Clinic staff who allowed me to hang around to observe and learn from their work. Special thanks go to Dr. Henry Abwao, then head of the Radiotherapy Department, Mrs Roselyne Opindi, the

nurse-in-charge of the Radiotherapy Clinic, and Mr. Caesar Barare for their gracious support during my observation at the cancer treatment centre. Many nurses, support staff and doctors in the cancer ward provided me with welcome encouragement and friendship. I fondly remember the tea and regular chats in the staff and ward rooms. I am particularly grateful to Mrs. Elizabeth Mbeti Owino, the then matron of the cancer ward, and Dr. Ndung'u, who welcomed me to the ward and encouraged me to feel at home 'like one of us.'

I could not have completed this dissertation without the unrelenting support of my supervisors and advisors. My principal promoter, Prof. Dr Sjaak van der Geest, has played an invaluable role since the inception of my PhD project. My interaction with him dates back several years to when I was seeking admission to the University of Amsterdam. He accepted my request to be my first supervisor and guided me through the application processes and PhD research as a mentor, philosopher, friend and many times like a father. His encouragement to maintain my patience, consistency and resilience contributed a great deal to my personal growth. He was the first to encourage me to embark on this project as a study area that is consistent with my interests and my desire for higher professional and career training. I would also like to express my heartfelt gratitude to my second supervisor, Dr. Fred Zaal, who has worked for many years in Kenya and has a wide range of experience in the country. He often made me aware of the significance of many aspects of local livelihood which I was tempted to take for granted as a 'native anthropologist'. His critical comments and enthusiasm for my work since the stages of proposal development helped me better organise the arguments in this book and in oral presentations related to my PhD training. Sjaak and Fred helped me at every step, from preparing applications for funding to finalising this dissertation. I am also grateful to them and their families for contributing to my orientation in the relatively new environment of the Netherlands.

Dr. Diana Gibson of the Department of Anthropology and Sociology, University of the Western Cape, South Africa, provided significant support as my day-to-day tutor during the first year of my PhD trajectory.

I acknowledge with sincere gratitude the role played by Prof. Dr. Anastasia Nkatha Guantai of the Department of Pharmacology and Pharmacognosy in the School of Pharmacy, University of Nairobi. As my local adviser and hospital supervisor, Dr. Guantai facilitated my entrée in the hospital, arranging for my introduction, orientation and working space in her department within the hospital. This eased the feeling of being a 'professional stranger' as most social science researchers in clinical settings see themselves. I am also indebted to Prof. Dr. Isaac K. Nyamongo, the director of the Institute of African Studies at the University of Nairobi, my other local supervisor and adviser. He was supportive and committed to providing useful guidance, making time for me from the

beginning of my application for admission to the PhD programme and funding to pursue this study at the University of Amsterdam. He consistently encouraged me whenever we talked and corresponded.

The University of Amsterdam generously funded my entire PhD study and fieldwork through the Amsterdam Institute for Metropolitan and International Development Studies (AMIDSt). I am very grateful for the comprehensive support I received from AMIDSt and its entire staff during my whole PhD study period in the Netherlands and Kenya. I extend special gratitude to the manager, Drs. Gert van der Meer for his support and encouragement. Members of the AMIDSt secretariat also played an invaluable role in facilitating my study and stay in the Netherlands. Special thanks to Guida, Marianne and Puikang Chan for their generosity each time I sought their assistance. Numerous informal interactions with Prof. dr Ton Dietz, Dr. Mario Novelli and Dr. Valentina Mazzucato who always spared time for me, enriched my social and academic experience. I am also indebted to the research group Livelihoods, Environment and Governance (LEG), directed by Prof. dr. Isa Baud, for offering an important environment for academic and social interaction that contributed in a special way to my PhD trajectory and apprenticeship. My first and second supervisor were both great assets as they facilitated the academic connection between AMIDSt and the Medical Anthropology Unit, ASSR and the CERES programme. I benefited immensely from the PhD orientation and coursework that these institutions facilitated. I also thank my employer, the Catholic University of Eastern Africa, for granting me study leave and a stipend for basic family support during the challenging PhD research journey.

I wish to thank all my friends and colleagues in Kenya and the Netherlands who contributed to the successful conclusion of my study in one way or another. I can mention only a few of the colleagues and friends in Kenya by name. Dr. Maurice M. Sakwa sustained his supportive friendship when I arrived in the Netherlands as he completed his PhD study at Radboud University, Nijmegen. Dr. Ekisa Anyara, Mr. Bethwell Owuor, and Mr. Peterson Mwangi also provided constant moral support, and their interest in my work encouraged me. Fellow PhD students and staff at AMIDSt, ASSR, Medical Anthropology Unit and the CERES were invaluable companions throughout my stay in the Netherlands. Just to mention a few of my colleagues in the Netherlands, I appreciated the companionship and support of Josien de Klerk, Christine Dedding, Miranda van Reeuwijk, Christine Böhmig, Anna Laven, Kees van der Geest, Edith van Ewijk, Marloes Kraan, Johan Roest, Inge van der Welle, Babak Rezvani, Grace Akello-Ayebare, Dr. Getnet Tadele, Dr. Adano Wario, Emmanuel Nyankweli, Dr. Francis Obeng, Ruya Gökhan Koçer, and Jacob Boersema. During my final year at

UvA, my successive housemates at Sondastraat, Mounir, Stefan Minica and Bart, were great companions with whom to share my experiences.

Members of the PhD promotion and Hospital Ethnography reading clubs provided both social and academic forums. I was privileged to be part of these working groups, and am indebted to them for their constructive criticisms and comments. Similarly, the CERES working group on Health, Population and Well-being in which I was a PhD representative provided an important audience for discussion. I am grateful for the comments of participants in the Second AEGIS European Conference on African Studies at African Studies Centre in Leiden in July 2007, as well as suggestions from participants in the Symposium on Methodological and Theoretical Aspects of Hospital Ethnography, May 1-2 2006, at the Medical Anthropology Unit, University of Amsterdam.

I owe a special debt of gratitude to Cate Newsom who carefully read and edited the manuscript at a critical moment in its revision and to Edith van Ewijk who translated the English summary into Dutch. Similarly, I would like to express my earnest indebtedness to Dr. Dick Foeken of the African Studies Centre in Leiden for facilitating the publication of this dissertation in the African Studies Collection. I also wish to thank the members of my promotion committee for their evaluation and recommendations on this dissertation. While it is true that I benefited from advice and encouragement from many sources, any errors of fact or of interpretation in this book are my sole responsibility.

I wish to thank my larger family for their continued support and solidarity during the challenging times of my study. Thanks to my late father, Ezekiel Mulemi Munyasa, and my late mother, Mary Nyagoha Mulemi. My parents gave me an invaluable foundation for education, patience and life as my first mentors and role models. Just as many of my respondents did not live to see this book, my mother passed away as she awaited my “party in August”. I thank her for her unrelenting inspiration. I also give my special thanks to my brothers and sisters for their constant moral support.

This research entailed one year of coursework followed by one year of fieldwork. I was away from my family for the first year and rejoined them during the fieldwork period. I was away from them again in the third and fourth year of my PhD programme. During the long period of my absence from home, my wife, Prisca, bore the burden of taking care of our lovely daughters, Lillian Nyagoha (Lillie) and Sidney Kathomi (Sidi). I wish to express my deepest gratitude to her for her patience. Her support during the fieldwork was a source of great inspiration. My heartfelt thanks are also due to Lillie and Sidi who had to miss the company of their father for such a long time, but bonded with me fast when I returned. I am indebted to those relatives and neighbours who reached out to com-

fort my children at the height of post-election violence in Nairobi when neither my wife nor I were with them in Kenya at the time.

Benson A Mulemi
Nairobi, March 2009

Treatment and persistent struggle scene

Mr. Misaka Masseyi,¹ 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

¹ 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 2nd. 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.

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 contribute data for theoretical debates on illness experiences and patient satisfaction and quality of life. Hospital ethnography also reveals realities about wider contexts of healthcare experiences within and beyond medical settings. Therefore, ethnographic approach has important practical applications in health policy initiatives. 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 University 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 patients and their families. The leaflets and other documents available at the hospice 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 in to 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 Barnett (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 English¹, as well as a few patients I talked with in both Luhya 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-

pital 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 (*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-

servation 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.

The cancer ward: Hope and endurance

Most people out there know that if you turn out to have cancer 'then you are gone'. When I was told I had cancer, those notions came to my mind, but the surgeon encouraged us. He told us: 'no, this thing can be dealt with. We can treat it if only you are courageous to accept. Do not just accept that you are going to die. You just have to know that cancer is a disease like any other'. My faith helped me a lot. I believe that any thing is possible ... When I came to this hospital, I knew that I would be fine since the doctor told me that it is possible to be cured. Because of the facilities available in Kenyatta (hospital); my expectations are that after treatment, I will go home a fully- healed person to continue with normal life. That is my highest anticipation; that I will not continue (being) 'sickly' time after time. I hope I will be healed and continue with normal work, to serve my family. Church and community ... And continue even with work until I reach the retirement age in good health. (Mr Jabari)

Patients came to the hospital with renewed confidence and hope. The national referral hospital represented the space for long-awaited, superior medical and patient care resources. The reality in the hospital in general and the cancer ward in particular, however, was one of emotional disruption, calling for emotional coping resources to improve patients' endurance of cancer and hospitalisation hardships. Most of the patients who participated in this study turned to religious beliefs for comfort, and to cope with the realities in their treatment setting. Another patient emphasised this when he said:

When I came here, everyone said; 'if you go there, you will be cured'. They said: 'you are going to a high-status hospital. The good doctors are there. You will be cured'. I saw the way the machines are and believed that God will help me ... (Mr Kassi)

Admission to the cancer ward signified renewed hope of better rehabilitation. The reputation of the National Hospital as a place for better healthcare strengthened patients' hope. Hospital staff reassured patients constantly and this rein-

forced their confidence. Religious faith sustained hope for the hospital's potential to restore physical well-being. The National Hospital is at the apex of the public healthcare sector, and most low-income people viewed it as the source of superior treatment and care. However, the hardships of cancer treatment and emotional distress caused by the hospital environment undermined patients' confidence and hope.

This chapter describes the physical and emotional space of the cancer ward. It highlights the implications of this setting for in-patients' well-being and quality of life. This includes patients' expectations of the hospital space and its significance to them. The chapter also underscores the hospital staff's perceptions, showing that as patients and their families enter the ward with great expectations, hospital staff conceal their reservations about the ward's potential to meet those expectations. The chapter then describes the physical layout of the ward and the human and non-human resources available to in-patients. The second part of the chapter deals with patients' experiences of treatment in the prevailing ward circumstances. It points out aspects of the ward that challenge patients' emotional resilience and endurance of cancer and the hospitalisation experience.

'District hospital'

The cancer ward, also known as Ward GFD (Ground Floor 'D') is part of the 'old hospital' complex. The old hospital was established in 1968, five years after Kenya gained independence from British rule. The building is distinct from others which are part of the hospital's new phase. The ward was among the few that remained in the old hospital premises; similar ground floor wards closed in mid 1990s in response to the World Bank's recommendation for a reduction of wards in the National Hospital. The main aim of the World Bank recommendation was to restore the hospital's referral status and reduce the hospital's funding burden. The adult cancer ward was briefly in the current renal clinic adjacent to it. The present-day ward was initially meant to serve as a female cancer ward following the changes in the hospital, but recurrent blockages of the sewage system led to the transfer of both female and male patients, and the absence of a separate ward for teenage cancer patients. The hospital complex's tower block is its landmark and houses the majority of wards, but the cancer ward was not one of them. Nurses said that their colleagues in the rest of the hospital seemed not to know about the adult cancer ward. Viewed this way, the cancer ward seemed to be quite isolated, like a semi-autonomous little hospital. One nurse remarked:

When you tell colleagues that you work in the cancer ward they ask; "and where is this ward?" Is it part of this hospital?

The cancer ward is adjacent to a renal surgery clinic and close to the main hospital entrance to the East. This entrance leads to different hospital depart-

ments and wards in the ‘tower block’. Nurses were concerned about the apparent ‘seclusion of the ward from the rest of the hospital system’. They described themselves as working in a ‘District Hospital’ rather than within a National Hospital. A nurse remarked:

We work in a District Hospital, not in the tower building ... Many people do not know that this ward exists. Our nurse told a visiting doctor at night that she did not know where the blood bank is. The doctor did not believe it ... She said disgustedly, “then this ward is not part of the hospital ... It is not a ward. You should have it closed!”

The public healthcare sector in Kenya caters to most of the population and especially low-income people. The official health sector operates on at least four levels. At the community level, there are ill-equipped health centres, clinics, dispensaries and maternity homes. The next level of health services is the primary or district hospitals, followed by secondary or provincial hospitals, which cover wider areas. The national referral hospital is at the top of the healthcare system and it is expected that all its units have a higher profile compared to those in lower-level hospitals. Primary and secondary hospitals face varying degrees of staff and facility shortages. Healthcare providers at the National Hospital enjoy a higher status and better working conditions than their counterparts in the lower-level hospitals and healthcare facilities.

Key informants indicated that the cancer clinic used to be an operation theatre, whereas the adult ward was a paediatric observation ward. From the 1960s until the late 1980s, adult cancer patients were treated in ‘ward 45’. This was much closer to the present-day radiotherapy clinic on the first floor of the old hospital complex. The ward moved to its current location in early 1990s, when Ward 45 became an emergency ward dedicated to treating accident or assault victims mostly from the city of Nairobi. Thus the cancer ward and treatment centre were not a result of deliberate planning to cater to the needs of the patients and their carers. The staff complained about their workplace environment, which they found stressful. They made efforts to disguise the real conditions of the patient care environment on special occasions, trying to paint a rosier picture during main ward rounds or at times when the hospital or cancer unit expected special visitors, for example. During such times, cleaning and tidying were more prompt and thorough. Both patients and staff noted this momentary attempt to protect the ward’s image to visitors and senior hospital staff. Some staff in the cancer ward attributed the cancer ward’s perceived low status and poor condition to the lack of attention to the disease not only in the hospital but also in the country. Doctor Bedohai, for instance, observed:

People believe that once you have cancer, you are dead. Most of them even today do not know that we can do something about cancer ... The same attitude exists in this hospital. The management does not give us what we are supposed have ... Work facilities are scarce. ... We are just seen as a *ka-peripheral* (minute peripheral) unit compared to departments like

surgery, obstetrics, and gynaecology. The main problem is that most people think that once you have cancer the prognosis is already determined ... They give more priority to other departments, like the medical department ... and diseases like HIV/AIDS.

As aforementioned, poor prognosis and low survival rates of cancer patients partly shaped opinions of the ward. Respondents said that their colleagues in other departments often described the cancer ward as 'less busy', 'a resting' or 'light' ward. Its physical location away from other units reinforced feelings about its perceived isolation from other units. The staff likened the ward to a district hospital as the ward experienced inadequate staffing and supply of patient care resources. (Many district hospitals in Kenya are also relatively remote from central health sector organisation and the staff are often dissatisfied.)

In fact, the ward did seem distinctly separate from the rest in the hospital. It was geographically the last, located near the entrance leading to the main wards in the modern 'tower block'. During visiting hours, crowds of people filed by on their way to and from the other wards and units. As for those who did come to the ward, apart from relatives who had come by several times, visitors seemed lost at first. The cancer ward appeared to be hidden, at the margin of the hospital. According to the staff, the location of the ward isolated them and the patients from the rest of the hospital. This was a significant aspect in the staff's perception of the cancer ward's low status. Some considered their redeployment to the cancer ward and treatment centre to be a demotion. A nurse observed:

When people are posted here, they think they are being misused. It is like being thrown out of the (hospital) system. When new nurses are sent here they feel that they are being punished. Doctors have been posted here, but at the end of the day they tell you; "I cannot nurse patients who are not going to survive. What will the outcome be? People will see me as someone who nurses the dead ones." Everyone wants take care of patients who will survive.

The location and structure of the ward appeared as a metaphor for the reality of cancer. Nurses and medical staff had reservations about the cancer ward's contribution to the overall healthcare outcomes in the hospital. Poor treatment and patient care results conflicted with the conventional association of the hospital with curative medicine. However, patients retained their confidence and hope in the cancer ward. This was the only accessible source of treatment for them after peripheral hospitals and health centres failed to relieve their suffering.

Ward layout

The ward has five rooms with a bed capacity of 32. The first two rooms, with seven and eight beds, and a third smaller room with three beds are reserved for female patients. The ward arrangement facilitated limited separation between male and female patients. The remaining two rooms with a capacity of seven beds each were designated for male patients. The ward management occasionally added two beds in each of the room's corridors and one in the smaller room when

the number of patients exceeded bed capacity. The smaller room was supposed to be reserved for either very sick patients or for those with infectious ailments; however it accommodated female patients instead as they always outnumbered the males. A corridor with front and back doors separates patients' rooms from the other spaces (see Appendix 2). The main entrance, matron's office, nutritionist's room and patient's rooms are on the same side. A treatment room where drugs are prepared and a staff room are located near the back, by the emergency door. The staff room was mainly used by nurses and ward assistants as a tea and social room. The other side of the corridor houses the medical records room, a staff toilet and two bathrooms, one for female and the other for male patients.

Near the staff-changing room is a room labelled 'private', where bodies of the deceased lie before a porter can take them to the morgue. A curtain screen partially shields the room from curious passers-by. Patients went past the private room and attempted to peep in on their way to their shared toilet and the nurses' desk. The curtain screen was occasionally drawn after cleaning the room or the removal of a body. The private room opened and closed as frequently as deaths on the ward occurred. Patients and some staff estimated that at least two deaths occurred per week, an estimation that was close to ward statistics (Appendix 3). Patients said that they were always frightened to go to the toilet at night since it is adjacent to the 'private room'. Mukuru, for instance, noted:

People had told me that this might be the disease that will kill me ... I see people dying here and I become very afraid. I start feeling that if I was not here I would not have seen a person die ... So I thought it would be better to be at home than here. We frequently see people taken out to that room ... We are always aware of what nurses carry in and out of that room. We know when they carry away the deceased. If it is from this side, you imagine that when it comes to this other side, I will be the next to go ... You will be happy when morning comes ... When darkness falls we are even afraid to go to the toilet. You think maybe it is me who will be taken to the room tomorrow.

The location of the private room worsened patients' anxiety about death in the ward. The room was the focal point of the cycle of death I describe later. The nurse's desk was almost in the middle of the ward past the private room and the patients' toilet. After the nurses' desk, there were a drug store and sluice room, where dirty linen, used items such as bed pans, vomit-bowls and urinals are soaked and kept. Next to the sluice room is a minor storage space for used and recycled items, and a bigger storage space for supplies from the main hospital store. Nurses and ward assistants prepared tea and kept utensils in a pantry room near the emergency door.

A television set that staff and patients watched was above the nurses' desk. Patients sat on two benches in front of the nurses' desk as they either watched television or waited for nurses to assist them. The television set, like the radio cassette player below the nurses' desk, was secured with metal enclosures. Ad-

joining the cancer ward were the busy renal surgery wards, where distraught children are often heard crying. Patients came to ward with confidence that its medical care facilities and expertise were superior to the ones available elsewhere.

Care services and facilities

The ward admitted patients with head and neck, breast, cervical, colorectal, prostate, and gastric cancers. The majority of them were on chemotherapy while others were on radiotherapy and 'supportive management'. This included intravenous feeding, treatment of wounds and general palliative care. A few of the patients were treated by a combination of radiotherapy and chemotherapy. The Haematology, Obstetrics and Gynaecology units and amenity wards managed other types of cancer. While the cancer ward was different from other general wards due to the special needs of patients, it was not as high quality and comfortable as the amenity wards. These are part of the hospital's project to provide services equivalent to those in private hospitals. The amenity wards were located in the 'private wing' of the hospital in the tower block. Patients pay more for their care in this wing, which was initiated to enable the doctors to combine private practice and public service within the National Hospital. A few cancer patients are referred to the cancer ward when they no longer afford the higher charges in the amenity wards. These wards were less congested and had more patient-centred services compared to other wards.

Duration of therapies and hospital stay varied with the cancer type and its stage. Apart from long-term cases, patients stayed in the ward for either three or six days of each chemotherapy session. Others underwent eight to 25 radiotherapy sessions, which were often followed by chemotherapy. A maximum of six chemotherapy courses with an interval of three weeks were administered before further reviews. A combination of radiotherapy and chemotherapy entailed a relatively shorter duration of each therapy. The drawbacks to the hospital treatment in general included bad side effects from the drugs, holiday and weekend pauses, poor responses to therapy, low blood count, and some of the patients' irregular attendance at hospital appointments. Shortage of subsidised drugs for poor patients also interrupted the treatment process. Patients had to buy drugs from expensive private pharmacies and dispensing chemists when they were not available in the hospital. Treatment plans were in principal based on medical records. However, some records from referring health facilities were insufficient. Several patients, for instance, reached the referral hospital after numerous unspecified treatments elsewhere.

Cancer in-patients had access to required services from both the ward and other related units. They went for radiation therapy and clinical reviews at the

Radiotherapy Clinic. They also relied on the personnel and services in medical laboratories, X-ray, and scanning rooms. Due to the heavy workload at the radiotherapy department, treatment of in-patients was often postponed to the evening hours. High turnover of both outpatients and in-patients increased the treatment waiting time at this unit. Each day approximately 130 patients would turn up for treatment at the radiotherapy clinic, for a total of about 800 patients each month. With only one radiation oncologist working at a time at the clinic, patients' treatment planning (simulation) did not take place on time and this contributed to backlog in the waiting queue. New cancer cases reporting to the radiotherapy department were increasing. Unpublished figures at the radiotherapy department showed that there were 659 new and 3,890 re-attendant cancer cases in 1995. This totalled to 4,549 cases. Of the 10,809 cases in 2003, 1,135 were new, while 9,374 were re-attendant. The number of patients needing radiotherapy (cobalt) was 23,190, and 1,139 were on chemotherapy. In 2004, there were 1,499 new and 9,761 re-attendant cases, all requiring radiotherapy, whereas 1,164 also needed chemotherapy. (In-patients require radiotherapy in addition to chemotherapy at some point.)

The hospital had two Cobalt-60 units, which were the only ones accessible to the public countrywide. One of these machines was installed in 1983 and the other in 1993. The former machine required replacement, which is usually due after 15 years. A similar machine was available at a private hospital, but was accessible to only those few people who could afford the higher fee charged. The other functioning equipment at the radiotherapy clinic included one treatment planning unit and mould room facility. Immobilisation devices, breast boards, head and neck unit and masking devices were functional. Frequent breakdown of the machines increased treatment waiting time and the backlog of unattended patients. Technical experts and spare parts for indispensable machines came from abroad, especially Canada and Germany. Mr Abeid, a senior radiologist remarked:

We had a machine called the superficial X-ray machine ... When it stopped working we *searched internationally* (emphasis added). We went to Germany to the manufacturers and they said they were no longer manufacturing it!

Political commitment to raising the profile of cancer in Kenya could resolve the insufficiency of essential treatment facilities in the hospital. The purchase, installation and maintenance of the main equipment require large amounts of money. Moreover, safe and accurate operation of cancer treatment equipment requires highly trained personnel. A treatment simulator installed in 1993 was not functional during my fieldwork. It would cost 10 million shillings to repair it (one Euro bought about 100 Kenya shillings). Mr. Abeid reported that experts from the International Atomic Energy Agency (I.AEA.) advised the repair would

be uneconomical. They instead recommended the purchase of C-am X-ray equipment which serves a similar function. The Radiotherapy department was meanwhile using a C-am X-ray machine which they had borrowed from the X-ray department.

Replacement or repair of cancer treatment machines is expensive and takes a long time. For the duration of my fieldwork, a brachytherapy machine was not functioning. Doctors referred cervical and prostate cancer patients to other hospitals abroad if they could afford it. Others, such as Ms. Souda, received only palliative care and pain relief when they returned to the ward. Ms. Souda had tried to gather funds for over one year for brachytherapy in Uganda but she did not succeed. She was eventually discharged through the Nairobi Hospice for weekly palliative care sessions. Both the High Dose Rate (HDR) and the Low Dose Rate (LDR) brachytherapy machines were not functioning. Mr. Abeid said that the hospital was waiting for an engineer contracted from Europe to come and repair the LDR. It had been broken for about three years. The HDR machine had been removed because it was emitting dangerous radiation to the surroundings. Barely one year after its installation the machine could no longer be used, and had not been functional for two years. The cancer treatment centre required a new or reconditioned room if the machine was to be re-installed for safe use. Doctors tried to improvise in order to give patients some help in spite of the insufficiency of such essential machines and facilities. Doctor Martina for instance remarked:

We have been trying our best since the brachytherapy machine has been unavailable ... We try to improvise with whatever machines we have to treat patients. We refer those who can afford it to clinics out of the country. Some go to Uganda; some to South Africa, Tanzania or other overseas countries depending on their financial abilities.

Poor condition or lack of cancer treatment machines affected the well-being of both in-patients and outpatients. Delayed treatment and complaints about missing or inaccurate laboratory results were common. Doctors occasionally recommended repeats of tests and examinations done in the hospital facilities. They preferred diagnostic tests from outside the hospital when diagnostic results were missing from the patients' files. Similarly, they often found it necessary 'to confirm' the reliability of diagnostic results from the hospital's laboratories. Patients interpreted this as conflicting with the high expectations with which they came to the hospital. They initially hoped to find a self-sufficient hospital since they regarded it as the ultimate source of medical care among public and some private hospitals. The condition of treatment facilities accessible to patients shaped their experiences of and attitude towards technical care. The ward topography on the other hand had implications for in-patients emotional stability. The patients' ex-

perience of hospital treatment was an outcome of the psychological impact of the ward layout and effectiveness of available human resources.

Human resources

Nineteen nurses of different training backgrounds and levels in the hierarchy worked in the cancer ward. Two of them opted for early retirement, while two more were on study leave. Others combined work with part-time certificate or diploma courses in palliative care or counselling. The hospital administration had posted about half of the nurses to the cancer ward on 'medical grounds', meaning the nurses were considered to be frail and unable to work well in 'busy' or 'heavy' wards. For this reason, about half of them could not manage night shifts. Two to four nurses worked together during each shift, depending on the current workload.

A typical day for patients generally followed the routine of the nurses and medical staff, beginning around 4 am when the shift nurses took vital signs. After this, at around 5 am they helped patients to their baths, and assisted those patients who were not able to bathe. A kitchen assistant served breakfast between 7:30 and 8 am before nurses made the beds. Treatment, dressing and patient observation followed between 8:30 am and 12:30 pm. Lunch was served between 11 am and 12:30 pm. Nursing and treatment procedures resumed during the 5:30 pm to 7:30 am night shift.

A physician with the designation of Medical Officer of Health was in charge of the ward. He or she handled admissions and chemotherapy. The physician also tended to patients in other units, such as the 'amenity' (private wing) wards, who needed chemotherapy. Patient care demands challenged the ward doctor and nurses many times. The perceived low status of the cancer ward as aforementioned, partly contributed to its understaffing problem. The general attitude that there was 'no work' in the cancer ward apparently justified the inadequate staff posting. The ward doctor was not able to cope with the workload and was not available for patient care at night. Mrs Nedi, a nurse who was often in charge of the ward observed:

We operate without a doctor at night. They say we do not have emergencies. In case we have anything requiring his attention we call him on his mobile phone. He often tells us that will come the following day. So we just do our work and wait for the doctors to come the following day. We know the doctor is on call but he is over-worked.

In the words of Mrs Nedi, the main ward physician was 'a general practitioner familiarising himself with cancer treatment.' Doctors who were in charge of the ward during my fieldwork were not trained in oncology; they were apprentices, 'learning on the job'. Dr. Martina attributed the shortage of cancer treatment specialists to medical students' general lack of interest in oncology. On the other

hand, lack of policy on oncology training in Kenya was apparent from the small number of practicing cancer management specialists. Similarly, informants noted that there was scant focus on cancer in existing medical training programmes. Consider the comments of Mr Darius, a radiographer and Dr. Martina below:

... We need to restructure the training ... None of the doctors at the undergraduate level gets more than ten hours of teaching on cancer. Not even training, teaching ... I have also talked to the nurses. They indicate that the reality of cancer confronts them only after their posting to the radiotherapy clinic or cancer ward ... (Mr Darius)

... Very minimal time is dedicated to oncology in medical training. It only comes up during clinical years from the third year ... We have big rotations such as obstetrics-gynaecology, surgical and paediatric rotations ... There is no oncology rotation per se. This is just put out for students in their extra time ... You 'pass by' Oncology. Maybe students will see a cancer patient during the general rotations. I should say that teaching on cancer gets only an eighth of the total time of medical training ... It is much less. There is a lot of emphasis on the other specialities (Dr Martina)

There were only four qualified oncologists who served in the cancer treatment centre. One oncologist left the hospital to go work abroad at the beginning of the present study. The remaining doctors provided expert services to the ward and other units as consultants. They led the major weekly ward rounds in turns. Consultants are doctors with specialised training in their field, as will be further explained in Chapter 4. They attain the title of consultant after several years of service as specialist registrars and earning a master's degree in their field of specialisation. Ideally, registrars are experts with basic qualification in their specialties. They serve in wards for at least two years as they wait for the training that can lead to their qualification as consultants. However, adult oncology training is not available in Kenya. The four adult oncology consultants at the cancer treatment centre included one who had just completed specialisation training abroad. Their specialisation focused on radiation oncology and one of them was a nuclear medicine physician. They were also involved in part-time work and consultancy in private hospitals.

Only five qualified therapy radiographers served both inpatients and outpatients. Two more radiographers were on study leave. An additional seven untrained radiographers worked in the department. Three oncology nurses and three medical physicists worked at the Radiotherapy Clinic. A full-time nutritionist facilitated patients' diet and feeding needs on the ward. Trainee dieticians from university and mid-level colleges frequently worked in the ward. The nutrition office was handy for counselling sessions with a few patients and their relatives. Counselling sessions addressed eating and diet issues and some questions about cancer and its treatment in general.

A porter, records clerk and three housekeepers or cleaners worked in the ward in shifts. Other personnel attached to the ward included a laboratory technician, a physiotherapist, an occupational therapist and a social worker. Chapter 4 will

further examine the roles and interactions of all these and other actors. Patients' kin and friends complemented the care-giving roles of the hospital personnel. Their presence and roles were more noticeable during official visiting hours, between 12:30 pm and 2:00 pm; and 4:30 pm and 6:30 pm. Patients' social networks and the hospital staff constitute important sociability space in the hospital. Artefacts of medical technology and the physical ward environment contribute to the comprehensive context of patients' hospitalisation experience. These aspects had further implications for patients' endurance and emotional space. Physical conditions of the ward, daily occurrences and shortage of human and medical resources portrayed the hospital as a place in which patients experienced increased uncertainty, anxiety and desperation. The hospital and the ward emerged as a setting in which cancer in-patients gradually felt less attended to. It was a setting in which they experienced prolonged or recurrent states of limbo characterised by distress. Waiting for treatment, examination results and responses to daily physical and emotional needs became part of patients' daily life in the ward. Being an in-patient in the cancer ward also entailed a sense of physical and emotional vulnerability. The ward aggravated this situation by increasingly exposing its patients to threatening conditions and the reality of death.

Bed scarcity, waiting and care delays

Patients linked their narratives of experience in the referral hospital to previous help-seeking events. They had been through many tests in community health centres, private and peripheral public hospitals. They took various paths to the cancer ward. Many of them were referred there at different levels of public health care. Most patients had sought help from either private facilities or public hospitals before their current admission. Others came directly to the cancer treatment centre and ward through the hospital's casualty unit. It gradually dawned on them that the national referral hospital did not guarantee the prompt and reliable treatment they expected. Rather, admission to this hospital implied continuity in waiting for treatment and appropriate care. As pointed out earlier, this resulted from inadequate hospital resources, patient's financial constraints and the unpredictability cancer treatment outcomes. Being in the hospital and the ward was therefore an extension of the period of waiting and delayed relief.

Arrival at the cancer treatment centre did not mean outright access to treatment. Availability of hospital resources determined when patients could be admitted to the ward and their treatment begun. Out of over 100 patients who turned up every Monday for regular admission, only 20 or fewer secured beds. The admission of patients who needed urgent attention on other days further limited the number of beds that would be available on Mondays. Patients and /or their relatives had to be at the clinic by 5 am in order take the first 30 positions in

the queue. This increased the possibility of securing beds from 8:30 am when doctors began their work. Mr. Hassan commented on what he described the 'scramble for beds' in the words below:

It is a matter of 'first-come-first-served.' One must come here by 5 am to be sure of a bed. There may be only two beds against over 10 patients ... You find people have already arrived very early in the morning, by 5 am ... The person who arrives first collects the cards from others and files them in the order of arrival. He or she then presents the appointment cards to the doctors when they arrive ... Once the beds are filled up, they tell you, "there is no bed, go home and come back next Monday ..." When you go back home you postpone your problem. It has happened to me before three times ...

The range of bed occupancy was 50% to 83%. Between January 2005 and July 2006 in-patients statistics in the ward showed a higher rate of female admissions compared to the males. Therefore, the turnover and death rates among the female patients was more visible in the ward and in the statistics (See Appendix 3). Fewer men turned up or 'qualified' for admission. Patients 'qualify' for admission if they fulfill several conditions: their blood count should be sufficiently high; the urine analysis should be normal; and they should be able to buy drugs that are not available and pay hospital admission fees. Some patients were not eligible for admission because they failed to meet only one of the criteria. Others who qualified would still fail to be admitted due to the scarcity of beds. Fluctuations between under- and over-admission were also apparent in the ward. Low bed occupancy was related to low turnout for appointments, lack of eligibility among patients who reported for admission and the effects of holidays. Many patients missed the chance for prompt treatment due to bed scarcity. Lack of available space also meant the impossibility of adding beds from elsewhere. Nevertheless, at times the ward very few patients were admitted, and the few who were present were on short chemotherapy sessions of two days each. On such occasions the ward was virtually empty by Wednesday.

Delays in treatment and care persisted even after patients' admission and during their stay in the ward. This constitutes a significant aspect of suffering that being in the hospital engenders for cancer patients. The delay was often related to a shortage of patient care resources which included drugs, treatment equipment and personnel. Respondents complained of the inadequate attention they received late in the night due to staff shortages and the non-functional calling system. (The bell system was not functioning for the duration of my fieldwork.) Patients therefore relied on shouting for help from nurses, physicians and other available staff. Responses to their calls were not prompt, and this symbolised the general delay in meeting in-patients' emotional and physical needs. The hospital and ward environment was seen as a barrier to expected treatment and care by both patients and other actors; regardless, most cancer patients who participated in this study regarded the chance for admission to the hospital as a

blessing in disguise. The ward and the hospital constituted their final physical and emotional spaces that they felt obliged to face up to. Most of the respondents cited a need to tolerate their treatment setting in order to maximise the potential medical benefits of being there.

Enduring the ward situation

The hospital environment and specifically the ward is a physical space with emotional implications for cancer patients. Patients engaged in rationalisation in order to ease the distress that this treatment space caused. Some respondents viewed the cancer ward as the climax of hospital treatment. They did not anticipate finding any alternative hospital treatment setting with higher expertise and medical technology they could easily access. They considered the present treatment setting better or more promising than the other places they had previously been. An important aspect of this consideration was that treatment and care encounters prior to the present hospitalisation did not restore their well-being. The cancer ward also seemed better because once patients secured admission; they did not share beds as in other wards in the study hospital and other public hospitals. They also perceived the diet and nursing care in the cancer ward to be generally better than what they found or observed elsewhere. Some respondents noted that the condition of the cancer ward did not necessarily confirm the bleak picture that popular discourse about the hospital often portrayed. Echoing Ms. Nadia's view cited in Chapter 1, Mr. Jabari remarked:

... People out there say that this hospital is filthy. They say service has declined, but what I have seen is contrary to this view. I have had quite good service during the days I have been here ... The nursing care is quite in order and very good. ... It is better than many other hospitals ... It makes our healing process a little bit quicker because we can see that the treatment is good. They give us medicine on time. The doctor who gives chemo is very punctual ... This is very encouraging ...

Patients focused on the positive aspects of the ward in order to anticipate positive results from their stay. Low congestion in the ward and availability of curtain screens for some privacy were additional aspects that encouraged them to persevere. They tended to explain away ward inadequacies and any related anxieties. The view that their 'main interest was to get cured and go back home' offered more consolation. Patients restrained their critical evaluation of the quality of ward amenities. They instead focused more on either their need for more subsidised drugs or for compassionate care, as shown in Chapter 6. They desired more emotional consolation and prompt response to their physical needs. The fact that they did not share beds and that none of them was sleeping on the floor as in other wards was comforting. Others praised the relatively unique diet, staff approach, and somewhat cheap treatment and services. They tried to find the

positive attributes of the ward that made life there bearable. The ward was generally 'not a bad place' for most of them, as it was the only exclusive cancer ward they had been to. Positive experiences enriched their resources for psychological adaptation to anxiety and uncertainty in the ward environment. However, the ward constantly exposed them to threatening conditions and anxiety about death. In this sense the ward environment worsened patients' emotional vulnerability.

Threatening and unpleasant circumstances

The ward atmosphere unfolded the ominous reality of cancer. A poster at the nurses' desk had a positive message: "chances are that you do not have cancer." However, it reminded the reader to confirm this through appropriate medical examination. In the nutrition counselling office, there was another placard on how to cope with cancer through balanced diet. Subtle discourse about the risk of cancer and visible events in the ward often punctuated the hope for restoration of well-being. Patients witnessed the suffering of others in the open ward rooms. Beds were too close to each other and curtain partitions did not adequately screen undesirable treatment side effects such as diarrhoea, vomiting and constipation. Patients with different types of cancer and on diverse treatment regimes and courses lay next to each other. Those who could not stand the suffering of others pestered nurses and doctors to discharge them earlier than scheduled. Some feared that they would contract other illnesses on the ward. A respondent commented:

There might be some infections here. Patients have other problems, such as bronchitis or similar to the one I have. Somebody may have throat cancer and all the time will be spitting here and there. You may be lying near him and you can contract the disease ... Some patients have wounds and flies can transmit sickness from those wounds. (Mr. Mati)

Some patients indeed stayed in the ward longer in order to treat other illnesses such as chest infections. There were a few cases of malaria and additional sicknesses that required further investigation. The ward management did not separate patients according to their conditions as some desired. The small room meant to accommodate patients whose conditions would put the well-being of others at risk was rarely used for this purpose. Patients also wished the hospital would provide them rooms according to the nature and level of their treatment. Treatment side effects and especially vomiting and diarrhoea were more prominent patients in undergoing the first three courses of chemotherapy. This caused discomfort among patients who were not experiencing similar symptoms. Others were anxious that probably some cancers were contagious.

Shortage of cleaning detergents, the nature of cancer illness, blockage of ward drainage system and poor patients' hygiene on occasion caused the ward to stink. This increased discomfort and fear of transmission of illness among both patients and ward workers. The squalid atmosphere also triggered nausea, vomiting and

poor appetite among the patients. Some patients complained about the effect deodorants that some hospital workers and ward participants used. These also increased their vulnerability to nausea and vomiting, especially during chemotherapy. Many patients also found the smell of ward cleaning detergents to be too strong and unpleasant. Frequent drainage and sink blockages and poor drainage in patients' bathrooms and toilet worsened the physical and psychological distress among the patients. Flooding of bathrooms and delays in cleaning the patients' shared toilet were frequent phenomena. Some patients preferred using bed pans and portable urinals due to the fear of using the toilets. However, nurses did not always empty these hospital utilities in time due to their busy schedules. In order to control use of the toilet and frequent requests for bed and urinal pans some patients said that they limited their food and drink intake.

Patients repressed direct criticism of the ward environment in spite of their unpleasant experiences. They emphasised positive aspects of the ward in order to mobilise their emotional resources for coping with other challenging hospitalisation experiences. Silence or covert complaints about the ward were their strategies for safeguarding the 'good patient' picture. Similarly, holding back negative evaluation of the ward facilitated patients' positive thinking about their hospitalisation. The ward was the setting of hope and hence called for endurance of its negative characteristics. Their experiences and the discourse of carers within and outside medical settings generated idioms of hope which facilitated endurance. The idioms refer to expressions that manifested patients' optimism in spite of uncertainty and anxiety that resulted from their treatment circumstances, mitigating emotional distress and sustaining hope for positive outcomes of hospitalisation. Patients also invoked hope expressions in order to promote their confidence in hospital intervention. Their hope thrived on the confidence they had in the technology and expertise of the hospital. Religious faith among patients and their carers renewed hope. This facilitated coping with the anxiety and uncertainty that the physical and emotional ward space created.

The medical staff added an authoritative voice to patients' hope idioms that facilitated their endurance of the treatment setting. They often assured patients that 'there is some treatment for the disease' or 'something could be done' to alleviate their suffering. Many respondents found consolation in the view that the ward environment reduced loneliness. They said that it was easier to share experiences with fellow sufferers in the ward. One respondent for instance observed:

We have more people here to comfort us here than at home. We comfort each other. People who are okay cannot comfort you. They cannot understand when you tell them about pain ... They cannot relate to it when they are not sick! (Ms. Marina)

Mutual support among cancer in-patients provided them with the sociability space they required. As Chapter 4 will illustrate, sociability is an important

aspect in patient care relations. Many patients viewed the ward as an appropriate place to learn how to cope with physical suffering; however, the physical space and available human and non-human resources can have emotional consequences. Daily life experiences in the ward further influence the contribution of physical and emotional space to patients' well-being. Patients recognised the part played by the ward in strengthening emotional and objective coping resources. Mr. Johana for instance, remarked:

We build immunity to the illness from this ward. Someone can tell the other how he is unable to eat, how he has had sores in his mouth, or what medicine he used before a wound disappeared. I do not feel like an island even after I am discharged to go and 'live alone'. I always remember that I have a problem that my "colleagues" are coping with well. After this learning experience I do not feel that my condition has reached an end and that 'I am going' (to die). When my mouth dries up ... I know it is something somebody else has managed ... The ward introduces us to conditions even before they come to us.

Being in the cancer ward entailed significant encounters and interaction with fellow sufferers. Patients got the chance to evaluate their condition in relation to others. They reckoned with the reality that some of the cases were even more severe and hopeless than their own. While this intensified their emotional stress, it also provided them the space for learning from each other about how to cope. However, frequent and prolonged hospitalisations implied more exposure to episodes of death in the ward. This constituted the most significant challenge that the ward presented to in-patients' emotional resilience. Some patients feared that being in the ward enlisted them into what they perceived as a sequence of death when it occurred. They held that death seemed to follow a particular pattern within ward rooms with an end to the cycle in the 'private room.'

Cycle of death

A ward assistant's sentiments below provide a view of the experience of death in the ward.

... This was my first posting in a hospital. I previously worked in a company where I was dealing with healthy people. I used to hear about death in hospitals but I never experienced it the way I see it nowadays ... I almost resigned during the first three months of my posting. I was shocked. I thought this environment was not friendly. So a matron did some sort of counselling for me to help me continue, because I was about to tender my resignation ... I used to hear that people die but not at rate death occurs here. The mortality rate is very high, because you can easily lose five or seven people in a week! This means one patient daily. It is shocking. So one day, I followed a programme on television, they were saying; if you see a coffin, if you hear people crying at the mortuary, you should know that is the way ... And when you see the coffin you should be reminded that death is real ... Then the programme reminded me that I will also sleep (die) one day. That is why a corpse cannot scare me. I can even prepare a body for burial ... Yes, we clean the body, wrap it in nice sheets in preparation for mortuary preservation ... It has come to be a routine job in this ward ...

The 'private room' was almost at the centre of the ward. It was also very close to the spaces that were essential for patients (see Appendix 2). It was partly or

fully open on occasion, exposing an empty bed or the deceased and the mystery of life. Ward assistants at times washed the room with a strong-scented decontaminating cleanser after a body had been removed. The location of the private room did not conceal the frequent deaths or the reality of the low survival rates in the ward. The death rate was very high relative to the ward's small capacity (see Appendix 3). It was inevitable for patients to witness fellow patients' distressing last moments of life. Beds were close, but the ward personnel did not isolate very ill patients. Some respondents describe situations in which they feared the 'cycle or succession of death' in the ward. As Mukuru's remarks in the section on ward layout above indicate, some patients believed that death followed a sequence. Coincidentally, when very ill patients lay in adjacent beds they were likely to die in a succession. Mukuru observed:

I feel so much fear when I see someone dying. I would not see people dying if I were not here ... I saw the patient who was here and the one who was there dying. I fear that I will be the next to die. If we followed the cycle I thought that I would be the next ...

There was subtle fear of beds and spaces which dead patients had occupied. Patients categorised deaths in the ward as 'painful, sudden, or peaceful (silent).' Long-stay patients had more exposure to the processes of dying in the hospital. The cancer ward unfolded the reality of death as an outcome of hospitalisation. It is in this sense that some ward personnel indicated that their colleagues in other departments likened the ward to a repository of very ill and dying patients. The experience of the cancer ward as a place with the most number of deaths was traumatising for patients and their kin as well as hospital carers. Stella, a long-stay breast cancer patient recounted her distressing experience of witnessing four deaths in a week. Her son was anxious when he found she had been moved to a bed that had been vacated after a deceased patient had been wheeled away. "I also wonder if this means I should be the next to go (to die)," Stella remarked.

Some ward staff and patients associated the ward with physical deterioration and death rather than cure or healing. They speculated that frequent deaths resulted from toxic chemotherapy or neglect of patients in distress. They argued that many patients appeared strong upon admission and prior to their deaths. They therefore questioned the safety of the ward and some of the chemotherapy regimes. In a conversation with Stella about this, she said:

They come when they are still a bit strong. Therefore we feel they can be assisted. Many patients deteriorate all of a sudden ... Most of them die at night. The woman who was here was eating well. I thought she would be all right ... I cannot understand whether there is no medicine. Maybe they delayed buying the medicine ... Her husband has been coming and I think he bought her medicine. I do not know if they (staff) used the medicine ... I do not know why she passed away. She did not deserve to die ... You come here when you are still a bit strong, but you become exhausted, then you just die silently. They have not told me anything about my case ... yet; the doctor comes and treats the other patients. We may be

talking just as we are doing now, but after a short time somebody changes abruptly and dies, just like that ...

Some patients associated the ward with exposure to the risk of “undeserved death.” They argued that hospital staff could fail ‘do their best’, making hospital stay futile. Therefore the ward provided space for either professional concern for sufferers or lack of it. In this regard, considerate staff were often prompt in responding to patients’ calls for help. If carers had ‘done their best’, patients would describe death as a chance for the sufferer ‘to go and rest.’ Viewed in this way, the hospital was a mere transition place for patients beyond medical help. This notion was applied to long-term hospitalisation cases or patients whose critical illness or desperation was more noticeable. The same consideration related to patients who died relatively old in spite of cancer and unsuccessful hospitalisation. Some patients were eager to tell relatives about what they perceived as undeserved deaths. They attributed some of the deaths to staff laxity and insufficient treatment resources. Nurses on occasion transferred such patients to other rooms in order to control their tendency to turn fellow patients and relatives against hospital staff.

Issues in patient-carer relationships featured in narratives of incidences of death in the ward. Patients feared that their reactions could upset the hospital staff, thereby affecting their treatment as Chapter 6 illustrates further. They speculated that hospital workers could bring about some suffering or refuse to provide appropriate care due to negative attitude towards particular patients. They associated some aspects of suffering and death with either lack of compassion among carers or their temperament. Some patients therefore believed that some deaths and prolonged suffering were due to carers’ avoidable errors. The excerpt below illustrates patients’ views about suffering and death that they associated with either vindictive carers or professional errors.

... so many people died and I was very scared ... Six deaths occurred within five days! This terrified everybody. We felt that it was better to go home because we did not know who would be next. Mabeywo’s death disturbed me for over a month. She had been well and jovial ... She used to wake up early and bathe by herself until a doctor came to administer an injection. He said he would inject her in the stomach instead of the hand ... Mabeywo accepted reluctantly ... She later started complaining of severe headache. The doctor and nurses told her that she would be well ... The next day a nurse brought her water, but she said that she was unable to bathe ... She was unable to wake up. We knew that in her condition, she ‘was going’ (to die). Nurse Debra came in to ask how she was faring, but she did not reply ... The nurse took ‘the bed’ away. (Mrs. Pakot)

Patients were suspicious of some hospital staff whom they associated with untimely death and suffering. They were ambivalent about the hospital as a place in which they hoped to find a remedy for their physical and emotional adversities. The hospital seemed to be a dangerous place the increased suffering which many patients linked to their initial medical treatment elsewhere. As an example, Ms.

Stella said that doctors in a district hospital were to blame for her mastectomy because they injected directly the breasts. Others felt that the hospital would control suffering and deaths if physicians would avoid some surgical operations and ‘dangerous chemotherapy drugs’. While it is true that the referral hospital was the setting for cancer patients’ they also perceived it and especially the ward as a dangerous place. Therefore long-stay patients and those who had experienced numerous hospitalisations tended to oscillate between discreet resistance and compliance. They resisted staff that they perceived as responsible for unsafe or inappropriate medications. In relation to this, Mrs. Pakot remarked:

... If that doctor came to give me medicine, I would excuse myself. I told him; let me take it another time. If he insisted I would take the medicine politely and pretend that I wanted to take it. I would just throw them away later (laughs). I would not take his medicine. Everyone in the ward was worried when he came around to give medicine. People really fear that person ...

Patients concealed their resistance. Sometimes they argued with physicians and nurses about the treatment they were refusing. Episodes of physical deterioration and death in the ward challenged patients’ emotional resilience and prompted their resistance. However, the patients and their kin still struggled to sustain their faith in the hospital’s medical technology and expertise. Hope idioms were handy in the face of death. The medical staff encouraged the idioms and these facilitated patients’ endurance of hospitalisation. The staff often reminded grieving and occasionally bitter relatives that they all ‘did their best’. Hospital staff and patients apportioned mutual responsibility for successful treatment, as shown in Chapter 5. Experiences in the ward, however, provided patients and their families with the chance to come to terms gradually with the reality of cancer treatment outcomes. Long-term and repeat stays in the cancer ward revealed the intrinsic helplessness of the hospital staff. Treatment efforts are therefore part of their encouragement for patients to disprove the notion that death is the obvious or imminent outcome of having cancer. Patients and ward staff repeatedly referred to the idiom that ‘death does not result from cancer alone’. In this sense, the ward was a place for endurance of the prolonged suffering that cancer causes. The notion that not only cancer, but also ‘other diseases and accidents cause death’ consoled suffering patients. In this regard, the ward is a place where health workers and patients combine material and emotional resources to cope with indefinite treatment, increased uncertainty and a frequent lack of answers to cancer management challenges. A patient’s remark below is an illustration of this.

I was shocked ... I refused to let them amputate my leg. I could see that the disease is not curable. I later accepted the amputation. I considered that even if I stay with the leg, so many thoughts would hurt me. I responded to God and he still has helped. There are many people who have died and cancer did not kill them. Even the doctor told us that the first thing a per-

son needs to do is to accept the disease ... That is how he or she will start to heal faster. The doctor said that it does not help to think too much that cancer is not curable. He said that if you believe and take the medicines, they can cure or reduce the (cancer) cells. (Mr. Toi)

Sentiments of religious faith intertwined with hope idioms to ease anxiety among patients and hospital staff. Being in the hospital represented a struggle against a seemingly 'incurable disease'. While exposure to death in the cancer ward increased anxiety and uncertainty, the staffs' dedication to treatment sustained most patients' optimism. Mr. Ndege demonstrated this hope in spite of an apparently contradictory reality when he said:

... My friend who was here died two days after I was admitted ... The one who was here has also gone (has died) ... The nights have gotten too long ... You know, treating and healing are two different things. You treat and it is the work of God to heal. People believe that cancer is a deadly disease, but which one is not deadly? Malaria is also deadly and can kill you in a day ... As we get the treatment we also need to learn about spiritual life. I always wonder when someone says, 'that ward is for cancer people and cancer has no medicine.' Here we are, buying the medicine ... Why are we doing it? Why can't we just go home to wait for the day (to die)? (Mr. Ndege)

Medical staff and other carers inspired patients to accept the disease and tolerate the treatment. Doctors were the first credible hospital contacts who strengthened patients' anticipation to restore their well-being. Religious beliefs and attitudes facilitated their endurance of the emotional distress that the disease treatment environment engenders. Adherence to treatment and healthcare instructions was an important aspect of religious belief and faith. In the end, patients perceived the success of hospitalisation in terms of a combination of factors, including the adequacy of medical resources and services, and personal endurance of treatment and its context. The type and stage of cancer determined the success of hospital intervention. Shortages of medical facilities and patient care personnel further shaped patients' experiences in the cancer ward. This context did not guarantee that therapy in the hospital would be successful; daily life in the ward entailed a persistent struggle to improve the sufferers' quality of life.

Summary and discussion

Most patients and their family carers believed that being in the cancer ward implied privileged access to superior medical technology and expertise. They perceived the referral hospital as the ultimate source of hope after their previous, unsuccessful treatment trajectories. However, the hospital staff concealed their sentiments about the perceived limitations to cancer management in the hospital. The ward seemed to embody the intrinsic weaknesses of physicians and other staff with regard to meeting the physical and emotional needs of patients fully. Ward and other hospital staff's views of the treatment environment mirror their

uncertainties about the hospitalisation outcomes of cancer patients. The cancer ward seemed secluded from the rest of the wards located in the modern block of the hospital. Some ward staff connected the ward's isolation with its apparent invisibility within the hospital system. Discourse about the cancer ward reflected its perceived low status. The ward was not as physically visible as other units in the hospital, a fact which caused uncertainty and suggested low esteem with regard to the careers of the hospital staff responsible for treatment and care of cancer in-patients. Their experiences in the cancer ward reflect inadequate cancer management resources in the hospital and the Kenyan healthcare system. An important element that this situation portrays is the low priority given by the healthcare system and public health policy to cancer management in Kenya (Murray *et al.* 2003). Healthcare policy in Kenya, as in other developing countries, somewhat neglects cancer. This results from the fact that cancer is a complex health problem, which requires extensive human, technical and financial resources. According to the International Network for Cancer Treatment and Research (INCTR) (2008), this acts as a disincentive to national policymakers and international agencies to address the cancer problem. Available resources in Kenya remain inadequate for dealing with basic public health issues and the menace of communicable diseases. Therefore, non-communicable diseases such as cancer receive negligible funding allocation from the national healthcare budget.

Cancer in-patient care in the present study took place in premises that were not planned for this purpose. This had negative consequences for patients' comfort and the quality of care they received. The architecture and configuration of the cancer ward and clinic also affected the gratification that the hospital personnel derived from their work environment. Similarly, the physical layout and setting of the ward had implications for patients' physical and psychological comfort. This constitutes part of a 'healing hospital environment' or design that contributes to patients' satisfaction (cf. Van de Glind *et al.* 2007). Ward arrangement, adequate treatment facilities, and human resources are significant aspects of a favourable treatment environment. Prolonged and subsequent hospitalisations in the cancer ward exposed the limitations of the treatment setting, and this gradually undermined the confidence that most of the patients came with to the referral hospital. Ward environment and structure are part of the healthcare design which influences patients' well-being, quality of life and the recovery process. Patients' access to comforting views through the window, for example, may have a positive effect on patients recovering from surgery (Ulrich 1984). Conversely, the ward environment in the present study increased anxiety and uncertainty. The corridor of the main entrance exposed patients to distressed visitors reacting to news about the death of their kin. The open ward arrangement further compro-

mised patients' privacy and dignity, which are essential to patients' satisfaction with care (Whitehead & Wheeler 2008; Zaman 2005). The curtained screening in the dormitory-like rooms did not guarantee privacy and self-esteem especially during treatment, visiting time, and when patients were experiencing adverse therapy side effects such as diarrhoea and vomiting. Similarly, the ward arrangements could not provide adequate visual and auditory privacy when they needed to rest.

Contrary to patients' expectations, the ward was a place for further waiting and care delays. Heavy workloads, a broken calling system, and occasional congestion constrained nurses' prompt attention to patients. Shift nurses remained busy with paperwork at their desks when they were not performing routine duties. Patients were often out of the nurses' sight, and nurses could not attend to them spontaneously due to the ward's design. The current design thus constrained effective nursing care as it did not facilitate maximum contact between nurses and patients (Seelye 1982). Patients who were not able to call out for a physician or nurses waited until staff could come around or sent available people to them. A shortage of cancer treatment facilities increased the waiting time in the ward for appropriate care. In addition to inadequate cancer treatment equipment in the hospital, a shortage of specialists worsened in-patients' quality of care and life. The large workload and few functional machines also restricted treatment. This situation contributed to a backlog of unattended patients and a decline in treatment accuracy (Onyango *et al.* 1987). The referral hospital did not guarantee the timely attention to both physical and emotional needs as patients anticipated. The cancer ward did not offer the final refuge after the multiple formal and informal referrals that characterised the help-seeking trajectories of cancer patients in Kenya (Onyango & Macharia 2006). Delays in meeting treatment and general care needs during hospitalisation worsened patients' physical and psychological suffering. Being in the ward implied further uncertainty, anxiety and unforeseen treatment postponement and interruptions.

The cancer ward, like other medical settings, is a context for specialised treatment and patients' search for physical comfort. The experience of illness and its unpleasant aspects contribute to sufferers' emotional vulnerability. The ward therefore constitutes both a physical and emotional space for patients and their carers. Technological limitations to cancer treatment and exposure to some physical conditions in the ward shaped patients' feelings about the care setting. The configuration of the ward had either direct or indirect effects on patients' emotions. The ward exposed patients to events that threatened their endurance and hope. Frequent deaths were apparent to most patients, especially in the temporary repository for the deceased. This was the most threatening experience that caused greater doubt and anxiety about the outcome of hospital treatment of can-

cer. The constraints to emotional space in the ward also included their exposure to fellow patients' symptoms, and both physical and psychological suffering. Patients in distress seek both the emotional participation and empathy of their carers. The ward constitutes a setting for medical treatment and the 'sociability' that affect patients' non-material coping resources. While it is true that the open ward design exposed patients to emotionally threatening conditions, it is also true that the layout granted them the opportunity for interaction with each other. Such an arrangement reduces feelings of loneliness that in-patients would experience if they were admitted in single, isolated rooms (cf. Van de Glind *et al.* 2007: 159). Exposure to the experiences of fellow patients while they are not very ill provides them with good mutual learning opportunities for coping with cancer treatment. Similarly, the ward setting provided a chance for favourable mutual emotional and social support among fellow sufferers, Who offer better consolation to each other due to their shared experience of cancer and treatment (Kelly *et al.* 2004).

The hospital workers have an important role in ameliorating patients' emotional space. Some of the staff in the cancer ward attempted to enhance patients' emotional resilience through verbal encouragement. This was essential for patients' endurance of their hospital stay and treatment circumstances. However, cancer management professionals understated the reality of limited resources, low survival rates, poor prognosis and limitations of medical interventions in cancer management. This constitutes a coping strategy for specialists facing uncertainty during patient care. The hospital in this regard becomes a place of sociability immersed in a specific cultural context in which heightening the secrecy surrounding medical practice increases uncertainty, anxiety, and desperation (Comelles 2002: 271). The lived experience in the treatment setting causes gradual and inevitable erosion of patients' confidence and hope in the hospital. In the present study, the cancer ward turned out to be a place where time prevailed over the limitations and contradictions of the hospital's management of cancer. Arguably, the medical professionals facing such a challenge may use hope idioms as rhetorical tools to justify their healthcare efforts in cases they perceive as hopeless (Good *et al.* 1990). In this regard, medical professionals' positive evaluations of treatment progress tend to contradict patients' subjective experiences.

The physical and emotional space of the cancer ward shaped the patients' endurance and hope further. They tended to overlook the inadequacies of the treatment setting in order to keep their focus on the objective of pulling through. Avoidance of directly criticising the treatment environment helped safeguard their hope. This attitude denotes an important aspect of patients' hopeful adjustment during life-threatening illnesses and treatment effects. As part of coping

with unpleasant conditions, most respondents sustained talk that could promote 'positive thinking' and curb less positive feelings (cf. Wilkinson & Kitzinger 2000: 809). As an example, patients argued that the ward was good, after all, because it was better than the other wards in public hospitals. Maintenance of hope among patients entailed their active engagement in life as they attempted to identify and emphasise what was positive for them (Elliott & Olver 2007). This is in conformity with the expected role of 'the good patient', that is, the one who does not complain much about available treatment, care and the hospital living infrastructure. Taking on the good patient role, patients may accept the hospital environment as given and as a setting for treatment different from home (Sommer & Dewar 1963). They believed that an appreciation for their treatment environment would facilitate their goal, that is, 'to get treatment and go back home'. The resort to idioms of hope facilitated emotional endurance of treatment and hospitalisation circumstances.

The setting of treatment may either increase or allay the suffering that results from severe illness. Patients expect the hospital to facilitate both physical and emotional healing; however, the medical setting and especially the ward arrangement and available care resources may cause emotional suffering. The cancer ward in the present study can thus be viewed as a new context for patients' lived experience of the body (Scheper-Hughes & Lock 1987). Satisfaction with the hospital living infrastructure has consequences for the constituent parts of the body, especially the mind, psyche and self. These aspects interact in influencing the way patients experience suffering, health, illness and quality of life in the hospital. The treatment setting affects patients' emotional predisposition. This may result in subtle resistance and despair. Emotions as such serve as a means for transforming knowledge into human understanding, which brings intensity and commitment to human action (Blacking 1977). In this sense, the physical and social environment of the ward may be emotionally disruptive, thereby affecting patients' hope and endurance. Events in the ward and its physical space contribute to patients' experiences of adversity, uncertainty and anxiety. This characterised the cancer ward as the physical and emotional space which embodied inevitable and increasing tribulation that patients had to endure. Physical and emotional discomforts are often experienced as inescapable consequences of treatment (Radley & Taylor 2003).

The cancer ward revealed the truth about cancer as a fatal and terminal disease. However, idioms of hope in spite of the reality of death point to the fact that patients may consider the possibility of death, but not its certainty (Little & Sayers 2004). Persistent hope for cure and life over death redeemed anxieties about death. Patients construed some deaths as 'deserved' when supposing that genuine treatment and care efforts had failed. Deaths were either undeserved or

unacceptable when patients evaluated hospital personnel and kin's efforts to save the lost lives as insufficient. Due to this, the hospital setting is not only a physical and emotional space but also a 'sociability' space. The ward provides space for both social and therapeutic relations that are germane to patients' well-being. The suffering body is dependent on and vulnerable to the feelings, wishes and actions of others (Scheper-Hughes & Lock 1987: 21). The hospital is in this sense an arena of social relations and interactions that influence therapeutic processes. Therefore the reassurance of medical personnel, encouragement from fellow patients, and support from other actors' underpin patients' struggles to cope with uncertainty, which was visible in the cancer ward environment.

Patient care interactions

A middle age woman is bedridden. A consultant says that he suspects metastasis of cancer to her brain. He expresses surprise that the ward physician did not refer her for further investigation although she has already been in the ward for one month. He scolds the ward physician. The patient has not been eating well and she looks weak. The consultant asks if her relatives could help to feed her. A nutritionist notes that it would be difficult for the relatives to help since they were often drunk when they visited. (Field notes March 2006)

The above excerpt provides a glimpse of patient care interaction, in this case during the major ward round, which took place every Friday, between 9:00 am and 11:00 am. A consultant discussed patients' cases with the ward physician, matron and a pharmacist during the main round. Consultants expected the matron (or nurse in charge) and the physician to give essential details about patients' progress. The nurse in charge drew on observations and shift nurses' daily notes and verbal reports to explain patients' experiences. They reported mainly on how patients ate, experienced pain, responded to medication or slept. The team members talked little to the patients in spite of their apparent desire to give details about their experience. Doctors' characteristic brief responses to patients included phrases such as; 'you will be given more medicine', 'we will take your blood for examination ...' or 'we shall change your medicine ...' Either the ward physician or consultant then flipped through files as other participants looked on or talked among themselves. A quick scribble of summaries and prescriptions ended short patient reviews. They had little time for case discussions and evaluation.

The major ward round was in effect the ‘main event’ that brought key patient care participants¹ together. The composition of the group varied from time to time, with medical and paramedical staff, pharmacy and nutrition students, and some ward assistants forming a full team. An oncology consultant led the ‘major ward round’ on Fridays, and attendance was compulsory for the main cancer management actors assigned to the ward. The major ward round represented the ideal picture of professional collaboration in cancer management. The ‘minor round’, in contrast, was held by a ward physician (also known as the Medical Officer of Health) on Tuesdays. This was a less flamboyant event, obligatory for the matron or her representative, a records clerk, porter and a pharmacist. There was more laxity in the timing and attendance of the ward physician’s than the consultant’s round.

Two to five participants attended the physician’s (minor) round, whereas five to fifteen members were present in the consultant’s (major) round. Members’ interactions reflected their positions in the hospital’s social and medical hierarchy. Patients often contended with the passive role imposed on them by this hierarchy and associated power relations, which placed family members and lower level staff in peripheral actor oppositions. The presence of key ward participants - the consultant, ward physician, pharmacist and senior nursing officer - subdued the voices of other actors during case discussions. Hierarchical relations had an impact on patients’ social, psychological and physical well-being. Changing situations, availability of resources and perceived positions in the ward hierarchy influenced the participation of stakeholders in patient care.

Chapter 3 described the physical and emotional context of patient care. Available space and artifacts form the environment for treatment and recovery. However, human relations played out in this context have implications for patient care and their experiences of hospitalisation. This chapter describes the relations and interactions of various actors in the ward. It situates patients’ experience of treatment and daily life in the social and medical interactions of which they are part. Daily activities and events in the ward bring to attention issues in social and medical hierarchy and their implications for participation in patient care. This chapter further explores and discusses the network of healthcare relations in the cancer ward. The assumption in this chapter is that a hospital ward is a microcosm of social interactions of different actors in patient care. The hierarchical and power relations in this context influence different actors’ participation.

¹ The minor ward round was typically comprised of the ward physician, the matron or a senior nursing officer in charge, a records clerk, a pharmacist, a porter and nutrition and/or pharmacy students. A typical major (consultant) round include a consultant, physiotherapist, social worker and radiographer in addition to the members who participated in the minor ward round

Hierarchy and participation

I use the concept of hierarchy in its broad sense, referring to a group of individuals ranked according to authority, capacity or position (Walton 2006: 229). This implies both the medical and social hierarchy enacted in hospital settings. The organisation of modern hospitals into hierarchical structures places medical hierarchy at the top. Doctors are often more visible in the healthcare team, but their levels of seniority determine the weight of their participation and roles. The hospital hierarchy imposed in the cancer ward included mainly doctors, pharmacists, nurses, radiotherapy staff and ward assistants. Actors' positions in the hierarchy influenced their participation in patient care processes.

Participation refers to mutual discussion of contributions by all actors in patient care (cf. Coghil 1981: 30). Conceptualised in this way, this entails the participation of all the ward staff, relatives and the patients themselves. In the present study however, the relations as well as the actual discussion of cases revolved around a few hospital actors. It is from this perspective that I describe and examine the nature of patient care interactions and collaboration in the ward. Participants in healthcare settings depend on each other's input in order to achieve optimal results in patient care. Hospitals provide the framework of interdisciplinary, participation-based formal divisions of labour among the professionals. Achievement of therapeutic goals also depends on interactions with and participation of patients and their relatives.

Actors in patient care in the cancer ward had different opportunities for mutual discussion and contribution. Unequal participation was related to individuals' positions in either the medical or the social hierarchy. Some actors were thus more visible than others in terms of their influence in patient care decisions. The resulting formal and informal interactions defined the nature of therapeutic collaboration. Social relations determined the way existing resources were tapped for the improvement of patients' well-being. Patient care interactions reflected power relations associated with hierarchy. This was apparent in the way different actors responded to and handled conflicting views and perspectives on patients' well-being. As expected, doctors took the dominant position which defined their interactions with pharmacists, nurses and other team participants. The relative power of doctors was most evident during rounds and procedures in which oncology consultants, ward physician and other professionals were present.

Consultant and ward physician

Chief and subordinate medical authority

Patients and staff recognised the power and influence of doctors in the rank of consultants. Some patients referred to them as *daktari mkubwa* (the big doctor).

Consultants are doctors who have risen through the ranks to the top of their specialty (Keating 1993: 28). As noted in Chapter 3, there were very few clinical and radiation oncologists in Kenya. In fact, key informants emphasised that there were less than 20 oncologists in the country, yet cancer ranked among the top three causes of deaths in the country. All the available senior oncologists were based at the cancer treatment centre in the present study hospital. Some patients identified those who admitted them or ordered surgical operations as their personal doctors. Similarly, consultants tried to follow personally the progress of particular patients whom they identified as their own.

Consultants made the main decisions during evaluation clinics and ward rounds. Ward physicians were responsible for decisions during daily treatment procedures and the minor round. They were general practitioners, with a hospital designation of Medical Officers of Health as indicated above. They were not specialised in oncology but they got hands-on experience in the ward. They made decisions semi-autonomously and contacted consultants when they encountered difficult cases. Sometimes consultants on call rescinded some of the decisions ward physicians made regarding the treatment and discharge of patients. A ward physician often yielded to a consultant's opinion when conflicting views emerged. Ward physicians occasionally had to withstand reproach by consultants before patients other staff.

Three physicians served in the cancer ward successively during the fieldwork. They had been "learning on the job." Their professional authority and decision-making were subordinate to those of the consultants. They planned to move on to specialised training in cancer management after at least three years of apprenticeship. Three years of specialised training gave apprentices the certification necessary to be consultants. Ward physicians yearned for this rank, which would rescue them from the tedious daily routine of in-patient treatment and care.

Senior consultants worked fewer hours in the hospital compared to their juniors and apprentice physicians. They had the privilege of running private practices and working in other hospitals. Some patients said they occasionally had appointments with some consultants in their private practices or in other hospitals where they worked part-time. They worked fewer hours at the public hospital even though it was their main employer. This implied that they had less contact with patients than the ward physicians did. The physicians conducted daily treatment activities with the help of pharmacists, nurses and pharmacy interns. A ward physician was also the doctor on call, but was rarely available when nurses called for help at night. The often-overworked ward physician would be too exhausted to go back to the ward for all emergency calls. He or she spent more hours throughout the week treating patients and attending to other obligations in the hospital and ward.

A ward physician did not benefit from rotational work shifts due to a shortage of staff. Available physicians either lacked basic experience in cancer management or were not interested in this field. Cancer ward physicians therefore rarely rested sufficiently. Nurses for instance often expressed concern for Dr. Bedohai, whom they said would suffer burnout. He was responsible for nearly all the cases of patient re-admission, treatment, and related paperwork. The minor ward round on, main admission process on Mondays and clinic reviews on Wednesdays were also obligatory for the physician. Availability of consultants determined how many patients the physician would assess for treatment and admission. A ward physician often continued with the clinic reviews long after his seniors had left for the day.

Consultants were not always available for discussion with the ward physician. He or she therefore grappled with some difficult decisions alone. They occasionally discussed matters briefly with consultants during clinics, ward rounds and over the telephone. Consultants gave instructions or specific information during their short verbal interactions with the physicians. A consultant would even reproach a ward physician or nurse for decisions they had made or were unable make. This occurred in spite of the reality of heavy workloads, inadequate hospital resources and unavailability of consultants to approve critical decisions. Some questionable decisions were however part of the strategy for coping with challenging patient care circumstances. This also applied to senior staff as shown in the next sections. Staff in lower positions did not express openly their misgivings about doubtful decisions of seniors. They tried to avoid antagonising their seniors with open criticism or objection to their decisions. Hierarchical and power relations were evident in decisions about treatment and patients' discharge.

Discharge and treatment decisions

Several factors influenced decisions to discharge patients. Consultants repealed some discharges by ward physicians, as they perceived them as untimely. The appropriate discharge occurred at the end of a treatment course without complications. Doctors occasionally discharged patients who nagged them about perceived inadequate treatment and care. They also yielded to relatives' requests for transfer of their patients to private wards or other hospitals. Doctors and nurses also tried to get rid of patients they considered uncooperative. They also arranged to release patients for whom no more treatment was available on the ward. This included patients in the terminal phase of their illness. The reason for discharge "before recovery" was not always clear to such patients. Doctors and nurses merely told them that they would send them home 'to rest'. They gave them several weeks to 'rest at home' before new clinic appointments at the hospital.

Some patients got hints about their poor prognosis when ward staff asked them to attend subsequent clinics in health facilities that were nearest to their homes.

Inability to meet the treatment costs also necessitated the discharge of some patients. Those whom the hospital had allowed to take treatment on credit were often victims of such decisions, particularly when the hospital ran out of essential cancer drugs. Mr. Jos, 27 years of age, for instance suffered from nasopharyngeal carcinoma. He missed admission three times consecutively due to lack of money for the essential costs. The hospital administration then allowed him admission for treatment on credit. He completed required radiotherapy sessions after about two months. However, the hospital ran out of the chemotherapy drugs he required for subsequent treatment. Facing a dilemma caused by a lack of patient care resources, the ward management must decide whether to continue hospitalisation or discharge patients. In Jos's case, they contemplated what to do with him for over two weeks. The conversation below illustrates hospital carers' decisions as part of their attempts to cope with scarce patient care resources and patients' inability to meet treatment costs.

Consultant: ... we used to 'help the patients abscond' in Ward 39 and 40. We assessed a patient in the first week of admission. If we found that he or she could not pay, we would help them abscond (laughs). If the patient could not pay and we are 'not doing anything for him', we would discharge him or her. We even would give them (bus transport) fare and escort them to the bus stop! We would tell them to go home and rest. You can help such patients to abscond ...

Porter: Then people would remain writing statements (to explain why the patient left before completing treatment).

Physiotherapist: If you do that today, you will be indicted.

Radiographer: That is very bad ... It is very dangerous ...

Consultant: That would save the hospital a lot of money. When we realised that a patient could not pay, we would discharge them and give them fare ... There is no need to keep the patient. We are doing nothing for him, yet he is eating ... you end up discharging him anyway, but who pays the bills? You can help the hospital to save a lot if you help such patients abscond. (Field notes, June 2006)

The ward staff had difficulty implementing some decisions, even when senior members approved them. The brief reactions to the consultant's suggestions above exemplify the difficulties in cancer patient care decision-making in the study hospital. Many situations presented both professional and ethical dilemmas for the medical professionals. The consultant's comments above indicate the occasional use of some unorthodox strategies to cope with the constraints of cancer in-patient care. This on occasion coincided with patients' dissatisfaction with their hospitalisation outcomes. They expressed their disappointment that some hospitalisation sessions either did not improve or worsened their health. However, cancer treatment specialists concealed the truth about cancer and treatment limitations of the hospital during most of their interactions with patients. Discharge from the hospital "before (full) recovery" disturbed many pa-

tients. Paradoxically, some patients resented staying longer in the ward when from their perspective it was not “doing anything” to relieve their suffering. It is essential to note here that patients and medical staff have different perspectives about the value of hospitalisation time and appropriate health care decisions. Interactions between these two categories of hospital actors did not synchronise their understanding of the relevance of hospitalisation while their physical, social and emotional adversity persisted.

Discussion among stakeholders in patient care was limited. Actors often reserved their opinions of their seniors’ decisions, but grumbled indirectly about their implementation. Their precaution not to antagonise senior staff constrained mutual participation. Consultants either dominated discussions or made decisions outright, some of which other participants found difficult to execute. Junior medical staff and nurses were ambivalent about implementing some of their seniors’ suggestions; however, they were reluctant to contest those decisions and provide alternative suggestions. Decisions that seemed unpopular were inevitable for all staff, particularly in challenging situations. Conversely, senior staff reprimanded their juniors for ‘unpopular’, or unconventional, decisions that may have been their coping strategies in the face of a difficult dilemma.

Unpopular decisions

‘Unpopular decisions’ contradict established treatment processes and patient care ethics. However, decisions that professionals found acceptable were not necessarily popular among patients. Cancer patients evaluated care decisions about their cases against their lived experience of illness and treatment. Ward rounds were the climax of crucial decisions. Patients and their relatives waited eagerly for the decisions, and to hear a consultant’s position on them. This included issues surrounding treatment planning, discharge, and change or continuity of treatment regimes. Established treatment procedures defined the objective basis of the decisions’ acceptability and scope of variance from conventional practice. However, individual perspectives and experiences influenced ideas about appropriate choices among staff and patients.

The position of actors in the hospital hierarchy shaped their responses to contentious decisions. Low-level staff had to justify and defend their decisions to the senior staff. Nutritionists and pharmacists had similar encounters with consultants in relation to diet recommendations and medication. Situations that compelled a hospital worker to defend him or herself before patients and colleagues caused tension. This had negative implications for professional credibility. However, patients were not always able to follow the content of decision disputes, but they expressed awareness of some of the contradictory views. Uncertainties regarding senior staff’s suggestions did not generate direct criticism.

Senior staff often diffused possible doubts of their authority by allowing brief open discussions among available colleagues. Arguably, this pre-empted censure and significant doubts about professional reliability. Power relations played a role in the communication and adoption of potentially objectionable decisions. The excerpt below underscores this.

The cheek of a man with head and neck cancer is swollen and he is in pain. The consultant is worried that it might be worsening. The patient has just completed the first course of chemotherapy. After some discussion with the ward physician and a pharmacist the consultant asks, 'can I make an unpopular decision?' No one answers. Everyone looks at him apprehensively. He goes on: "He has to be marked and go for radiotherapy next week ...". None of the other staff responds. He notes the summary in the patient's file. He instructs the matron and ward doctor to arrange to take the patient for 'marking' the following Monday in preparation for radiotherapy. (Field notes, December 2005)

Doctors rarely considered a patient for radiotherapy after one course of chemotherapy. No one in the ward round expressed agreement with the consultant or offered an alternative view. A week prior to the above case, Dr. Wario had cleared Mrs Ndunduri's discharge during a minor round. He said that he was discharging her 'to avoid fighting with her'. Ndunduri had been in the ward for two months. She persistently demanded to go home because she said she had not been receiving any treatment. On the Friday that followed, an angry consultant cancelled the discharge and reprimanded Dr. Wario dramatically. He insisted that they needed more investigation to determine the primary cause of Mrs. Ndunduri's problem.

Consultants have the authority to overrule decisions, and they often did. Junior medical staff exercised their freedom in their absence. They succeeded in implementing some decisions autonomously when the senior staff were not available to vet them. Patients on the other hand drew on their subjective experiences to resist treatment or complain about their care in general. When they perceived their hospitalisation as worthless, for instance, they found the decision to prolong their hospital stay as unacceptable. While medical staff evaluate the acceptability of hospitalisation and treatment decisions based on established objective experiences, patients' personal experiences may contradict the claims of hospital staff about positive outcomes of treatment and hospitalisation. Some patients, for example, attributed their suffering to what they considered erroneous decisions, as shown in Chapter 3 in (see 'cycle of death'). The ward staff, therefore, were sensitive about safeguarding their credibility among not only their colleagues but also the patients. Interpretation and communication of decisions was often a serious challenge in patient care procedures. Sometimes This necessitated superficial incorporation of low-rank, non-medical staff in case discussions.

Help from lower ranks

Views of consultants, physicians, and a resident pharmacist dominated key decisions. The physician ideally sought second opinions from the consultants. Other members of joint patient reviews either reserved their views or did not anticipate that their opinions would count. A nurse in charge of the ward facilitated an understanding of patients' experiences by probing them. Doctors relied on the close interaction of nurses with the patients to understand their experiences of cancer and treatment. Nurses emphasised to patients the negative consequences of non-compliance. They reported some patients' perceived resistance to hospital care activities to the doctors. They often complained about patients' interruption of treatment devices such as drips, avoidance of medication and 'refusal to eat'. They criticised patients before doctors in order to control behaviours they perceived as obstructing their treatment and care. Daily interactions between nurses and doctors were formal, and the focus was on patient management and medical issues. Doctors talked to nurses briefly about particular patients and gave specific treatment instructions.

Nurses collaborated with other staff regardless of their rank to facilitate doctors' communication with patients. The hospital workers faced limitations in translating health care information to those who had little competence in either English or the national Kiswahili languages. The ward represented a microcosm of the diverse local Kenyan languages and cultures. Therefore, ward assistants frequently supported the professional caregivers by taking on the role interpreter. They felt honoured to be directly part of main patient care procedures as interpreters. The difficulty of translating technical information, however, challenged the staff across the board.

Conversations through interpreters were brief and sometimes inconsequential. Interpreters did not always relay the conversation well between doctors and patients. This sometimes ended up as only two-way conversations, between the interpreter and the patient, causing temporary exclusion of doctors and other members participating in ward procedures. Translation and interpretation were also cumbersome and time consuming. In addition, patients became uncomfortable when interpreters did not give feedback regarding the conclusions they derived from their conversations. Some patients could follow discussions without interpreters but vague conclusions frustrated them. Discussions that were open to all participants lacked sufficient moderation. Patients and staff alike were unable to decipher final authoritative conclusions in such instances. Consider the case below, for example:

A woman suffering from mandibular cancer tells a consultant that she cannot eat well. She says that she has a 'hole' at the back of her jaw... The jaw has swollen and she speaks with difficulty. She tries to explain her experience in Kiswahili. She reverts to her ethnic language when she realises the consultant understands it. He sighs and keeps quiet, thoughtfully. He

addresses the matron: "... She has something like a hole at the back of her cheek. Food is accumulating in it ... the doctor is stranded ... I don't know what to tell her ...". The nurse says that she will ask the nutritionist to talk to the patient. After a short while, a nutritionist comes in while the nurse and the consultant are still talking about the patient. The nutritionist says she should eat softer food or take fluids, which she can remove easily from the hole ... The nutritionist says that she would explain this to the relatives too. A porter interjects to suggest that the patient can try to eat from unaffected side of the mouth. The doctor leads the review team away without approving any conclusion. (Field notes, November 2005)

Many patients still sought clarifications about their cases after discussions were over. They reached out to members whom they had seen in just-ended or previous ward procedures for explanations. Some patients were visibly frustrated as they tried to call after staff that were either busy or hurrying to attend to other obligations. Doctors would promise to get back to patients to explain or clarify matters. They hardly kept such promises.

Participation of staff in low positions in the hospital hierarchy did not guarantee that their views would be considered. Senior staff either reached conclusions autonomously or left the issues to the personnel next to them in hierarchy to figure out what to do. This diminished team members' commitment to collective discussions. The leading staff on occasion resorted to humour to present and stimulate discussion about challenging situations. Senior staff used such strategies to pre-empt criticism about their decisiveness, as shown earlier. Some case discussions involved humour to downplay challenges inherent in some cancer cases. The healthcare teams at times joked about patients' anxieties and curiosities about their health and treatment.

Some participants made non-committal remarks directed to either patients or fellow staff. They were either indifferent to or uncritical of decisions made by senior medical staff. Some team participants concealed dissatisfaction with the dominance of medical, pharmacy, and other senior staff. Junior staff criticised indirectly what seemed to them uncertain healthcare decisions made by senior staff. The level of assertiveness exercised by doctors, pharmacists, and some nurses reflected their relative authority patient care decision-making. Pharmacists were close therapy management partners for doctors. Nurses, ward assistants and patients referred to them as doctors, too. The rest of the staff played complementary yet marginal roles in case discussions as shown later.

Pharmacists

Two pharmacists worked alternately with doctors in the cancer ward. One of them was away for further training during this study. They facilitated acquisition of drugs and informed doctors about the medications that were available for the treatment of different types of cancer. Doctors relied on a resident pharmacist to know the quantities of available drugs in order to regulate admission of patients

who were unable to buy them. Pharmacists updated doctors and nurses on patient medication and addressed prescription enquiries. The resident pharmacist dealt with queries related to supply, delays, or shortage of anticipated drugs. She worked with the nurse-in-charge of the ward in ordering medicines through the central hospital pharmacy. Patients got the drugs on first come first served basis. Those who were already getting credit for medicine had the first priority. The pharmacist sometimes negotiated with other staff about admission on behalf of patients known to them.

Pharmacists and nurses tried to ensure that nurses stored drugs well. They expected nurses to find out if patients had bought any medicines that required special storage. Miscommunication about storage and administration of medication caused some tension between pharmacists and nurses. Some drugs needed prompt preservation in the refrigerator, but nurses at times failed to do this. A pharmacist also worked with the ward doctors to sort out medication errors and correct them. They discussed issues such as double prescriptions, for example, from the surgical and cancer clinics. Pharmacists and ward doctors were wary that their seniors would blame them for medication errors. However, prescription issues highlighted broader criticism of current coordination of cancer management in the hospital. A pharmacist noted:

We should have a cancer treatment centre. If we had a proper cancer treatment centre all the consultants from all the specialties would collaborate in helping patients. Surgeons, haematologists, clinical oncologists, and radio-oncologists would see and discuss patients' cases in one place. If all those key players see patients in one unit, they can discuss issues and resolve them together. Patients can therefore get optimal treatment ... You might see two patients with the same diagnosis but different prescriptions because they landed in different units at first ... This is the source of contradictions in the regimes that we give here. ... There are many other cancer patients scattered in other units ... There are many consultants who know what they learnt, and none of us knows what they learnt ... Each of them just thinks of the personal credit to earn ... Everyone continues to manage patients differently ... I have many issues especially with prescriptions from units that are not well organised. Some units admit oncology patients but do not have a resident oncologist and oncology consultants ... Some consultants prescribe doses over the phone ... and issues like that ... It has been difficult trying to consolidate all these ...

The remarks above highlight conflicting views about cancer treatment regimes. This threatened professional collaboration between pharmacists and doctors. Subtle conflicts about dosages and prescriptions had negative implications for pharmacists' role and treatment outcomes. The pharmacist who made the remarks above also complained about conflicting treatment recommendations by different consultants. According to her, some consultants even 'dictated' what a 'medical officer' or registrar (ward physician) prescribed. This practice caused some 'errors in dosages that at times went uncorrected'.

A pharmacist however collaborated closely with the ward physician during admissions and ward rounds. They consulted each other about admission, treat-

ment, extension of hospital stay and discharge. They had more regular daily contact with in-patients than the consultants. Pharmacy students occasionally assisted them with preparation and administration of chemotherapy and other treatments. They were handy when many patients turned up for chemotherapy. Tuesdays and Wednesdays were the busiest days and the ward doctor required more assistance. Additional treatment duties for the pharmacists and doctors in the hospital constrained their treatment tasks in the cancer ward. A resident physician at times struggled alone with treatment procedures. Issues and tensions emerged regarding preparation of medicines and observation of patients. Criticism and blame with respect to patient care errors seemed to flow from consultants to ward physicians and the assisting pharmacists. Ward physicians' frustration with treatment workload affected their relations with pharmacists and nurses. Dr. Wario's complaint below exemplifies ward physician's dissatisfaction with other actors' participation in patient care. He said in part:

... The purpose of admitting patients to this ward is their observation. I am surprised that the other people would like to give chemo at night and go away. This means that they do not observe patients and this negates the purpose (of hospitalisation). They should understand that we admit patients for observation ... When you give chemotherapy at night and go away you are not observing them ...

The ward doctor sometimes delegated monitoring of treatment to pharmacists and nurses. Due to heavy workloads and shortage of staff, nurses and pharmacists often failed to meet the doctor's expectations. This caused conflict and tension in daily patient care interactions among doctors, nurses, and pharmacists. Some staff however tended to emphasise occupational boundaries to resist additional patient care responsibilities. Some nurses for instance either shirked what they considered as the role of the doctor or other colleagues. They waited for doctors to fix lines and answer most of the patients' questions. Nurses were however closer to patients than other staff on the ward. They inevitably had to deal with an array patient care issues at times grudgingly.

Nurses

Nurses are the most represented and visible patient caregivers in the hospital. Nutritionists and nutrition students performed some tasks in common with nurses. Patients therefore referred to females in both categories of caregivers as 'sister'. Conflicts frequently emerged between nurses and nutritionists with respect to their different roles. This was specifically the case when dealing with issues related to errors in patient care. A resident nutritionist defended herself frequently against nurses' doubts about her competence in matters related to nursing. Doctors at times made condescending demands for proof of scientific documentation of nutritionists' diet recommendations. Nutritionists found diffi-

culties playing the double roles of dieticians and patients' counsellors on diverse issues.

Nurses of varied cadres served in the cancer ward as noted in Chapter 3. Some linked their posting to the cancer ward with its perceived low profile within the hospital. There was talk about some of the nurses' inability to perform in other 'busier wards'. About half of the nurses in the cancer ward worked there 'on medical grounds'. Therefore, only a few nurses were eligible for night duty and being in charge of nursing shifts. Some nurses criticised the competence and performance of their colleagues. Hierarchy of nurses was evident in their interaction, peer evaluations and selective alignments. Nurses in higher positions tended to keep social distance from those in lower ranks. Some of the nurses had taken or were in the process of taking extra professional courses to improve on their social and career positions in the hospital. They anticipated either promotion to higher ranks or transfer from the cancer ward upon completion of their courses. Division among nurses and cynical reactions to others' performance were evident in daily activities. A registered nurse once remarked:

... some of these nurses do not know anything ... They are sick ... they are special cases. They are passing time in this ward, leave them alone ...

Nurses excluded others from some nursing procedures. They claimed that not all of their colleagues had the qualification to perform procedures such as wound dressing. They said that some of them lacked even the basic skills for interaction with patients. There were therefore subtle segregation tendencies among nurses of different cadres. Some affected nurses occasionally kept busy with non-nursing tasks, such as registration of patients and making tea. Mrs. Orwa for instance was a sickly midwife and was struggling to cope with her near-redundancy in the cancer ward. She said:

They expect me to have made tea for them after their procedures. I always prepare tea, clean the tables, and take the utensils to the kitchen ... I make sure that they get tea in time ... They will miss me when I retire ... I always soak the seat cushion clothes and wash them at lunchtime. You see, I am very useful in this ward ... Matron focuses all her attention on patients and very little on the staff ... I do a lot of work that others cannot do ... No one does this work because the hospital has not assigned it to anyone. The assistants do not think it is their work ... They say it is not their work to make tea for nurses. I used to clean and brush everybody's shoes. Our ward assistants were surprised ...

Team leaders and the nurse-in-charge reserved 'easier tasks' for nurses who could not perform well. They reluctantly excluded them either on medical grounds or due to their incompetence. Other nurses observed patients on chemotherapy and administered injections and oral medication. They assisted the doctor and performed general nursing duties that included what they referred to as 'total nursing care' of cancer patients. They also spent some time preparing patients' daily reports. They wrote notes on patients' daily condition, progress, and res-

ponses to treatment. They prepared patients' discharge sheets and wrote statements about noteworthy incidences such as accidents and deaths.

Nurses also participated in registering patients and taking their social and medical histories. They responded to some of the patients' questions about treatment but often reminded them to ask the doctors about treatment. They feared that talking to patients about treatment would antagonise doctors. They sponge-bathed weak patients and provided them with bed and sputum pans. Stress from workloads and definitions of responsibility boundaries occasionally caused tension between nurses and other staff. This was apparent in their relations with subordinate staff and the ward physician as noted earlier. Nurses were busier between Mondays and Wednesdays, when many patients turned up for chemotherapy. Patients' demands for extra attention and compassion added to their work stress. Patients held that cancer, unlike other diseases, made them more vulnerable both physically and emotionally. They argued that the nature of their suffering required more unconditional compassion. Not all nurses met this expectation. One patient noted:

... They should be gentler and avoid quarrels with patients ... A person with cancer is like a child. They should treat us with kind hearts as they do to their children or kin ... If you irritate a patient, she or he reacts like a small child ... We are different from people with other diseases ... We get very sick and need more sympathy. They should pamper some of us more. The disease reduces our reasoning and we may not appreciate what nurses do for us ... When we are in pain, we may think that sisters (nurses) or doctors are just doing useless work ... They give us medicine at 8 PM ... but a patient expects more medicine once he or she is in lot of pain. We may ignore the truth that this medicine is poison and not *Githeri* (bean stew) that we can eat now and then. A patient will be quarrelling with the sisters ... 'when we come to this hospital you cannot serve us well ... ' Some doctors or nurses do not have a good approach in answering a patient. You know the patient's head is not good, because of pain ... Some say, 'no I don't want to be disturbed'. The patient calls but a doctor just goes away; yet the patient is indeed suffering ... (Mrs. Vyakawa)

Many patients perceived nurses who were available for informal conversations as more understanding and sympathetic. This gave them the opportunity to ask questions and relate to them more informally. Nurses who could share jokes with patients facilitated their emotional support. Delayed responses to calls for help contradicted patients' expectation of prompt and considerate care. Nurses' tasks were heavier when there were more patients who needed 'total nursing care'. This entailed care for bedridden patients who required help in virtually all their daily needs.

Two nurses attended to a maximum of fifteen patients. They had paperwork responsibilities in addition to this. This affected their promptness in responding to the patients' calls. Some of the patients' concerns were probably beyond nurses' abilities to handle. They bought time to seek assistance from doctors or senior colleagues. They were however apprehensive of misunderstandings related to delayed assistance to patients. This caused mutual reproach and anger. Stress-

ful working conditions intensified tension that resulted from inadequate miscommunication about patient care caused. Some disagreements emerged nurse-in-charge's inspection of nurses' work. There were issues about inconsistency between pending tasks and some nurses' notes indicating services they had rendered. Some aggrieved patients tended to report nurses to their seniors either directly or through their relatives. Nurses are more visible and present in the patients' daily lives in the ward than other hospital workers. In the present study, they joined doctors and pharmacists in the day-to-day patient care activities. They interacted intensely among themselves, and with ward assistants and patients' relatives. Other patient care professionals seemed marginal in joint case discussions and daily patient care roles.

Marginal professionals

The contribution of a radiographer and a physiotherapist to the discussion of Jos' case cited earlier was short and not very enthusiastic. A medical social worker, physiotherapist, and occupational therapist were also appeared not so eager to comment. A counsellor was absent from the ward round as in the daily patient care activities. Nutrition staff and interns attempted to provide counselling services during talks on diet with patients and their relatives. Interdisciplinary collaboration, which is an essential part of rehabilitative care in cancer management, did not materialise fully. Some cancer management professionals were on the periphery of key patient care interactions with other stakeholders.

Radiotherapists

There was very little exchange of information between radiotherapists and patients. This also applied to the interaction between radiotherapists and other staff linked to the cancer ward. A consultant recommended radiotherapy either before or after patient admission. Radiotherapists had limited prospects for direct contribution to patients' reviews as it was apparent during the ward round. Their experiences with both out-patients and in-patients indicated some irregularities in treatment attendance. However, radiotherapists did not get the chance to discuss their encounters with patients in the treatment rooms. Inadequate chance for radiotherapists to discuss their experiences with patients hindered essential treatment follow-up.

Radiotherapists had very busy daily schedules. This influenced their interaction with patients. As pointed out in Chapter 2, in-patients went for radiotherapy between 6 pm and 10 pm, after the treatment of outpatients. They tried to avoid long queues in the night, and the ensuing struggle to get back to the ward when no porter or other support staff were available to help them. Long waiting time reduced patients' enthusiasm to keep radiotherapy appointments. In a few cases,

both patients and the ward staff did not remember the radiotherapy schedules. They tended to lose track of the radiotherapy sessions, especially when side effects and holidays interrupted the process. Others missed radiotherapy due to either poor record keeping or lack of help to the treatment rooms when a relative or the porter was not available. Radiotherapists worked independently from other cancer ward personnel. They attended to patients who were present in their units and had little to do with those who did not turn up.

Radiotherapists seldom provided verbal updates about their experiences during ward rounds. Similarly, they did not refer to patients' experiences of radiotherapy. This constrained discussion of issues that had negative implications for their role in cancer patients' rehabilitation. Some patients waited too long before returning for radiotherapy. Ms. Lenida, for example came back after over a month. She had completed two courses of chemotherapy and one-month observation after re-admission. A consultant recommended another radiotherapy session. During her first admission, she had gone through 14 sessions. She looked worried and anxious as she entered the simulation room. A radiotherapist noted that she had probably become pregnant and that might have made her skip the appointment scheduled earlier. Simulation work began 20 minutes later after a radiation oncologist (consultant) arrived from his usually busy review clinic on Wednesdays. The consultant instructed Mark on how to adjust the simulator. A medical physicist did the treatment simulation markings. Mark and the physicist talked to the patient more than the consultant did. They did not try to establish why either Ms. Lenida did not return the treatment scheduled earlier or looked very anxious and disturbed during the treatment planning process.

Consultants often gave instructions to radiotherapists without significant discussion. Patients attempted to initiate conversations to complain or get information without success. They seemed more at ease with the physicists and radiographers than the consultants. Communication constraints between caregivers and patients in the radiotherapy unit replicated the situation in the ward. Some patients attempted to find out if they could communicate in their ethnic languages. This eased communication problems and reassured them to the point that they perceived the treatment as being more favourable. The attempt to identify with caregivers through common language was not always successful. Health caregivers did not consider patients' negative emotions in assessment of their care needs. These included issues about long waits before the start of procedures and insufficient communication about their treatment. Dr. Bedohai occasionally mentioned issues related to patients' discontinuities and delays in radiotherapy sessions. However, the ward team rarely followed up such issues yet they affected the patients' well-being.

Radiotherapists had misgivings about the professional collaboration in cancer management in the hospital. They interacted with some in-patients on a daily basis but still felt they had inadequate involvement in professional teamwork. Their interaction with patients began with treatment planning (simulation) and became regular during treatment sessions. They helped radiation oncologists, or clinical oncologists and the medical physicists in treatment simulation. However, they were entirely alone during the daily delivery of treatment. One radiotherapist regretted that his expectation of working with other partners did not materialise. He was disillusioned about the lack of collaboration with surgeons, medical oncologists, haematologists and radiation oncologists at different times. He commented:

... Somebody does his bit and goes ... We are usually the last people. By that time, maybe the disease is advanced ... Patients refusal of treatment is within their rights ... However, I tend to think they are not informed enough to make the decision about treatment ... We counsel them but we need professional counsellors to help them ... Why should a surgeon do an unnecessary operation? When the patient comes here, we may find that it was not necessary and we start asking, "Who was this surgeon? Of course, you do not discuss when the patient is there because you do not want to embarrass somebody. Such things happen ... You find that they operated somebody and this should not have happened.

The above remarks indicate further the insufficient coordination and integration of cancer treatment in the hospital. Crucial procedures and case discussions either excluded or marginalised some key patient care partners. A radiotherapist who attended ward rounds regularly expressed dissatisfaction in low tones to me and some of his fellow staff. An important aspect of these sideline comments was a complaint about inadequate communication among caregivers. It emerged, for example, that some hospital staff did not hand over cases appropriately for follow-up in their absence. This affected the quality of care and caused dissatisfaction among the staff about the nature of their collaboration. In one distinct case, a breast cancer patient had been on pleural effusion tubes to drain fluid from her chest. She had removed one of the tubes and said it was because she was uncomfortable. A consultant scolded her for "removing the tube that was helping her." He told the patient that he would ask the doctor who had fixed it to come and assist her. The ward physician who fixed it the previous week was away. The colleague who was relieving him could not fix the tube due to unknown reasons. As the consultant screened the bed to check the patient, a radiotherapist murmured to me:

... I talked to you about this kind of problem. There is inadequate coordination and discussion here ... Maybe it is due to shortage of staff ... You see the patient is waiting and has even removed one tube. I think people (staff) are too complacent ... I do not know how to put it ... There is no time to follow up on the deserving cases. All patients deserve attention but ... we need to sit down after the ward round to discuss ... That never happens. People are working alone and going away. We may not know where they reached ...

The patient in the above case had to wait for the doctor who had initially inserted the tube to deal with it. The present doctor-in-charge may not have had a full report of the case. Similarly the doctor may not have been available for verbal handing-over. The complaint in the above excerpt also reflects radiographers' experience of poor follow-up due to inadequate information about some cases. It was difficult to determine the interventions needed for periodic absconders and cases of interrupted treatment. While radiographers' participation in treatment discussions was limited, input from patient support professionals was virtually absent. Physiotherapists, social workers and occupational therapists seemed to play a negligible role in cancer in-patient care. A ward assistant emphasised this when he remarked:

... There is very little physiotherapy in our department. When you tell these officers to come, someone tells you that he is covering five to six wards or departments ... The person comes to work at eight o'clock in the morning, and goes back at home at five in the evening ... Will he help even 10 people exercise in a day? Social care is also not provided on this ward yet the histories of our patients show that most of them are 'social cases'. There is also a problem with occupational therapy These officers should be here to try to make our patients self-reliant ... They need to learn how to serve themselves even when lying on beds ... to get something from the table, to hold something

Physiotherapist

A physiotherapist was a titular member of the consultant's ward round. He was the least frequent participant of this procedure. He was among the invisible professionals in daily patient care activities. Whenever he was present, he followed silently besides the main actors in the ward round. An occupational therapist, social worker and ward assistants did the same. This constituted a category of nominal professionals who participated in the general minor discussions among themselves during ward rounds. They were apparently less enthusiastic in their sporadic comments about patients. Recommendation for physiotherapy for some patients was a mere formality. Mr. Bedokufa, for instance could not access physiotherapy services in the ward for over a month. He complained:

My wife massages the leg and we have to carry on with this almost every day... I asked if a physiotherapist is available and they say there is one here ... He has never come to help me. I have waited for too long and I feel that the legs are getting numb again ... One came only once and never returned. A friend brought me a student physiotherapist ... the student massages me when he passes by ...

Nurses suspected that some patients were suffering from Deep Vein Thrombosis (DVT) and needed physiotherapy. DVT affects leg veins due to immobilisation related to hospitalisation. The main cause of DVT is clotting of blood in the veins and regular exercise can prevent it. Multiple myeloma patients such as Mr Bedokufa and those hospitalised after surgery are more prone to DVT. One female patient who nurses said had developed DVT died. Several patients, in

particular women, experienced swelling of legs and pain due to this condition. The hospital, however, had only 67 of the required 86 physiotherapists (Kenyatta National Hospital 2005) on staff. Low priority was given to the cancer ward by the essential patient support professionals in spite of hospital staff shortage. Medical social work and occupational therapy were equally underrepresented in the daily patient care activities.

Medical social worker

Twenty-nine out of the required 46 social workers served the entire hospital. A social worker joined the consultant's weekly round in the cancer ward as mere formality. The social worker did not follow up with patients to address their psychosocial concerns described in Chapter 6. Cancer patients' experiences and condition require personalised attention of social workers and professional counsellors.

A few patients and their relatives interacted with social workers out of the ward. This interaction involved patients whom the ward staff referred to as 'socials'. Chapter 7 will describe further the idea of socials in relation to patients' livelihood struggles. They sought a social worker to certify that they were poor and needed exemption from the required hospital cash payment for treatment or discharge. A social worker and the matron signed documents for patients to be considered for hospital credit. The cancer ward however lacked the proper professional support of social workers.

Medical social workers ideally assist families and patients in need of psychosocial help. However, their input was negligible on the cancer ward. Social workers were seldom available to facilitate psychosocial coping among families and patients. They did not facilitate the expansion and strengthening of patients' sources or networks of social and emotional support. Similarly, they did not make significant contribution to other staff's efforts to offer psychotherapy or supportive counselling. An occupational therapist was present during ward rounds to complete its composition as the physiotherapist and social worker occasionally did.

Occupational therapist

Patients' daily life in the cancer ward revolved around staff's routine and procedures. They were largely recipients of care rather than mutual participants. They did not participate in activities performed for them by hospital staff and other healthy people. Similarly, healthy people in local cultures tend to exempt the sick from everyday activities. This is partly an expression of sympathy and a gesture perceived to facilitate recovery. Patients may postpone doing anything for themselves and wait for assistance from other people. This attitude, coupled with insufficiency hospital resources disguised the role of occupational therapy for can-

cer in-patients. They had little opportunities for improvised activities to occupy them when they were idle. They also lacked the chance for occupational activities to facilitate their recovery and improve their quality of life. A patient observed in this regard:

... in my case, there is only some swelling ... I do not feel any pain. People like me should find a way to keep busy. I used to play football. I can play ... so the hospital should make a football field. Those who feel energetic like me can go and play. I just wake up, take a bath, take tea, and just follow the daily ward schedule. I get tired. (Mr. Mukuru)

Patients had difficulties dealing with the monotony of daily life in the ward. Formal occupational therapy activities could facilitate both their psychological and physical well-being. Occupational therapy facilitates meaningful occupation to assist people with debilitating conditions such as cancer to achieve healthy and balanced life. This further leads to easier inclusion of disadvantaged people in society so that they can participate to their potential in daily occupations of life (Townsend & Polatajko 2007). There were 41 out of the required 53 occupational therapists in the hospital. The occupation therapist assigned to the cancer ward also served on the pediatric oncology ward, the patient support centre and the adult 'private wing' wards. Repeating the sentiments of other staff about workload, the occupational therapist commented:

... I have too much work. I am not able to give quality care to patients. I do little here and little in the other places and this affects the quality of care I give.

The occupational therapist was unable to help the patients to take part in daily activities. The inadequacy of the physical space as pointed out in Chapter 3 contributed to this. While it is true that the hospital also suffered shortage of occupational therapists, it is also true that essential equipment for occupational therapy were scarce. Occupational therapists shared or borrowed the available equipment such as cards, scrabble boards and knitting or lampshade making materials. Cancer patients never benefited from these shared equipment during the present study. The occupational therapist assisted nurses in dealing with patients' discomfort in their bedding on few brief occasions after ward rounds. With regard to the scarcity of appropriate material in the hospital, an occupational therapist said:

We do not have the occupational therapy material here. This patient for example has breast cancer and her hand is swollen ... We need an 'aero plane splinter' to make her comfortable but we cannot get the material ... We improvise using pillows ... Other patients are now developing pressures and we cannot get materials like the 'lump stone'. We are not able to help them adequately. We improvise with cheap materials which are not very effective.

The occupational therapist gave up trying to help the cancer in-patients. The basic assistance would be to enhance performance of tasks such as bathing, eating and making beds. However making beds for and bathing weaker patients is part of the nurses' compulsory daily procedures. They also asked relatives to help

feed the patients who are unable to feed themselves. There was an apparent conflict of roles in the case of occupational therapy in the cancer ward; some of the tasks which nurses and relatives assisted patients with should have been left for the occupational therapist to cover with patients. Nurses preferred doing some of the tasks such as making beds; these tasks were part of their daily activities which the matron or nurse-in-charge evaluated their performance. They hesitated to allow patients to perform the tasks since they did them slowly and clumsily. Nurses wished to finish their procedures systematically according to their routine. This left negligible opportunity for the occupational therapist's professional role.

Some patients, however, took their own initiative to engage in some activities. These included discussion of the Bible and delivering meals to fellow patients. Others occasionally attempted to make their beds and drain the water from bathrooms. Some ward assistants were not comfortable when patients did 'their work'. This would result in either reproach or disciplinary action from their team leaders and the ward administration. Nevertheless, patients could also participate in cleaning their lockers and bed spaces but these were duties of ward assistants. Patients called assistants *watu wadogo* (small people) and valued their psychosocial support.

'The small people'

Cleaners, porters, records keeper, and food distributors had daily contacts with most patients as nurses did. They worked silently, but chatted once in a while with patients and some nurses. Patients referred to them as the small people, owing to their relatively subdued position in the hospital's occupational hierarchy. Patients appreciated the daily and informal interaction with the 'small people'. They shared their social and emotional concerns related to current hospitalisation and general daily lives. A large majority of the patients applauded the contribution of ward assistants to their support and venting their anxieties. Mr. Memba for instance noted:

We have a good relationship with doctors, but they do not spend time with us. Then there are the workers who come to clean and change our beddings ... Some just come to sweep and go. Others come to spread the beds and go. Some bring cleaned bed sheets and go. Then the doctor comes. There is the chief doctor who will come to set the lines and drips ... The others belong to the clinic and do not come here always ... It is good when someone is passing by to ask; old man, are you feeling well? How are you feeling today? Only the small people try this.

Ward assistants came next to the nurses in terms of the amount of personal interaction they had with patients. There was also more interaction between the ward assistants and nurses, especially those in lower cadres. They chatted, at times humorously, on a variety of issues in the staff room during their breaks.

They shared common experiences of their daily interactions with patients. Some patients contrasted the emotional support from low-level staff with the less personal approach of those who were higher in hierarchy. Patients noticed this as Mr Chepia's comment below illustrates:

Those who are close to us are different from those who are up there. You feel a kind of loving care you would like to receive when they are close ... Those who are close even chat with us... They try to find out how we are doing. It is so irritating when somebody runs away from you. I get discouraged and feel rejected. We relate more to these 'small people ...' Doctors and some sisters are up there ... The people who bring food, medicine and the cleaners are more loving ... they talk to you well ...

The ward assistants attempted to fill information gaps for patients, drawing on their general knowledge. They discussed some basic issues that patients desired their healthcare professionals to talk about. They chatted about their uneasy interactions with some medical and technical staff. Informal chats between patients and ward assistants included their perceptions of compassionate caregivers. They cited examples of their discomfort with the ward actors they perceived as impersonal. They said that some staff such as laboratory technicians were both mechanical and impersonal in relating to them. Some patients for instance found a laboratory technician's approach to be both intrusive and unkind. He scolded patients who seemed to delay his procedure. His presence was always noticeable from typical commanding shouts: "... give me your hand!" or "... just sit on the bed, I will come there!" He often evaded questions about delayed, 'spoilt' or lost results. He always reminded patients that his role was only to get blood samples. Doctors were equally frustrated about delayed or missing diagnostic results.

Communication regarding medical tests was insufficient and frustrating for both patients and doctors. Dr. Bedohai contemplated sending patients outside the hospital for tests to avoid to such disappointment. Insufficient communication contributed to inadequate feedback to patients. In these cases, patients sought any available explanations, and extended their quest for treatment information to non-professional hospital staff and visitors. Ward assistants were handy in such situations; drawing on clues they had about medical issues and cancer management in their attempts to address patients' questions. Since they shared a non-professional perspective, they communicated easily about some health care matters.

Routine duties such as dusting drawers and windows, warming bath water and preparing beverages facilitated personal bonds between patients and the cleaners. Patients appreciated ward assistants' flexibility in sustaining informal conversations. They also could be obliged to run small errands for patients. Some patients called cleaners to make their beds and facilitate comfortable sleeping postures. A few nurses however interpreted such activities as infringing on their roles and threatening their relations with patients. Some ward staff were also suspicious of and criticised colleagues who related closely to patients as noted in Chapter 6.

Patients held on to the ward assistants' comments that seemed relevant to understanding their experiences. A porter, for example frequently shared treatment experiences observed through helping patients to radiotherapy and X-ray units. However, he was cautious, like his colleagues, about possible accusations from their seniors about either 'misleading' or 'inciting' patients. Some medical and nursing personnel expressed the concern that subordinate staff would undermine their authority in front of patients. Ward assistants therefore took precautions while interacting with patients to avoid antagonising their senior colleagues. Nevertheless, the only information some patients had about the issues that concerned them was what they had learned from fellow patients and subordinate staff. This included details about the outcome of chemotherapy and radiotherapy.

Patient care interactions entailed information flow and the coordination of practical matters. Occupational and social hierarchies situated the roles of different actors. In interactions concerning their own care, patients take part both as both beneficiaries and as actors. Their communication with ward assistants indicated their desire for improved information flow. Interaction with nurses and ward assistants presented the opportunity to receive informational and emotional support. Patients craved more participation in discussions and activities related to their well-being. Professional health caregivers' perceptions of the position of patients influenced the patients' participation.

Patients' participation

Patients were positive about teamwork among the ward staff. In their view, the present hospital and ward had the most elaborate treatment collaboration in the course of their cancer treatment trajectory. Nevertheless, patients grumbled about insufficient opportunities for their direct participation. They wished to have more chance to report and get information about their experiences. One respondent said:

They refer to the files and plan among themselves ... We do not follow what they discuss. I am always eager to hear what the doctor is saying about me. They should tell us, 'you know now the doctor is saying this and that about you ...' Sometimes they ask questions among themselves ... They leave me wondering, what did they find and what did they say about me? I am lucky because I can understand some English. Others do not get any English words. They are left wondering, what did they say? Did they say I am going to die or what? It is better if the doctor also speaks to us directly ... (Mr. Jabari)

Patients could not follow discussions about their care for several reasons. First, most of the discussions were among the hospital caregivers and rarely involved patients. Second, time constraints led to doctors' preference for very little communication with patients. On ward rounds, for example, the team continued discussions about one patient as they physically moved on to the next. Third, the main part of the discussions was held in English, yet many patients

had very little or no command of the language. As for those patients with a good grasp of English, many still could not follow discussions because they involved unfamiliar medical terminology. This caused language interpretation difficulties, as noted before. Similarly, patients lacked relevant knowledge to judge health care choices the hospital staff made excluded them from active vetting of decisions.

Communication problems limited patients' participation. On the other hand, hospital caregivers had conflicting views about patients' direct involvement in discussions and some care activities. Some hospital staff deliberately excluded patients from taking an active part. This imposed a passive role that many patients tried to maintain. Some medical staff feared that involvement of the patients in health care activities would either increase non-compliance or compromise their professional authority. The conversation below exemplifies conflicting views about patients' participation:

Matron: ... some of these patients are impatient with the drips. They try to regulate them when they think they are too slow or too fast.

Pharmacist: That is okay. It is good some of them seem to know about the drips. They can help in regulating them.

Consultant: Do not allow them to do that! We should not allow them to do whatever they want ... They should be told straight that they are here to be treated by us. That is why they are here. If they do this for themselves, they will die! Some patients think they know better than the people treating them do. Nurses should monitor the drips ...

The busy hospital schedule and heavy workload distracted nurses, pharmacists and the ward doctor from monitoring treatment. Ambulant patients often took the initiative to do something for themselves when nurses were delayed in responding to their calls. In addition, some nurses hesitated to perform tasks such as fixing and adjusting treatment apparatus, perceiving such tasks as the doctors' or other staff's responsibility. Other nurses did not have the confidence to perform some of the tasks. For these reasons, some patients said they had learnt do a few things for themselves. They occasionally reported having blocked lines when drips were not flowing or when they caused bleeding. Patients who were unable to wait for assistance took the initiative of adjusting lines or other therapy devices, and sometimes accidentally or deliberately disconnected devices such as lines and tubes. Nevertheless, patients generally strove to enact the passive role in order to safeguard their care relationships with the hospital staff. Relatives also had to avoid overstepping the boundary of their roles. Their approach would either strengthen or undermine patient care relations with the ward staff.

Relatives: 'Visitors' or care partners?

Involvement of relatives in the care of hospital in-patients in Kenya is restricted. Hospital staff referred to patients' relatives and informal social networks as 'visitors.' They stayed in wards only during designated visiting hours unless they have special permission to stay longer. This included accompanying patients to medical examination units and clinics for reviews. They also facilitated communication with doctors, as well as buy medicine and health care devices that are not available in public hospitals. In the cancer ward, relatives mediated communication between hospital staff and patients on a variety of issues. Nurses and nutritionists collaborated with relatives who were more involved with patients' welfare. They conveyed information about medication and devices, such as catheters, which patients occasionally had to buy.

The ward staff were strict about specified visiting hours. They allowed some relatives to stay longer to assist weak bedridden patients. However, they could not stay during procedures or in the night after 9:00 pm. Hospital staff tended to hang back during 'patients' time with their visitors.' They in turn expected visitors to vacate and give way for cleaning and other procedures at the end of visiting hours. Immediate family members helped patients with feeding, the toilet, and general hygiene. They brought changes of clothes and took away dirty ones for washing. Relatives and friends played an important role of connecting in-patients to experiences outside the ward. They supplied alternative medicines, homemade food, and patented food supplements. Patients' visitors also ran errands for them, such as buying snacks, newspapers, and mobile telephone air-time.

Relatives helped patients get physical exercise, and also prayed with them. They helped patients get to medical examinations and appointments in other clinics and treatment units when a porter was not available. Some relatives visited regularly, even daily, to keep patients company. Patients whose kin and friends could not visit regularly were lonelier. They lacked adequate social support and essential connections to the outside world. Such patients had to bear with the monotony of hospital food as described in Chapter 5. Visits however also led to conflicts between relatives and ward staff on issues concerning the alternative medicines the visitors supplied, as well as forbidden foods. There were also problems with relatives who remained in the ward after visiting hours. There was also some antagonism expressed over visitors' infringing upon the roles of the hospital staff. Nurses perceived some relatives as arrogant and 'boastful'. Perceived position in social hierarchy and connections in the hospital influenced relatives' interaction with the ward staff.

'Boasting' relatives

Patients and relative were cautious about safeguarding relationships with hospital staff. Amicable interactions guaranteed favourable treatment. Patients may have contributed to the management of a positive relationship by taking a passive role during the hospital stay. They were aware of the potential impact of their visitors' approach in relating to the ward staff. They believed that hospital caregivers would be either compassionate or less caring depending on what they perceived their visitors' attitudes to be. Some relatives and friends assumed the role of patients' advocates. However, hospital staff resented what they considered as visitors' undue evaluation of their performance.

The hospital staff did not necessarily recognise kin and friends as in-patient care partners. Rather, staff considered them to be visitors whose participation marginally complemented hospital care. Conversely, relatives and friends wished to intervene directly when they were anxious about patients' conditions. Some negotiated for patients' care through hospital staff they knew personally even if they were working in other units. They at times expressed dissatisfaction with the available patient care services. This was a main source of conflict between the ward staff and patients' networks of social support. Better-educated and relatively well-off patients and kin were more assertive in bargaining for services. According to the ward staff, some of the patient's relatives and friends were arrogant and undermined their work. A patient's visitors' approach had implications for that patient's care. A patient who had observed this commented:

Some nurses are not happy when relatives visit. They are not attending to my friend here because of her relatives. Nurses think that her relatives are boastful and come here to show off. They say her relatives are interfering with their work ... They annoyed nurses when they asked for information about her treatment ... Another woman told a certain man (doctor): "write for me the names of the tablets that you are giving me, so that I show my relatives" That man felt so bad. Now the patient fears that the doctor is killing her ... Understanding between the staff and relatives is not very good. When a patient is frank with relatives, nurses feel that relatives have come to spy on them. (Ms. Stella)

Inquiries about medication, patients' food, deaths and accidents often caused tension between relatives and the hospital staff. Some relatives were also dissatisfied with the interventions and measures that were available to prevent fatalities or accidents. They also complained about patients' hygiene, diet and staff responses to their calls for help. Patients often shared their frustrations with their visitors. The advocacy role that some relatives took threatened patients' therapeutic relationships with the ward staff. Some of them even challenged controversial relatives or friends to either withdraw the patients from the ward or take over their treatment. Some relatives attempted to complain to higher levels of ward administration about the welfare of their patients. As I pointed out in chapter two, some patients considered me as a neutral visitor and an audience for

some of their complaints. Visitors' responses to particular patients' complaints was a potential source of threat to the patient-hospital carer relationships. This threatened patients' well-being and quality of life during their hospitalisation.

Summary and discussion

The hospital offers the physical, emotional and social space for patient's recovery. The cancer ward, as other medical settings ward is an arena of social and interactions. These interactions shape therapeutic relationships, patient satisfaction and care outcomes. In this sense, all actors in the medical setting contribute to the physical and psychosocial well-being of patients. Doctors, nurses, pharmacists and ward assistants were the main participants in daily patient care in the cancer ward. Medical hierarchy and inadequate integration of different actors influenced their participation in promoting patients' well-being. The hospital hierarchy put doctors at the top, nurses and other caring personnel with service functions below. Patients are often at the bottom of the hierarchy as receivers of services and care. Different kinds of knowledge and the power which different actors derive from it shape the hierarchical structure of the hospital (Samuelson 1991). The structure influences the way different hospital workers respond to each other and patients' healthcare needs. Nurses and low level workers found more time than doctors to address the effects of cancer that go beyond physical disturbances. They attempted to address the social and psychological disruptions that cancer and hospitalisation cause. This drew them closer to patients than were medical and technical specialists. Indeed, this study shows that nurses and low-rank hospital workers positions attempted to get closer to individual patients' illness experience and its treatment. However, patient care interactions in this study should also be understood in the context of a shortage of resources, limited ward space and insufficient incorporation of essential professional patient support services. This situation limited the comprehensive care that cancer in-patients required.

Doctors and a pharmacist managed patient care interactions and treatment decisions. A nurse-in-charge facilitated treatment and care decisions drawing on other nurses 'daily reports. The nurse probed patients during main procedures to ensure their compliance with hospital care plans. Patient care interactions drew on a weak structure of healthcare teamwork. Proper health care cooperation implies coordination of professional staff in sharing information and working interdependently (Crawford & Price 2003; Jünger *et al.* 2007). This did not materialise fully in the care of cancer in-patients in the present study. Hierarchy and notions of division of labour in healthcare relations, as well as a shortage of resources, influenced cooperation and mutual participation among staff. Their relations with patients tended to be paternal as was apparent in the consultant's ward

rounds. Efforts toward coordination of healthcare services focused mainly on patients' obedience. This targeted the success of biomedical treatment goals than patients' broad concerns.

Patients often upheld their low positions and held their tongues in ward interactions in order to safeguard therapeutic relationships. They tended to maintain a subordinate position in the hospital interactions as a means for guaranteeing themselves better treatment and care. Patients often repress their views and complaints while interacting with medical carers. Through these means, they attempt to protect good relationships that would ensure a positive outcome of hospital care and medical treatment (cf. Tanassi 2004: 2069). In this sense, social relations influenced patient care activities as patients tried to avoid antagonism in order to maximise hospitalisation benefits. They enacted the role of care-recipient rather than mutual participant in healthcare. They tried to reconcile themselves with the role of passive recipient of healthcare instruction, and the choices that the hospital staff made.

Hierarchical differentiation among medical and other healthcare professionals influenced communication among themselves and patients. A common feature of this communication was the expectation that junior staff and patients would concede to senior professionals' views. Medical professionals perceive their juniors and patients as lacking legitimate knowledge basis for questioning their authority (MacCormack 1981; Taylor 1982). This may cause subtle resistance to medical workers' dominance in patient care interactions. Lower-level staff refrained from critical evaluation of patient care decisions proposed or vetted by their seniors. The junior hospital workers also tried to protect their integrity against their seniors' upsetting dominance and reproach. Contradictory views about patient care became apparent in procedures and especially during ward rounds, which were also the main occasions for hospital actors in cancer management to collaborate directly. Divergence of views among hospital staff reflected their differences in career and professional statuses. As expected, conflicts are likely to emerge in professional teamwork because the teams consist of individuals with different characteristics and views (cf. Jünger *et al.* 2007: 348). Similarly, professional socialisation, power relations and status differentials, and the vertical management of professionals, can undermine attempts to work collaboratively (Reeves & Lewin 2004). However, doctors in the present study tended to seek the views of staff in lower ranks as a last resort or as a way of coping with challenging cases. Seeking some views of low rank staff did not necessarily imply collaborative decision-making and mutual participation.

The interaction between the hospital staff and patients minimised patients' participation. Some medical staff perceived patients' attempts to negotiate or participate in their own care as an expression of resistance. Patients therefore

concealed their opinions and negative emotions. The medical setting imposed a separation between patients and medical experts. Doctors attempted to maintain professional distance at the expense of close communication and understanding patients' experiences. Healthcare practices in such bureaucratic medical settings tend to disregard patients' human expectations (cf. Andaleeb 2001: 1367). Consequently, patients perceived medical staff that were higher in hierarchy as less compassionate. They valued the more informal interactions they had with ward assistants and some of the nurses, which facilitated communication and emotional support. Nurses and ward assistants spent more time with patients [than did doctors or consultants] and attempted to respond to their suffering in a more personal and comforting manner. However, heavy workloads and insufficient hospital resources constrained patient-centred care among doctors, nurses and other caregivers.

Occupational therapists, physiotherapists, and social workers were present mainly during the mandatory ward round. They were unable to cope with the workload in the hospital since they worked across several wards. They often skipped the cancer ward, probably due to its perceived invisibility in the hospital. The ward round embodied the ideal of collaboration and teamwork; in practice, however, collaboration was fragmented and transient. Doctors and other professionals tended to work separately from one another. Such fragmentation constrained treatment follow-up and interdisciplinary collaboration. Role ambiguity and conflict were evident in case discussions and individual attempts to perform their professional tasks. The manifestation of role conflict was understated. Role conflict in similar medical settings relates to the attitudes of professionals working within teams (Jenkins *et al.* 2001), and further demonstrates the impact of hierarchy in healthcare. Role conflict and the tension introduced by hospital hierarchy accounted for inadequate communication between professionals and undue occupational opposition. Development of better communication with other professionals (Borgesteede *et al.* 2007) would ameliorate interdisciplinary collaboration. This requires more interaction and discussion of patients' treatment and care at all stages of hospital care and treatment.

Ward assistants and relatives attempted to mitigate the suffering of cancer in-patients. However, their role was ambiguous and marginal. Relatives took the position of 'visitors' and their interaction with staff and participation in patient care were restricted; hospital staff in effect took over the responsibility of caring for the patients from the family. Hospital staff and relatives often assume that available professionals can adequately provide for in-patients' personal care and emotional needs (cf. Glaser 1970); relatives' visits are therefore part of cultural gestures of compassion and support. Relatives' attempts to exercise their sense of duty and support for sick family members by advocating for patients caused

conflict with hospital caregivers. Patients feared that their relatives' participation could interfere with care relations with hospital staff. In contrast with the practice in other developing countries (Martin 2009; Zaman 2005), family members in Kenyan hospitals do not participate in sensitive patient care duties such as dressing wounds and administering drugs. Relatives and patients are always aware of possible accusations of either undermining the hospital staff or usurping their roles. Patients' social statuses were already apparent in the ward, and their visitors' personalities and characteristics made their perceived socio-economic backgrounds even more visible. This had implications for their care and could shape their differential treatment and experience of care (cf. Anderson 2004). The social interaction context of the ward had implications for patients experience and expression of their main physical symptoms. Relative success of interaction among hospital actors shaped further the patients' emotional and physical experience of cancer symptoms. Patients grappled with pain and eating difficulties as the main physical symptoms of the disease that they needed to express and cope with.

Struggle with pain and eating difficulties

Mr. Sony had been in the cancer ward for three months. A doctor in a district hospital referred him to the National Hospital for further investigation and treatment. Numerous medical examinations had not revealed the type of cancer he suffered from. He repeatedly complained of constipation, lack of appetite and 'watery diarrhoea.' He reported unremitting inflammation and pain in his left limbs and prostrate area. He was on chemotherapy and analgesics as he waited for results of the investigations. He complained during ward rounds that he was unable to eat. In response, a nurse-in-charge once said that "patients would find any reason to avoid eating the hospital food." Mr. Sony also complained of problems with his bowel movements, particularly that his stools had become "very hard" and constipation made him uncomfortable. After he belched during a ward round, Dr. Wario told a pharmacist, "... he is now removing the 'stool' (faecal matter) through his mouth ... we call this *flatulence*, because the breath that comes out is very smelly." He told the patient that nurses would give him laxatives.

A nutritionist and matron advised Mr. Sony to take more fluids to ease bowel movement. The nutritionist reminded him that he always had enough juice on his table yet he did not drink it. The nutritionist asked Mr. Sony to take more fruit juices and *mala* (sour milk) 'to ease digestion.' However, the matron noted that Mr. Sony did not like sour milk and fruit juice "because he claimed that he had stomach ulcers." Dr. Wario wondered why Mr. Sony had not complained about the stomach ulcers during his consultation before admission to the ward. "He should have said something so we could treat him. That is why he is here!", Dr.

Wario exclaimed. The nutritionist attempted to question Mr. Sony as to whether doctors at the district hospital had diagnosed the ulcers he claimed to suffer from. Dr. Wario and his team in the meantime abandoned the topic and moved on to the next patient. In the two subsequent minor ward rounds, Mr. Sony complained of having problems swallowing food. He said that whenever he managed to swallow anything, he suffered constipation. Dr. Wario read Mr. Sony's file and reminded him that a consultant had discharged him. Dr. Wario asked him if he had changed his mind. The doctors tried to talk to him in Kiswahili, the national language, about his condition, explaining that instant constipation caused his eating problems. Once the doctor realised that the patient's "communication skills are not good", however, he seemed fed up, finished his summary, and started to go away. Mr. Sony was dissatisfied and tried to draw the doctor's attention:

Mr. Sony: Excuse me ... err ... and what about this issue about food?

Dr. Wario: (Looks at him, ignores the question and walks away). He keeps asking me about food and I do not like it ... Maybe we should ask Lena (nutritionist) to talk to him about that...

The ward physician's characteristic interaction with patients followed the pattern in the excerpt below:

Dr. Wario: Are you feeling any pain?

Mr. Sony: Yes ... but there is a lot of air in my stomach ...

Dr. Wario: (interrupting) Are you feeling pain or not? That is what we want to know ... Are you feeling any pain today?

Mr. Sony: (after a long pause) Yes, but not much today.

Dr. Wario: Okay, we will give you painkillers and other medicine ...

Experience of pain and eating problems were the main aspects that embodied suffering among the cancer in-patients. Pain and eating difficulties tended to intensify with the duration and frequency of hospitalisation. These effects of cancer and its management deepened patients' subjective experience of the interruption of the rhythm of their lives. Life in the cancer ward entailed a daily struggle to cope with pain and a reduced ability to eat well. Therefore, issues related to pain and food featured prominently in patients' narratives of physical well-being. Medical staff routinely asked patients about pain as the main physical symptom to which they directed their treatment efforts. Patients on the other hand perceived both pain and constraints to normal eating as significant symptoms of deteriorating well-being. They complained of either inadequate pain relief or frequent eating hardships. These constituted the main physical manifestations of increasing vulnerability in spite of hospital treatment. This chapter is about patients' experiences of pain and eating difficulties, and their attempts to communicate about them. It describes hospital workers' responses to cancer patients' needs related to pain and their quest for relief. It depicts patients' experiences and

relevance of available medicines which the medical staff recommended and used to allay their physical suffering. The chapter illustrates that chronic pain and illnesses, as well as hospital staff's responses, contribute to patients' disillusion about hospitalisation. As a result of their disillusioned state, in-patients resort to alternative explanations, foods and remedies in spite of their hospital treatment and care.

Unspoken pain

Cancer inpatients narrated either their own or fellow patients' pain ordeals. The patients who were relatively well narrated the sufferings and struggles of others vividly rather than their own. Those who were in pain did not speak much, if at all. Others preferred to 'leave those suffering alone' until they got relatively well. They perceived attempts to probe people in pain and distress as a source of further discomfort and irritation. Such patients seemed withdrawn and deep in thought when seated on their beds. They gradually or suddenly became quiet and occasionally left those adjacent to them apprehensive and lonely. The experience of pain isolated both the sufferers and fellow patients who relied on them for company. Mr. Ndege was often afraid that the silence of his 'neighbours' was ominous. Other respondents confirmed his view that gradual silence and withdrawal of patients symbolised the onset of pain and the dying process. Ndege said that persistence of this behaviour signified that the sufferer was probably 'going' (dying). Patients who had either some knowledge of cancer or observed others suffer pain viewed severe pain as a sign of imminent death. Whether the patients knew the exact outcome of their disease or not, they observed that the nature of pain indicated the uncontrollable or fatal nature of their ailment. Many long-stay patients said they had seen others die after 'suffering in silence.' Moaning, grimacing, and intermittent vocal sounds often preceded verbal complaints of pain. Some patients decided to keep to themselves when they believed that help was not forthcoming.

Several patients said that they preferred to 'suffer in silently' when no one seemed to understand their difficulty. Others saw no point in expressing or explaining their physical suffering because they noticed that the ward staff failed to make meaningful efforts to assist them. Some patients sat on their beds for long stretches of time with their heads cast down, not talking to anyone. They would respond to anyone who called their names by looking up briefly. According to some nurses and patients, people suffering in pain gradually became bitter and angry. Some patients who were in such moods seemed to resent further hospitalisation, especially when they felt that the hospital did not alleviate unremitting pain. Groaning and loud grieving was characteristic of some patients experiencing unrelieved pain. Other patients, especially men, seemed to endure pain

in silence, seated or lying on their beds. When they felt like not talking to people while in pain, they occasionally covered themselves up completely in their blankets.

Expression of pain and quest for relief

Mrs. Omari, a 49-year-old breast cancer patient is seated on her bed crying. She has tried to dial her mobile telephone many times. No one seems to answer her call. I talk to her after finishing with another respondent. She replies to my greeting as she sobs: "I'm in so much pain. I have called them (nurses) but they won't come. They have not come to see how to help me. It seems they do not have a solution and they are avoiding me ... I am calling my husband but he isn't answering." (Field notes, October 2005)

The patients called for attention for numerous reasons. They called loudly, to the extent of pestering nurses, when they needed urinals and bed or spittle pans. They also called the nurses or the doctor to check the drips, intravenous lines or to explain their uncomfortable sleeping postures and treatment procedures. Nurses' workloads and judgement about which cases deserved urgent attention influenced their responses. Patients on the other hand perceived any delayed response to their calls as the hospital workers' inability to empathise with them. They described circumstances in which either their 'calls for help fell on deaf ears,' or hospital workers fulfilled their expected roles of supporters and comforters.

Ward assistants were helpful for listening and giving emotional support. They tried to console patients and link them to nurses, medical staff and their relatives. Some of the ward assistants offered their mobile telephones to distressed patients who wished to communicate with their relatives. Patients also comforted each other, drawing on their personal experiences of pain and other physical symptoms. Those who could communicate with each other shared information on how to endure both mild and acute pain. Ms. Marina noted that the hospital staff might ignore patients' calls for attention because they did not share their experience of illness and pain. Like a few other patients, Ms. Marina viewed the ward as the appropriate context for patients to experience their 'world of the sick', as noted in Chapter 3. They believed that being at home instead of in the hospital would deny them the opportunity to share their experience. Nevertheless, some patients concurred with Ms Marina's view that healthy people, including the ward staff, may be unable to fully empathise with people in pain. They argued that people who have never experienced acute illness and pain could not fully relate to this personal reality.

Language barriers and the elusive nature of cancer pain constrained communication about it with the medical staff. Patients who might have called for help at one hour, for instance, would later tell the physician that they were no longer in pain. The pain would 'return' soon after the medical staff or nurse had left. Pa-

tients in persistent pain on the other hand said that they could not locate it consistently. It occasionally ‘engulfed the entire body.’ For many patients, cancer pain seemed to elude medical examination and treatment, confounding their expectations about admission to the study hospital.

Elusive reality

Patients described their pain as difficult to find and localise. Most reported that their pain was most severe at night when it was difficult to access sufficient help. The intensity of pain at night also portended death, which inpatients and hospital staff alike associated with night time. On occasion, there were moments of silence in the ward during the day; these were times when patients fell asleep after a long night’s struggle with pain. However, some felt that intermittent episodes of pain or its prolonged disappearance obviated the need for further hospital stay. This implies that some patients associated hospitalisation with the struggle to relieve or eradicate pain. Unremitting pain complicated the mystery of cancer, whether patients were aware of it as cancer or not.

Subjective experiences of intractable pain contradicted the discourse of hope in the ward. Unrelieved pain also created some awareness of the unpredictability of hospitalisation outcomes in cancer management. Difficulties in defining cancer pain and controlling it signalled the complexity of diagnosing and treating the disease. This became apparent with subsequent hospital treatment sessions. Many times, cancer in-patients were unable to determine the source of their pain. While doctors and nurses simply attributed the pain either to the disease or its treatment, patients felt that it could have resulted from other illnesses as well. Irregularity and vague location of cancer pain contributed to patients’ perception of it as difficult to define and communicate. One respondent remarked:

Sometimes, it may not be painful. It can go on for a long time before it disturbs someone. It is very painful at other times, and affects other parts of the body ... The pain goes round to the back. You feel backache and your legs sometimes lose strength. It may not be very painful at its site but I feel pain in other parts of the body. It is difficult to understand that because at the beginning it didn’t hurt. I just felt something swollen here (in the stomach), something small. When you go to the doctor and say you have something like that, they just give some medicine. They let you go away, with a feeling that it is not anything serious. (Mr. Mati)

Patients’ narratives portrayed their struggle to understand and explain their pain experiences. This influenced their levels of satisfaction with the responses of their hospital carers. They expected that once they had explained their experiences, medical personnel could provide remedies that would treat their pain after a short while. However, lack of verbal equivalents to express the experience contributed to patients’ frustration. Medical personnel could not fully understand patients’ descriptions of their suffering and hence failed to address it adequately.

The communication of pain was frustrating for patients and hospital staff alike, as the excerpt below shows.

The consultant decides to exclude a middle aged-woman from the ward round review. The nurses' observation card and an X-ray report are missing from her file. The consultant says that they will have to wait for the X-ray and nurses' daily reports. They also decide to leave out the case meanwhile because the patient's communication is not coherent. The patient had been complaining of back and limb pain. She calls out the consultant to wait so that she can talk about her experience. Patient (in Kiswahili): "Yes doctor, I am feeling a lot of pain in the whole body. In fact, I have 'a lot of backs' (*Nina migongo mingi*)." The doctor laughs and says he does not have any idea what that means. He asks for interpretation. The matron says that the patient is translating her experience directly from her ethnic language. "You know she is speaking Kikamba (language) ... that means that she has back aches in different places." They laugh and move on to the next patient without responding to the patient's concern. (Field notes)

Patients' descriptions of their pain were often difficult to understand. Several descriptions of pain sounded amusing. Hospital workers openly reacted to the humorous aspects of patients' complaints by attempting to make light of the way patients presented their experiences. Nurses and other staff on occasion tended to regale patients and their colleagues with some joke about patients' descriptions, which apparently frustrated and annoyed some patients. Difficulties in communicating pain could thus give rise to anger in patients and conflict between them and their caregivers. Though some explanations may have sounded absurd, patients expected sympathetic responses and medical prescriptions. They took note of instances when the hospital carers either 'just laughed' about their complaints or went away without providing any remedy. Therefore, in some patients' view, being in the ward did not guarantee the pain relief and consolation they expected.

Eating problems complicated the experience and expression of unrelieved pain and suffering. Severe illness, hospital circumstances and treatment side effects interrupted the daily rhythm of life. Daily life in the ward meant frequently missing meals, if the patients had access to the appropriate food at all. Hospital treatment of cancer required efforts to strengthen patients' coping with pain, resolve their eating difficulties and meet their dietary requirements simultaneously.

'Missing chances to eat'

Cancer management is generally associated with diminished appetite and food intake. Mild and acute pain interrupts patients' normal eating patterns. However, factors that are unique to the treatment context and sufferers' subjective experiences contribute to the patients' eating difficulties. In this study, we found that timing of the meals and treatment schedules, hospital surroundings, inability to eat due to illness and perceptions of appropriateness of the food served in the hospital contributed to patients' eating difficulties. Therefore hospitalisation

implied increased instances of ‘missing chances to eat’ and susceptibility to eating difficulties.

Meal times and treatment schedules

... We need a better treatment schedule. This would help us organise how to eat. I did not take any fluid this morning because I knew I would soon be on a dripHowever they have not come to treat us yet. We do not know when they are coming ... They should have a specific chemotherapy schedule so that we can organise our eating programme. I do not like taking meals when I am on the drip. It is not convenient. I may need to wake up, use the spoon ... and maybe get water, or wash a spoon. Sometimes a spoon falls down by mistake, what will I do? If I call for help, a nurse will tell me; “wait, I am coming ... ” The nurse then may complete whatever he or she is doing then forget that I had called for assistance. Then the nurse may come after 15 or 30 minutes. At such a time the desire for food is gone! That would be a missed chance to eat something. We should have a definite schedule for meals ... Sometimes they bring breakfast at 9 AM. That is the earliest they can manage or have ever managed ... They sometimes serve breakfast at 9.30 AM, 10 AM or after 10 AM ... They sometimes do this immediately after we have just started taking chemotherapy. When you start taking chemotherapy, it disrupts the digestive system. One cannot eat at such a time. The stomach gets upset! We end up skipping the meal ... That is also a chance missed for a meal. (Mr. Hassan)

The excerpt above summarises patients’ sentiments about timing of meals in the cancer ward. Breakfast was comprised of tea with bread, porridge, fresh milk and occasionally boiled eggs. The official serving time was between 7:30 am and 8:30 am. Between 11:30 am and 12:00 noon, the meals attendant usually brought in rice and bean stew or beef stew and/or cabbage for lunch. Between 4:30 pm and 6:00 pm, they served supper, which was mainly *ugali* (meal made from maize flour), cabbages and bean or beef stew. Irish potatoes and green grams constituted the alternative stew for lunch or supper. Patients on chemotherapy were uncomfortable with the timing of either breakfast or lunch, especially when it came immediately before or after their treatment.

Actual daily meal times in the hospital wards depended on when food was ready from the central catering unit, and were therefore irregular. Breakfast and lunch were often barely on time and occasionally early. However, many patients found supper was always too early, and there were no snacks for them in the long night. They found the time in between supper and breakfast to be too long. Owing to illness and effects of treatment, some patients could not eat enough during supper. Treatment procedures were often either earlier or later than patients expected. Chemotherapy and radiotherapy affect patients’ appreciation of food tastes. In this sense, patients who expected treatment before or immediately after common mealtimes wished for special consideration. They argued that this would enable them to cope with some of the immediate and lingering effects of treatment, such as tastelessness of food and low appetite. Some patients declined to eat or take any fluids before chemotherapy for two reasons. First, they feared

that they would lack help with the toilet while on the drips and due to body weakness after treatment. Second, they dreaded nausea and vomiting that are more likely after chemotherapy.

All the cancer patients I talked to said they developed more problems with nutrition during their hospital treatment sessions than they had when they were out of hospital. Most of them experienced drastic reduction in food intake and substantial weight loss while in the cancer ward. For many, the cancer diagnosis and hospital stay curtailed their desire for food, altered their eating habits, and consequently, their body weight. Increasing concern and anxiety about food consumption and maintaining weight characterised their hospital stays. The experience of pain and the side effects of treating it also accounted for their reduced desire for food. Mr. Johana, for instance, said:

Each time I am on chemotherapy for five days, I lose so much weight. I cannot eat anything during this time. In fact, when you see food you wish to run away. I may also not be able to eat because this place is not good for eating. Perhaps a dining room in the ward would be good for some of us ...

Unpleasant ward surroundings

Several patients attributed nausea, vomiting and loss of appetite to what they considered unpleasant conditions of the ward. Kabba for instance, could not help vomiting the whole day each time he was admitted. He said he could not stand the smell of the ward and no sooner did he walk through the door than he started vomiting. For some nurses, this was a consequence of 'psychological conditioning' because he did not like the ward. Commenting on his experience in the cancer ward, Kabba said:

I do not usually feel well as soon as I get here. I even vomit when I am not being given the chemotherapy. When I get to the ward, I just begin to vomit. Sometimes (it is because of) the toilet ... When you go in, there is dirt which other patients have left there. The smell nauseates me and I start vomiting.

People generally may dislike the smell of the hospital, which emanates from medicines, human odours, bathrooms, toilets and cleaning detergents. As pointed out in Chapters 1 and 3, the public still believed that the Kenyatta National Hospital was dirty due to previous experience. This was also the general expectation about the condition of other public hospitals in Kenya. Despite improvements in the sanitation and hygiene of the hospital after reforms in its management, some patients remained unconvinced, contributing to the lingering opinion that some wards were substandard. There were times when the sanitary conditions of the cancer ward declined due to blocked drains and patients' personal hygiene. Patients had to reckon with some unsanitary extremes in the ward on several occasions, which affected both their desire to eat and their actual food intake. Ward

conditions thus can be seen as interrupting patients' usual eating routines, which in turn had implications for their overall day-to-day well-being, and was detrimental to achieving a favourable therapy outcome. In addition, sharing a space with fellow in-patients who were experiencing the disease and treatment side-effects further shaped patients' perceptions of the ward as an unsuitable place for meals. One respondent complained:

People on chemotherapy have very bad side effects. They vomit and have diarrhoea desperately ... Some of us are not yet on these drugs and we cannot eat in such a situation. When we see people have diarrhoea or vomit we cannot eat. There should be separate rooms for chemotherapy and radiotherapy patients and those who are not yet ready for the treatments. Mixing patients who are getting different treatments is rather unfair and uncomfortable. A person may vomit and become very helpless ... This scares us. You cannot eat! Our environment in this ward affects our appetite and yet we need to eat a lot in order take the drugs ... It would be better if there were separate spaces so that everybody in one category of treatment could be in one room because they tend to behave uniformly ... If I were totally stuck without anyone to help me to the toilet, I would have to 'do it here.' You see if all the other patients can walk and go, everybody forgets about me and I end up making noise. You can see, they have brought the bedpan and they may come for it or not ... They bring me the bedpan, but when they do not come for it, 'I get into problems' I therefore 'think twice' before I start eating. (Mr. Ndege)

It is possible that some patients limited their food intake because they feared having to go to the toilet, which they could not access by themselves. The overall condition of the ward environment, however, had an impact on the desire to eat. The air in the ward or some of the patients' rooms was often squalid, to which uncollected bedpans, insufficient patient hygiene, and frequent blockage of sink and toilet drainage systems contributed. Patients' conditions, such as chronic wounds and shortages of cleaning and laundry supplies made the situation worse. In addition, blockages in the drainage system of the adjacent surgical clinic (see Appendix 2) resulted in an unpleasant smell in the cancer ward which sometimes was unbearable. Some patients also complained that the smell of the detergents the ward assistants used to clean the floor was unpleasant and induced nausea or vomiting. Most of them said that their illness and treatment increased their sensitivity to the smell of detergents and other strong odors. The strong odors they loathed included the smell of particular foods, especially when the catering staff used different amounts and types of cooking oil to prepare them.

For some patients, the ward seemed to be an 'unsafe' place both to stay and to have meals. According to such patients, the behaviour of hospital workers indicated that the ward and other hospital spaces were dangerous. Mr. Kassi, for example noted:

... They (cleaners) cover their mouths and noses. I asked them, "you are now pouring these detergents here to clean, yet we have not covered ourselves. Again, you come when people are getting food. I asked them, 'what do you people think we are?' I also asked them today, 'when you come to work here, you cover your mouths and noses completely, yet we patients do not ...' They also come to clean while patients are still eating. I asked, 'is that not dan-

gerous?’ They did not reply. Is it not better for them to wait for the patients to finish eating? Those who are able to walk can then either go outside or cover themselves with blankets afterwards as cleaners and nurses do their work ... I was surprised that while we were still eating they were just pouring the disinfectant, yet it smells ... Then some of us started vomiting. Again, when we go to the toilet, I tell them, the water submerges sandals and even shoes ...

Owing to illness, treatment effects and the ward environment, many patients described eating as a ‘struggle with food.’ According to Hassan, a typical struggle entails the notion that “cancer patients eat out of *pressure* and not *pleasure* (his emphasis)”. Patients struggled to eat out of necessity, including their awareness of the importance of nutritional care as an important part of their therapy and daily well-being. All the patients I talked to referred to the phrase: “food defeats me” to describe their not-so-successful struggles to eat. As noted earlier, cancer and its treatment alter sufferers’ usual appetite and desire to eat. Physical eating difficulties due to illness and the often-unfamiliar hospital menus also contributed to patients’ apparent struggle to eat. This coupled with other situational factors to determine the level at which they were able to eat adequately.

Food ‘defeats’ me

The phrase ‘food defeats me’ (*chakula kinanishinda*) indicated regrets about inability to eat, which resulted from either lack of appetite, pain or other subjective factors. Similarly, monotony of the hospital food, as well as inadequate encouragement and support at meal times reduced patients’ ability to eat. In view of this, one patient remarked:

At home I can eat the type of food I choose any time. Since this disease returned we eat only rice in this ward. I am unable to eat the food; it defeats me. I do not worry much because I usually do not stay too long here. I come on Monday; get the medicine Tuesday and leave on Wednesday. I just persevere. I tell myself; I will persevere for the three days, then go home to eat ... At home the person who brings me food does not go away immediately. If the person wants to go away, I ask him or her sit a bit with me so that I can eat. When I am alone on this bed, I eat only a little, then find the food boring. They serve only *ugali* or rice here. If you do not like the taste of *Ugali* or rice, this will ‘defeat’ you. If nobody is near you to visit, then you will have a problem. I eat a little of what is served here ... Since they serve rice with something else such as *Minji* (green peas) or *Ndengu* (green grams), I tell them to serve me only the stew. I do not know what has happened to me. When I eat rice, it sticks in my throat. It chokes me and makes me vomit ... I prefer food with tea, but we have only water and nothing else at meal time in this place ... (Mr. Toi)

Many patients had to depend entirely on the food served in the hospital. Their relatives were either poor or did not live close enough to the hospital to provide food prepared at home, so those patients could neither supplement their diets nor access alternative food. The nutritional information available that addressed the need for extra indigenous and other special foods was not quite useful because the hospital did not serve such varieties of food.

Some patients attributed their difficulties swallowing food to poor preparation of the meals or inadequate sauces, which they said induced pain and vomiting. In such instances, food was either 'too dry' or relatively cold. Several patients wondered if the hospital treatment of cancer required that they eat cold food, though it was almost unpalatable for them. They found cold food to be tasteless, nauseating, and that it sometimes caused vomiting. Others complained of too much oil or salt in the food. A number of them disliked main meals such as *ugali*, or mashed potatoes served mixed with stew or sauce on one plate. Significant constraints to eating and swallowing that most patients reported related to the effects of cancer therapy. Patients who were fortunate enough to attend counselling sessions with nutritionists became aware of the negative effects of chemotherapy and radiotherapy on food intake. They went over dietary recommendations and ways to relieve eating difficulties. However, the nutritionist was not able to arrange systematic counselling for all patients. Nutrition counselling sessions thus did not provide adequate practical guidelines for all patients' control of eating difficulties in the hospital.

Implementation of ideas from nutritional counselling for dealing with treatment effects on eating (see Appendix 4) was inadequate. Some patients complained of persistent throat blockages or dry mouth that caused painful eating and swallowing. They looked to those around them to find ways of facilitating eating and swallowing relatively dry food. They wished to be served food with adequate soup, sauce, stew or beverages such as tea or fruit juices, as Toi's case above showed. The experience of mouth soreness and blisters due to radiotherapy further reduced patients' ability to eat well. Intravenous feeding was often a last resort; however, this came too late for patients who were already suffering dehydration, malnutrition and significant weight loss. Due to personnel shortages, many patients received negligible support at meal times, as noted earlier. The ward staff maintained that both the patients themselves and their relatives were responsible for the patients' own food intake, including the responsibility for eating the appropriate foods. The ward nutritionist emphasised avoiding oranges, soda, red meat and carrot juice among other items considered inappropriate foods for cancer patients. Relatives who failed to give patients' fresh juice, but gave them carrot or artificially prepared juices instead disappointed the nutrition team. The nutritionists and patients alike complained about what they termed confusing mass media advice on the appropriate diet for cancer patients. Cancer patients and hospital carers did not necessarily agree about appropriate food during hospital treatment.

'Inappropriate' food

Personal experiences, preferences and available dietary information shaped patients' notions about the appropriateness of hospital food. Actors in cancer management had conflicting views about what was a suitable diet for cancer inpatients. This caused a dilemma for patients, as one respondent noted in the excerpt below:

Some people advise against carrot juice, while others say it is fine. It is not clear from the hospital either. We listen to programmes on the radio and some doctors say that this cancer thing feeds on glucose. They say that glucose makes the disease grow faster. Therefore, we have to avoid things with high sugar content. However, when we come to the ward they give us tea with sugar. I always wonder ... we cannot understand exactly what is what. We do not get clear messages on diet for cancer treatment patients. Are they supposed to take sugary things ... such as juices and the like? I think it came out only when I was doing radiotherapy. They told us not to take soda because of the acids and sugar it contains ... They also discouraged eating cold or very hot foods during radiotherapy. They said fruit juices are not good. Even so, when we come here for chemotherapy people just bring sodas and patients take it. Nobody explains clearly why we should not use this and that. The doctors might be doing a lot, but we do not know that juices like *Quencher* or soda can harm us. People bring soda and we are tempted to take it, having missed it for such a long time ... (Mr. Johana)

The nutritionist tried to get internet literature about an appropriate diet; however, the debates surrounding the diet for cancer patients, such as the suitability of red meat, were confusing. As noted in Chapter 4, doctors on occasion challenged the nutritionist and dieticians to provide documentation for their food recommendations. They backed off when they could not argue adequately about the existence of scientific reports supporting the diets and related issues they talked about. Many patients construed the absence of a particular food such as meat from their daily menus as a confirmation of that food's inappropriateness. Due to the monotony of the hospital menus, some patients argued that the catering unit was not aware that the food served in the ward as was the type ill people generally dislike. They held that the hospital did not provide the "food that an ill person is supposed to eat." According to some respondents, cancer and its treatment made them very selective of what they ate, yet the hospital did not provide a variety of food to choose from.

Some patients silently rejected food that they considered worthless. Mrs. Pakot for instance often said that food such as maize flour porridge only "fills patients' stomachs." The patients thus had their own notions about food that would be "appropriate for sick people." The monotony of the food in their view implied that the hospital did not take the nutritional aspects of cancer therapy seriously. Patients who required special diets due to other medical conditions such as diabetes occasionally felt neglected. Food attendants often found out that special orders for particular patients, including the diabetics, were missing. At times, attendants inadvertently mixed the special food deliveries with the regular ones. A frustrated elderly male diabetic patient on occasion left the ward to get food

from nearby kiosks. Nurses criticised him for his initiatives, which they said were responsible for his worsening condition. Other patients struggled to avoid some of the food due to either confirmed medical conditions or subjective experiences of discomfort after having eaten the food over time. Food aversion due to personal reasons was a potential source of conflict between patients and hospital workers, especially doctors and nurses. Patients lacked the opportunity to explain their food aversions and to have access to alternatives as they usually would at home. Personal perceptions of negative effects led them to attribute certain pains and suffering to eating foods that they would rather avoid. This was the context of the dissatisfaction that Mr. Sony expressed at the beginning of this chapter. Another patient similarly noted:

Nurses say that I refuse milk, but for a long time I have not drunk milk as such. I usually have problems with milk. When I was a child I used to drink it a lot until my 'heart refused.' Nowadays I have to take it in porridge. The milk they gave me is still here. I am waiting for my aunt. She will prepare it in porridge and bring it to me the next time she visits. Since my operation, I have no appetite for tea with milk. I take something else like chocolate, or a soya milk drink ... They should give patients appropriate food and some choice. We avoid foods that cause painful reactions in our bodies. We hardly eat chicken and meat here, yet that is what I would like. When meat does come, it is very dry. I think they get meat from cattle that feed on poor silage ... I know enough about meat. If you bring me the meat of such cows, I may eat, but suffer. I vomit after only five minutes when I try eating such meat ... when I see such food 'my heart' (*roho yangu*) 'tells me very fast' and I get nauseated ... (Mr Saulo)

Some patients linked physical discomforts such as stomach ache and constipation to the food they ate. They may have experienced the distress in due course which in turn led to a food aversion. Other patients related their avoidance to certain unconfirmed conditions, which they described as having indigestion, ulcers, allergies, or heartburn. Hospital staff did not investigate to confirm these as the causes of patients' perceived eating difficulties. Therefore most patients associated being in the cancer ward with both the inevitability of or forfeiting the chance to eat and the gradual loss of the ability to eat.

Eating problems and frequent episodes of pain presented a daily threat to the patients' well-being. These problems interrupted further the rhythm of daily life and made recuperation seem either unlikely or transient. Temporary absence of pain and eating problems only increased patients' uncertainties about recovery and return to normal life due to the unpredictability of how they would feel from day to day(and from meal to meal). Hospitalisation thus entailed a continued struggle with pain, eating problems and anxiety regarding the origins of current suffering. This necessitated frantic efforts to find satisfying responses, care and efficacious medical remedies. Dissatisfaction with available responses and medicine paved the way for patients' gradual disillusion with hospitalisation, leading patients to participate more actively in the search for aetiologies of their suffering, and to supplement available treatment and care by drawing on indigenous

illness ideas and personal experience as show later under 'patient inputs'. Hospital workers' responses to patients' initiatives and complaints ranged from holding them responsible for their own slow recoveries to providing them with some remedies.

Caregiver responses and patient satisfaction

Routine casual responses

Responses to patients' expression of distress ranged from hasty attention to discussion and the promise of medicine. It was apparent that some hospital workers' responses to patients' calls for help were non-committal due to a shortage of appropriate medicines and alternative foods. Patients expressed frustration with the outcome of their conversations with nurses and doctors. Patients interacted routinely with nurses and expressed their suffering either verbally or non-verbally. The ward physician and consultants asked directly about pain during treatment and ward round procedures. They apparently provided routine responses to patients' queries about their suffering. As noted earlier, patients reported that pain was most severe at night. It was during such times that nurses responded least to their calls. Ms. Stella's narrative, which I quote in part below, illustrates patients' frustration when they sought solutions for their pain and other discomforts.

... then at night they (nurses) give us medicine up to around nine o'clock ... They are a bit difficult with patients at night. A patient may be suffering and in deep pain but no one comes to help ... Look, for instance, the woman who is just sitting here. She cannot sleep even on her back ... You may find the nurse getting annoyed with her, saying that the patient has been told to sleep but has refused ... You cannot force a suffering patient (to sleep) ... I don't know why they should try to force her ... She is a patient and you have to understand. She is in pain ... Nurses get annoyed that she refuses to sleep. Because of this, the patient cannot take the medicine ... She has a bad feeling that the person who's giving her medicine after scolding her might be bad ... (Ms. Stella)

The longer patients stayed in the ward, the more they were aware of certain routine responses from the hospital staff. The routine responses included the following: "We shall prescribe/ give you painkillers", "it is caused by the medicine or disease", "it will take some time, but you will be alright." Medical staff habitually asked patients if they had any pain. They rarely pursued the response. One could easily notice expressions of suspense among patients who were seeking more information and medicine for pain and other physical symptoms. Inadequate human resources in the hospital and particularly in the cancer ward constrained therapeutic encounters between patients and their care providers to a great extent. The staff spent very little time with patients, especially during treatment, observation and assessment procedures. They either prescribed or

promised to dispense available analgesics. On occasion they seemed to avoid any communication about pain at all.

Patients' curiosity about pain and eating discomforts remained unsatisfied most times. They found the medical staff's explanations either too brief or ambiguous. Plain attribution of pain and other physical discomforts to the disease or treatment side effects did not satisfy patients' curiosity. Medical staff's routine explanation of pain indicated simply that pain was part of the recovery process which patients had to endure. The mere confirmation that the pain "may take some time to go away" was hardly satisfactory for patients. Many wanted more information about the causes of pain and an assurance of definitive treatment.

Medicines

Doctors prescribed either pain relief injections or oral medication depending on patients' condition. Whenever the ward physician was not available, the matron or a senior nurse could recommend painkillers for patients who needed them. Some patients demanded injections instead of oral analgesics when they experienced unremitting pain. Others asked for a change of oral painkillers. Such demands often antagonised the medical and nursing staff. Fastidious patients pestered and upset nurses who performed treatment procedures. Some patients had problems choosing between the compliance the hospital staff expected, and the rejection of what they perceived as inappropriate medicine and care. Their attempts to negotiate treatment and care annoyed doctors and nurses, as this amounted to interference in professional care. Some nurses reacted angrily to distressed patients' nagging calls for medicines. Nurses either had no solution for suffering patients or were busy with other responsibilities. It is worth noting here that the lack of time to attend to patients and the shortage of drugs shaped hospital personnel's reactions to the in-patients' expressions of suffering. The advanced stages of cancer made the situation worse, rendering the medical staff almost helpless in managing the patients' hardships.

Shortages of medicine presented a real challenge to patients' and hospital staff's health care efforts. Available painkillers were ineffective and patients expressed little confidence in them. Hospital treatment did not relieve pain and other physical symptoms in the long run. Consequently, afflicted patients tended to give up complaining in due course. They viewed complaining as worthless because they would receive neither 'proper medicines' nor sympathy from their caregivers. They perceived some limits to complaining and expressing suffering. Some respondents indicated that this turned out to be emotionally frustrating. One of the patients I talked to commented:

... when they came another time they asked if anyone of us was feeling pain. I was one of those who said "yes I feel pain". Then another patient also said yes. The physician then

asked “what medicines are you using?” I said I was using Bruffen. I told them that this medicine was not helping me ... So if there was any other medicine ... ‘Hey!’ The person, a man, was enraged. I was surprised. He said, ‘Oh! I know where you come from ... You believe that you can direct the doctors on how to treat you ...’ But why did he ask me? He could have just kept quiet. I just wanted him to give me an alternative medicine. When I go to the clinic the doctor asks, ‘What medicine are you using?’ He asks so that he does not repeat giving medicines that are not helping me. Why is it then a mistake to do the same in the ward? ... I told him, ‘Now my friend, I came here alone ... I am not representing my ethnic community.’ Then he became furious again. Since he is the doctor, I kept quiet ... (Mr. Kassi)

Some ward staff occasionally referred to cultural stereotypes regarding issues in patients’ compliance. This implied attempts to evaluate patients’ reactions to distress and treatment in terms of perceived ethnic tendencies. There was a general claim that patients from certain Kenyan communities believed that medicines through injection relieved their pain better than oral drugs. Pain relief in the cancer ward was restricted to a few common analgesics. These included mainly ibuprofen (anti-inflammatory), Panadol, paracetamol, and aspirin. Most of the simple analgesics were accessible to patients in regular markets; therefore many expected that since they were in a national hospital they would get ‘better’ or ‘stronger medicines.’ They felt discouraged when the hospital seemed to give them the ‘normal’ or ‘familiar medicines.’ This included the medicines which they said they could easily access in shops, private pharmacies and kiosks to relieve mild pain without a doctor’s prescription. They believed that such analgesics and over-the-counter medicines were not effective for pain relief.

Doctors recommended morphine for some patients. The drug, which is the main strong analgesic available for cancer pain management in Kenya, was accessible to cancer in-patients through the Nairobi hospice, which is within walking distance from the cancer ward. Nurses informed patients’ relatives of the prescription and asked them to purchase the morphine from the hospice. Destitute patients rarely obtained this drug; indeed, a majority of cancer patients did not gain access to morphine. The ward physician sometimes recommended sedation as an alternative to managing insomnia or delirium due to persistent pain. Doctors’ and nurses’ responses generally pointed to their struggle to treat patients and provide care in spite of scarce resources. They also attempted to keep details about hospital treatment and care outcomes to themselves. For hospital workers, minimal disclosure about cancer and its treatment outcomes was part of their strategy to safeguard patients’ hope.

Disclosure

Experiences of unrelieved pain and suffering often contradicted the hope discourse in the ward as described in Chapter 3. Inadequate disclosure increased patients’ uncertainties and anxiety. Some patients were not aware of the nature of

their disease in spite of their lengthy course of treatment elsewhere and in the current hospital. Unconfirmed reports about cancer inside and outside the cancer ward exacerbated fear and the sense of hopelessness. Patients desired detailed information about cancer and related physical suffering. Episodes of pain evoked intense fear and speculation about the seriousness and threat of the disease. This was particularly worrying for patients who were struggling to understand how and why they contracted cancer. The lack of information about the probability of curing the disease worsened anxiety among patients and their relatives. For a long time, they had only vague information about cancer and its treatment, as the remarks below show.

I did not know anything about my illness when I started treatment. I had never experienced radiotherapy. As a patient I just had to accept what I was being given. I later realised that I was getting weaker and I was in increasing pain. The doctor had told me in advance that it would be fine. I never got well. Then I realised that I was in a cancer ward. The best thing doctors can do is to disclose everything. A patient will then come to understand what this is ... There is nothing you can hide when the body is sick. After all, in some days to come, a patient will be in that condition of pain and weakness ... I think doctors fear that they will disturb a patient. They fear that patients will commit suicide if they know the truth. They think that the patient will commit suicide ... Yes, some people will commit suicide because they fear the disease. Other people think that cancer means the end of life. (Mr. Chepia)

The severity of cancer became apparent to many patients with time. They dreaded the possibly irreversible interruption of normal life. Cancer pain appeared gradually to defy available hospital treatment. Several respondents described the pain as a trail of destruction within the body that rendered living worthless. Suicidal thoughts represented the onset of disappointment and dissatisfaction with available treatment. Ms. Marina also contemplated suicide, and said she had already bought poison. Increasing pain, hopelessness, the loss of her job, and the apparent pact of secrecy regarding her illness between medical staff and her relatives contributed to her resentment of further treatment. Family members often acted as gate keepers of information, and nurses and doctors considered it a normal practice to disclose 'bad news' to family members before informing the patients. However, as Mrs. Ndunduri's son once observed, not all relatives were privy to the 'guarded secret' of cancer diagnosis and the likely hospital treatment outcomes. To some patients, hospital workers' responses to their plights were not only superficial but also blocked them from the truth. While it is true that they longed for sympathy and emotional support in the face of pain and eating difficulties, they also wanted more information about cancer and its treatment outcomes. Pain increased the fear of other physical symptoms of cancer treatment. Patients' narratives pointed to the perception that they could endure such cancer treatment side effects as nausea, vomiting, body weakness, fatigue, and loss of hair, but that pain eroded their will to endure these effects in order to complete the hospital course of treatment. Frequent bouts of pain with

varying levels of intensity alerted them to the reality of cancer as a threat to life. They felt that the medical staff concealed this fact from them. Similarly, many patients believed that the hospital staff were colluding with some of their family members to hide the truth about their conditions from them.

Chronic pain increased feelings of isolation and anxiety about incapacitation and death. Afflicted patients sought hospital chaplains and other religious workers for sacraments of the sick and prayers in presence of some family members. Pain triggered worry about ill-timed death, especially when patients felt that they had not prepared their families adequately. Due to unrelieved pain, several patients wished to give instructions to their children, just in case persistent pains indeed portended death. Mr. Kassi told me:

... it was hurting me so much and my children had come to see me. I told them frankly about my suffering and pain. I told them that it would be by the grace of God that I would be there (live) or die. I told them: 'you must be humble ... I have four brothers ... You can see they are helping me. One brings me medicine in the hospital and the others bring food ... they brought me to hospital ... They will educate you if you will be humble. If you are rude, they will not waste time on you because they also have their own children. I am telling you this so that you know because I am in pain. I am ailing and if die I will not be the first one. Everyone goes (dies) at his or her own time. Life is like a public transport vehicle. It goes as people alight. One alights after two miles, the other one goes even up to Nairobi before alighting. Nevertheless, he or she alights ... If God planned that, I will alight in my 60s, no problem ... (Mr. Kassi)

Experiences of pain, uncertainty about living, impaired food intake and loss of weight were concomitant. Some patients recounted how they amazed many people by remaining alive in spite of their suffering and dramatic loss of weight. Bouts of pain triggered anxiety about the welfare of family members and especially children. Pain also evoked feelings of the urgency for confession, reconciliation with kin and giving final instructions to family members. The rate and levels of despair varied among sufferers. Persistent pain and eating problems preceded the expression of individual agency, resistance and surrender. Patients' perceptions of inadequate disclosures about cancer treatment and available medical care shaped apparent or subtle acts of resistance and dissatisfaction with hospitalisation.

Resistance

It was common for nurses to blame the patients for "refusing" to do as they instructed. Nurses and other hospital staff often referred to cases of "refusal to comply" to remind other patients of their responsibility for recovery. They scolded patients for refusing to eat or take medicines. Food, medicine and attempts of hospital workers to help suffering patients elicited emotions on the part of both the sufferers and the caregivers. Pain management and issues about food

were therefore potential triggers of conflict between cancer in-patients and hospital workers.

'Refusing to eat'

A food server announced the arrival of food loudly at meal times. She or he mentioned the type of food available. The server then asked patients to say if they wanted to eat or felt like eating. Some declined to take food. Only a few who took the food finished eating their portions, if they attempted eating at all. The server returned after about one hour to collect the plates and other utensils for washing. Shift nurses recorded how well patients ate and who among them did not eat at all. They reported the patients who refused to eat to the physicians through the matron or a senior nurse. Affected patients described this as being unduly treated as children, a practice they hated. Nutritionists organised some counselling sessions on cancer management and diet with randomly selected in-patients. Ways of coping with the effects of treatment on eating was an important part of the counselling sessions (see Appendix 4). In addition, the ward nutritionist occasionally advised patients in each room of the ward about the value of proper eating habits for their recovery.

Doctors and nurses reminded patients of the importance of eating well, which would help them to endure weakening effects of treatment, particularly chemotherapy. During ward round procedures doctors and pharmacists focused attention on pain relief and other treatment. Nutritionists and nurses on the other hand emphasised patients' eating patterns and compliance with ward treatment and care procedures. The nutritionist often attributed the supposedly successfully treatment cases to patients' and their relatives' cooperation in ensuring proper eating and dietary habits. The case of Mr. Misaka Masseyi as shown in Chapter 1 was considered exemplary before his death. Apart from the patients for whom the doctor recommended intravenous feeding, the ward staff expected that others would try to eat on their own as much as possible. Nurses and other ward staff expected this to happen in spite of apparent or less explicit constraints to patients' ability to eat.

Nurses viewed patients who did not eat as attempting to 'refuse hospital food and care'. Such patients seemed to reject food served in the ward with or without sufficient personal reasons. While the ward staff recognised many objective constraints to cancer patients' food intake, they also expected a patient to 'make some effort to eat.' The shortage of staff implied that patients could only rely on visiting friends and relatives for emotional and physical support during meal times. Weak patients had little support from nurses from which to benefit at meal times. Some staff blamed patients for 'finding reasons to avoid the food served in the ward.' On some occasions doctors or the nursing team dismissed patients'

reports of eating problems as a ‘phenomenon of the mind’ and hence not real. The ward personnel frequently stressed to patients their personal responsibility for their own well-being, which the personnel linked to eating habits. A nutritionist’s daily rounds and interactions with patients further emphasised this connection, and represented another attempt to persuade patients to eat, as the extract below illustrates.

A nutritionist comes in to the women’s Room 1 to distribute fresh milk. She gives a patient a packet of buttermilk and asks others if they would like to have some milk. None of them wanted the milk. The nutritionist then talks to them about dietary requirements. She complains that patients “refuse to eat’ the food she advises them to eat, perhaps because they are not aware of the effects of treatment. She says (partly addressing me), ‘they seem not to have been told thisWhen you are being treated for cancer, you might lose your hair, vomit, lose your appetite, have diarrhoea, feel nausea ... but this is not because of the food we give you. It is because of the treatment. Even if you vomit or have diarrhoea, you might lose only half of what you eat. You do not have to fear eating because of these side effects ... You know that diarrhoea is also good because it cleans the body. That is why, in hospitals abroad, doctors give patients medicines that induce diarrhoea.’” (Field notes)

Refusing treatment and care

Increasing disillusion about the significance of being in hospital affected patients’ cooperation in various ways. Some gradually gave up on their attempts to report about their experiences in detail. They perceived delays in responses to their calls for help as an indication of lack of sympathy among the hospital carers. The calling system in the ward was out of order. Shouting to call nurses or sending messengers to them was both strenuous and discouraging. This contributed to delays in nurses’ responses to patients’ calls. Sometimes they did not get help at all due to the scarcity of hospital resources, as mentioned earlier. Long-term in-patients adjusted to this situation by limiting their interaction with hospital workers. For example, they would deny feeling any pain during ward rounds, yet they expressed it by crying or groaning before or after the round. Some frustrated patients attempted to cover up their irritability and resentment of treatment in order to safeguard therapeutic relationships. A few long-stay patients and those who were relatively better off socially could easily overcome the fear of antagonising hospital carers.

Some patients gradually gathered the audacity to argue with hospital staff as a reaction to distress. These arguments also served as an explicit expression of resistance to treatment and other forms of care some patients considered inappropriate. They attempted to point out faults in the hospital treatment and care. As noted in Chapter 3, several patients tried to find fault in the treatment of fellow patients in order to report it to their relatives. However, the level of emotional disturbance that patients suffered shaped their expression of resistance. Mrs Pakot, for instance, declined to take the painkillers a nurse gave her, saying she

had problems with Brufen and Paracetamol because ‘they increased her blood pressure and heart pulse rate.’ She argued that she had used the medicines at home and had a problem with her blood pressure. Mrs. Pakot told the nurse that ‘her doctor’ had advised her never to use Brufen or Paracetamol while she still took Tamoxifen. She insisted that ‘her doctor’ had recommended she should not use the painkillers even if another doctor prescribed them. After an argument, the nurse dejectedly advised Mrs. Pakot to trust the medicines recommended by the doctor in the ward ‘if she needed to get well.’

Mrs. Pakot and other patients ingeniously avoided taking medicines that particular staff supplied. They hid the medicines and threw them away secretly when they felt that they did not trust the hospital staff who prescribed them. Similarly, some patients resisted taking painkillers that they believed either were not effective or hurt and caused more pain. Mrs. Ndunduri, for example, resisted taking any more medicines despite her frequent episodes of delirium and groaning that nurses attributed to pain. She was among the patients whom doctor Wario wished to discharge in order to avoid ‘fighting with them,’ as noted in Chapter 4. During treatment and ward round procedures, nurses accused Mrs. Ndunduri of hiding medicines in her blankets. Fellow patients and nurses said that she was responsible for her condition because she shirked medication and ‘refused to be helped.’ In a conversation with her, she once told me:

Then they saw that disease and they gave me medicine. They told me “this disease of yours is defeating the doctor ...” I told that doctor, you are a big doctor. Tell me the things you must tell me ... If you see it is the (deadly) disease ... and that I will die, just tell me. I will go home to die! I am waiting for nothing here! Yes ... if you are helping me, you should know what you are doing ... If you know I will recover tell me ... I will stay well ... I will pray ... (Mrs. Ndunduri)

Several patients attributed their worsening experience of pain to either chemotherapy or the oral medicines. They speculated that many patients suffered desperately due to toxic treatment or painful oral medicines. They felt obliged to discontinue using medicines that either hurt or increased suffering. Mounting disillusion led them to gradually question, doubt and resist hospital treatment and care. They drew on their subjective experiences and non-professional knowledge as they attempted to fill gaps they perceived in the explanations and management of their condition.

Patient inputs

Patients’ inputs encompassed personal initiatives to understand the aetiologies of their ailment and find alternative remedies.

Patient-centred aetiologies

Suffering patients always sought new information, care and support that could supplement hospital treatment. Past daily experiences and indigenous ideas of disease aetiology were handy for patients who perceived gaps in current medical explanations. Non-professional ideas about origins of suffering were the basis for patients and their relatives' attempts to complement hospital care. Patient-centred aetiologies compensated for the psychologically uncomfortable effects of inadequate disclosures about cancer. Medical personnel either obscured or withheld full explanations of causes and treatment outcomes of cancer from patients. Unbearable pain, eating problems, and other physical symptoms of health deterioration triggered a sense of urgency for more knowledge about the disease. Nurses or doctors offered only brief information about the nature and management of physical symptoms including the severe ones; that is, pain and food intake inabilities. As an example, a physician would sum up an explanation for pain and eating difficulties as simply 'the effect of disease and its treatment.' Such short answers often left patients in suspense, expecting more details to emerge and contribute to the understanding and meaning of their illness.

Patients' narratives gave extra clues about their experiences that were not documented in their medical records. They explored many probable origins of their suffering. Many feared that their problem could have been hereditary, contrary to what the social and medical histories in their files indicated. The nature of the disease and its outcome nevertheless remained obscure to many patients during a significant part of their hospital treatment periods. Unremitting pain, eating problems and other physical symptoms further complicated the mystery, and contradicted patients' expectations that the national hospital would finally offer precise definitions of causes of their physical symptoms and offer effective treatment. Admission to the cancer ward did not seem to end the uncertainty about the aetiologies of the disease and treatment. One respondent commented:

They were treating me for tuberculosis, malaria and other illnesses for a very long time. Another doctor had said that it was *Mungai* (mumps) ... This causes the swelling in the neck and glands under the cheeks. I tried treatment for *Mungai* for a long time ... My expectation now is that by the time I finish the sixth course of chemotherapy I will be quite well. However, it seems that the tumour is not disappearing. It has gone down a lot though. I am happy for that because now I can eat comfortably ... I can enjoy life and I can even laugh ... I am able to lead a normal life ... It is just sad that the tumour has not disappeared completely as I expected. I thought that I would have recovered by the time I finished the chemo. It seems that this is not the case even as I end this sixth course... It seems the fight is not yet over. We still have to fight. (Mr. Hassan)

Patients and their relatives did not rule out non-scientific illness aetiologies. A female patient of cancer of the tongue, for instance, believed that she was suffering the consequences of a quarrel she had had with an elderly neighbour. This was one instance where patients believed that their current suffering resulted

from curses. Such aetiological ideas facilitated patients' psychological adjustment to the difficulty in understanding cancer and its treatment. Prolonged hospitalisations and encounters with medical personnel did not resolve the mystery about causes of cancer. Protracted treatment and the increased suffering it entailed created more uncertainty and emotional distress. Subjective patient-centred aetiologies resulted in discreetly resorting to alternative remedies that relatives and other visitors supplied to the in-patients.

Alternative medicines

Some patients used traditional and other therapies in the ward and at home, in between hospital treatment sessions. They drew on personal and indigenous perspectives on the aetiology of current suffering. A section of patients sought alternative medicine while in the hospital and after their discharge from the ward. Some critically ill patients perceived hospital admission as the climax of suffering, which they attributed to witchcraft, sorcery, or spiritual causes. Other respondents linked their present suffering to past daily life experiences, such as lifting heavy objects, falling while drunk, or disagreements where counterparts were hurt and used mystical powers in revenge. Subjective ideas about illness causality and insufficient understanding of cancer influenced patients' views about the efficacy of some medical procedures. Personal experiences of cancer and treatment at times seemed to contradict medical reports indicating health improvement and 'good response to treatment.'

Patients and their relatives were keen to separate the use of hospital medicines and other healthcare resources. This implied a dilemma for patients and family carers who believed that hospital medicine and other available treatments are complementary. They were often cautious not to use treatment resources they obtained outside the hospital openly. These included products from various licensed and informal dealers in modern and indigenous alternative medicine. Some patients and their relatives were familiar with and had access to patented alternative health care products, including packaged food supplements which some local marketers and patients usually mistook for medicine. One afternoon, a female patient accompanied by her daughter went to find out about packaged alternative remedies from the doctor. She was not sure if it would be necessary for her to continue using the "other medicines" in the ward. Doctors and nurses often cautioned patients against substituting chemotherapy or radiotherapy with food supplements or indigenous African medicines.

There were reports of patients who discontinued hospital treatment to try other medicines. They resorted to popular food supplements and indigenous African or Chinese medicines. Some of such patients returned to the hospital in worse condition. Cautious transactions in alternative remedies thrived in the study ward.

Dealers visited discreetly to sell alternative medicines and food supplements to patients and nurses alike. Although nurses and medical staff openly warned patients against the use traditional and other alternative medicines, they silently tolerated the practice. This caused further dilemmas for patients seeking relief from pain and other causes of physical suffering. A respondent confirmed such dilemma:

We even shared some with my friend here (fellow patient) yesterday. It was as if we were taking a stand. We said that if it is chemotherapy, we go for it and stick to it. If it is *mitishamba* (traditional medicine), we go for it fully. There is a woman ... I think she was together with my friend earlier in this ward. I think this is now her fourth course of treatment ... she had breast cancer. This woman was getting chemo and at night she would take some things and rub them on her breast (demonstrates) ... She would say, 'my mother said I should be applying this. ...' My friend's relatives had also asked her to do the same. They advised her that before she goes for radiotherapy, she should use *mitishamba*, then come back ... I think this spoils the treatment doctors are giving. (Ms. Souda)

A number of patients argued that any kind of alternative remedy was useful after hospitalisation; the time in between subsequent hospital admission was therefore appropriate for the application of alternative medicine. Chinese medicine and other forms of non-African alternative medicine available in the Kenyan market appeal to patients with life-threatening illnesses. Subjective ideas about cancer and personal experiences of treatment result in trials of multiple remedies in the hospital and at home. An important factor in the eclectic search for cures among cancer in-patients relates to their perception of unrelieved pain as an indication of the failure of hospital treatment. Similarly, they believed that current treatment had not identified ways of treating pain and illness that they attributed to past accidents, injuries, machinations of witches and other spiritual causes. These causes of pain and suffering, from the patients' perspective, defined the limitations of chemotherapy, and available hospital medicines. Therefore, patients who used alternative remedies in the ward concealed related activities to avoid reproach from the medical staff. A pharmacist complained that they occasionally could not be sure whether some of the patient's physical reactions resulted from the effects of biomedicine or the traditional medicine the patients used secretly.

Patient-centred aetiologies were the basis of their resort to alternative medicines, and resulted from desperation due to persistent pain and eating difficulties. These constituted indicators of gradual disruption of the daily rhythm of life, and also implied loss of control over one's own body and basic livelihood. The frustration patients experience in attempts to express their feelings partly account for their irritability and emotional vulnerability. Having lost personal autonomy due to chronic illness, intractable pain and eating difficulties, most of the patients seemed to regret the looming loss of the sense of life's inherent worth. This feeling shapes what nurses in the cancer ward described as patients' 'bitterness

and anger' which their suffering caused. Acts of patient resistance and their search for alternative explanations and medicines resulted from gradual disillusion about hospital treatment outcomes.

Summary and discussion

Pain and eating difficulties embodied the threat to a normal rhythm of life. Although health care professionals in the ward often asked patients about pain, they did not pursue the details. This left many patients dissatisfied and in an uneasy suspense. Physicians limited their questions to knowing about pain as a physical fact, but patients desired attention to this phenomenon as part of their total experience of suffering. While physical pain may be a particularly vivid and emotionally laden symptom, it can only be understood in a cultural context by seeing it as part of a wider spectrum of personal misfortune. This implies that pain, like illness in general, is only a special type of suffering (Helman 1990: 182). Eating difficulties, like pain, challenged cancer in-patients not only to seek sympathy, but also treatment and the meaning of their experience. Doctors and other carers in the cancer ward asked patients about pain in a rather hasty manner and offered only brief responses. This was part of their routine which patients likened to ordinary detached greetings. However, physicians did not have adequate time to deal comprehensively with patients' experiences of pain, food intake difficulties, and other worries.

Linguistic and cultural diversity among patients and hospital carers further complicated communication about pain and general distress. Culturally defined languages of distress influence how sufferers signal pain to others, and the types of reaction expected of them (Helman 1990). Differences in cultural origins and social classes between sufferers and their caregivers constrained communication about suffering. Patients and their carers may also have different expectations on how a person in pain should behave and how they should be treated. Health carers' responses may indicate their helplessness due to unavailability of appropriate pain relief drugs. Health professionals' unsatisfactory responses to patients' calls for help resulted from fatalistic attitude they acquired in the setting of scarce pain relief drugs. Kenya for instance, is among the low income countries that have failed to take relatively cost-neutral steps that are crucial to improving access to pain treatment and palliative care, such as adding oral morphine and other opioid-based medicines to their list of essential medicines or issuing guidelines on pain management for healthcare workers (cf. Human Rights Watch 2009: 24). Therefore, physicians' and nurses responses should be viewed as their way of coping with cancer pain in order to safeguard patients' confidence in hospital treatment. However, sufferers construed health professionals' casual responses to their experience of pain as an indicator of reluctance give appropri-

ate compassionate help. Patients called for attention mainly to receive medical treatment and compassionate responses. Many of them became too dependent on hospital carers as their pain and distress overwhelmed their endurance, and attempts at self-treatment using common analgesics such as aspirin failed. Hospital caregivers needed sufficient empathy to understand the patients' experience. This could be facilitated in some measure by the experience of hearing the sensual, effective and embodied narratives of the sufferers (cf Good 1994: 140). However, the hospital workload did not leave cancer ward staff with sufficient time to follow details of patients' suffering and empathise effectively. The fact that pain and suffering always resist objectification in language (Scarry 1985; Frank 2001; Emad 2003; Van der Geest 2007a) calls for more time and patience in attempts to help those who experience it. Communication about pain and suffering is difficult both for patients to express and for their caregivers and researchers to grasp. The cancer inpatients expressed pain and discomfort both verbally and non-verbally. Contrary to their expectations, they felt that not all hospital staff could offer caring responses to their plight. Patients' expression of pain and discomfort implies a social relationship with those around them (Helman 1990). Some patients believed that only fellow patients or people who have experienced similar suffering could provide more emotionally supportive relationships. They perceived hospital workers' delayed responses or failure to provide remedies as an indicator of their inability to grasp pertinent verbal and non-verbal expressions of pain and suffering. For the patients, the caregivers who responded relatively fast and provided some solutions and emotional support were acting in this manner because they were compassionate. In this sense, compassion was the substitute for personal experience of suffering that enabled some ward staff to perceive patients' distress and respond appropriately. Sufferers have particular expectations when they attempt to communicate distress, and especially pain (Lewis 1981). They often consider the likely responses and socio-psychological costs and benefits of revealing their pain. Cancer inpatients' decisions to express their illness and pain, as well as the manner, in which they communicated it, depended on two aspects. First, they considered the individual hospital worker's perceived potential for providing care. Second, they expected medical treatment and sympathy. The tendency of caregivers to hold patients responsible for their sickness contradicted the sufferers' expectations of care. This had negative implications for communication and therapeutic cooperation between the patients and hospital workers. The sufferer may feel isolated from other people when they perceive that no one empathises with them. This may worsen the experience of pain and illness as private phenomena that isolate the sufferer from the rest of the social world (cf. Murphy 1990).

The visibility of chronic pain and distress to other people gradually disappears, and this isolates patients further. This was particularly the case with prolonged and multiple hospitalisations. Sufferers in this condition try to find new ways of displaying their private pain and distress in public 'performance' (Brodwin 1992). The performance may communicate patients' despair in general, and dissatisfaction with available care and treatment. Such reactions included silence, withdrawal and withholding details of personal experiences from medical personnel. Rejection of medicines the patients perceived as either ineffective or increasing suffering also characterised their public expression of despair and disillusion. Pain and eating hardships worsened their anger, resentment and tendency to resist hospital care. While these responses may imply non-compliance to hospital treatment and care, as most cancer ward staff presumed, it may also be an expression of deep personal suffering. Since pain and physical distress are aspects of a wider range of human suffering, treatment through available drugs only may be partial and unsatisfying. Emotional and social support is therefore essential, as part of the effort to relieve suffering that seemed to reach its climax in the phenomena of pain and eating difficulties. Response to patients' expressions of suffering in this regard should take into account the social, moral and psychological elements associated with hospital treatment of cancer. Caregivers of cancer patients need also to bear in mind that moderate to severe pain has a profound impact on quality of life (Human Rights Watch 2009). Similarly, persistent pain has physical, psychological and social consequences. It can lead to reduced mobility and consequent loss of strength; compromise the immune system; interfere with a person's ability to eat, concentrate, sleep, or interact with others (Brennan *et al.* 2007). This worsens suffering from depression and anxiety for which most of the cancer in-patients require personal attention

Generalisations about patients' problems drew on common clinical knowledge. Some caregivers had stereotypes of patients' responses to suffering and treatment preferences. This contributed to ward staff's decisions occasionally to dismiss patients' complaints of pain and eating hardships as 'conditions in their minds'. Murphy (1990: 14) preferred to call this perspective 'psychosomatic aetiology.' He observed that this aetiology is handy when standard tests fail to reveal a somatic disorder. Hospital caregivers' tendency to attribute a complaint to a patient's mind therefore becomes one way of blaming the patient for suffering. This may antagonise patients and affect their communication and cooperation with caregivers. Bates *et al.* (1997: 1439-1444) report of patients who resisted suggestions for psychological counselling when they perceived that doctors attributed their suffering to their 'heads' (minds) rather than the actual sites where they were experiencing pain. Conversely, patients often seek empathy from their caregivers for mutual problem-solving. In view of this, Kleinman *et al.*

(1992) discourage healthcare givers from using 'ethnic stereotypes' in their attempts to understand how and why people respond to pain. Medical professionals instead need to understand and sympathise with the unique qualities of pain and distress affecting a particular person. Pain may be a universal human condition, but its definitions, descriptions, people's perceptions of it and its control may have culture-specific and idiosyncratic dimensions. Pain and its control should be viewed as inner and subjective experiences of the person who is in pain (Free 2002). Patients' caregivers should consider any form of expressed suffering as a unique personal story and assess it individually. This can facilitate more attention to personal fears, wishes and expectations that each patient comes with to the hospital.

The struggle with pain and other physical symptoms among patients in this study reflects a resource-poor context of cancer management. Meagre health care funding in Kenya is responsible for the shortage of cancer treatment drugs and analgesics. In addition, inadequate food supplies and nutritional programmes restrict the implementation of proper feeding of cancer in-patients. Lack of hospital resources constrained the provision of the recommended diet and adequate pain relief in the cancer ward. Similarly, patients did not receive adequate emotional and social support due to a shortage of staff. Shortage of hospital supplies and the high cost of analgesics for severe pain, especially morphine, hinder the efforts to relieve cancer pain in Kenya (Murray *et al.* 2003, Joranson 1993) and other developing countries (Koshy *et al.* 1998). A negligible proportion of the cancer in-patients in this study had access to morphine. Contrary to patients' expectations, admission to the cancer ward did not significantly reduce the perceived threat of the disease; instead, admission to the hospital and a subsequent stay in the cancer ward tended to increase pain and eating difficulties. Cancer therapies and the ward environment worsened patients' experiences of pain and eating difficulties.

Inadequate food intake is frequent among cancer patients. This reduces the chances of favourable treatment outcomes and survival. However, very few in-patients in this study received adequate information on diet and how to control the impacts of cancer treatment on their food intake. While patients may feel the need to discuss dietary issues with staff, they do not succeed in doing so (cf. Lassen *et al.* 2005). There was no system in place for patients to make complaints or give feedback to catering staff. The diversity of patients that the national hospital serves poses some problem in addressing patients' issues about culturally appropriate food and special diets. In such a large hospital, in-patients who require special diets may either be frequently forgotten or underserved (cf. Savage & Scott 2005: 29). Similarly, the lack of food variety was the biggest problem that cancer in-patients wished the hospital could resolve.

Food intake difficulties result from cancer and its treatment, as well as the hospital environment. While cancer may increase metabolic expenditure, which requires an increase in nutritional intake to maintain weight, the patient may feel less able to eat due to nausea, pain or obstruction of the gastro-intestinal tract (Coates 1985). Some types of cancer, such as throat cancer, and the treatment process in general also affect eating and food intake processes. This may worsen the experience of pain and inhibited food intake that characterise illness episodes in general. Iatrogenic malnutrition – that is, malnutrition as a consequence of hospital diet, hospital processes and shortcomings (cf. Savage and Scott 2005: 10) – contributed to rapid physical deterioration and rapid loss of weight. Various ward conditions constrained patients' ability to eat. Many of the patients' nutritional status apparently declined rapidly during their hospital stays. In this sense, most respondents wondered why patients who "were okay on admission" seemed to get weaker and wasted away as they continued to stay in the ward. Inadequate hospital resources and inpatients' poor socio-economic backgrounds also constrained the implementation of the nutritional care that the ward staff recommended. There was furthermore an inconsistency between the guidelines in the available information on nutrition and the actual food served in the ward. Lack of communication between the nurses and patients, or between members of the healthcare team also limited the chances for adequate nutritional care. In addition, poor quality hospital food, inflexibility in food service and lack of information about practical ways of improving food intake increased the risk of iatrogenic malnutrition (cf. Council of Europe 2002).

Cancer in-patients' resort to alternative aetiologies and remedies was the consequence of their increasing disillusion. When pain and other physical symptoms lead to intense suffering, biomedicine seems to offer little in the way of a conceptual challenge to patients' ideas about health and healing (cf. Vaughan 1991: 24). Specifically, the scientific explanations of the onset of cancer can only offer limited information about its precise causes. This partly accounts for the insufficient disclosure about cancer that characterises the encounter between patients and medical staff in most cultures, especially in non-western countries (Hunt 1998; Bennet 1999; Kaufert 1999). Patients' concurrent or sequential resort to alternative medicines in spite of hospitalisation should be viewed as an expression of their agency due to desperation. They may use 'performances' of pain and eating problems to express social and psychological problems linked to the experience. Helman (1990) observes that chronic pain and psychosocial and interpersonal tensions are often reciprocally linked. Therefore, patients' 'performances' may be a way of signalling extra personal distress, which hospital care did not address adequately. Expressions of pain and eating difficulties may also entail the desire for attention to and sympathy for other physical and psychosocial dis-

stress. Subjective experiences of unrelieved physical, social and psychological misfortune weakened patients' optimism about hospitalisation.

The ‘extra baggage’: Unmet psychosocial concerns

We do not spend a lot of time with the patients ... however, we try to listen to them because of their condition ... We do not have enough time with them. I have only seven minutes per patient. They are always looking for a place to empty their problems. They are looking for somebody to tell about their misery. They want someone who is ready listen to them. Patients have many problems that they bring along to the hospital. Some of the problems may be about their homes ... Perhaps things were not working well there. Due to this the patient may think that the world is too heavy to carry, and just needs somebody who can pay attention. We try to listen more than we talk to them. Our aim is to listen and find a way of giving some encouragement. (Intern Chaplain)

Patients attempted to express their concerns during doctors’ rounds and other procedures, but medical consultations on first admission and subsequent clinic reviews offered very little chance for expression of emotional and social anxieties. As doctors and nurses summarised the medical and social histories in patients’ files, their conversations with the patients were often very brief, as shown in Chapters 4 and 5. This was typical of communication during subsequent therapeutic interactions. Lack of time and pending responsibilities limited patient-health provider contact. Dr. Wario described some of the patients’ complaints and questions as ‘extra baggage.’ These were concerns that he and some of his colleagues viewed as not being part of their routine medical care responsibilities. Overlooking or preventing some of the patients’ complaints would therefore save time for medical procedures. Dr. Wario often reminded his colleagues or said when patients seemed to pester him that there was ‘no time for extra baggage.’ Hasty interviews and case summaries focussed mainly on pain, treatment and, on occasion, eating issues. Physicians and nurses alike asked, for instance, ‘Is there any pain? Is there any problem today?’ This questioning approach restricted

patients to responses about pain and outcomes of medical treatment. Medical staff and nurses sometimes reminded patients that their questions simply required either 'yes' or 'no' answers.

Frustration was visible on some complainants' faces due to unexpressed or inadequately addressed personal concerns. These related to emotional and social issues that affected their well-being and quality of life while in hospital. Insufficient human resources limited hospital worker's attention to patients' personal concerns. Besides, the patient care programme in the cancer ward apparently focused on clinical more than psychosocial issues. I describe the patients' emotional and social concerns during their hospitalisation in this chapter. The concerns emanated from personal experiences of physical deterioration, and delayed and inappropriate disclosure. Worries about social support, stigma and self-esteem made uncertainties worse. Moral ideas related to cancer as a life-threatening disease become apparent as patients seek consolation, social and emotional support. Personal experiences of physical symptoms and progression of disease shaped the in-patients' concerns as this chapter shows. Before describing the patients' perspectives on stigma, I illustrate their metaphors of physical vulnerability. Description of existential concerns follows in the last part of the chapter.

Disintegrating bodies

Chronic pain and multiple or long-term hospitalisations were ominous to most respondents. They described cancer and its treatment as the systematic destruction of their bodies. Various respondents likened cancer to an evil agent 'ripping the body from within'. Experiences of pain, body weakness, wounds and blisters symbolised the unpredictability of the outcome of the disease and the therapies designed to treat it. Mrs. Gatoro described the disease as ripping through her body sporadically. She, like several other respondents, complained of unpredictable pattern of pain and body exhaustion, which rendered both patients and the physicians helpless. Patients often used the imagery of 'slow body decay' to express their fears about this experience. They were uncertain about the manner and the potential pattern in which their illness would spread. Speculations about how the disease spreads to 'delicate' inoperable places, especially the heart and the brain, horrified many. Some described the perceived imminent bodily destruction in terms of the disease agent 'eating from within'.

... cancer is something that eats the bones. It can eat, just like a virus. (Mr. Ajwang)

The idea of a 'disease eating the body from within' shaped early anxiety about possible degeneration, incapacitation and death. Notions of being half-dead emerged from these perceptions of irreversible body disintegration. This contradicted the optimism that current hospital treatment could restore normal healthy

lives. The unpredictability of the disease seemed to challenge the confidence with which many patients came to the ward. The notion of 'being half-dead' was common and distressing. As noted in Chapter 2, some nurses also struggled to fend off the notion that they were 'nursing the dead.'

Being 'half-dead'

Hospital staff and patients alike viewed the cancer ward as a representation of extreme suffering. It had the highest number of deaths per week in the hospital. The sight of several patients who seemed on the brink of death was worrisome. Contrary to popular expectation, some apparently hopeless cases lived on. This experience made some respondents consider their illnesses comparatively less severe. Mr. Ader for instance said:

... this is a place for very sick people ... They are not silent, but moaning all the time. They need a lot of care ... The one who was on this bed has left me (died). He had a wound but did not feel pain. He could not speak, as if he was already dead. When you come to this hospital, you realise you are not the worst. You say 'mine is not very serious.' But you wonder how much time you have before the 'final death'. This makes me feel like going back home on my stretcher.

Mr. Ader had a deep wound in his thigh. He said that all his fingers could fit in the 'hole,' or in the wound. Body weakness, chronic wounds and unrelieved pain reflected the fate of others who had died. Mr. Ader's reference to 'final death' reflected other patients' uncertainty and the notions of the transitory nature of life in the ward. Abrupt deaths also instilled a sense of hopelessness. The apparent misery of fellow patients contributed to more anxieties about inevitable physical deterioration and death. Most of the patients felt that the quality of their care and treatment decreased with their length of stay in the ward or frequency of hospitalisation. They argued that newer patients received more attention. Such patients appeared healthier, and long-stay patients viewed them as receiving more medical attention.

Symptoms of chronic illness and negative treatment outcomes aggravated worries about survival. Sufferers therefore perceived the ward as a place for the gradual transition from vitality to disability and the end of life. The ward embodied imminent exclusion from active social lives. Nurses expressed worries about patients' gradual degeneration and emotional dissatisfaction issues. They strived to address patients' need for physical comfort and psychological reassurance, and struggled to provide intensive, person-centred care in spite of their demanding workloads. 'Preservation of the body' became a central theme and concern in the nurses' view of caring for cancer patients. Satisfaction in their work implied keeping cancer patients' bodies in good condition even if they would not pull through. Nurses' construction of successful cancer in-patient care tended to

include notions about the good condition of patients' bodies when leaving the ward at the end of each hospitalisation session. One nurse remarked:

This is a 'total-nursing' ward. We struggle with this because we know many of our patients are terminally ill. Some are not even able to turn when they are sleeping or lying in their beds ... We try to make sure that their skin and bodies are intact. Even if a patient dies, the skin and body need to be intact, without bedsores and bad wounds. We are happy if we achieve this. (Ms. Jenifer, senior enrolled nurse)

Some patients also worried about how their bodies would look when they died, making on occasion apprehensive comments about the conditions of the deceased. They had impressions about the way bodies deteriorate at the terminal stage of cancer illness. Some occasionally caught a glimpse of bodies awaiting transportation from the 'private room'. This heightened their concerns about death and the possible image of their own bodies at the end of treatment. Concerns about the body had three dimensions. First, radical treatment caused indelible scars and drastic alteration to or loss of some body parts. These images of the outcome of cancer and its treatment were indexical of therapy and future ordeals to endure. Second, nursing chronic wounds and sores was distressing, involving pain and fear of possible spread of the wounds. Nurses and patients alike had to endure odours from wounds and unhygienic conditions associated with cancer illness. This also threatened the social interaction that is crucial for cancer patients' emotional support. Thirdly, therapy side effects altered body images and affected individual identity and self-esteem as shown later in the description of patients' experiences of stigma. The fear of the effect of treatment on the body drove resistance to initial surgical operations and subsequent therapies. As an example, a woman who was adjusting to the new identity of a leg-amputee remarked:

Doctors decided that the leg needed an operation. They told me that they had to remove it. I was very afraid and I refused. After one month, they interviewed me again. Professor Ondeng told me, "Just accept this ... If they do not remove the leg, you will have only a month or two more to live ..." Am I not half-dead now? They removed the whole of leg. Am I not half-dead? No one reaches out to me. They have forgotten me because part of my body is already in the grave ... That is very painful ... (Mrs. Vyakawa)

Limb amputees and victims of breast mastectomies were anxious about interrupted physical and social functions, and attributed perceived discrimination and neglect to their new physical disabilities. They talked about the trauma of amputation, mastectomy or skin grafting. According to some patients, loss of body parts implied higher possibility of permanent loss of normal functioning. They struggled to overcome anxiety about the ominous idiom of 'being half-dead' which they used to describe people with some body parts cut off. In local Kenyan culture, indigenous beliefs portray the removal of a body part due to an accident or disease as an early phase of death. 'Burial' of a part of the body marks the

beginning of life as an incomplete physical and social being. Reduced social interaction, as in the case of Mrs. Vyakawa, could symbolise a process in which living people forget the deceased. The loss of body parts thus meant a major disruption: the loss of physical health and social life. This implied a new set of uncomfortable labels for cancer in-patients: being ‘half-dead’ and ‘an incomplete person’. In this regard, a nurse testified:

... people feel that someone is no longer a woman after a mastectomy. There have been many reports that men (husbands) have run away from our patients. They no longer count a breast cancer patient as a woman because she does not have a breast. Many women get so emotional. When she arrives, you may not be looking in her direction, but she just feels you are looking at her breast. Many have walked in and said, “You know I don’t have a breast. I know that is what you are looking for!” The disease affects such women psychologically and disfigures them. They lose shape. They do not count themselves as human beings or ‘total women’. (Mrs. Jumatano, Senior Registered oncology Nurse)

Severe physical treatment side effects caused low self-esteem. Patients were sensitive to the attention they attracted due to their physical changes. This caused discomfort as it attracted what many considered observers’ undue curiosity about them. The altered physical images also implied a perceived decline of social worth and a new phase of psychological suffering. A delirious woman astonished everyone in the ward when she asked to stay in the (private) room for the deceased. She instructed nurses to inform her relatives that she ‘was dead’. She had complained that her relatives were no longer visiting her because they no longer regarded her as fully human. She argued that her relatives had abandoned her as if they knew she was already dead.

The imagery of partial death also applied to the actual or suspected threats that cancer and hospitalisation presented to marital sustainability. Some single mothers linked difficulties in their marriages to their current illnesses and prolonged hospital treatment. The incomprehensible origins of the disease, especially cervical cancer, caused moral suspicions between spouses. Patients and kin acknowledged social responses to cancer that threatened marriages. Mrs. Pakot, for instance, had been managing breast cancer for over four years. Her husband said that he was resisting pressure from kin and social groups to marry another wife. Interrupted sexual life and patients’ absence from home threatened their family and social lives. Another patient observed:

... even staying with my wife is now difficult (*kuishi na mke inakuwa balaa*) ... I cannot relate to my wife sexually (*siwezi kufanya kizazi na mke wangu*) because ... my body is spoilt up to the spine. I do not have the strength. Since I have come to Nairobi, my children do not see me, yet they are still small ... my wife understands. She knows that I will be well ... we pray to God that I get well again. (Mr. Tarus)

Hospitalisation of cancer patients meant confronting both physical and social disruptions. Patients needed empathetic support in order to deal with the physical and emotional suffering their conditions brought about, as shown in Chapter 5.

Similarly, many patients craved disclosure about their disease and treatment outcomes. As shown in Chapter 5, many patients' low awareness (or even total unawareness) of cancer and the possible outcomes of hospital treatment ultimately proved to be a source of great frustration for them. Severe physical symptoms, however, warned them that death was a possible outcome in the struggle with the disease. Patients perceived the hospital workers' (sometimes incomplete) attempts at disclosure to be both insensitive and unempathetic. This apparently further strained the quest to forge emotional relationships between patients and their hospital carers. Confirmation of the danger of cancer to life, regardless of the details of disclosure, required empathy as a mechanism to facilitate patients' emotional adjustment and support. Mounting fear, anxiety and emotional distress resulted from non-disclosure, which was then made worse by what patients viewed as the hospital staff's unempathic approach of highlighting the reality of the disease and potentially physically devastating or even fatal treatment processes.

Fear and information flow

Increasing fear

Information from fellow patients and non-professionals underpinned speculation about the fatal outcomes of cancer. Long treatment trajectories in clinical settings did not guarantee sufficient awareness of the disease, as noted in Chapter 5. Therefore, mounting fear and anxiety characterised patients' attitudes about their types of cancer and the possible outcomes of treatment programs. They clung to the hope that their condition would not turn out to be fatal as it had been for others whom they had observed in the ward. Some got some clues from their medical records or during subsequent stays in the ward that they indeed had cancer. They singled out words such as 'cancerous cells', or 'tumours' as suggestive of the 'guarded information'. They believed that medical staff deliberately denied them information, assuming it was because their cases were desperate. In this sense, experiencing fellow patients' gradual debilitation and death increased their fear of death. Discussions about cancer were nonetheless inevitable during ward procedures, and some patients overheard them. This increased patients' worries and distress, particularly with regard to the unknown reasons why the medical staff seemed to withhold the truth. Some respondents seemed unaware of their fate despite a relatively long stay in the cancer ward. One respondent made frantic efforts to explain that he was not suffering from cancer during my conversation to him. I had asked him directly to tell me about his experience with cancer management, not knowing that he was not aware that he had the disease. He said:

... but I think this is not cancer ... I do not think this ward (room) is for people with cancer. This is for people who need radiotherapy (*kuchomwa*, 'burning'). Even this one over here and that other patient have come for radiotherapy. I think people with cancer are in the other ward (room). These ones here need radiation on the leg, hand and so on. I think this ward is not for cancer patients. Nurses have taken me to that other side, but then they told me, 'You are not for the other side.' They brought me back here. The ones who have cancer are apart. (Mr. Memba)

While some patients were not ignorant about having cancer as such, they expressed intense fear of the disease. The medical staff contributed to this fear by couching information about the disease in an aura of mystery and concealment. Open discussions about cancer did take place among staff during hospital procedures, often directly in front of patients, but the patients were never directly involved in conversations and discussions in which explicit references to cancer were made. At the end of a conversation among themselves, hospital personnel would simply inform patients of either the decision to continue treatment or a projected time for discharge, both in general terms. Patients, however, were concerned about the physicians' perceived lack of interest in clarifying the issues that disturbed them; they expected physicians and other therapists to address their concerns conclusively. Physicians and nurses instead withheld information or gave it in bits to safeguard the patients' hope. Nurses, on the other hand, tended to deny patients information in order avoid antagonising the medical staff.

... (W)e fear taking the blame for telling patients about their conditions. We also fear the patients' emotional reactions ... If you tell someone, 'you have cancer,' you do not know how the patient will react. If the doctor has not told the patient at the clinic what she or he is suffering from, we do not tell them. We fear that this might cause us problems if the patient reacts badly ... they may abandon treatment and kill themselves. (Ms. Salma, Enrolled Community Health Nurse)

The ward staff desired to safeguard patients' hope and therapeutic cooperation through limited disclosure. Some said that disclosure of bad news would negate treatment efforts. They relied on patients' hope for a cure to keep them on the treatment course. They were anxious that patients might have extreme reactions to bad news, and especially that they might contemplate suicide. However, the more patients felt marginalised from the flow of information by hospital staff and kin, the more they felt uncertain about hospitalisation. They were, however, cautious about asking many questions and expressing negative emotions. This precaution related to the concern about maintaining good relationships with medical staff to ensure better treatment. Some patients feared asking about their condition because this would further threaten their well being, as the extract below indicates.

People are afraid to talk ... They think, 'if I say or ask anything, this person (the doctor) can even kill me!' If I speak about you and you are the doctor, you may not treat me ... Everybody would be thinking like that. Somebody can give you some trial medicine and kill you. You see you will have diverged from a healing path to that of death ... This causes a lot of

harm because nobody is telling the truth ... You cannot tell the truth! You cannot ask to know. If you tell the truth, you will die! (Mr. Ader)

Fear increased patients' dependence on the whims of medical communication and decisions. They perceived a risk in cancer and its therapies on the one hand, and a risk in antagonising hospital staff on the other. They tried to avoid reactions that would upset their carers and further endanger their lives. They feared that their carers would withdraw favourable treatment, so they tried to suppress negative emotions. To some patients, asking too much questions would amount to challenging the credibility of their carers. Physicians' and nurses' used rhetorical questions to subdue patients when they were seen as delaying their work by being too inquisitive. The typical questions were: 'Do you want to treat yourself?' and 'Did you come here to treat yourself?' They described some patients as 'thinking that they know more than the people treating them.' This practice and the attitude behind it, reinforced in-patients' apparent inclination to keep their emotions pent-up. Conversely, these experiences also fuelled patients' quests for compassion and support during their treatment and information-seeking attempts.

Unempathetic revelations

The doctor came in and said they would cut off my leg. I was shocked. I took courage and my father supported me. That doctor told me bluntly, 'You have cancer and we will cut your leg from here ...' She looked at the papers and told me, 'we shall cut your leg here ...' She did not bother how I felt. I asked her what she meant and she said, 'I am serious!' Even as I went to the operation theatre, I thought she was joking. When I woke up I realised she had been serious. I found my leg was gone ... (Mr. Ajwang)

Patients carried memories of the traumatic beginnings of their treatment trajectories with them to the cancer ward. Some respondents talked about disclosures of diagnosis and treatment plans that had been inconsiderate of their emotions. As discussed in Chapter 3, some respondents felt that medical personnel treated them 'carelessly'. Another respondent observed:

... (I)t was a minor operation ... He (the doctor) frowned and called my name. He asked my age and if I had any children ... I think this caught him by surprise. He said, 'I think you have a ... a rotten cervix.' I asked, 'What?' Then he realised that it was not the right way to tell me ... He told me to rule out the issue of the coil ... It was not what was causing my bleeding. He said it was something more serious ... But he reassured me that whatever it was, they were going to deal with it. 'Do not be scared ... Just relax, and wait for the results,' he said. I started praying hard to God to let me accept the outcome. I remember how the doctor frowned and I could see it was something very serious ... After three weeks; the doctor hesitated to give me the results ... Finally, he said: 'Unfortunately, Souda, you have cancer of the cervix ...' I wanted to scream but I went blank. He had dropped a bombshell. I gathered some courage and I asked him, 'What next?' Then he opened up and started telling me how I was supposed to start treatment. He told me that fortunately it was still at an early stage ... It was still at 'II B'. He said they would take me for surgery. He said, 'We are going to remove the whole uterus and you will be okay ...'. (Ms. Souda)

Anxiety revolved around unclear details regarding diagnosis and projections of treatment outcomes. Patients noticed the severity of their illnesses only after subsequent operations or courses of treatment. Ms. Stella and Mrs. Kadri described how physicians had informed them of the diagnosis of breast cancer and mastectomy “as a joke”. Initial experiences of diagnosis and treatment featured the difficulties of emotional adjustment. Unresolved trauma and inadequate preparation for daily life with cancer were apparent in patients’ narratives. Some were struggling to adjust to conditions that necessitated the use of crutches, artificial legs and wheelchairs. Mrs. Vyakawa fell twice in the bathroom and injured her pelvis while she was manoeuvring herself using cumbersome wooden crutches. Patients with similar difficulties moving needed occupational therapy and physiotherapy services, which were not available to them. Inadequate preparation for treatment and its consequences for daily life reflect the problem of partial or non-disclosure of fundamental information. In this sense, cancer patients experienced hospitalisation and associated hardships as part of a wider spectrum of misfortune unfolding in their lives, as noted in Chapter 5. They struggled with intertwined social and medical concerns that arose gradually in the course of their daily lives in the cancer ward.

Unfolding misfortune

Many patients construed current hospitalisation experiences as a climax of an array of misfortunes in their lives; however, their files contained scant information on their social and medical histories. These interwoven dimensions of experience featured in informal conversations I had with them during this study. They wanted to pursue and address issues in their social and medical histories that had affected their well-being.

Social history

Medical social status forms provided a summary of personal data. These included information on employment, family history and livelihood. There were notes on each patient’s general appearance on admission, indicating whether the patients were ‘well groomed’ and what the relationship was between them and the accompanying person. There were also comments on the mode of transport they had taken to the hospital, and particulars about the people responsible for paying the hospital bills. The hospital intended the medical social status assessment form to be used to facilitate debt control and contacts for patient support. The forms contained important clues about the social contexts of patients’ health adversities, yet the health carers rarely examined them. Details that could inform practitioners about issues related to personal quality of life were either insufficient or recorded superficially.

Destitution and instability of social support were apparent in the frequency of patients' visitors. The quality of supportive activities varied with the patients' social status and abilities to forge new relationships in the ward. Some patients desired emotional and material support through available hospital resources more than others did. An array of social issues influenced their well-being, including the quality of family relations; when family relations became poor in quality, the patient's anticipated support was threatened. Exhaustion of support caused anxiety even where relations were stable, as further explained in Chapter 7. Frequent hospitalisations reduced the supportive strength of existing social networks.

Economic hardships that were common to the patients, their families and social networks shaped the support they received. Distance of relatives and friends from the hospital further affected in-patient support. Ward assistants, nurses, visitors, religious officials, and fellow patients were handy as extra sources of social support. According to most respondents, hospitalisation reminded patients about the significance of associations of mutuality. Daily life in the ward facilitated a revitalisation of reciprocity values. Extreme suffering and associated anxiety in the hospital strengthened the desire to establish new social relationships and maintain those that were already in place. In relation to this idea a respondent observed:

... When I saw an ill person before I became sick, I thought illness was a personal problem. Now I have discovered that it is everybody's problem. It can be everybody's problem. We have to take care of those who are suffering. A few people say that this disease is my own burden. They say perhaps I wronged someone and the person went to a sorcerer to punish me. However, many people say that this is a problem for all of us, and I deserve their support. (Mr. Tarus)

Social support for cancer patients dwindles as treatment progresses. Length of stay in the ward and frequency of hospitalisation influenced social support as depicted in the number and frequency of inpatients' visitors. However, some patients suspected that people could be reluctant to support them in hospital and at home as they struggled with cancer management. They supposed that community attitudes about who deserves support during their suffering determined the social support in-patients received; in other words, they felt the community believed that some people deserved support in times of misfortune, while others did not. In this sense, there were sufferers whom community members held responsible for their own predicaments, thereby hesitating to support to them. The ability to demonstrate innocence in spite of current adversity guaranteed more unconditional support; the struggle to fend off stigma was therefore part of cancer patients' efforts to solicit social support, as illustrated later. Similarly, patients were concerned that prolonged illness would exclude them from any

support based on ideas of reciprocity. A single mother of three teenage children observed:

... I have learnt something ... This is my first experience with prolonged illness and hospitalisation. I have learnt that a person who is not ill cannot know how people are suffering. It is only once you fall ill you know who your friends are. You know who your closest friends are when you are weak ... I knew how people valued me once I fell ill and came to hospital. (Ms. Nadia)

Severe chronic illness and hospitalisation affected the strength of mutuality in social relations. Among the in-patients I talked to, their perceptions of their own worth in their social relations influenced the quality of the support those relations provided in times of need. Sufferers in this sense pondered their 'value' based on how often different people visited them in the hospital. They gauged their own social worth by evaluating the level of effort others made to console them. Ward staff who often listened to patients did not pursue the details if the patients' concerns about available support were aired, which featured issues such as broken marriages, unsupportive spouses, and kin. Many respondents were eager to hear new ideas for restoring and sustaining supportive social relations. Chronic illness and prolonged hospitalisation, however, threatened the cultural values of reciprocity and mutuality. Reciprocity seemed to diminish with protracted illness and repeated hospitalisations. Similarly, the illness tended to minimise an individual's value in existing relations of mutuality. Kin and friends tended to reduce their support as they expected less in return from terminally ill patients. Prolonged treatment and hospitalisation also drained social capital, as noted in Chapter 7. In the end, sufferers felt that reciprocity operated mainly within already-strained nuclear families. Misaka commented:

... friends may disappear, but I have my family to fall back to. A friend advised me to bear with the situation, to be patient and not to worry...People always know that they have something to gain in the future from a relationship. They expect that they will get back something at some point. Where do you get assistance if have nothing? A good friend has to follow you up to the bitter end ... However, friends desert you in a situation like of ours. This is happening to me because I do not have any more financial value ... (Mr. Misaka)

Optimism about the resilience of family members provided emotional consolation. For some patients, daily hardships and inadequate social support in the hospital evoked regrets and demoralisation about what they considered unreciprocated support they had given other people. Maxims about forgiveness helped console patients as they attempted to cope with the reality of inadequate or diminishing social support. Mr. Memba, for instance, said, "If I want to live, I have to forgive others." He blamed the inadequate support he received on his siblings' selfishness and the dynamics of jealousy in his father's polygynous family. Patients also adopted a conciliatory attitude from religious discourse in the ward. Some nurses and religious agents in the ward often reminded patients that 'heal-

ing comes with willingness to forgive others.’ In their categories of people to forgive, some patients even included ward staff that they perceived as uncompassionate. Poorer patients grudgingly regretted that their social groups were either too poor or too far away to help. They had to bear interrupted treatment due to drug shortages, delayed discharge because of pending bills, and loneliness. Meanwhile, patient-centered social and medical history and morbidity of kin proved to be a constant source of grief, relating current illness and treatment hardships to the entire context of social experience and support.

Medical history and silent grief

Medical records contained details about patients’ physical symptoms on admission, and nurses and doctors added more notes to these during medical procedures. This represented a written record of patients’ experiences in a long trajectory of treatment seeking. The question about whether there was a history of chronic illness in their families stood out in the records, and remained a significant source of anxiety with regard to the origins of current suffering. The majority of the respondents, however, had indicated that they had no experience of such illness in their families. The question about the origins of the disease lingered and the meaning of the associated misfortune distressed them. One respondent observed:

... my first thought was, how did I get it? I thought it was something contagious but I wondered how this could be ... I had never heard about cancer in my family. I was healthy apart from a small swelling. When I went in for the biopsies, the first results got lost. They discovered that it had become cancerous after the second biopsy. I asked, ‘What is it that I have done to my God?’ Sometimes people asked me, ‘If it is a disease, why can’t it just be diagnosed and treated at once? Must it take you through all these injuries?’ ... People link such occurrences to indigenous beliefs and traditions ... Even if you do not understand those things you start imagining that maybe someone has done something to you ... But what do I have that would make an evil person want to harm me? Since I am still looking for an answer, I do not rule out these beliefs ... I believe my God can do wonders ... (Mr. Johana)

I learnt from conversations with Mr. Johana that his mother had suffered from a chronic illness. He suspected that this might have been cancer; however, his medical record indicated that he did not suspect any traces of chronic illness in his family. Acknowledgement of chronic illness in families attracted a stigma, which many cancer patients feared. In the belief systems of local Kenyan communities, such illnesses symbolise evil of a mysterious origin. People often look for clues of personal responsibility along family lines for such illnesses; therefore, people of the local cultures hesitate to report clues of health problems in their family histories. They often do not perceive the relevance of reporting suspected family chronic illness to the management of their own current diseases. Arguably, concealing awareness of chronic illness in their families did help some cancer patients avoid the social stigma associated with this phenomenon. Where

cultural notions about chronic illness and curses linked suffering with family lines, ruling out hereditary origins of the disease for patients and their kin they search for other spiritual meanings of the suffering. Difficulties in diagnosis and treatment worsened the mystery surrounding personal experiences of cancer.

Medical history records focused on eliciting information about known causes of cancer. A few patients had confessed to predisposing lifestyle behaviours, especially smoking and drinking habits. Some cervical and breast cancer patients worried about providing the required data on the number of children they had had, and their age at first delivery. They were concerned that access to some of these personal details would heighten their experience of self-reproach. They feared that health providers' views of personal responsibility would influence their treatment relations. For these reasons, they tended to exonerate themselves by avoiding information that would stigmatise them. Subsequent informal conversations however led to the gradual revelation of worrying health trends in families. A few patients reported knowledge of deaths of family members due to unknown causes, and sought to understand the implications of these experiences for them and their kin.

Anxiety about health troubles in the patients' families was twofold. First, they worried about the threat of cancer or unknown fatal diseases, which meant giving up a normal life. Patients therefore desired to know the implications of actual and subjective medical histories for their own survival and the health of their relatives. Secondly, clues about a family history of diseases with characteristics similar to those of the current cancer condition deepened concerns about obscure hereditary misfortune. Cancer illness fell into the category of misfortune stemming from incomprehensible sources. Many respondents feared that such misfortunes had the propensity to interfere with individual fate and social responsibilities much more than misfortunes with traceable origins did. Hardships such as hospitalisation and cancer management were therefore seen as intertwined with other unfortunate experiences and misfortunes in patients' and their close relatives' daily lives. The fact that close kin's health and fortune determined the extent of individual in-patients' socio-economic support and emotional reassurance reinforced this connection. External physical and social misfortunes that involved patients and their relatives influenced the way cancer in-patients coped with hospitalisation. One long-term patient for instance lamented:

I have this problem yet several others come. Why do they target me particularly? My mother fell sick after my first course of chemotherapy. As I tried to rush home so that I could visit her in hospital, gangsters robbed me. My mother had been through an operation to remove her kidney ... Yet, the thugs robbed me of all the money I had. I have been asking questions ... If God designs problems, why does he give me all of them? (Mr. Johana)

For patients, life in the cancer ward meant an on-going search for the meaning of misfortunes. This was more significant when extra adversity tended to coin-

cide with cancer management hardships. For some patients, adverse medical situations and concurrent daily life troubles signified important spiritual messages. They interpreted these as either tests of faith and endurance or spiritual warnings and retribution. Current medical experiences as well as medical history could trigger silent grief over a series of fateful life events. Mrs. Pakot, for example, who was struggling with recurrent breast cancer, frequently referred to a time when she thought she had pulled through after a mastectomy about five years earlier. Following a second-line course of chemotherapy, she underwent two surgeries for uterine cancer. She often remembered with sadness and wished to talk about her first-born daughter who many years before had died of leukemia in the same hospital. The study hospital also reminded her of her other daughter who had died of malaria in childhood. Mr. Mukuru similarly had series of sad occurrences to ponder. His father had died ten years earlier, and his niece had died of leukemia in another ward while he was in the cancer ward for radiotherapy. In addition, during his hospitalisation his sister was undergoing treatment elsewhere for severe pulmonary tuberculosis. Such sequences of adversity involving cancer in-patients and their kin caused psychological distress for which they craved consolation. Another patient expressed similar grief when she noted in part:

My husband died while I was staying this side getting treatment. I got the report that he simply felt bad; he had bouts of malaria ... People who were home took him to a nearby hospital. They later decided to rush him to another hospital. They agreed to rush him to private (hospital). Nurses and doctors in public hospitals were on strike then. The driver and nurse who were with him did not have any money. They discussed how to get money to admit him to (a) private (hospital) for quicker treatment. He passed away as they discussed this. I just went to the funeral ... (Ms. Stella)

The hospital did not document much of what would constitute individual patients' social and medical history. Unrecorded history and experiences amounted to patients' unexpressed anguish. On-going interactions with hospital staff did not capture grief and pent-up emotions. This study offered some audience for patients' expression of their extra concerns. These comprised worries that had implications for coping with hospital treatment of cancer and inpatients' quality of life. Severe physical symptoms and emotional distress brought back sad memories. Personal biography and family medical history became tied up in the burden of patients' current cancer management. Sufferers viewed their afflictions as a part of a larger trajectory of misfortune. They grieved silently, seeking someone who would listen to them, as the chaplain intern said. Healthcare needs were related to social and medical concerns in an intricate way. Patients added their experiences of being stigmatised due to their cancer and hospital treatment to their overall load of misfortune. Cancer in-patients' perceptions of the stigma that results from having the disease and undergoing treatment varied, as did their

perspective on how their attitudes and emotions regarding the stigma had been shaped by being in the ward. The cancer ward, it seems, provided in some small way a refuge from stigma and related negative emotions.

Stigma and hospital refuge

Cancer and its treatment can have a variety of stigmatising effects on patients. Patients expected that being in the hospital would guarantee sufficient refuge from stigma relative to their experiences outside the hospital. Chapter 3 pointed to the feeling among some cancer ward staff that this hospital unit was of low status relative to other units. The ward itself suffered from a certain stigma stemming from the low status that hospital workers ascribed to it, since they felt the high death rate in the ward meant it made negligible contributions to improving patients' health. Some hospital staff likened the cancer ward and treatment centre as a 'repository for the cursed.' Patients on the other hand were troubled by the possibility of lingering social reproach that cancer and similar chronic illness triggered outside the hospital. They were also concerned about the excessive curiosity that fellow patients and other people had expressed about them in medical settings.

Social reproach

In several Kenyan communities, personal suffering due to 'unknown' or 'incurable' disease evokes speculation over the extent to which the patient might be personally responsible for his or her condition. Cancer patients were concerned about the possibility of such conclusions. They expected that admission to a ward in the national referral hospital, with its reputation for superior technology and expertise, would save them from such stigma. Confidence in hospital intervention waned as prolonged investigations, treatment and subsequent inconclusive hospitalisations increased patients' anxiety and suspicions about the nature of the illness. The perception that physicians might be withholding the truth from them made the cancer stigma seem even worse, particularly when physicians recommended additional laboratory tests and medical examinations without clear justification. Physicians' occasional failure to refer to the results of tests they had ordered prompted even more reservations about the disease. Postponement of some patients' progress reviews due to delays in medical examination results further increased suspicions, uncertainty and patients' sense of guilt. Patients and members of their social networks tended to look for additional meaning in doctors' occasional disqualification of medical examination results as inaccurate or 'spoilt'. Repeated testing and examination had both emotional and financial implications. Similarly, delayed reports for diagnosis and treatment progress were worrying.

Difficulties in naming the disease and initiating conclusive treatment subjected the sufferers and their families to gossip. This entailed speculation about moral issues that some people suggested could have caused the disease and parallel misfortunes for patients and their or kin. In local communities, people often implicate the sufferer or other personal agents when the cause of illness is difficult to define as aforementioned. Social scrutiny increased for cancer patients as hospitalisations became more frequent and the length of stay in the cancer ward expanded. Unproductive hospitalisations signified a personal struggle with an ailment perceived as mysterious and life threatening. Gossip and indirect reproach characterised some social responses to the difficulties cancer patients faced, and included suspicions about personal laxity in preventing misfortune. Notions about personal responsibility also included issues in patients' willingness to take action to receive appropriate treatment. This included the dilemma about combining hospital treatment with traditional remedies, especially when hospitalisation proved to be unproductive.

Physical symptoms of cancer and its treatment, such as drastic weight loss, diarrhoea and hair loss resemble those manifested by HIV/AIDS patients. Many local people associated HIV/AIDS with moral laxity and a lack of personal responsibility; health conditions that bore similar symptoms to this disease evoked suspicions about the sufferers' morality. Cancer patients were therefore concerned about the possibility of social reproach linked to the disease. While one or two cancer patients also tested HIV positive, non-professional observers speculated that there might be an infection among the majority of patients. The life-threatening nature of both HIV/AIDS and cancer made these diseases particularly stigmatising in local Kenyan communities, which linked them with cultural ideas about curses, witchcraft and ritual impurity, further implicating sufferers with some sort of personal responsibility for the causality of their conditions. Patients thus feared the moral implications that outside people might associate with cancer and hospitalisation. Incidentally, many patients referred to the phrase, 'people thought I have/had AIDS' in their descriptions of their misfortunes and perceived stigma. They supposed that people could not differentiate between the two diseases, given their similar symptoms, and implied that they were linked by the degree of horror with which they were both viewed.

Some of the cancer in-patients I interacted with believed that the stigma of cancer was gradually surpassing that attributed to HIV infection. They argued that HIV infection could be more easily detected than cancer. Similarly, they felt that modern medical care and hospital management of HIV/AIDS assured patients of longer life with the disease than cancer patients had with theirs. The phrase 'it is as if I had AIDS' expressed the dread of both the suffering and social stigma associated with cancer. Other patients were anxious that prolonged inves-

tigation challenging the primary cause of their illnesses would indeed reveal HIV infection. Mr. Jabari recounted how he and his wife “cried every day,” fearing that he could have ‘mysteriously’ contracted HIV/AIDS. Confirmation of colon cancer was therefore a blessing in disguise for them. The worry that other people could mistake cancer illness for HIV infection affected psychological adjustment to the diagnosis. Others were afraid that misunderstandings about cancer would accelerate their social segregation. Coincidentally, some respondents linked insufficient support from their social networks to perceived stigma related to cancer illness. As an example a long-term cervical cancer patient said:

... they did not give or tell me anything after the first examination ... My relatives distanced themselves and they did not want to know what I was suffering from. They thought I was trying to hide from them that I was (HIV) positive ... You know when people hear that you are a single parent; they think “You are just out there ...” My people (relatives) were not ready to pay my bills ... They became more curious as my second diagnosis approached. They still thought I was (HIV) positive ... My brother asked me, “What? You are suffering from cancer of the cervix? What brings it? Is it an infection or what?” That is loaded... Moreover, after chemo you suffer ... You change, so people think that you are (HIV) positive. They gossip saying this one is positive ... You know your hair drops off ... and your body changes. Fingers point at you. People say, ‘this one has been bitten’ (*huyu ameumwa*). (Ms. Souda)

Stigma threatened emotional, social, and material support, and prolonged medical diagnosis to determine primary causes of cancer and initiate treatment plans made it even worse. Questions and uncertainty about cancer and hospital treatment outcomes characterised patients’ daily lives in the cancer ward. Patients did not get adequate information to satisfy their curiosity, as noted earlier in this and the previous chapter. Similarly, carers did not help them adequately to resolve their questions about their own health. The curiosity of other people in and outside the hospital further contributed to the patients’ emotional discomfort, increasing the cancer stigma rather than providing the consolation they needed.

Uneasy personal and observer curiosity

Personal curiosity resulted from distressing yet unanswered questions about cancer illness and its management. Health carers’ responses or references to the disturbing issues created more unease; some patients, as described earlier, perceived them as inquiries lacking empathy. They particularly disliked some of the ward staff’s noncommittal, casual responses. Some ward staff reacted teasingly to patients’ inquiries about treatment and its side effects, seeking to reduce patients’ psychological distress through light-hearted responses; however, jocular responses disturbed patients even more, giving them the impression that the hospital staff were insensitive to their concerns and suffering. Mr. Jos, for instance, was concerned about his gradual hair loss. Dr. Bedohai teasingly told him that all his body hair, including the beard, had yet to fall off. In such cases, pa-

tients who sought answers to their questions expressed dissatisfaction with the staff's cheerful responses, which sometimes contributed to their uncertainty about the hospital treatment's efficacy in restoring their health.

Many patients did not understand the implications of treatment side effects in specific terms. Clear information on how to deal with these effects was often unavailable to them. They wondered about the duration and reversibility of side effects. Some shaved their heads clean to try to conceal stigmatising hair loss. Counselling was either unsystematic or provided to only a small number of patients. A few lengthy counselling sessions focused mainly on nutritional aspects of treatment. Communication about deep emotional concerns was superficial, with medical staff either dismissing patients' anxieties and questions, or circumventing details in their reactions.

Patients were also disturbed by other people's curiosity about their conditions. They were concerned with possibly irreparable alteration of their bodies by cancer and treatment effects. Surgery, chemotherapy and radiotherapy transformed patients' body images, which in turn made them more sensitive to what they construed as other people's undue attention to their altered identities, as describes earlier in this chapter. This presented a further struggle against stigma, and a threat to self-esteem and composure. Curiosity and attention from people in the hospital and elsewhere sometimes made them feel uncomfortably conspicuous, particularly as they reconciled themselves with acquired disabilities and unpleasant treatment outcomes. Some complained that people focused too much on aspects of their physical and emotional vulnerability. One victim of leg amputation remarked:

People who did not know that I lost my leg wonder ... They are surprised and come by my house to see me. They are curious because this is a strange disease. They inquire about my lost hair and the constant cough ... The disease affects many people in this way, but people still find leg amputation very strange. They speculate about the causes of the problem, but I am unable to answer them ... (Mr. Toi)

Attempts to pre-empt rumours about the cause of current suffering proved difficult for many patients, who either lacked sufficient facts or found it pointless to explain. This led to uncomfortable social interactions in the cancer ward and outside the hospital. Affected patients at times struggled to assert their capability in spite of the consequences of cancer and hospital treatment. Some resisted exemption from some tasks such as making beds because of their acquired incapacity, considering it unnecessary sympathy that compromised their autonomy, self-reliance and determination. Such patients resorted to concealing their difficult experiences from other people. This partly insulated them from either superfluous sympathy or stigma. Selective reporting on personal experiences prevented feelings of hopelessness, dependence and helplessness. Ms. Nadia reported:

I told a few people about it, but I felt that it was not good to tell them. I told my friends, but instructed them not to tell other people. I then wondered later ... what would I tell them this disease was, instead? They would ask: 'What kind of disease does she have?' I therefore saw no need to hide it anymore. I later decided to tell anyone who came to see me. My appearance changed and I became very black because of radiotherapy. People wondered what was wrong with me. I used to not eat anything. I just took some milk ... There was a hole in my nose ... people could not hear me when I talked and they were curious ...

Reluctance to reveal details of personal experiences was a strategy for emotional protection. Some patients felt that revealing their vulnerability to selected people would safeguard their self-determination and emotional autonomy. This would control stigma and avoidable isolation. They found withdrawal from some interactions to be a way of protecting themselves from excessive curiosity and sympathy. This momentary isolation facilitated endurance and emotional resilience. However, isolation *per se* influenced patients' capacities to cope emotionally with cancer management and hospitalisation hardships.

Dimensions of isolation

The phenomenon of isolation had at least three dimensions, which affected therapeutic interactions and patients' hospital care outcomes: experiential isolation, precautionary isolation, and social exclusion. Several hospital carers and patients' relatives attempted to help sufferers address anxiety linked to the different dimensions of isolation, and the negative implications for their recovery it entailed.

Experiential isolation

As noted in Chapter 5, patients felt that their experience of pain and adverse symptoms isolated them from other people in the ward. They often argued that the incapacity of healthy people to relate fully to the suffering that illness and drastic therapy caused worsened their loneliness in hospital. They held that no one else, apart from some fellow patients, shared their experience of disease and hospital treatment difficulties. In this sense, illness experience, physical and emotional pain constituted a deep-seated private affair. Inadequacy of hospital facilities and a shortage of staff shaped cancer inpatients' satisfaction with the results of their attempts to share their personal experiences. Similarly, some medical workers' perceptions of patients' social and emotional concerns as superfluous non-medical issues isolated those patients, further depriving them of the empathy they felt they required. Hospital circumstances also seemed to deny them the opportunity to manage their physical illnesses in their personal contexts of current misfortune. Many of the cancer in-patients tended to struggle alone with parallel social and emotional concerns that affected their well-being and overall quality of life.

Precautionary isolation

Both patients and healthy people alike engage in precautionary isolation of the ill. This related to fears of infection from cancer victims. The nature of some forms of cancer illness induced fears of evil influences that might have caused them. The mystery of cancer illness prompted unspoken fears that the disease could be virulent and exceptionally contagious or infectious. Patients also wondered if some types of cancer were infectious, as noted in Chapter 3. Some patients made efforts to reassure people around them that this fear was ungrounded. A respondent, for instance, reported:

One woman asked me, 'Is this cancer contagious?' I told her, 'It is not air-borne! She asked me, 'Will I also get cancer if I touch you?' I told her, 'No!' Other people believe that this cancer is fatal and has no cure, but actually, there is a cure. I believe there is a cure because some people get well. I have been with people in this hospital who finished chemotherapy and were healed. (Mr. Kabba)

The precautions people took around patients emphasised the stigma inherent in having a life-threatening disease. This affected interactions with patients experiencing particular types of physical symptoms including diarrhoea and wounds. Some patients perceived daily hospital activities as a reinforcement of precautionary isolation. As the excerpt below shows, some patients viewed hospital workers' safety precautions as discriminating against sufferers.

I have been asking myself whether this disease is infectious. We are curious to see nurses coming around in masks. They wear 'extra uniforms' (gowns) ... We are wondering, is it (cancer) contagious? Should we also wear masks as we move around? ... is it dangerous for us to be together? Should colon cancer patients be together with other people? Can one get throat cancer when a patient who has it coughs? We want to know ... because even those serving in the clinic have some small things hanging on their chests ('radiation detectors'). They say those gadgets protect against cancer ... something like that. How about the others and patients without any protection? (Mr. Jabari)

The fear of contracting cancer or associated illnesses from other patients prompted anxiety about the proximity of patients' beds to each other. Patients were more worried and uncomfortable about being too close to those with severer symptoms. The ward environment was often foul smelling, and this increased the fear of contracting other illnesses. As shown in Chapter 3, many respondents recommended isolating patients who were suffering severe effects in separate rooms or wards. Treatment side effects such as diarrhoea and vomiting caused inevitable negative reactions from fellow patients, and in turn caused further emotional distress for sufferers.

Social exclusion

Chronic illness, severe symptoms and prolonged hospital stays contributed to patients' sense of social exclusion. They relied on visitors and mobile telephone communication to maintain a link with events and life outside the hospital. A few

of the ambulant patients benefited from the ward television at the nurses' desk to follow daily news. Informal conversations with some hospital workers were handy in meeting long-term patients' need for social integration in the ward. Many patients reacted angrily and emotionally to the perceived indifference of other ward actors to their need for socialisation and informal discussion of personal concerns, which contributed to the tendency of some patients to withdraw from social interactions in the ward. Others tried to avoid social relations that they construed as intrusive in their privacy. This attitude was related to frequent requests of medical staff and visitors to view affected body areas. Mrs. Kadri for instance asked for a picture, which she could show curious people who wanted to see her mastectomy site. She and other affected patients were uneasy about what they perceived uncompassionate curiosity and remarks about their suffering.

Confinement due to cancer, treatment effects and hospitalisation were in themselves socially isolating. Frequent or long-term hospitalisation of cancer patients alienates them from relatives and other social networks. Moreover, some patients suspected that other people excluded them from social interactions due to their illnesses. The most affected were victims of limb amputations, mastectomy as noted in Chapter 5, and the bed ridden. They attributed their apparent loss of friends and associations to their constrained mobility. Kabba for instance observed:

The disease and hospital visits have affected my friendships ... Sometimes, people think I am sick and I cannot be with them ... But I do not always think of myself as a sick person.

Basic sociability in the ward involved conversation with fellow patients and staff. This included getting help with essential needs such food, medicines, water and going to the toilet. A few patients encountered difficulties in interacting and accessing help from fellow patients and staff. This prompted increasing anxiety about social reintegration for daily living after hospitalisation. Relatively younger patients pondered their disrupted education and career training. Hospital treatment and cancer management in general entailed gradual exclusion from social support groups as described further in Chapter 7. Services for reintegration of cancer patients into community life did not exist during this study. Most of the burden of social support was borne by ill-equipped families and informal religious groups. Patients struggled to return to the level of social functioning they had before cancer diagnosis. They desired support for dealing with concerns about disrupted physical and social existence.

Daily living and the future

Worries about personal and family survival at the present and in the future intensified with subsequent hospitalisations. Hospital treatment either coincided with

or accelerated deterioration in most of the patients' health, as pointed out in Chapter 5. Their initial optimism waned with subsequent hospital admissions. Unremitting cancer symptoms, treatment side effects, isolation and emotional distress increased uncertainty about personal future prospects and family welfare. The cancer ward over time became a place for reliving painful desperation that characterised current and previous cancer treatment efforts. Daily life in the cancer ward gradually exposed the limitations of biomedicine in dealing with the disease. Doctors' and nurses' occasional acknowledgment that there was 'nothing more to do' further diminished the hopes that patients had brought with them to the hospital. They did not take hospital workers' direct or indirect hints about the irreversibility of their physical deterioration lightly. Observation of fellow patients' marginal recovery chances and misfortunes evoked further existential worries. It was common for doctors and nurses to remind some patients that they would go home 'to rest' for some time. Medical personnel recommended rest when either there were shortage of patient care resources or the disease seemed not to respond to available medicine.

Thoughts about vulnerability, death, and dying were inevitable when treatment seemed unproductive. Patients taking long-term treatment and palliative care expressed worries about how much longer they had to live, and were preoccupied by concerns over how their families would cope after their deaths or prolonged hospitalisation. In this regard, existence in the ward and after hospitalisation meant increased loss of personal autonomy. Patients further struggled to cope with the psychological discomfort resulting from the experience of 'being a burden to others', as is further described in Chapter 7. Increasing physical incapacity was apparently a noteworthy outcome of hospital treatment for most of the cancer patients in this study. Unrelieved pain, eating difficulties and drastic weight loss underlined their fears about survival. For many patients, these phenomena warned of further isolation and looming death. One respondent vividly illustrated this fear:

I had put on a lot of weight ... I used to be very fat ... This is not my normal body. Since I started getting sick, I have been short of breath. My strength and 'kilos' (weight) have decreased so much. I am frightened ... I think I am dying ... People say, 'I am going' (dying) ... I never knew people could be this sick! ... I have seen many with one leg here ... When I sat near the window, I saw another woman, just my age, going on one leg with crutches like mine. I am not alone ... I am afraid because I have become so thin ... (Mrs. Vyakawa)

The ward was at times unusually silent, yet most of the patients were awake. It seemed to offer them the space to meditate on their destinies. It also exposed patients to the more severe suffering of certain fellow patients. This provided the chance either to learn endurance or to foresee the possible outcome of cancer management efforts. Other patients' conditions and treatment outcomes were significant points of reference for one's personal fate. Patients inquired about

others to find out how they were coping. They were often happy to know that old friends they met in the hospital had either pulled through or were managing well in therapy sessions. Subsequent hospitalisations brought cheerful encounters when patients who had met earlier reunited and found that they were still relatively strong. They often asked each other and the ward staff about the whereabouts of others, looking for information about those who pulled through, died or were still struggling with treatment. Worries about death originated from at least three sources. First, patients' subjective experiences of symptoms and treatment caused feelings of vulnerability or threatened survival. Second, patients witnessed the deterioration and subsequent deaths of others. Deaths of patients who seemed stronger on admission or shortly before dying were particularly frightening. Thirdly, they perceived some people's reactions to be ominous or to emphasise hopelessness. This called for personal emotional resilience to enable affected patients to hang on during treatment, as the extract below shows.

... The disease and drugs have pushed us down ... Some friends fear getting closer or associating with us. They do not understand why we lose so much weight. I have a strong will to live on. Some people are astonished when I talk about this illness ... I tell them that the disease cannot kill me. It will take me nowhere! I am there to live ... Someone looks at you and goes out to cry. I ask them ... 'Who told you that I am "going" (dying)? I am not going!' They look at me and think that I am not going to live. They think my days are over ... But I have strong will ... When the entire village heard some wailing one night they thought I had gone (died) ... When they came they found that it was not me! People started wondering what was wrong with me ... Some think maybe I have HIV/AIDS ... They fear I will die soon. (Mr. Johana)

A Glimmer of hope against a diminishing future

Patients struggled with an increasing sense of dependency on the one hand, and the perceived threat of death on the other. Some expressed resignation to the feeling of having no future. Hospitalisation and cancer management *per se* increasingly isolated patients from the rhythm of everyday life. However, they took some solace from the religious discourse in the ward. As pointed out in Chapter 3, patients and cancer ward staff alike turned to religious faith to ease anxiety and uncertainty. The ward radio cassette always played Christian music, giving the ward a solemn ambiance. Religion offered an alternative to hospital treatment and traditional medicines as a source of healing. Hospital staff, religious patients and spiritual workers in the ward popularised the idea of 'peace of mind' as an important value in securing confidence about the future in spite of suffering. The discourse on spiritual peace was handy for suffering patients, and tended to facilitate their efforts to endure family worries, moments of hopelessness and the discomforts of their ailing bodies and therapy. The hospital provided space for both formal and informal religious workers to preach and pray with inpatients, as noted in Chapter 4. It is in this sense that the cancer ward further constituted both

physical and emotional space as I indicated in Chapter 3. Nurses in the ward and clinic included Christian religious ‘devotion’ sessions in their routines for starting their workdays. Drawing on Christian perspectives towards helping the sick, suffering patients found solace in the religious workers’ visits and their messages, viewing them as mediators ‘standing in the gap’ between hopelessness and alternative sources of hope and healing.

The cancer ward ultimately served as the space in which many patients gained some spiritual understanding of their suffering. They said that they had learnt to pray and be closer to God due to their experiences in hospital, and particularly in the cancer ward. English Bibles were available in each patient’s locker. Those who were literate in English described the Bibles as their daily companions, especially during quiet moments in the ward. They occasionally preached to each other. Some nurses and ward assistants also discussed spiritual themes with patients. Mr. Jabari was ‘the pastor’ for fellow patients during each of his hospital stays. He preached and prayed in each room daily after breakfast before the hospital’s daily activities. Nurses’ daily prayer sessions before their duties each morning motivated patients to seek spiritual redress. Two free-lance preachers counselled and prayed with patients once a week before the physician’s ward round. Chaplains visited occasionally, especially when particular patients required sacraments or special prayers. Such sessions often encouraged patients to sustain their hopes for continued existence in spite of their disease and treatment ordeals. However, some patients observed that the religious services did not adequately meet their individual needs, and they did not like the conversion attempts some spiritual actors made. Others resisted mere invitations to prayer without discussion of their specific personal concerns. Some felt that they would benefit more from spiritual services by representatives of their own religious denominations. It is worth noting here that only Christians from three denominations provided spiritual services to the cancer in-patients. All patients, regardless of their social and religious backgrounds, sought spiritual consolation and meaning of their suffering. Religious discourse on miraculous cure motivated their resilience in treatment. They increasingly became concerned about their ‘spiritual strength to forgive’ and heal relationships that mattered for their future well-being. Many respondents came to view their treatment trajectories as a process of ‘waiting for God’ to intervene with miraculous cure and healing. The cancer ward became a context for reflection on transience of life, existential and spiritual concerns.

Summary and discussion

According to most patients, medical staff tended to disregard cancer in-patients’ ‘non-technical concerns’ about their illnesses and care, considering concerns that

did not relate directly to the medical domain as superfluous. Patients' psychosocial needs did not fall under the established set of responsibilities for cancer management services. This resulted in pent-up emotions among the sufferers, who refrained from voicing their concerns as a precaution against antagonising the hospital carers. The hospital treatment process therefore lacked adequate attention to the patients' social and psychological issues. Such a scenario contributes to psychosocial morbidity as patients struggle with unresolved anxieties and depression (Turner *et al.* 2007). Medical consultations prior to admission involved brief interrogations, but patients could not disclose their anxieties fully in such encounters. Similarly, subsequent communication with the healthcare personnel did not offer patients support in coping with personal fears and additional hardships. Little focus on personal anxieties and negative emotions had harmful consequences for their quality of life. Social and psychological problems are closely connected to patients' experience of consequences of treatment and disease. As an example, pain behaviour may disguise an underlying psychological state such as an extreme state of anxiety or depression (Helman 1994). Medical personnel in the cancer ward needed time to interpret emotional messages in physical symptoms such as aches and pain, nausea and eating problems. Patients may tend to express unpleasant and emotionally uncomfortable experiences in non-psychological idioms, such as having pain (Kleinman 1980). This implies that psychosocial concerns may actually underlie patients' expression of suffering through self-reports of physical symptoms. These may require psychosocial remedies rather than material medicine.

Emotional experiences varied with different social circumstances in the hospital and at home. This calls for carers' balanced attention to both physical and emotional aspects of care; however, a shortage of human resources made it so that the available cancer ward staff would not have adequate time to interact with and understand patients' unmet needs. Doctors' lack of time meant that consultations were limited to ward rounds and clinics focusing on questions with a physical rather than psychosocial nature. Moreover, the hospital had a tendency to give low priority to the cancer ward in terms of psychosocial services such as psychotherapy and counselling as illustrated in Chapter 4. As Soothill *et al.* (2001) aptly observe cancer services have a propensity for being less responsive to non-clinical aspects of the disease. Workloads in both the cancer ward and treatment centre weighed down doctors and nurses and limited their chances of listening to patients' concerns. Therefore, this study provided a temporary forum for the patients' to express their dissatisfactions and unmet needs. Lack of time among hospital workers is the most noticeable factor that constrains their attention to patients' psychosocial concerns. Clinical practice routines, other priorities in the hospital and doctors' views about their role may lead them to avoid spending

time and energy to understand the details of patients' extra concerns. The tendency of doctors to spend little time with cancer patients may be their conscious or unconscious way of coping with the distress associated with caring for suffering patients. Owing to the interpretation of division of labour in the clinical setting, doctors tend to relegate most of the burden of psychosocial support to nurses and ward assistants, patients' informal networks of support and family members. Doctors may want to keep away from emotional confrontation (cf. The 2002: 226), thereby failing to contribute to meeting patients' 'non-medical needs.' As an example, nurses aptly felt that informing patients about their diagnosis and treatment outcomes was the doctors' duty.

Multidisciplinary teams including more social workers, counsellors and inter-faith spiritual workers could complement nurses' and doctors' efforts to address cancer patients' psychosocial concerns. Patients perceived a good carer as one who readily listened and offered reassurance. Not all hospital staff in the cancer ward staff met this expectation. In fact, at times their brief communication with patients actually created more anxiety and suspense. Such situations have implications for patient satisfaction and adherence to therapy (Pollak *et al.* 2007). Patient satisfaction therefore depends on how well the hospital actors constitute a 'care team' of both specialists and non-specialists (The 2002). While specialists concentrate on medico-technical aspect of patient care, other actors, including relatives can supplement their efforts by facilitating communication and additional patient support. Some patients attributed their anxieties about cancer and its treatment to the way the medical staff relayed information. Some of their approaches lacked due empathy and they were unable to respond to anxieties that were apparent in patients' reactions. This phenomenon limited a follow up on unexpressed concerns and this could worsen unaddressed medical problems (cf. Heritage *et al.* 2007).

Unresolved anxieties and inadequate psychosocial support threatened patients' cooperation in treatment. Medical staff tended to avoid or fail to acknowledge individual patients' perceived impacts of illness as patients' narratives in the present study indicate. Hospital workers may systematically avoid or underplay patients' experiences. This contributes significantly to patient dissatisfaction, likelihood of malpractice and reduced possibility of positive treatment and healing outcomes (Levinson *et al.* 2000). The cancer inpatients expected that being in hospital would help them reduce uncertainty about their fate. However, the social and medical histories in their files did not reflect the comprehensive context of fears and psychological distress fully. Patients' prior experiences with illness form the basis for describing and enacting current symptoms and for speculating about what is going on and what may happen to them. While patients may wish to volunteer narrative information about their social and medical history, health

caregivers in the hospital tend to lack time for this. Although doctors may acknowledge patients' disclosures, they tend to exhibit low receptiveness to such narratives, as they constitute 'extra baggage'. They may redirect attention away from patients' concerns by offering 'textbook symptoms' and related pursuits of biomedical agendas (Beach *et al.* 2005). This approach impeded patients-medical staff communication and denied patients the psychological reassurance they desired. Medical workers' tendency to delimit the scope of their medical duties to patients confirmed the view that health carers may be reluctant to enquire actively about cancer patients' concerns and feelings (Maguire *et al.* 1995). Some of them interrupted patients' accounts with other questions or inconclusive explanations. Many patients therefore did not express their concerns and negative emotions fully, sometimes withholding concerns that would have been relevant for biomedical care.

Hopelessness threatened emotional resilience in the face of hospitalisation hardships. Images of disability and death in the cancer ward increased patients' fear, leading to concerns that physical deterioration would be irreversible and would cause a loss of autonomy. Rehabilitation therapy for basic functioning was absent in the cancer treatment programme. Cancer in-patients needed more counselling on how to cope with physical disability, the disease, and treatment side effects, but most of them did not receive it. The prospect of getting back to their normal daily lives waned with the disease's progression. This experience intertwined with other conditions that influenced their social and emotional well-being. Addressing fears experienced and expressed by patients is as important as dealing with their medical concerns. Patients' anxieties may be subjective, but they may provide hints about the 'embedded context' (Goodwin 2003) of their suffering. This relates to additional aspects of cancer management that are tightly interwoven and not easily distinguishable from biomedical features of diagnosis, treatment, and prognosis (Beach *et al.* 2005). Patients' desire for professional opinions about both technical and non-technical issues did not preclude the support they desired from family members and friends. Since the ward staff spent more time with patients than relatives did, they were key agents from whom patients sought solutions for their distress. If nurses and physicians nurtured empathic responses and mutuality, they could meet these needs (Griffiths *et al.* 2002).

Treatment resulted in physical and psychological trauma characterised by feelings of depression over altered body and social images. The data in this study illustrate that body image and identity concerns are prevalent especially among women with breast cancer and patients experiencing drastic treatment side effects, such as loss of hair (Hansen 2007; Vos *et al.* 2006; Rosman 2004; Taylor *et al.* 2002). Changed body images caused further discomfort as patients associated

this phenomenon with what they perceived as the undue curiosity of observers. They suffered low self-esteem and were suspicious that healthy people deliberately isolated them. In addition, they were vulnerable to cultural characterisation of being 'less than full persons', and loss of womanhood or manhood (cf. Sered & Tabory 1999; Hansen 2007). This relates to some of the patients' experience of the negative impacts of cancer and its treatment on their social roles and personhood.

Cancer stigma thrives on experiences of prolonged diagnosis and the effects of hospital therapies. The possibility of gossip about the patients and their families represented an extra concern for them. Patients struggled to deflect speculations that either they themselves or their entire families had caused their suffering. Noteworthy is that fact that diseases that seem difficult to diagnose and treat embody misfortune in many Kenyan cultures. This perception has moral connotations for cancer sufferers. In this sense, patients experience the effects of cancer and HIV/AIDS in a similar way through the mechanisms of stigma. In fact, patients in the cancer ward perceived cancer as more stigmatising than other chronic diseases such as HIV/AIDS and diabetes. Greater stigmatisation results from either the perceived severity of cancer illness or a decrease in functional health status (Fife & Wright 2000). The most devastating dimension of the cancer stigma results from victims' gradual inability to participate in normal social life. Cancer inpatients perceived the experience of cancer as more desperate and obscure than that of HIV/AIDS, as cancer patients perceived the availability of more favourable care for HIV/AIDS patients than for cancer patients in the hospital. Both patients and their family carers perceived cancer as more dreadful than other diseases because its progression seemed more rapid and unmanageable during its terminal phase. Similarly, other people's curiosities about cancer caused patients discomfort, as this drew attention to their vulnerability more than consolation did.

Patients always sought consolation in relationships (Griffiths *et al.* 2002), and they perceived a higher chance of achieving this in the hospital than in the 'outside world'. Illness adversity necessitated their attempts to sustain mutuality in relationships that they had access to in the hospital. Suffering patients often crave such relationships with close kin, friends and healthcare professionals (Sered & Tabory 1999; Soothill *et al.* (2001). They look out for responsiveness and empathy among the hospital staff, fellow patients and visitors. In this regard, cancer in-patients (and their relatives) tend to express cohesion on the basis that they share the stigma of the disease (cf. Wilson & Luker 2006:1665). However, sufferers whose kin were inaccessible were lonelier and felt more isolated when they failed to find consolation in their interactions on the ward. The opportunity to share experiences of suffering and stigma in the ward made some patients 'feel

at home' in the hospital. Conversely, others felt stigmatised due to the lack of reassurance in some of their interaction in the hospital. Their experiences of stigma and other concerns highlight the need for reappraisal of the quality of care for cancer in-patients. Patient satisfaction derives not only from biomedical thoroughness, which physicians strongly emphasise, but also from the attention accorded to social aspects of care. Health carers need to devote time to these social aspects. They need the skills to address stigma not only by giving patients advice, but also by listening to them (Scambler 1997).

In addition to a scarcity of time, health carers may lack the training and motivation to help patients to disclose their concerns (Pollak *et al.* 2007). Many of the patients' problems remained unexpressed during the hospital processes of taking medical and social histories. Physician-patient encounters do not always guarantee a natural environment for the complete listing of patients' additional concerns (cf. Robinson 2001: 640). Therefore, informal conversations in the present study provided patients the chance to define their concerns in detail and express their dissatisfaction. They highlighted their perceptions of the interwoven physical, social and spiritual experience. They depicted concerns about personal biographies and family histories that affected their peace of mind and quality of life during hospital treatment. They contemplated their fates and misfortunes in a comprehensive framework of medical, social, emotional and spiritual experiences. They were uncertain about the sustainability of their social capital in spite of hospitalisation hardships, which translates into worries about the family and future (Hill *et al.* 2003), especially among younger patients and those with dependents.

Perceived vulnerability was a key feature of cancer in-patients' concerns. Unpredictable outcomes of hospitalisation threatened their social, physical, emotional and spiritual resilience. Therefore, they relied on all the actors present in the ward to listen to them in order to allay their anxieties. They experienced each day as a struggle with existential suffering (Morita *et al.* 2004). This further shaped anxieties about personal and family vulnerability and survival. Each hospitalisation session provided some opportunity for personal reflection and search for meaning in their suffering (cf. Lee *et al.* 2006; Murray *et al.* 2004). Religious discourse facilitated the processes of deciphering meaning and messages from the severe experiences. Spiritual discourse in the ward was handy in the face of despair, helplessness, isolation and fear of death. Religious activities offered some consolation, but patients needed more personalised spiritual counselling. Proper provision of spiritual care in the context of a diverse population of seriously ill people is complex and calls for patience and thoughtful screening (Holmes *et al.* 2006). This can contribute to the realisation of more person-centred patient care.

This also necessitates consideration for the mutual implications of cancer management and hospitalisation for personal existence and livelihood.

Livelihood, treatment and hospitalisation

I was a caretaker in a house rental agency in Nairobi. If you are employed by this company you cannot be out for more than two months on sick leave. They tell you to go home until you feel better. They neither sacked nor granted me retirement; they just saw that this disease was becoming too much for me. They told me: 'we cannot keep you on because we will not have anyone to do your work. We just parted 'amicably' ... and I have been ill for the last two years. This has affected me and especially my home so much. I have sold many things ... I sold some cows and several small things when I needed treatment urgently. I sent for the money from home ... I have debts with friends ... Sometimes my wife gets a loan and we pay the debts slowly. It has been difficult to pay rent and buy food. That is very difficult because I cannot give up eating and yet I should not fail to pay rent. (Mr. Bedokufa)

Cancer management and hospitalisation constituted an additional threat to patients' fragile livelihood. Resources for daily survival were susceptible to the whims of long-term illnesses and hospital treatment. Hospitalisation for cancer management tended to exhaust material, social and emotional capacities to cope. Most of the patients who participated in this study were either not formally employed or earned low wages. Current illness and hospitalisation costs and daily cancer management costs were compounded with other livelihood struggles. The unemployed grieved over the loss of autonomy and dignity in daily life due to protracted illness. Hospitalisation caused further impoverishment as it involved rapid loss of income, unmanageable treatment costs, depletion of assets and declining social support. This chapter considers how patients experienced treatment and hospitalisation in relation to their distinct livelihood circumstances. It describes the social and economic realities that were manifested in their experiences in the ward, and examines the implications of individual and family coping strategies for livelihood organisation and security. The chapter demonstrates

that coping with cancer and hospitalisation entailed additional livelihood vulnerability, while differential access to formal and informal sources of support shaped individual experiences of hospitalisation and the cancer burden.

Livelihood backgrounds

Ten respondents consented to follow-up visits in their homes, as noted in Chapter 2. Observations and informal conversations in the hospital and at home provided useful clues about the cancer inpatients' socio-economic backgrounds. Hospital treatment was set against fragile livelihood conditions. Daily survival struggles and cancer-related health-seeking behaviours had mutual consequences. Patients' social and economic backgrounds were noticeable in their daily lives in the ward. Cancer treatment processes and livelihood security were interlinked in an intricate manner. Insufficient social, financial and emotional support in the hospital characterised the daily lives of patients who ultimately fell into the category of 'socials' or 'social cases', as the ward staff preferred to call them. Very few of the patients admitted to the ward could count on a fixed income at the end of the month; their social and economic capital was unstable, and those who held salaried jobs constantly worried about their employment security.

Some patients whose fight with cancer had started while they were still in primary or secondary school were still financially dependent on their parents and kin. Others had completed their final school examinations and had barely begun being self-employed activities when they fell ill. Hospitalisation and entire treatment experiences reflected the relative strengths of individual patient's social networks. Cancer diagnosis and treatment journeys interrupted the petty entrepreneurship of jobless school leavers. Some of them were married with one or three children or planning to settle down to family life before they became ill. Several of them had families with children and had been trying to adjust to living autonomously with their nuclear families. Supporting their families while completing the required hospitalisation sessions was an enormous challenge for most of the inpatients, often resulting either in patients' absence from the ward or unreliable provision of family support. Patients were unable to keep up with treatment while attempting to meet the needs of their children and other dependents. Families were worse off if the cancer victim was the household's primary breadwinner. Hospitalisation increased the burden of daily livelihood struggles with single parents, with separated and widowed women experiencing the greatest impact.

A few patients who were in regular salaried employment met hospitalisation costs and concurrent family needs with relative ease. However, the cancer ward admitted only a few patients who were in formal and well-paying jobs. Middle-class and relatively well-off patients in the ward had come there after depleting

their resources through failed treatment attempts in private hospitals. Some had transferred there from the high-class private wing wards of the study hospital due to the unsustainable high cost of care and treatment in that ward. Medical and housing expenses, school fees, special diets and other daily family expenditures were challenging for patients with regular salaries and the unemployed alike. A few of the formally employed patients were lucky enough to have spouses and kin who could supplement their incomes with their own regular salaries. The number of kin in formal employment influenced the strength of an individual's network of support. This offered an enhanced emotional and material support which destitute inpatients lacked. Destitution in the ward was often visible through the frequency of visitors, supply of home-cooked food, and access to volunteers to run errands and advocate for individual care. The length of the treatment trajectory before and during current hospitalisation also affected available social and financial support. Multiple hospitalisations further exhausted accessible sources of financial and social support.

Small-scale food and cash crop production supplemented the incomes of most patients. For those few who lived in urban areas and did not have access to personal arable land, kin would occasionally stop by when they visited the urban area and would supply fresh foods they had cultivated. However, the unpredictability of weather often reduces expected yields from subsistence and cash crop production in most parts of Kenya. As an example, the spell of drought during this study adversely affected livelihoods of Kenyans in many regions. Crop failure and famine increased the strain of individuals and families that were struggling with cancer management. As mentioned above, the current cancer treatment efforts for most patients had started between three months and five years earlier. Experiences of the burden of cancer as perceived at the time of the fieldwork were therefore just a fraction of the suffering that families and individual patients had endured over time. In addition, a significant proportion of patients admitted to the cancer ward were part of that (larger) half of the Kenyan population that lives below the poverty line, a group that continues to grow as unemployment rises and young people increasingly lack skills and reliable sources of livelihood. The onset of cancer illness marked the beginning of a long trajectory of physical, emotional and material strain, where the disease and its hospital treatment constituted an additional burden to daily livelihood insecurities.

The burden

The burden of patients' current hospitalisation and cancer-related treatment mounted on top of earlier healthcare costs they had incurred, and subsequent hospital admission fees and extra costs of patient care reified the livelihood misfortune that cancer illness portends. Similarly, the concurrent needs of entire

families tended to compete with cancer patients' health-seeking efforts. Inpatients' in these circumstances barely met their own social and material needs during the hospital treatment process. Many patients, for instance, found it hard to have consistent access to the special foods they were told could facilitate subsequent treatment and their recovery.

Earlier treatment and referral costs

As mentioned in Chapter 4, a majority of the patients arrived in the cancer ward after multiple referrals, which were usually from public hospitals in rural and peri-urban areas. The referrals were often accompanied by sequential or simultaneous consultation with other sources of healthcare. This pattern of help-seeking contributed to the cumulative cost of cancer management. Private healthcare facilities, indigenous and modern patent complementary medicines, and food supplements constituted patients' recourse before and after admission to the public hospital system. Each stage prior to admission in the cancer ward entailed the expenditure of material and non-material resources with an increasing impact on livelihood security. Each subsequent admission to the cancer ward portended an additional strain to family livelihood. Current hospitalisation costs coincided with additional family medical expenses and other household expenses (see Appendix 5, Tables 1 and 2). Every three weeks, chemotherapy patients and their families had to contemplate how to raise money for drugs and other hospitalisation fees. They worried about mandatory hospitalisation and drug costs in spite of other unforeseen expenditures for treatment and care in general.

Hospital fees and treatment costs

Previous diagnoses and treatment prior to admission to the cancer ward had already exhausted most of the patients' resources. Earlier and current radical treatment procedures, such as surgery, left a long-term impact on patients' livelihood. They recalled their resource-draining treatment journeys in both private and public hospitals. Current hospital treatment meant a continuation of the struggle against the devastation that cancer management can bring to social and financial capital. Covering hospital admission charges was often a challenging task for most patients and their families. The government of Kenya subsidises hospitalisation and treatment costs in public hospitals in accordance with their cost sharing policy; however, poor patients often struggle to raise the subsidised fee. Moreover, the prevailing condition of poverty makes specialised treatment financially inaccessible to many families. Cancer management is particularly expensive and hospital treatment becomes unsustainable. Protracted diagnosis and treatment and persistent shortages of the subsidised drugs worsened the cancer burden for patients and their families. Adverse treatment side effects and recurrence of the disease implied more expenses to sustain patients' quality of life.

Cancer treatment plans do not always produce the desired results; occasionally doctors changed a treatment plan due to poor response of the disease. This entailed an additional emotional and financial burden as patients and their families made efforts to buy new drugs. Treatment side effects and new treatment plans necessitated by the interruption of a previous cancer management course worsened this burden. Doctors and pharmacists tried to prescribe treatment options that they considered relatively affordable for particular patients. As an example, the first option in first-line chemotherapy for breast cancer cost almost double the price of the second option (Appendix 5, Table 4). There were three options for second-line chemotherapy for breast cancer, and these cost over five times the price of the options per course in first-line treatment. Many patients had difficulties raising money for whatever treatment option they received.

Radiotherapy cost a minimum of Ksh (Kenyan shillings) 7,500¹ for the required 25 sessions. This fee was exclusive of other hospitalisation costs and expenditures; patients also needed money to spend on additional food and miscellaneous personal effects such as toothpaste and soap. Both chemotherapy and radiotherapy fees excluded medical examination charges at home and in the ward. The management of treatment side effects also entailed extra financial and emotional burdens. Before the initial and subsequent therapies, patients needed to present results of different diagnostic tests including urine analysis, blood tests, scans and X-rays, all of which they had to pay for separately. They spent more on tests when they had to repeat them to confirm or replace missing reports. Cancer treatment side effects and poor diets in the hospital and at home affected patients' blood count. Doctors' advice to patients to 'eat well' implied that they needed adequate financial capital to improve their nutrition both in the hospital and at home. Only a few of the patients received a regular supply of additional food from home and could afford food supplements.

Treatment costs varied with the stages of the disease on admission to the ward. Three respondents did not proceed with second-line chemotherapy for breast cancer because they could not afford it. They also perceived the treatment process as futile and an 'unnecessary burden' to their families. They were cautious about accumulating bed charges and other hospital care costs. Prolonged hospitalisation also alienated the cancer sufferers from their social relations and livelihood projects. They perceived these as burdensome to themselves and their close kin, as discussed later in this chapter. The most remarkable episode of intermittent hospitalisation and discharge lasted at least six consecutive months. During this period, the lives of patients and their significant others oscillated around clinics, therapies tests, and medication.

¹ One Euro bought Ksh 86-90 during the fieldwork and for a long time afterwards.

A negligible number of patients whose 'blood count' was low could afford Neupogen (Appendix 5, Table 3), a drug that helps boost white blood cell counts more rapidly than the natural process of replacement through proper diet. Opportunistic infections in the hospital and at home reduced patients' blood counts, whereas poor living conditions and lack of proper diet at home affected several patients' body preparedness for subsequent treatment courses. Many poor patients could not afford drugs such as Amokalvin, which would combat infections and consequently boost their blood counts. When available in the hospital, this drug costs Ksh 600; in private pharmacies, however, the cost of the drug varied from Ksh 1,500 to Ksh 2,250 (based on the prices found in the private pharmacies in the town closest to Mr. Ajwang's home). The cost of such extra drugs depleted the resources of already poor families, most of whom were struggling to earn one Euro per person (less than Ksh 100) per day. Drug prices varied among pharmacies outside the hospital, but were generally expensive. Private pharmacy prices were at times double those charged in the hospital, as shown in Table 3 (Appendix 5).

Extra costs and special food

The extra financial demands of having a cancer patient in a family included expenditure on special food. Mr. Mukuru, for example said that he could barely afford the diet recommended in the hospital. The nutritionist had advised that he eat cow liver three days a week, and daily intake of beef, vegetables, and at least a glass of milk. He had to buy most of the recommended foods from outside sources, apart from indigenous vegetables, which his mother grew. Neither his elderly mother nor he had the money to buy a glass of milk costing Ksh 10 or a quarter kilogram of liver at Ksh 40 regularly. He estimated that the minimum daily cost of the special foods he was recommended, including cabbage, eggs, and a variety of fruits, was Ksh 100, which he could not afford. The ability of families to pay for an ill relative's special needs on top of the greater household needs varied as Tables 1 and 2 in Appendix 5 indicate. Due to a lack of income or inadequate wages, most patients said that they had been 'surviving on hand-outs' from friends, relatives and well-wishers. Ms. Souda decided that she would always 'use handouts to buy and stock food' that would last her family between two and three months. Due to financial constraints she often decided to forego the required special foods and chose to 'just eat what is there.' Transport to the hospital or local medical facilities for examinations entailed additional costs that most of the patients worried about. Accompanying relatives also cost money for transport fare and subsistence during each hospital visit. Kin who lived far from the hospital and lacked the funds to commute could not meet the daily needs of

patients in the ward. Hospitalisation and treatment expenses also sometimes interrupted family members' education and training.

Hospital treatment of cancer constituted a cycle of illness and treatment episodes that often overwhelmed the affected people. Many patients were apologetic about what a burden they had turned out to be for their families, as illustrated later. Owing to the patients' impoverished socio-economic backgrounds, hospitalisation meant severe additional strains on already fragile family livelihoods. Cancer management expenses tended to take the highest share of monthly household expenditures, as respondents' reported in their estimates (Appendix 5, Tables 1 and 2). The amount of expenditure on cancer treatment and care alone tended to exceed the total income available to most families. Cancer treatment and associated hospitalisations mirrored a wider spectrum of individual and family livelihood struggles.

Livelihood strategies

The youths admitted to the cancer ward were either unemployed or self-employed before they began their hospital treatment, and were therefore financially dependent on their kin with regard to significant issues that affected their lives. Some of the other inpatients were either unemployed or self-employed breadwinners of their households. A small proportion of the respondents was in salaried employment and could count on close kin with regular income for support. Adverse effects of cancer management on livelihood constituted the common denominator in the experience of all the cancer inpatients in this study. There was a mutual influence between hospital management of cancer and individual as well as family livelihood strategies.

Financially dependent youths

Financially dependent youths were primary or high school leavers. They were still in either their final year of school or had just started to establish their modes of livelihood before they were diagnosed with cancer. The three cases that follow (see also Appendix 5, Table 1) illustrate the livelihood experiences and struggles among the youths who were admitted to the cancer ward.

Mr. Mukuru

Mr. Mukuru, a 22-year-old primary school leaver, was the youngest-born in a family of five. His father died five years before his diagnosis, leaving his two sons and three daughters. Two of the daughters were married and living in the area, while the youngest was a single mother and lived in her mother's house. Mukuru had been living in Mombasa, on the Kenyan coast, where he had gone to look for a job, and had earned a living selling fruit. When his undiagnosed illness

became severe, he was forced to return to his rural home to seek help. Medical diagnosis at a hospital in his home district revealed that he was suffering from nasopharyngeal carcinoma. The doctor who attended to him referred him to the national (study) hospital after removing a tumor below his right ear through a minor surgery. He was admitted to the cancer ward for 25 sessions of radiotherapy. He remained hospitalised for about two months due to therapy side effects, as well as holidays and weekend pauses that interrupted the treatment process. He could not commute because of the distance and a lack of money for transport to and from the hospital. His only contact in the city was a jobless cousin who lived about eight kilometres from the hospital in a slum. Patients who either had relatives in Nairobi or lived near the hospital attended the daily radiotherapy sessions as outpatients.

During the study, Mr. Mukuru lived with his elderly mother in a rural area about 120 kilometres from the hospital. They inhabited a three-room timber house with a rusty corrugated iron sheet roof, and old newspapers stuck on the walls as both decorations and wind stoppers in the timber gaps. A small water tank that was used to harvest drinking water from rainfall from the roof stood in a strategic corner outside the house. The floor was regularly sprinkled with water to ease the dust, as typical in semi-permanent wooden houses in the area. A small extension of the house served as a kitchen in which Mukuru's mother prepared their meals using firewood. Mr. Mukuru could barely afford the diet the ward nutritionist had recommended he follow, as noted earlier.

Mr. Mukuru's aged mother grew beans, bananas, vegetables, and maize for their own subsistence on a small family plot. They had about one acre of family land, a section of which had been bequeathed to his brother, who was now living on it with his wife and four children. Due to increasing population density, subdivision of family land among sons in the area has given rise to the existence of ever-smaller portions of arable land per household. The tendency to sell small 'plots' of land for additional income has left families with barely enough land for their own subsistence. As in other villages in the district, Mr. Mukuru's family was gradually replacing coffee trees or intercropping them with food crops. They had small sections of land on which they grew French beans and about five macadamia trees for cash. Farmers were gradually planting Macadamia trees as a supplement or alternative to coffee, which is losing its financial value for small-scale farmers in Kenya. Macadamia trees are valuable for their nuts, from which salad oil is extracted.

Since the near-collapse of the coffee industry and poor returns from tea in the 1990s, many small-scale farmers were either uprooting or neglecting these cash crops. However, the macadamia trees take too long to harvest after planting. Seedlings may take from eight to 12 years to bear fruit and the quality of the nuts

may be unpredictable due to an unfavourable climate. Reasonably good trees produce 30 to 50 pounds of nuts at 10 years of age, and the crop size gradually increases for many years.² During the drought that occurred during my fieldwork, macadamia farmers suffered a great loss. The nuts were dislodging from the trees soon after production due to inadequate water in the soil. Failure of yields from small-scale cash crop production and subsistence farming had implications for the support of needy patients like Mr. Mukuru. His family had virtually nothing to sell to meet both his financial and social support needs. His kin hardly visited him in the ward.

His elder brother was just recovering from the death of his own 14-year-old daughter, who had died of leukaemia in the same hospital, but in a different ward as mentioned in Chapter 6. His brother owed the hospital Ksh 90,000 for his daughter's hospitalisation, and had agreed to pay Ksh 1,000 per month to clear the debt. Their 27-year-old sister, a single mother of one child who lived with their mother, had just completed treatment of pulmonary tuberculosis in a nearby district hospital when I first visited their home. Mr Mukuru was discharged after radiotherapy and was due for chemotherapy. For over five months and by the end of my fieldwork he did not succeed to be readmitted to the ward for the treatment. He did not have the money for further hospital treatment.

Mr. Toi

Mobilisation of support depended on the strength of the economic, social and cultural capital (such as kinship ties) of relatives and friends. These were important factors that influenced the self-reliance *Harambee* fundraising events described further under 'informal support'. *Harambee* is a word in Kiswahili that denotes "pooling together". It is derived from the norms of communal solidarity in self-help events. Since Kenya gained political independence from the British in 1963, this idea has been used to fundraise for needy individuals, institutions and families. People also draw on the *Harambee* spirit to raise money for treatment and hospital bills, education and other financial needs that individuals and smaller groups cannot manage.

Individual and communal livelihood strategies that coincided with cancer management varied. The range and strength of kinship and other social networks shaped strategies further. Unlike Mukuru, Mr. Toi, 26 years of age, was diagnosed with osteogenic sarcoma at the age of 22 after he had just completed high school education. He lived with his parents and three siblings about 50 kilometres away from the hospital on a small homestead with two small timber houses with corroded corrugated iron sheet roofs. About four kilometres of the road

² See Waikwa Maina, "How Macadamia farmers can avert crisis" *Daily Nation*, Thursday February 9 2006, pp. 23-25.

connecting his home to the main road was hilly and almost impassable. A large tract of land with eucalyptus and a few neglected coffee trees belonged to his extended family. This land was not arable as it was situated in a hilly and sandy area. He said he had to wake up before 5 am to get a ride in a neighbour's car to make it to his hospital appointments. His parents were peasant farmers with a few coffee trees that earned them a small income. His unemployed father was rarely at home during my visits. On all the three occasions of my visit, Mr. Toi's mother or sister called him over from what they called 'the boys' cottage' where he spent most of the time alone. However, neighbours stopped by frequently to greet him and those present in the compound.

Before his diagnosis, he was earning a living from petty business in a market centre near their home. He often looked through his photograph album and seemed to regret the loss of the vitality he had before amputation. Three years after the amputation of his right leg, he was on second-line chemotherapy for recurrence with metastasis to the lungs. His kin and family friends contributed 160,000 Ksh at a fundraising event to help him meet the hospitalisation costs. He attributed the perceived success of the fundraising event to the strong mutuality in his lineage. He was confident that the money would be sufficient for all the subsequent courses of chemotherapy. However, unforeseen complications of the recurrent and spreading cancer later brought additional costs. Mr. Toi suffered opportunistic infections and lost his battle with cancer before the end of my fieldwork.

Mr. Ajwang

Mr Ajwang, 21 years of age, was the second-born in a family of three. He lived about 86 kilometres from the hospital with his parents in a timber house with an old corrugated iron sheet roof. He was diagnosed with osteogenic sarcoma as he was just about to take his final high school examination. His teachers contributed money for treatment costs when his leg was amputated in a local hospital. They supported him afterwards until he completed chemotherapy in the study hospital. He walked around on an artificial leg and was able to participate in some subsistence activities on his parents' small piece of land. Mr. Ajwang's father was a casual labourer working as a mason about 30 kilometres away from his home. According to their estimates, his monthly wages were about Ksh 4,500. On the two occasions that I visited Mr. Ajwang at home, his father was not there. He had rented a one-room house in the township where he worked because he could not commute to work from home. On the weekend I met him in town, he gave me directions to his rural home but remained there to work on a construction site. Mr. Ajwang stayed home with his mother while his brother was in boarding school; their sister was married and living in the same district. Their mother was

a housewife, managing the home and subsistence activities on their farm. They worked together on about a quarter acre of land where they grew vegetables and peanuts for sale. He was happy that his 'amputation did not interfere significantly' with his participation in basic livelihood activities on their farm. The family had few coffee trees and about a quarter of an acre of land with tea bushes. These supplemented their source of livelihood with subsistence produce such as vegetables and maize.

Mr. Ajwang's younger brother was in school 'on credit' as his parents struggled to scrape together his fees. The bursary scheme in the district gave priority to orphans and especially victims of HIV/AIDS. The socio-economic impact of this disease haunted the well-being of cancer patients inside and outside the hospital, either directly or indirectly. Mr. Ajwang regretted that neither his brother nor he could access assistance through the local bursary scheme even though they were needy. He viewed cancer treatment and management in general as a great impediment to his personal development for the future. He said that he had performed well in the high school examinations in spite of the time he had lost seeking treatment. Most of the youths who participated in this study perceived cancer management and hospital treatment as a hindrance to their present and future livelihood. Mr. Ajwang for instance lamented:

Since I had the amputation, I lost a lot of time. It happened while I was still in school. Also my father lost a lot of time in this. He is the one who took care of me when I was suffering and during the hospitalisations. He loses a chance for the casual work he does when he has to come with me to the hospital and go back for me on Wednesdays after chemotherapy is over. Our farm production has also been affected by this.

Patients who perceived themselves as very dependent on their parents agonised over their lost autonomy. Their daily coping struggle included dealing with negative emotions about being a burden to others. This affected their emotional well-being, as they felt a loss of the self-esteem and dignity that came with earning one's livelihood. Ms. Marina for instance lost her position as a laboratory technician when pain and hospitalisation interrupted her job performance. She said that she had contemplated suicide since losing her job meant losing her sense of worth at the present and the motivation for facing the future. Cancer and hospitalisation equally strained unsalaried patients who attempted to deal with the disease and meeting the needs of their dependents more or less single-handedly.

Household providers without wages

As in the case of Bedokufa in this chapter's introduction, some patients had lost their jobs because of chronic illness, while others feared that they would lose their retirement benefits because of prolonged and frequent work absenteeism. Several respondents with dependents regretted the loss of their livelihood from

self-employment due to the disease. Social support for unemployed patients was uncertain, and many times they relied on the capricious gestures of reciprocity from relatives and friends. Apparently, ailing single mothers went through more material and social struggles than patients who were either single or married.

Ms. Souda

Ms. Souda, 39 years of age, was single mother of four children. She had separated from her husband before the final diagnosis that revealed she had cervical cancer. Before this diagnosis, she had suffered and tried to treat a prolonged illness of unknown cause. She lost her job as an accounting clerk in a local corporation in Nairobi. Her estranged husband did not support her or the children, while the father of her first-born provided unreliable to negligible support during her treatment. She relied mainly on her elder brother and friends for additional support. Her medical costs at home included laboratory examinations and regular analgesics purchased from the hospice.

Ms. Souda lived with her four children in a cramped two-bedroom flat on the third floor of a slum tenement about 10 kilometres from the hospital. I walked through a large garbage collection point outside the building. Her daughter made an effort to prepare tea and meals on a small paraffin stove, which she often moved to a corridor near the entrance to the kitchen pantry, to avoid the suffocating effect of smoke from the cooking stove. There were two large containers for water storage in the corridor. She often reminded her children to 'use the water wisely' as there were frequent shortages, which sometimes lasted several days. Each time I visited Ms. Souda, a number of friends and neighbours called to see her. They brought food and drinks on occasion, to the delight of both Ms. Souda and her children. Some people came in twice with food supplements to sell to her. She said that they hesitated to pitch their products to her because she had introduced me as her 'visitor from the hospital' and they feared that I could be her doctor.

Friends from church spent more time with Ms. Souda to chat, help with house cleaning and cooking. As I talked with her one time in her home, a woman walked in to speak to her. She seemed uneasy in the presence of myself and the two other visitors in the house at the time, lingering as we talked but later excusing herself and leaving. Ms. Souda later informed me that the woman sold 'soya milk' to patients, and had been encouraging her to try an herbal therapy since she had been in so much pain and had not had any painkillers. Interestingly, she said that the woman was a member of a church whose pastor dealt in herbal medicine for cancer. They claimed that there was a woman with cervical cancer who was gradually getting well after using the herbal medicine and 'soya milk' and related food supplements. It is worth noting here that similar transactions

also took place in the cancer ward with some nurses' facilitation. The woman promised to return after the other visitors and I had left. Ms. Souda seemed to be in a dilemma as to whether or not to take the herbal treatment, but talked freely about the food supplements, such as the 'soya tea' that she used. She had been unable to return to hospital as scheduled because she did not have money to pay for the treatment and hospital admission. She had also been unable to send for more analgesics from the Nairobi hospice due to a lack of money.

Ms. Souda lay in a woven chair propped up with pillows as she could not sit up for long. She had a small colour television placed on top of a sideboard. On the shelves of the sideboard, bottles of medicine and packages of food supplements were visible. She occasionally reminded visitors that she would not take tea with them as she preferred taking a 'soya drink'. Her rent was in arrears; in fact she indicated that she had not paid the rent for up to three months at the time of the study. Two of her children had dropped out of high school as she could not pay their tuition fees; the other two children did not have means for further training after high school and were unemployed. She could afford neither her special food nor regular meals for her family, as noted earlier.

As evidenced by Ms. Souda, some patients who lost either their formal employment or informal livelihoods due to cancer illness and treatment had been the main or sole providers for their families. Their struggle, as expressed in estimated household income and expenditures (Appendix 5, Table 2), indicates that there were coping difficulties similar to the experience in households where younger patients were financially dependent on poor kin. Those who were self-employed or working in the informal sector as casual labourers went through similar financial hardships. Hospital treatment and admission worsened financial and social strain in poor families. Kin who were available were equally poor, attempted to provide emotional support through regular visits at home and telephone calls to patients. Only a few of the patients I talked to enjoyed regular salaries from formal employment. Those who were even luckier had spouses or close relatives with reliable incomes who were willing to help.

Patients with regular income and kin support

Table 2 in Appendix 5 shows the estimated expenditure of respondents who were in stable, formal employment. Mrs. Pakot and Mr. Jabari's cases highlight the fact that patients who had monthly salaries to count on were nevertheless not free of financial worries during hospitalisation. However, most of them readily qualified for subsequent treatment and managed hospital costs better than unsalaried patients. The struggle with cancer treatment for some of the salaried patients often got a boost from close relatives such as spouses who had a monthly in-

come. Other patients with stable monthly salaries were the main household breadwinners, and this influenced their coping struggles.

Mrs. Pakot

Mrs. Pakot was a 49-year-old breast cancer patient undergoing treatment for a recurrence. She had completed courses of chemotherapy after a mastectomy over the previous five years. The recurrence also manifested as a metastasis of cancer of the uterus. She lived with her family in a rural area about 200 kilometres from the hospital. Two of her daughters and one son were married, while three were dependent and still in school. Her married, unemployed step-son had a semi-permanent house with mud-plastered walls, though the roof of iron sheets indicated that the house was not very old; in fact, it had probably been completed just a few months prior to the my fieldwork. Mrs. Pakot and her family had about one and a half acres of land where they grew food crops, tea, and coffee. They also kept two cows on 'zero grazing'. Her step-son, who was trying to settle and start a family, had a portion of the land that he used for his subsistence. On the occasions I visited, a young man and a woman helped them with farming and grazing the animals, and household activities respectively. Mrs. Pakot stayed at home while her husband and some female casual labourers picked tea leaves and coffee berries and prepared them for the local collection centres. Portions of their land had vegetables, beans, and a few stalks of sugarcane and maize for family subsistence.

Mrs. Pakot was a primary school teacher and the main breadwinner in her family. Her husband, Mr. Pakot had no formal employment after having lost his job as a treasurer for a cooperative society for local coffee farmers. Like most people in low-paying jobs, Mrs. Pakot needed to make constant efforts to supplement her family income through farming, trading, and small business ventures. The onset of serious and chronic illness portended a major disruption in her fragile livelihood. She developed complications after the first course of her current second-line chemotherapy that affected her intestines and required urgent surgery. She was transferred to a different ward for surgery after prolonged investigation and stayed in the cancer ward. Having exhausted the loan facility that was available to her through the teachers' savings and credit cooperative society, she had to finance the loan through paycheck deductions that left her with too small a salary to live on. Her family earnings from tea and coffee were inadequate, especially after the long drought that occurred during my fieldwork. Mr. Pakot mobilised extra support in the form of handouts from relatives and friends, but after a not very successful fundraising attempt in the city, she eventually agreed to be discharged to a hospice in her home district. She passed away before the end of my fieldwork. Her hospital treatment efforts had entailed an enormous

and continuous expenditure of financial, social and material capital that had lasted about six years.

During Mrs. Pakot's hospitalisation, an extension to the veranda of their permanent stone house which they had turned into a village kiosk remained closed. Before her relapse, Mrs. Pakot's family were trying to supplement their livelihood by selling small household items in their village. They ran out of kiosk stock when her disease recurred and started a second phase of hospitalisations. They hoped to revive the small business after her series of hospital treatments. Mrs. Pakot's family house itself was poorly finished; lacking ceiling material and proper window panes, and the floor plastering was incomplete. There was a bicycle in a bad state of repair in one corner of the house. Smoke and soot that had accumulated from the cooking room had turned the walls black, and though there was a cooking space with a chimney in the house, the firewood they used caused excess smoke to find its way into the other rooms. A black-and-white television stood in the centre of the room connected to a car battery that was kept below the television stand. There was a bottle of home mead carrot juice on the table for Mrs. Pakot to take whenever she felt she could. Her husband frequently reminded me of what he told me in the hospital about how to prepare carrot juice for patients; since people recommended carrot juice for recuperating patients, and the family did not have a blender, they improvised to extract the juice by grating carrots and squeezing the juice through a piece of cloth. As mentioned in Chapter 2, Mrs. Pakot stayed with her sister or her husband's cousin in Nairobi to minimise the transport and care costs incurred during the interlude of discharge from the hospital. Her husband's cousin usually prepared his guest room for them when they needed short-term accommodation, which was ideal for the duration of diagnostic tests before readmission and the shorter intervals between hospitalisation sessions.

Mr. Jabari

A few patients who participated in this study had fairly diversified livelihood backgrounds, which contributed to relative ease in coping with hospital cancer treatment. Mr. Jabari's estimated expenditures on treatment and other family needs (Appendix 5, Table 2) indicate that a close relative's regular salary coupled with the patient's monthly earning mitigated the impact of cancer management on the family's livelihood. This also facilitated relative success of hospitalisation and treatment outcomes.

Mr. Jabari worked as a technician in a pesticide factory. He thought that he might have contracted cancer from the factory environment. His wife worked as a teacher in a primary school near their home. They lived in a permanent stone house in an urban setting about 200 kilometres from the study hospital. He

owned an old car in which he commuted to work with his wife. They also had three pedigree cows, which guaranteed them regular supply of milk which they used and sold the surplus, as well as a plot of land with several rental houses that augmented their monthly income. Their four children, a daughter and three sons, were pursuing their education relatively comfortably. Their daughter had successfully completed high school studies and was waiting to join one of the public universities for a degree programme in nursing. One son was a second-year university student, while his two brothers were in boarding primary and high schools.

Mr. Jabari received confirmation that he had colon cancer in the present hospital after a series of referrals to other hospitals. Medical examinations had previously failed to identify his ailment, and he had spent a lot of money over the course of one year trying to determine the cause of his ailments. Despite the delay in receiving an initial diagnosis, treatment after referral to the cancer ward progressed without significant interruption. Mr. Jabari always 'qualified' for treatment because of his relatively steady livelihood. As explained in Chapter 4, patients 'qualified' for hospitalisation in the cancer ward if they fulfilled several conditions, including being able to pay hospital admission fees, buy the required medicines promptly, and follow the appropriate diet at home and in the ward to facilitate recovery and favourable physical response to treatment. An adequate blood count is necessary in order to proceed with or resume cancer treatment, and a patient with low 'total blood counts' did not qualify for admission and further treatment. Sanitary home conditions safeguarded patients from infection that would also affect other patients' total white blood cell count, so it was significant that Mr. Jabari's home environment met the hospital's standards for infection-free circumstances during cancer treatment. Unlike Mr. Jabari, very few patients could afford Neupogen (see Appendix 5, Table 1) and/or Amokalvin, the drugs that guaranteed quicker recovery of the requisite blood count, preventing possible delays in scheduled treatment. Mr. Jabari was among the few patients who attended hospital appointments promptly and qualified for readmission for all subsequent therapy sessions. He was always able to pay for his hospital admission and make his treatment down payments in good time. He also had his medical examination results on hand before succeeding hospital appointments as required.

Mr. Jabari could afford a means of quick transport to the hospital, ensuring he was among the first in the queue during his appointments despite the great distance between his home and the hospital. His white blood count was often adequate due a good diet and health-conducive living conditions at home. A clean house, good ventilation and curtains meant minimised exposure to infections, which often interrupted other patients' cancer treatment. His table always had a

variety of fruits, which his wife said she often ‘forced’ him to eat, and their dairy cows assured them of a reliable supply of milk as well as extra income. Similarly, his wife had a ‘kitchen garden’ within their compound and behind the house where they had planted spinach and certain indigenous vegetables that were prescribed in the diet for cancer management. Formally employed patients like Mr. Jabari also tended to have wider social networks, which was evident in the outcome of different patients’ *Harambee* (self-help fundraising) efforts, as I explain later. Mr. Jabari’s experience also indicates that formal employment and church affiliation of both spouses increased the network of social support. Such affiliations contributed to and the relative success in fundraising for cancer management.

The type of cancer patients had further shaped the implications of hospitalisation for their livelihood. Treatment regimes for colon cancer, as in Mr. Jabari’s case, were relatively cheap (Appendix 5, Table 4). Similarly, the government-run National Hospital Insurance Fund (NHIF) and private insurance schemes mitigated the impacts of hospitalisation on the livelihood of formally employed patients. The unemployed and those working informally lacked the benefit of any insurance coverage. Additionally, some patients who had requested early retirement found that cancer treatment had already exhausted their retirement benefits. Others who had already retired at the usual age of 55 years were on the brink of exhausting their savings and retirement benefits.

Mr. Jabari managed six courses of chemotherapy relatively well over six consecutive months thanks to such an expansive network of support. All the while he also successfully covered additional family expenses such as school fees, farm investments, commuting to work, and other monthly household costs. By the end of my fieldwork, he had completed first-line chemotherapy and had promptly started attending clinical reviews. Steady financial support from Mr. Jabari’s wife and access to medical insurance and loan facilities made coping with cancer relatively less of a problem for the family. However, like unsalaried respondents, employed patients still worried about the stability of their livelihood. Hospital cancer treatment often entailed trade-offs that had consequences for the whole family’s welfare, livelihood organisation and security, as well as the patient’s quality of life. Mr. Jabari’s daughter could not enrol for the computer classes she wished to take as she waited to start her degree programme, and seemed to feel sorry for herself that she could not start the classes until her father had completed his rather indefinite hospital treatment sessions.

Livelihood organisation

Strained economic and social capital

Hospitalisation of cancer patients entailed increasing stress on household budgets. The process of hospital treatment and care strained social and financial capital. Many patients aptly feared that hospitalisation endangered both their own futures as well as their loved ones'. Children, spouses and other people who supported them were trapped in the apparent dilemma of livelihood insecurity arising from the commitment to current hospitalisation cycles. Affected individuals and families had to make hard decisions in order to mitigate the effects of cancer on livelihood organisation. In this context, livelihood organisation refers to the arrangements and activities undertaken in order to earn a living. The main decision centred around the point of whether to spend available resources on cancer management or to ignore the disease for a period of time. The desire to minimise the social and economic impacts of cancer treatment on households implied further distress for patients.

Worries about livelihood organisation and security often resulted in postponing proper hospital treatment. Some patients and their families resorted to sub-standard or inappropriate treatment when they felt that current hospital treatment overstretched their social and financial capital. Nurses observed that some patients started their treatment in hospitals that offered cheaper, yet inefficient services. The Cancer Treatment Centre staff often doubted the competence of some of these hospitals and medical centres involved in attempts to manage cancer. Poor patients tended to revert to cheaper healthcare facilities or alternative medicines that did not guarantee relief. Such patients suffered more when they eventually returned to the cancer ward in worse condition, and also required stronger and more expensive therapy regimes. Although patients' worries about livelihood organisation and security motivated their tendency to decide against hospital treatment, this choice ultimately had negative implications for their quality of life, and increased future livelihood vulnerability.

Decisions about hospitalisation and treatment affected basic livelihood organisation in different ways. In the first place, cancer management causes a prolonged interruption in the livelihood activities of patients and their family caregivers. Patients who work informally stop working consistently, while those in the formal sector take frequent sick leave. Some of the formally employed patients contemplated or sought early retirement. They feared their employers would terminate their services due to regular absenteeism, causing them to lose their retirement benefits. Most respondents complained of stalled projects due to hospitalisation and related costs. One respondent remarked in a resigned tone:

People plan what they have to achieve in life ... As they plan they fail to anticipate that they can get sick. We just plan on a fixed schedule that by such a time we should have achieved a

particular goal, regardless of the fact that we might get sick. When this illness came, I had a number of projects to attend to personally. I had found my job but I had not worked for so long. I was just settling down to do a few projects that could help me in life. Then this sickness came. I discovered that cancer is a very expensive disease to manage. I diverted all the resources I had put aside for other things to my treatment, like money for building a house. In the beginning I thought cancer would be treated like malaria or something like that. Unfortunately, it is something that lingers for a long time. (Mr. Johana)

Onset of cancer treatment was tragic for many patients who were just beginning their careers and family life. This accounted for their poor living conditions during the hospitalisation period. This is one of the reasons they felt the temptation to skip hospitalisation appointments, and to seek substandard treatment elsewhere in order to preserve a secure livelihood for their families. They were anxious that a hospital stay would divert the financial resources they needed to sustain their projects. They also wanted to be at home to ‘attend to projects personally’. Some respondents had reservations about delegating the management of personal projects to spouses or other kin during their hospitalisation. They found it difficult to trust other people with the supervision of personal projects. Most long-term inpatients were afraid that it would not be easy for their businesses and economic activities to continue while they were away from home, and reported they would have felt more confident about the investment in and output of their farms and other enterprises if they were physically present at home.

The delegation of personal livelihood tasks during hospitalisation and periods of absence from home depends on the level of trust patients have in other people. Trust is an important livelihood value that facilitates mutual assistance in times of need. Married cancer inpatients in this study found spouses with regular income or other modes of livelihood more trustworthy than other kin. However, husbands or wives of patients still had to choose between regular hospital visits and the supervision of family projects. It was also taxing for formally employed spouses or those engaged in other projects to take up patients’ responsibilities. Cancer management thus had a significant impact on income-generating activities and social capital available to households and their members. In addition, some inpatients did not seem to trust even their close relatives with their livelihood ventures. They were worried about mismanagement of their projects. A respondent noted:

... for example, if you have a shop, you can inform your brother that you are sick and give him Ksh 40,000 to stock the shop. He will stock it with Ksh 30,000 instead and this becomes more expensive. (Mr. Mati)

Burdened families and caregivers

Inpatients’ relatives were also facing some social and economic difficulties similar to those patients experienced, which further limited the support patients could expect for their businesses. Kin who committed themselves to caring for

the cancer inpatients struggled to find time and money for hospital visits. This struggle contributed to the caretakers' personal and family livelihood challenges that they had to address simultaneously. Frequency of hospital admissions threatened informal or formal sources of livelihood among the patients and caretakers. Some relatives attempted to make schedules to alternate hospital visits and caring for their sick family members. Arrangements to take turns in patient care did not succeed, however, due to competing daily livelihood needs and expectations of formal employment. Ms. Stella's sister remarked:

It has been difficult to manage my own work while assisting my sister. My boss could sack me because some people are already complaining that I work fewer days. We are already in debt, so I cannot risk losing my job. I have to look for another job instead. The current one cannot sustain my own needs and the burden of treatment and care for my sister. I alternate with my brother. It is not easy because businesses are not doing well and we do not have an adequate income.

Some spouses or close relatives visited patients only at the beginning and end of each hospitalisation. Hospital admission and discharge processes were taxing and the patients could not manage them on their own. Several respondents indicated that they encouraged their relatives not to feel too pressured to visit since they understood their constraints. This helped minimise the loss of working time and commuting expenses. Some close relatives relocated temporarily to Nairobi to ease transport and time costs of frequent hospital visits. During my visit to Mrs. Pakot at home, her husband complained:

The farms are now not attended because all our income has gone to the hospital. You have seen for example we have not weeded the coffee trees. I need labourers there but I cannot pay for them. Like my cow there, (it) is not eating adequately because I am not able to employ somebody to get silage. And then the coffee seedlings are not sprayed regularly ... We are even unable to buy fertiliser, and these are the things we have to keep buying – fertilisers and pesticides. We are unable to do these things and that is why you have found the farm is not looking good. There is also a strain in managing our home because I always accompany my wife to Nairobi for treatment and check-ups. Next time she will be in the hospital for a week. When she is in the hospital, it is the house girl who is managing everything here and we are unable to have additional labourers. We need a young man to look after the livestock and maybe for the farm. We need about three people to assist us but we are keeping only one at present despite our inability to pay her properly. The farm and livestock are not attended well. We are also strained socially ... We both do catechism at our church but we have almost abandoned that job because we are always in Kenyatta (Hospital). When we happen to be home, she is in pain even on Sunday and we end up not going to church.

Cancer management and hospitalisation implied extra struggle for subsistence among patients and their family carers.

As noted in Chapter 2, some patients attempted to stay with relatives who lived closer to the hospital. They anticipated quicker recovery and an end to hospital treatment so that they could return home in good health. Mr. Ndege for instance moved to Nairobi with his eldest son to live with relatives. His son was

a high school leaver looking for employment. In the meantime, however, their attempts to coordinate daily family activities back home through 'messengers' and mobile telephone messages frustrated them. Those with little or no social support in the city faced even more challenges finding for themselves. Due to prevailing urban poverty and insufficient income, many urban households were unable to accommodate patients for a long time. This accounted for some patients' wandering with their family carers from one relative's house to another, and was a reason why patients' extended stays quickly became uncomfortable. Patients often desired to have places for their transition in-between their hospitalisation sessions; others would have liked to commute for radiotherapy and wait for the next admission at relatives' houses in the city.

Patients who had relatives living near to the hospital often felt guilty about requesting to stay with them due to the inconvenience they perceived themselves as causing their hosts. They felt that they were an extra burden on their families and other relatives, and were concerned about their diminishing personal autonomy. Ms. Stella chose to stay in her daughter's single room in a slum area although her brother and sister lived in relatively spacious houses in middle-income neighbourhoods. Mrs. Pakot and her husband sought accommodation on different occasions either at her sister's house or in single room that her husband's cousin offered. Mr. Tarus found it cheaper to rent a room about eight kilometres from the hospital than commuting from his home, which was about five hundred kilometres away. His wife and three young children stayed at home during his treatment. He said that his mother supported him and his family from the proceeds of his mini-wholesale shop. His mother managed for him while he was away for treatment. He stayed in the rented room for over five months during his treatment, but later died in the ward after an emergency readmission.

Some patients ignored treatment prescriptions and missed appointments due to the costs these would mean for their families, choosing not to buy medicines or go back to hospital as scheduled. This was a strategy to temporarily ease the strain of hospital treatment on their family livelihood. Many patients did not follow hospital treatment plans consistently due to lack of financial capital. Perceived costs and benefits of the treatment process also influenced individual decisions about hospitalisation. The options patients and families settled for implied inevitable sacrifice of either personal well-being or other immediate household needs. Livelihood circumstances and wider economic stagnation influenced the recovery process. Cumulative spending on treatment made individual and entire family livelihoods more vulnerable to future shocks. This threatened livelihood security and increased patients' concerns about the future, as described in Chapter 6.

Livelihood insecurity

Cancer and hospitalisation ruined young people's potential for a career and professional growth. Plans for improved housing waned as the youths either sold their building materials or diverted their savings to hospital treatment. The patients had very little hope of returning to their jobs or personal projects. Those who were not close to the retirement age were uncertain about their job security.

A significant and inevitable coping strategy was the interruption of family members' education or training, as pointed out earlier. This dilemma affected both poor and relatively well-off families. Ms. Nadia, 37 years of age, was a divorced single mother of three. She lived in a slum and earned a living through a petty second-hand clothes business. She struggled with the management of nasopharyngeal carcinoma for three years, stopping her business when she became critically ill. She talked about how frequent hospitalisation and illness had 'destroyed her life and the future' of her children:

My son is now 17 years old. When I fell ill he was going to standard eight (the final year of primary school). I left him at home when I first came to the hospital this year. I had saved some money to register him in high school but I have now used all of it here. He went himself and talked to the school head teacher. I do not know how it went. My mother has come from home to be with the children. I have no money to feed them.

Hospitalisation increased social and financial insecurity. Cancer management in the hospital and at home diminished income and available support. For younger people, as illustrated earlier, frequent hospitalisation threatened their career and professional growth. Prospects of family investment in the education of cancer patients dwindled. Prolonged hospital treatment sidetracked the resources that would otherwise have been invested in career training for other family members. Those who were in high school were uncertain about the likelihood of resuming their studies soon and catching up with their contemporaries. Moreover, their treatment costs had usurped the savings that were intended for their education and training. Cancer diagnosis and commencement of treatment after final primary and high school examinations signified a major tragedy for patients' families. For most families, this implied disruption of the efforts to invest in a family member's education and training. Treatment costs and subsequent deaths of family breadwinners increased uncertainty about the stability of dependents' careers. Hospitalisation *per se* threatened younger patients' careers, as those who were employed worried that repeated and prolonged hospitalisation would put their jobs and employment benefits at risk. As the excerpt below shows, many employed patients pegged their hopes on the sympathy of their bosses:

I did not expect to be in hospital for long because I had been quite fine the other days ... I am supposed to be on duty. Surprisingly, it was on the opening day that I was admitted and I am still here. So people at school may be wondering whether I am cheating ... They may be

asking; 'is she telling the truth that she is at hospital?' I did not talk much with my headmaster. Although he knows that I have (a) problem, he was expecting me to be back with the new term. He expected me to go and explain if I still had a problem or I would report on duty. I have not gone back. However they are waiting for me ... the nature of my work (as school bursar) does not allow me to leave without notice ... I have to tell them exactly whether I am resigning or able to resume work. The principle of my work is that one has to report to the office. They wait until you recover, but it depends on bosses since they are not the same. My headmaster has not told me anything ... I was to report and explain whether I will continue or if I am leaving work because I feel weak. I have not managed to do that ... So I am not sure whether I still have my job ... But, how am I going to maintain my children alone without work? My boss has been giving me my wages throughout the year because the sickness has just resisted and persisted. However, he has not told me whether time has run out ... (Ms. Stella)

Cancer treatment accounted for the largest share in the burden on available individual and family assets. Some patients, such as Ms. Nadia, did not have any assets to sell. Mr. Mukuru and Mr. Johana sold the material they intended to use to build their houses. A few families paid for hospitalisation from proceeds from the sale of family property such as livestock, land, produce and trees. The exigency of the treatment and competing household needs occasionally resulted in the sale of assets at throwaway prices. Transport fare, treatment, diagnostic and daily subsistence costs for the patients and their relatives increased with subsequent hospitalisations. Many respondents regretted having sold portions of their land and spent all the sale proceeds on cancer management. Their simultaneous or sequential adherence to both hospital treatment and alternative therapies increased their expenses related to cancer management. In most cases, initial help-seeking efforts and hospitalisations depleted the finances accrued from sale of land and other assets. Differences in access to land and social capital in relationships with family members were critical to household livelihood and capacity to deal with social and economic crises caused by prolonged cancer management.

The sale of land, livestock and other property indicated the loss of main sources of livelihood for entire families. Land is the main asset peasant families have; sale of part of the land not only did not resolve the growing cost of cancer management, but it also further impoverished affected families. The cumulative nature of cancer management costs overwhelmed the informal and formal sources of support that were available. Close family members took the biggest share of the burden in spite of their troubled and disrupted livelihood. This weakened further the already fragile informal sources of help and related cultural values of reciprocity and mutuality. Similarly, available formal supports proved inadequate for mitigating the impact of cancer management on the livelihood of patient and their families. Informal support tended to be unsustainable for cancer inpatients, while formal support was either absent or insufficient. This worsened patients' struggle to cope with hospital treatment of cancer.

Informal support

Family

Affiliation with kin groups is the basic source of support in Kenyan cultures. Other informal groups are either loose, bound by norms of reciprocity, or formed into structural associations. The latter often operate as frameworks of emotional and material support. These may be informal credit societies when members are more dedicated to sustaining them. The majority of the patients and their families did not belong to reliable informal support groups as described later in this section; instead, they often depended on their poor kin and social networks. The range of social networks accessible to patients and their families determined the nature and extent of their support.

Available family support was not sustainable, considering the high cost of hospitalisation and loss of livelihood that cancer patients have to cope with. Where kin ties seemed strong, the members of the group were as poor as the patients and their families. Conversely, weak ties characterised the relationship between patients and potentially rich members of their kin groups and other networks. In this sense, prolonged hospitalisation and chronic illness left patients and their nuclear families with negligible sources of extra financial sponsorship.

Limited social networks and shared poverty characterised the social and economic backgrounds of many of the cancer inpatients. Prolonged illness and hospitalisation challenged established cultural values of trust, reciprocity, compassion and mutual help. Prevailing hard economic times also reduced opportunities for mutual help. Most patients remained with their primary kin as the only source of continuous material and emotional support. The prolonged hospitalisations of cancer patients strained family recourses and threatened the commitment of primary kin to continue helping patients. Ms. Souda, for instance, complained:

A friend contacted my brother when I was in pain. He had promised to assist me, but yesterday he sent only Ksh 500. This is not enough for my re-admission and medicine. I was expected to go back to the hospital two weeks ago. I have been surviving on handouts from friends and some relatives ... I need medicine but my family needs food. My brother just told me bluntly: 'this medicine of yours is so expensive. I do not think anybody is going to be able to afford it ... You know I retired from my work' ... it would be easier if you were still employed. You have to fight your own battle' ...

Family members, relatives and friends 'got tired' of helping. This often reminded patients of their vulnerability, lost independence and what a burden they were to other people. They had lost the ability to contribute to informal social security through reciprocity for the help they received.

Self-help associations

A few respondents had some experience with support from informal social organisations. Informal mutual aid associations in Kenya are either religion-based or

secular with a wide range of memberships. Chronic illness, absence from association activities and general lack of participation weakened the link between cancer inpatients and informal self-help groups. Cancer management affected the contribution of both patients and their close family carers to their local association. Mr. and Mrs. Pakot regretted that their frequent hospitalisation trips affected their participation in their church-based association. The level of members' participation shaped both the material and social support they received from informal groups. However, cancer management drained the support individuals and families received from these associations. The frequency of material support from informal groups to individual members is limited to a few turns a year, yet the needs of cancer patients are perennial and exceed the capacity of the groups to intervene.

Poor organisation and mistrust characterised some of the informal insurance and credit associations that some respondents described. Mrs. Kadri, a 44-year-old breast cancer patient, worked as a housemaid and sold vegetables part-time before her diagnosis. Her husband was not in salaried employment, and she was the main household breadwinner. Her daughter, who worked as a casual labourer together with her spouse, supported her during hospital treatment. Mrs. Kadri used to be a member of a rotational self-help group called *makumi*. The group attempted to help its 200 members to cope with illness and funeral expenses. Members undertook to make a monthly contribution of Ksh 550. They saved 50 Ksh in a Cooperative Savings account and gave Ksh 500 rotationally to members. The association collapsed due to a decline in members' commitment to continue their contributions. Twenty-five members decided to continue with the association but they failed to raise the monthly contribution of Ksh 250 due lack of income.

Mr Ajwang's parents belonged to two separate self-help associations called *seti* ('set'). His mother's group had about 25 five members who contributed Ksh 100 monthly. His father's group had 60 members who contributed Ksh 300 each monthly. Members committed their assets such as bicycles, radios, furniture or livestock as collateral for defaulting on contributions. The waiting time for each contributor's rotation was too long, and in the end it did not benefit the family during Ajwang's hospitalisation and treatment; his parents were among the members who had to wait longer for their turn to receive their share of the revolving fund.

Local informal social security initiatives were also unreliable and poorly organised. Cancer patients and their families did not count on them for any significant financial support. The organisations were either non-existent in many places or too poorly organised to be of significant help. They gradually reduced their

expectations of social support owing to the awareness that ‘others get tired’. One respondent remarked:

Who can give you support? Maybe the closest relatives can. They can give you transport fare from home to Nairobi. Can we expect community help in our position? Forget that. That is why I think I need prayer to heal me. That will set me and my family free. (Ms. Marina)

Close family and some church members attempted to help patients and their families. This was most of the time limited to emotional and minor material support. Social, emotional, and spiritual support were necessary in spite of general low access to pain relief and affordable clinical or hospital care. This depicted a non-material dimension of the cultural norm of ‘pooling together’ to help those in need. Shared poverty rendered the livelihood value of communal solidarity fruitless for cancer patients seeking financial and other material support.

Harambee: Communal solidarity

Indigenous values of communal solidarity in Kenyan societies underpin people’s expectations of support during times of need. This was the basis for attempts by cancer inpatients and their families to mobilise resources in their social networks to ease the hospitalisation costs. They arranged *Harambee* fundraising meetings in Nairobi and rural venues. As indicated earlier, the concept of *Harambee* denotes the value of mutual effort to enhance collective welfare and quality of life. It defines a certain *esprit de corps* based on cultural norms of reciprocity and mutuality. This notion reminds relatives and friends of their duty to visit and help the sick at home and in the hospital. The composition and extent of patients’ and families’ social networks, however, determine the strength of the support they receive, and thus the efficiency of mobilising participants, attendance and financial contributions at *Harambee* fundraising events. Ms. Souda’s event, which she planned to take place at her house in Nairobi, did not materialise, but a handful of people handed in their contributions anyway. Mr. Toi’s clan-based *Harambee* at the family’s rural home was relatively successful, and he was confident that the proceeds were sufficient for the second-line chemotherapy, as noted earlier. Only a few people attended the meeting that Mrs. Pakot’s relatives organised in the city centre of Nairobi. Conversely, Mr. Jabari’s fundraising event in his urban church outside Nairobi was possibly the most successful, and demonstrated the idea that formal employment of both the patient and a spouse provided secure financial and social capital during hospital treatment times. Membership of both spouses in formal and informal associations increased the strength of collective support to individual patients. In Mr. Jabari’s case, the church offered an additional advantage as a framework for mobilising support resources during hospitalisation.

The strength of kinship ties, employment status and history, and membership in religious organisations shaped the support cancer inpatients received. However, individual fundraising events were limited to about two in number. Chronic illness, frequent hospitalisation and protracted cancer management made it nonetheless challenging to mobilise collective resources efficiently for patient well-being. Though the number of times families can mobilise social networks for financial contributions is limited, hospital treatment of cancer requires regular social and material support, which many poor people can neither easily access nor afford. Besides causing illness and death, cancer management can cripple poor people economically and socially with protracted expenditures on medicine and other needs. The burden of care most often falls upon the immediate nuclear family as the rest of the social network tires and retreats. This leaves either the patients' families virtually alone to fend for themselves, or the individual patients to 'fight their own battles,' as Ms. Souda remarked earlier. Patients and families tended to avoid asking for further communal assistance after making earlier attempts. Mr. Ader talked about a sense of guilt that made some patients avoid seeking further assistance from their networks of support:

It depends on the progress of the problem. Relatives and friends slow down and tend to withdraw if it takes too long. You cannot take this problem to them anymore ... they will think you are joking with them. (Mr. Ader)

Just like other primary school teachers and people in low paying jobs, Mr. Ader did not have insurance coverage. He also did not have other sources of livelihood apart from subsistence farming and his self-employed daughters. He struggled through hospitalisation without much benefit from formal support schemes. He was only two years away from retirement age, and the possibility of losing his retirement benefits due the challenges of cancer management worried him.

Formal support

Most of the patients in the cancer ward were poor and did not have access to formal institutional support; hospitalisation and cancer management therefore remained unaffordable for them. The hospital's credit scheme and the Nation Hospital Insurance Fund (NHIF) were the only formal support schemes that a small fraction of the patients could benefit from. A few formally employed patients had access to other unsustainable support from private insurance and loan facilities.

Hospital credit

The hospital considered providing treatment on credit for patients who needed urgent attention yet could not get money immediately to pay. They agreed jointly

with their relatives on how to pay hospital fees before discharge or afterwards in installments. Cancer inpatients nevertheless did not benefit significantly from the hospital credit scheme, since cancer treatment is expensive and protracted. Moreover, it was often futile to grant poor patients admission on credit, given the frequent cancer drug shortages in the hospital. In seven months of my fieldwork, the cancer ward admitted only 17 patients on credit. This normally entailed payment for partial treatment and negligible credit for subsequent hospitalisations. Initial admission and treatment on credit did not guarantee hospitalisation and care on the same scheme during hospital appointments that followed. Many poor patients did not succeed in getting credit even after going through the tedious application and vetting procedure. A respondent complained:

My bill is now Ksh 33,000, excluding the charges for the week since the doctor said I should go home. My mother has been going to the credit office since Monday. They just told her they could not help her ... She told me that today she does not have money for bus fare. I asked her just to stay at home because I have nothing to do. I have been in the hospital for two months. Even if I go home, I cannot look for work. My mother came from home (upcountry) to stay with my children. Well-wishers give them the food they eat. I cannot get my own money anymore and my mother does not have a cent ... The hospital people told my mother that they could not help until she comes up with money. (Ms. Nadia)

The hospital sometimes detained patients who were unable to clear their bills, which had the power to push patients and their relatives to find a means to pay. In the meantime, patients remained in the ward as 'social' rather than medical cases. Employees in the credit offices authorised the release of destitute patients on credit after confirming beyond any doubt that the patients had no means to pay their bills immediately. They also wanted to be sure about the patients' plans to pay hospital bill arrears before discharging them. The hospital eventually transferred the responsibility for all unpaid or bad debts to the Ministry of Health, including the debts of destitute patients who died in the ward. Detention of poor patients not only caused them psychological distress, but also added to their worries about their livelihood organisation. This was also an unwarranted expense for the hospital in the end, as noted in Chapter 4. Some of the detained patients contracted other illnesses, which entailed an extra financial burden for patients, families and the hospital.

Insurance and loans

The National Hospital Insurance Fund (NHIF) covered people in formal employment only. A small proportion of the patients had health insurance coverage from private companies. The NHIF only covered bed occupancy charges. The fund paid a flat daily rate of Ksh 1,000 irrespective of the type of disease. The balance after the bed charges per day was Ksh 550, which was hardly sufficient to ease the expenses of hospital care and treatment of cancer patients. Com-

menting on the struggle with the costs of hospital treatment for his wife, Mr Pakot said:

... She earns about Ksh 13,000 as a teacher and contributes Ksh 250 per month to the NHIF. But the insurance pays only a flat inpatient fee. We appreciate even the Ksh 1,000 it pays per day, but we still have to struggle to cover the balance. The NHIF pays nothing for drugs ...

A few patients were members of Savings and Credit Cooperatives (SACCOs) and other loan facilities. The government was planning to enable and motivate self-employed people to contribute to the NHIF, but many of the self-employed cancer inpatients and their spouses could not have committed themselves to this arrangement. Their wages were unreliable and they could not envisage making any monthly contributions regularly. On the other hand, insurance and loan deductions, together with the burden of protracted cancer care costs, considerably reduced monthly salaries of patients and relatives who had enrolled. As hospital bills for cancer treatment increased, patients and their families tended to sell everything they had invested in personal and family business, which in turn made it even harder for them to seek loans as they lacked adequate collaterals.

Some patients had supplemented their investment in private health insurance coverage with monthly share contributions to Savings and Credit Cooperatives (SACCOs). Both the SACCOs and certain private insurers facilitate access to loans. Most eligible patients had exhausted their loan facilities through frequent applications for financial advances to cover their hospital treatment needs. Mrs. Pakot had exhausted even her emergency loan facility. Deductions from her meagre salary to finance the loans reduced her take-home pay a great deal. She used all her savings and contemplated selling major assets such as land and furniture to clear her hospital bill. In other cases, some close family members also took on loans to facilitate patients' treatment and care. The hospitalisation of an individual due to cancer had a further impact on the livelihood of close family members. In addition to general hospitalisation charges, Mrs. Pakot and her husband spent money on diagnostic tests and a third surgical operation. Mrs. Pakot had already used the last available chance for a loan from her SACCO, and was already struggling to finance a loan advanced to her through a private life insurance policy. Faced with a similar predicament, three respondents were struggling to secure early retirement and its benefits to facilitate their hospitalisation.

Discussion

The experience of cancer inpatients in this study highlights the healthcare plight of a majority of Kenyans. Over half the population in Kenya is poor and unprotected from the impact of chronic illness on their livelihood organisation and security. Patients in poor countries suffer a disproportionately high burden of

disease yet they lack access to affordable, quality medicines (Malpani & Kamal-Yanni 2006). Most poor people are unable to pay for medicines out-of-pocket as expected. Cancer medicines are particularly unaffordable to the majority of low-income patients in Kenya and Africa at large. Informal arrangements evolve as a response to the lack of formal protection of the poor facing both financial and social support hardships. Cancer and associated hospital treatment intervention tend to exclude patients from participating in informal mutual assistance groups. This affects the sustainability of their benefits from informal sources of support. Since cancer management depletes individual and family livelihood assets over time, affected people remain virtually alone as they struggle to fend for themselves. Inadequate and unreliable formal and informal sources of support have negative implications for patients' quality of life.

The cancer ward admitted low-income patients that provincial and district hospitals countrywide referred to the study hospital. The cost of treatment and management of cancer conditions was unaffordable for many of the patients due to their poor socio-economic backgrounds. Their fragile livelihoods accounted for delays in presentation for initial hospital treatment. Some studies suggest that increasing costs of care could push the poor to postpone medical treatment (Dilip 2000), and that this may account for late presentation of cancer patients for hospital treatment in Kenya. Late presentation of cancer patients for treatment leads to higher treatment costs and lower chances of recovery, meaning a lower recovery rate among low-income patients as compared to relatively wealthy patients. Similarly, many cancer patients in Kenya are too poor to afford analgesics and essentials of care both at home and in the hospital (Murray 2003). Poor economic circumstances contribute to the inaccessibility of essential diagnostic equipment, suitable food and care assistance. This illustrates the need for public healthcare policies that increase financial accessibility for very poor cancer patients. This goal can be realised through attempts to ease the financial problems patients encounter and the socio-economic burden of their health care costs.

Research on illness and livelihood in developing countries has focused mainly on the impact of major communicable diseases such as malaria and HIV/AIDS (Rugelema 1999; Barnett & Blaikie 1992; Koestle 2002; Nur 1993; Chima *et al.* 2003; Onwujekwe *et al.* 2000; Russell 2004; Chuma *et al.* 2006). The economic burden of these diseases includes loss of labour on the part of patients and their caregivers, and reduced investment in both cash and food crops. HIV/AIDS is among the major threats to economic growth, social harmony and political stability (cf. Miller & Yeager 1994: 62). The HIV scourge and AIDS pandemic cause heavy losses of human life within the most productive groups and overwhelms the healthcare systems, thereby diverting attention from non-communic-

able diseases such as cancer, which is equally life threatening. The present study shows the need to step-up the focus on the impact of non-communicable diseases, too. The management of cancer, for instance, is protracted and takes the largest share of household expenditure in affected families. The impact of ongoing management of the disease is cumulative. Cancer impoverishes households more than other illnesses; cancer management causes more livelihood strain through income loss, prolonged and frequent hospital treatment costs and asset depletion. The emerging crisis of cancer in Kenya calls attention to the need to understand the impact of individual chronic diseases on the livelihood security of families.

It is difficult to have precise figures on the total costs of a cancer treatment trajectory. Families are unable to recall the exact ongoing hospitalisation and treatment cost. Given economic hardships and competing household needs, many patients and their caregivers were unable to recount precisely how they had managed financially up to the current hospitalisation. However, cancer management costs accounted for over half of the spending of available monthly income in affected households. The heavy indebtedness and depletion of family resources due to chronic illness imply loss of future earning capacity and ease of recovery, as well (Wallman & Baker 1996; Bogale *et al.* 2005; Russel 2005; Patterson *et al.* 2004). Chronic illness and hospitalisation costs added to the misfortune that cancer patients and their families already faced in their daily livelihood struggles. Cancer management threatened livelihood as it caused significant decline of physical, financial and cultural assets, capabilities and coping strategies (Kaag *et al.* 2004). Livelihood and cancer management have mutual impacts that coincide with struggles to cope with other daily life adversities.

Cancer patients came from already fragile livelihoods. Their care and hospitalisation implied higher livelihood vulnerability for their families relative to those without members suffering chronic illness. Hospital management of cancer interrupted daily livelihood since it led to stressful declines in income, consumption and capabilities (cf. Hulme *et al.* 2001). Poor households faced the risk of a gradual drift towards destitution and an inability to cope. Hospitalisation and cancer illness constituted significant threats to livelihood organisation because they drained material and emotional resources for coping. As pointed out by Freeman *et al.* (2004), protracted illness of family members, especially in rural areas, increases asset disposal, which in turn worsens the poverty situation. The majority of cancer inpatients in the present study had already used most of their assets in earlier treatment prior to admission to the cancer ward. As the cases in this study show, shared poverty and vulnerability between patients and their social networks contributes to the rate at which their physical needs remain unmet (Grant *et al.* 2003; Murray *et al.* 2003). In the face of common livelihood

threats such as drought, the capacity of available social support systems could not safeguard the livelihood security and organisation of individual inpatients and their families. They were, in the long run, grappling alone with vulnerability, in particular through their exposure to contingencies and stress, and their difficulties in coping with them (Chambers 2006; Chambers & Conway 1992). Coping strategies implied a dilemma of jeopardising either family members' livelihood security or the sufferers' quality of life.

Various factors undermine reciprocity, communal solidarity and compassion that would facilitate informal support of cancer inpatients. Cancer management is a long process that negates expectations of reciprocity. The nature of the disease and its treatment exhausts informal support within kin and kindred groups. This means that patients and their nuclear families remain virtually alone too soon, before satisfactory recovery. Similarly, modern economic and social changes contribute to the weakening of indigenous African kinship support (Kayongo & Onyango 1984; Kilbride & Kilbride 1993), which cancer patients could benefit from. Collective solidarity of the extended family, clan, and the ethnic group in many parts of Africa are rapidly weakening due to socio-economic changes and the consequences of serious diseases (Tostensen 2004). Consequently, some patients tried to refrain from being 'burdens to others' by concealing their care needs. Patients in struggling livelihood settings tend to feel guilty about bothering their caregivers or 'being burdens to others' (McPherson *et al.* 2007a, 2007b). Some of the patients were anxious about a possible loss of respect because of their inability to fulfil their social roles and provide for their families as Grant *et al.* (2003) also observed. Chronic illness and prolonged hospital treatment robbed patients of the satisfaction they had once derived from their ability to work. Hospitalisation deprived them of social dignity and a sense of worth, which partly constitute the emotional rewards of self-reliance and perceived livelihood autonomy. Conversely, hospitalisation affected patients' and close family caregivers' participation in informal social security institutions, leading to 'max out' their support from such sources.

The majority of poor cancer patients lacked adequate formal and informal institutional support. They did not benefit from the hospital credit scheme due to a shortage of subsidised cancer drugs. Awarding them credit would also be unsustainable because their treatment is prolonged and expensive. Arguably, awarding credit to cancer patients would reduce revenue collection, which is of course important to the hospital. Most of them struggled to settle bills through their meagre out-of-pocket finances. Their struggle to access hospital treatment and care amounted to an experience of social exclusion (cf. Russell & Gilson 2006). They lacked adequate protection against medical costs, and this deepened their poverty. However, inadequate funding for the health sector in Kenya limits

the acquisition of cancer medicines that poor patients and families can afford. In addition, the hospital debt collection policy may contribute to treatment delays and undue detention of poor patients. Although the government should cover poor people's healthcare needs, it often does not, in practice. As in many developing countries, the poor masses remain unprotected by formal means against main livelihood risks, which include serious diseases (Tostensen 2004; Jütting 2000; D'Haeseleer & Bergahman 2003; Ranson 2002). Life-threatening diseases such as cancer push vulnerable households into absolute poverty and desperate livelihood struggles. Individuals who are excluded from formal financial services may find solace from traditional small-scale rotating savings and credit associations (D'Haeseleer & Bergahman 2003). However, such associations in Kenya are very unstable due to poverty and issues related to trust. Similarly, management of chronic illness rapidly exhausts the chances of support from informal rotational and mutual assistance initiatives.

The introduction of cost-sharing in public hospitals in Kenya removed the most reliable source of formal support for poor patients (Mbugua *et al.* 1995). User fees for inpatient and curative outpatient services were introduced in government hospitals and health centres at the end of 1989 (Republic of Kenya 1989). This followed the economic problems the country had grappled with since mid 1970s that compelled the government to adopt the International Monetary Fund- and World Bank-supported structural adjustment programmes. A credit scheme for hospitalisation and treatment replaced fee-waivers at the referral hospital. However, a majority of the cancer patients could not benefit from hospital credit and the National Hospital Insurance fund schemes. The latter did not serve self-employed or jobless people, and only paid a flat rate for bed occupancy. The Kenyan government's initiative to establish a National Social Health Insurance Fund indicates an awareness of inequality in citizens' access to healthcare. The Ministry of Health envisaged that this fund would address fundamental concerns regarding equity, access, affordability, and quality in the provision of health services in Kenya (Kimani *et al.* 2004). The fund aims to include contributors irrespective of age, economic or social status. However, cancer sufferers will still experience social exclusion, since the proposed fund limits an individual contributor to only five hospital visits per year. There is still a need for policy to protect patients and their families from the overall burden of cancer management.

Conclusion

Expenditure on the management of chronic illness in Kenya as in other developing countries is tragic for household livelihoods. Apart from the impact of previous diagnosis and treatment, admission in the cancer ward entails heavier expenditure due to late referrals. Cancer management both in the hospital and at

home depletes available family resources and threaten livelihood security. The impact of cancer management is cumulative and leads to coping choices that compromise either a patient's quality of life or the sustainability of family livelihood. Ongoing hospitalisation of cancer patients interrupts family members' career development and depletes assets. Inadequate formal and informal sources of support imply that patients and their families soon remain virtually alone to fend for themselves. Exhaustion of social support and feelings of guilt about being a burden to others leads to further isolation of patients. Government policy to increase the attention given to cancer in Kenya can help protect individuals and families from the impoverishing effects of the disease. Giving priority to the protection of cancer patients and their families may mean the government should forgo attempts to generate revenue from cancer management services, instead making concerted efforts to facilitate access and affordability of treatment and pain relief drugs, and inpatient and clinical care. Government action also needs to include policies for sustaining the education of family members affected by the illness and death of breadwinners. Such policies can aim to target the children of divorced or widowed single mothers and people forced into early retirement due to cancer. Government and non-governmental organisations can also support the improvement of cancer patients' living conditions during the hospital treatment process, for instance by helping poor cancer patients follow a proper diet, receive medical examinations, and purchase of drugs.

Hospital ethnography and coping with cancer in Kenya: Conclusions and recommendations

The present study has highlighted a wide array of aspects of the lives of cancer patients in Kenyatta National Hospital; in this conclusion, I dwell on three crucial ones. I will first provide a summary of the most salient findings and then discuss the importance of hospital ethnography as a tool for both research and improved patient care giving. Next I will describe the ambiguity of a stay in hospital, and how the hospital both alleviates as well as increases human suffering. Finally, I will present some policy recommendations on how hospital treatment of cancer patients can be made more bearable and effective for patients and their families.

Summary

This monograph is a result of ethnography in an adult cancer ward in Kenya. The fieldwork took place between August 2005 and July 2006. The broad objective was to study the experiences of cancer patients in a Kenyan hospital and suggest ways to improve conditions in the hospital. Specifically, the study set out to find out how cancer patients felt about and made sense of their conditions and treatment. The second objective was to describe and analyse healthcare issues that emerge from patients' narratives and experiences. The third was to describe and analyse healthcare interactions among actors in the ward and the role patients played in their own care. Fourth, this ethnographic study explored patients' conditions outside the hospital in order to describe the wider social and economic

circumstances of their hospital experiences. Finally, the study aimed to contribute to hospital ethnography as a methodological research tool in developing countries, in particular Kenya. The study was patient-centred and focused on sufferers' experiences of disease and ongoing hospital treatment. This ethnography departed from the more usual way of hospital studies. Most research aims at gauging patient satisfaction in hospital settings, for instance, relying on data collected outside the hospital, often through post-discharge interviews (cf. Long *et al.* 2008: 76). In contrast, the present study situates patients' distress, dissatisfaction and satisfaction within the context of both the reality of the ward as well as patients' own socio-economic backgrounds.

Along with data gathered through observation, individual patients' narratives revealed the insufficiency of cancer management in the Kenyan healthcare system, reflecting social and political factors that shape the circumstances of patients' daily lives in and outside hospital settings (Baer *et al.* 2003). Poverty, unequal distribution of resources and scant access to (scarce) health facilities characterised the backgrounds of a majority of the in-patients. Consequently, late presentation for proper treatment, delayed diagnosis and apparent low survival rates characterised their treatment experience. Most cancer patients get their referrals for specialised treatment at very advanced stages of the disease (cf. James & Chindia 1998; Onyango & Macharia 2006). Those who participated in the present study perceived admission to the cancer ward as a new hopeful phase in their help-seeking trajectory, and had high expectations that the referral hospital would significantly improve their well-being and quality of life. A majority of the patients knew little about the reality of their kinds of cancer, and anticipated full recovery and restoration to health. Negative experiences in the ward environment did not necessarily deter their endurance. In addition, physicians and other hospital staff tended to conceal the reality of the disease and the possible outcome of hospital treatment from the patients. Ultimately, admission to hospital was an additional burden to well-being and caused chronic disruption in the lives of patients and their families. Activities related to cancer management and hospitalisation dominated patients' and their families' lives and tended to replace their normal livelihood struggles and social lives.

The limited interdisciplinary communication practiced in cancer management was apparent during daily activities in the cancer ward. The decentralisation of the available specialists' cancer management activities reduced patient care collaboration. Inadequate space in the ward, a shortage of staff, and the structure of nursing routines constrained the participation of patient support professionals. Numerous practical constraints also affected professional collaboration within the cancer ward and related hospital units. Temporal and spatial factors shape the nature of professional interdependence in the hospital (Reeves & Lewin 2004),

and visibly shaped partnership and interaction among patient care actors in the cancer ward. The social and professional order within the ward relegated patients to the lowest position in the hospital hierarchy. This approach to interaction in medical settings often leads to excluding other aspects of patients' experiences from consideration that may be critical for the implementation of medical recommendations (cf. Rodin & Janis 1982: 32). Although some patients wished to negotiate their own care, they nevertheless adopted the passive role that hospital staff expected them to assume, complying with available care instructions without questioning. Patients were concerned that the hospital staff might construe inquisitiveness and attempts at negotiation for care as resistance. Although patients may be less inclined to participate in decisions about their treatment, they show a strong interest in being well informed (cf. Ende *et al.* 1989: 28).

The patients' current hospital stays in this study reveal only a small part of their long and cumulative experiences of life interrupted. Serious illness disrupts the normal rhythm of life, thereby threatening patients' lifeworld (Good 1994). Their lifeworlds entail a daily struggle for a quality life. However, wider socio-economic issues outside the hospital also have a bearing on the struggle for well-being in the hospital. This ethnography shows that a hospital ward may conceal most patients' livelihood and treatment backgrounds – backgrounds that shape their hospitalisation experiences. Both objective and subjective factors within and outside the medical setting shape patients' interaction and satisfaction with biomedicine. Hospital ethnography therefore facilitates an understanding of an array of patient care issues that other kinds of hospital research may fail to reveal.

Hospital ethnography

Reception in hospital

Hospital ethnography was not familiar in Kenya and the study hospital before the current study. Moreover, medical authorities do not readily receive social science studies, especially qualitative research, in either developed or developing country hospitals. Reception of hospital ethnography is gradual and its success depends on continuous rapport building. Medical staff's reservations about qualitative research reflect a low awareness of its value in promoting patient care. Hospital practitioners' criticism of the fieldwork for this ethnography faded gradually, however, as they began to appreciate its immediate and ultimate contribution to patient care. Their initial criticisms and subsequent enthusiasm for the qualitative research furthermore signalled their commitment to the study. This enhanced our mutual interest in the project, not only as a contribution to hospital ethnography in developing countries, but also as a qualitative analysis of hospital management of cancer. Hospital ethnography is new to the cancer ward, just as it is new to

other medical settings in Kenya. For this reason, medical professionals in Kenya and other developing countries require an acquaintance with ethnography. The process of seeking entrée for this project indicated that medical scientists might have reservations about qualitative research, which they perceive as unscientific and subjective. However, medicine is more than the application of scientific procedures. Personal observation, reflection, and judgment are also essential for the translation of scientific results into the treatment of individual patients (Green & Britten 1998: 1230). In this sense, hospital ethnography systematically pursues research questions that experimental methods cannot easily answer. Although well-designed randomised control trials provide definitive evidence of the effectiveness of particular clinical interventions, there are some health interventions beyond medicine that are not readily amenable to rigorous experimental research design (cf. Popay & Williams 1998: 32). Contemporary hospital studies and clearance protocols tend to focus more attention on quantification at the expense of the qualitative dimensions of healthcare.

The protocol for research clearance in the study hospital did not have a place for hospital ethnography. Some criticisms of ethnographic design by medical scientists for the present study manifested the phenomenon of scientific ethnocentrism (Van der Geest 1995). Medical scientists' may be unwilling to learn about and from social science; they may make subtle efforts to protect disciplinary or professional areas from 'outsiders'. Owing to this, quantitative perspectives may override ethnography and related qualitative methodology. The protocol for hospital research projects focuses mainly on quantitative design with negligible attention to ethnography or qualitative studies. Social scientists working primarily within a qualitative framework may lose their methodological focus in seeking to develop more fruitful relationships with colleagues operating under other research paradigms (Popay & Williams 1998). Medical scientists may also use their institutional and professional power to overshadow hospital ethnography; biomedical scientists' research may make the contribution of qualitative researchers less visible. My entrée and data collection experience illustrated possible unequal social interdisciplinary relationships in health research within the hospital. Advocacy for social scientists to sit on Research and Ethics Committees (RECs), and supportive capacity strengthening for REC members on how to assess the quality in qualitative research protocols (cf Molyneux & Geissler 2008: 691) can promote the role of ethnography in hospital research and patient care.

Healthcare professionals may be suspicious of the presence of social scientists among them. They are often cautious that social science data might fuel undue criticism of their work. This is probably the case because many social scientists see their main role as critical analysts of social processes (including scientific and

health policy processes) rather than as ‘social engineers’ (Molyneux & Geissler 2008: 693). However, the present study demonstrates that even when ethnography focuses on patients’ experiences while they are still in hospital, it does not necessarily result in antagonistic analysis of patients’ interactions with biomedicine (cf. Long *et al.* 2008). Ethnography provides the basis for evidence-based healthcare rather than medicine. This implies going beyond medicine towards individual level interventions in other spheres of professional practice, such as social work, counselling and occupational therapy. Rather than providing data for scrutinising medical practice, ethnography offers an opportunity for hospital practitioners to learn about patients and find ways of increasing their satisfaction and cooperation in hospital care interventions. Data collection conducted while patients are still in hospital offers them an opportunity to disclose their concerns. This is an essential contribution to existing knowledge about patient satisfaction and the quality of care. Patients used the informal conversation situation in this study to let out their pent-up emotions about their illnesses and hospital treatment. Nurses noted that patients who participated in the conversations gradually opened up, and that this improved their communication with them. Patient-centred ethnography in this regard can facilitate patient-centred healthcare during and after fieldwork.

Patient-centred ethnography and care

The ward and hospital systems do not provide an adequate atmosphere for patients to fully express their concerns. Patients in this study were waiting for such an ‘opportunity to complain’ and talk about issues related to their current suffering in hospital. Physician-patient interaction in hospital is often so brief as to deprive physicians of an adequate chance to identify and fully discuss patients’ additional concerns (Robinson 2001). Similarly, patients may worry that the concerns they would express might appear as the kind of subjective complaint that healthcare professionals find irrelevant to their technical interventions, a waste of time, and sometimes irritating. Complaining directly would also contradict their efforts to maintain ‘good patient behaviour’. In day-to-day healthcare interactions, medical professionals tend to limit consultations to physical and medical issues, which systematically constrains patients’ expression of non-medical concerns. As an ‘outsider’, I was a safe audience for some patients; a neutral yet empathetic researcher. Respondents who feel they are at the mercy of other people for receiving essential care may endure perceived suffering in silence. They carefully choose the audience for and timing of their complaints. This helps them safeguard the respect and care of those people they depend on for support. Similarly, Van der Geest (2007b) found that the elderly in Ghana do not complain directly to the younger people they depend on for their material and

emotional needs. Such respondents may view a researcher as a safe audience for them, especially when the anthropologist is an 'outsider'. I was an outsider in the field because I am neither a medical practitioner nor an employee of the hospital; most patients were not afraid of letting out their pent-up emotions in my presence. Noteworthy is the fact that patients on occasion craved to speak about both hospital and family care as part of their emotional therapy.

Cancer inpatients' caution in making direct complaints to and about their hospital carers reflected their fear that complaining openly would compromise their chances for favourable treatment. They were aware that physicians, nurses, kin and other carers shared the burden of their illnesses, and concluded that carers would thus not take kindly what they might construe as a negative evaluation or criticism of their services. Not complaining could on the other hand also denote disillusion with what patients perceived as inadequate care and fruitless hospitalisation. Some of their complaints and concerns described in this ethnography also reflect their experience of discrepancy between very high expectations for hospital treatment and the lived reality. Social and medical histories often only unfold with subsequent hospitalisation, and admission interviews can miss important details that would help patients understand and cope with their suffering. Given these circumstances, a patient's "true" narrative might only come out after some days in the ward, when the patient feels more adjusted and comfortable enough to confide, usually, in a sympathetic nurse (cf. Kirkpatrick 1980: 84), low rank personnel or hospital ethnographer. Less formal interactions with patients help them to reveal their needs and the seriousness of their conditions for both medical and social support. Patients confide more when they feel that they have a more personal audience taking time to listen and empathise with them.

Controlled experiments and surveys can improve attention to patients' objective needs. On the other hand, ethnographic data on their subjective experiences contribute to an understanding of quality of healthcare issues. Analysing healthcare issues from the individual patient's level, as done in this study, provides insight into cancer patients' particular needs, and helps clarify the nature of the patient's experience, symptom expression and behaviour (Singer & Baer 1995). Patients may have similar diagnoses and symptoms, but their lived experiences differ and have to be assessed in their own right. Subjective data from patients in this study provide strong evidence about areas of patient care that would require improvement. Each patient requires unique modes of communication and approaches to diagnosis and treatment disclosures. Contrary to the general view that adequacy of technical facilities and medicine define healthcare quality (Kenyatta National Hospital 2005), important patient care issues go beyond these measures. Evaluation of the quality of patient care is better defined in terms of

patients' subjective concerns than adequacy of medical and physical resources alone. Quality of life should be viewed in terms of the comprehensive definition of health. This refers not only to the absence of disease and infirmity, but a state of physical, mental and social well-being. The measure of health-related quality of life should go beyond the quantitative values derived from self-reported and observed aspects of physical, social, emotional, cognitive, and psychological or behavioural traits. Most data concerning quality of life draws on quantitative assessments, which miss the rich descriptions of patients' experience (Gabe *et al.* 2004). In-depth ethnographic analysis can reveal the dimensions of culture and the patient's experiences of suffering that are important for reappraisal of medical care. Research and medical practice should therefore balance subjective patient experience with objective clinical measurements of quality of care. Patient-centred hospital ethnography in particular highlights important aspects of total contexts of patients' experiences.

Hospital ethnography offers a unique opportunity to assist hospital administrators and healthcare professionals in understanding patient experiences in their unique contexts. It implies a greater focus on the organisation and management of healthcare teams, service delivery and care settings. Data from patients point to the need for more effective ways of managing change at the level of individual professionals. Patients are the main healthcare consumers and hence their views and felt needs are important. They rely on the hospital to improve their well-being, and therefore their appraisal of the medical setting and perceived quality of care deserve consideration. Ethnographic data can help health practitioners become better observers of medical interactions (Stein 1985). Medical interactions often suppress patients' expressions, both verbal and non-verbal, which can inform decisions for their care. Some of the patients I studied, for instance, felt that their conditions would not have worsened if physicians had not made certain decisions. Some patients in the present study held on to the notion that medical intervention could "interfere with disease and worsen suffering". Good observation and consideration of patients' subjective responses can help safeguard patients' quality of life. As an example, they aptly associated increased adversity with some surgical operations and therapies for advanced cancers or tumours. Patients may not articulate their feelings about healthcare decisions in order to safeguard therapeutic relationships. They may accept some interventions under duress when they would otherwise negotiate if hospital professionals gave them an unconditional chance to do so. Patients' non-verbal responses may go unnoticed during medical discussions and procedures. They may not actively express their dissatisfaction in order to avoid antagonising their carers.

Patients' indirect reactions to care in a medical setting may point to important messages for professional carers. Webb (1995), for instance warns that informing

asymptomatic patients of benign conditions they may have that are nevertheless not affecting their quality of life only amounts to creating problems for them. Some patients may be victims of hospitalisation for the wrong procedure or unnecessary treatment. Therefore, it is always necessary to offer patients with certain conditions the opportunity to have nothing done. Some patients in this study seemed to suggest that 'doing nothing' would have been the best option to avoid their current suffering. They felt that they could decline drugs, meals and interventions they perceived as either not efficacious or hurting them further. Awareness of sufferers' subjective experiences is essential for comprehensive hospital management of cancer. An anthropologist working in the hospital can deal directly with some significant issues in-patient care, including quality assurance, patient satisfaction, and evidence-based medicine (Press 1985), and care. Researchers and healthcare providers can draw on hospital ethnography to obtain knowledge that might not be accessible by other methods. In fact, Physicians are increasingly looking to medical anthropology and other so-called 'softer' disciplines like cultural psychiatry, medical sociology and psychiatric epidemiology for answers to existential questions that cannot be reduced to biological or material "facts" (Scheper-Hughes & Lock 1987: 31) Patient-centred ethnography in the present study, for example, elicits data on the different ways in which people interpret and act on illness symptoms and available care. The resulting responses reflect context-specific issues that affect in-patients' quality of life. Integration of findings from qualitative studies in cancer management initiatives can facilitate the development of effective health-care interventions (Entwistle *et al.* 2002). However, therapeutic and care relations in a hospital ward constitute only part of the total context of patients' experience.

Wider hospitalisation contexts

The wider context of daily life shapes hospital treatment, yet it escapes health professionals' full consideration. Similarly, traditional medical and social science studies in hospitals do not consider the details of wider contexts. Hospital studies and care activities should therefore go beyond observation in the medical setting to include the wider socio-economic contexts of hospitalisation experiences. In this sense, hospital ethnography does not limit itself to observations in the ward, but views patients and their worries in the total context of their lives. This encompasses hospital conditions and life outside the hospital, including family dynamics, which affect patients' responses to medical care, as well as treatment outcome. Focusing mainly on what happens to patients in the medical setting yields an incomplete representation of issues in hospital treatment. Relatively successful cancer treatment cases, for instance, involved patients who had wider social networks and better sources of recommended diet, but hospital cancer care

may overlook the patient's socio-economic and cultural backgrounds. Moreover, social and even ethnic identities have significant implications for patients' views about illness and their responses to medical treatment (Kleinman *et al.* 1978; Foulks *et al.* 1986). This implies that patients' narratives that encompass the total contexts of their lives are essential elements of their care. The narratives reveal the significance of patients' socio-cultural and economic backgrounds, and how these may shape the distress patients experience and manifest in the hospital.

Attempts to describe total treatment contexts extending beyond the hospital entail practical constraints for ethnographers. Depicting the wider context of the experiences of patients and their caregivers means including double or multiple fieldwork sites within and outside the hospital, which in turn requires a continuous search for occasions and locations for overlapping patient care contexts. The limited financial and relational opportunities and resources accessible to the ethnographer may impede efforts to depict their study contexts fully (Amit 2000). Hospital workers on the other hand gain some awareness of patients' socio-economic backgrounds through their cursory social and medical histories; however, this does not translate into significant improvement of in-patients' quality of life. The cancer ward staff implemented personal rather than institutional initiatives to address patient needs related to life issues beyond the medical setting. Staff required more time, professional capacity, financial resources and manpower to address the comprehensive issues in the care of cancer patients.

The effect of the inadequate level of healthcare coverage in Kenya is reflected in cancer cases that reach of the national referral hospital. People in rural areas, for instance, have limited access to health facilities and cancer treatment specialists. There is a shortage of qualified personnel and medical equipment for early detection and management of cancer in regional hospitals. Caregivers and researchers in the national and other metropolitan hospitals need to consider these aspects in order to understand patients' delays in accessing appropriate treatment. Various phases of treatment delays characterise the health-seeking behaviour of patients in Kenya as in other developing countries. With reference to their study on maternal mortality in Haiti, Barnes-Josiah *et al.* (1998) suggest a three-tier framework for understanding treatment delays. This framework comprises delays in deciding to seek appropriate medical help, reaching appropriate medical facilities, and receiving adequate care at the correct facility. However, hospital practitioners often impute the main responsibility for treatment delays to the sufferers. Physicians' statements to patients on occasion may suggest that patients (and their relatives) are to blame for the advanced stages of illness (cf. Hunt 1995: 306). Such placement of blame also extends to discourse on the incidence of interruptions in treatment. Hospital workers in the cancer treatment centre and ward for example, often asked patients "where they had been" up to that point,

since the disease was so advanced. Such interrogation reflects the assumption that poor patients' ignorance and inappropriate health beliefs underlie their late presentation and inconsistent adherence to hospital appointments. Conversely, inadequacies of the healthcare system and slow-paced referrals affected most of the patients. Similarly, many lacked access to prompt diagnosis and treatment due to poor infrastructure, poverty and related socio-economic issues.

Many patients had to endure fresh investigations and prolonged tests to verify their disease. Previous experience with protracted examination phases and multiple referrals did not guarantee a precise diagnosis. The poor quality of life and suffering among patients in the cancer ward was in continuity with their previous treatment experiences. Inadequate healthcare conditions before admission in the referral hospital worsened patients' overall suffering. Medical records and personal accounts of previous treatment indicated several months or years of fruitless help-seeking. Many patients and caregivers spent a lot of time and other resources treating the 'wrong illnesses' due to misdiagnoses. Others stayed longer in the cancer ward for supportive care, which they could not find at home or in regional health facilities. An array of social and economic factors contributed to prolonged treatment and poor outcomes. Some patients for instance did not turn up for subsequent hospitalisation due to lack of money for transport fare to the hospital. Poor economic backgrounds also affected the nutrition status of many patients in the ward and at home. These factors shaped the duration and outcome of hospital treatment processes. Interruption of treatment was related to different issues of patients' greater circumstances that may not always have been visible to medical professionals and researchers, whose observations are limited to hospital spaces and events. There were numerous cases where hospital staff lost track of discharged patients whom they nevertheless expected to return for treatment follow-up appointments as required. Inconsistencies in treatment and clinical evaluation concealed underlying causes that often escape staff scrutiny in the hospital. These constitute intricate social and cultural circumstances that link hospital experiences to what was happening in the outside world.

Hospital care efforts tend to pay attention mainly to what is visible in patients' physical and other currently observable conditions. The social and medical history that hospital staff record upon admission tend to be almost exclusively the concrete facts that serve as the basis for treatment and care decisions. Many of the contextual issues that shape past, present and future treatment and care outcomes frequently remain unaddressed. Both social scientists and hospital practitioners need to be aware of the comprehensive issues that shape patients' experiences of disease and treatment outcomes. Unfortunately, many of the problems that hospital practitioners may perceive as non-technical attract the least attention. Conversely, patients' extra concerns may signal important medical and

psychosocial problems that need attention in order to promote the patients' well-being and quality of life. These 'extra' concerns further indicate the different dimensions of support that patients need in the hospital and at home. Apart from medical treatment and physical support, cancer patients also crave social support that can endure hardship during their treatment processes. Social support includes social relationships that enhance a sense of self worth among patients and offer them resources to deal with daily difficulties (Gabe *et al.* 2004; Nichter 2002). Patients also struggle to secure instrumental, financial, and informational appraisal and emotional support. Berkman *et al.* (2000) aptly consider these attributes of patient support to be the four most important dimensions of social support. These aspects are also relevant in attempts to understand the struggles of patients and their families in the process of cancer management.

Financial and material support for poor cancer in-patients and their families was negligible during their treatment. The support declined with the frequency of hospital admission and length of stay in the ward. In addition, both patients and their relatives operated in a context of inadequate informational support. The flow of information in the ward was low, increasing uncertainty and affecting the organisation of daily lives and treatment. Medical and other hospital staff were aware that not telling patients the truth was in the long run more harmful than advantageous to patients and their families. While a frank appraisal, including a possible timeframe for death, may be painful and traumatising, it would have helped better prepare families for issues such as management of estates and property. This would have eased livelihood transitions and improved continuity after patients' devastating hospitalisation sessions or death. Many cancer in-patients sooner or later succumbed to their illnesses, leaving affected families in noticeable disarray. Nevertheless, physicians and nurses found it difficult to disclose negative information about cancer and hospital treatment outcomes, and wished to inspire and safeguard patients' hope. This further shaped the ambiguity of hospital stays, when hope, fear and uncertainty characterised patient-caregiver relations and patients' subjective experiences of hospitalisation. Healthcare professionals exacerbated the ambiguity as they attempted to impart hope by withholding crucial information. Some of this "guarded information" was available to relatives, but they tended to conspire with the ward staff not to tell patients. The hospital was thus a context of increasing disillusion rather than sustainable hope, partly due to inadequate communication with patients about cancer. This further resulted from insufficient support for individual participation in appraisal of the hospital treatment process. Appraisal support encompasses the way various patient care actors make decisions, agree on courses of action and communicate them. Informational and appraisal support hinge on physician-patient relationships. Physicians' good communication behaviour results in a positive impact on

patient health outcomes, and vice-versa (Clark 1987; Arora 2003). Poor communication between physicians and patients may result in patients' resistance to hospital treatment and care.

The hospital and cancer patients' plight

Ironically, the hospital turned out to be a place of increased suffering rather than a haven of cures, pain relief and healing for many patients. Unrelieved pain and eating difficulties for example probably indicated to them the failure of the hospital to deal with cancer. Experiences of the disease, treatment side effects and limited hospital intervention alternatives increased perceived suffering. However, the patients' perceptions of the hospital as a centre of medical excellence (cf. Markovic *et al.* 2004) restrained their absolute resistance to hospitalisation. Admission to the cancer ward represented a significant yet transient stage in a long trajectory of help-seeking. Cancer illness and hospitalisation experiences increased the burden on their already weak livelihoods. As patients endured their hospital stays and treatment, their dependents' destitution was worsening. Some patients viewed the hospital as an embodiment of increased pain and imminent death. It was a symbol of an ominous separation from their families before adjusting to the growing possibility that their families' lives would continue without them.

Patients' narratives of social and medical histories portrayed current suffering as if it were the continuation of daily life adversities. This implies that cancer as a subjective problem is not limited to the disease process *per se*, but incorporates a much broader experience of its disruptive effects (Hunt 1999: 310). As the present study has shown, low-income cancer patients do not view the onset of cancer as a separate phenomenon in their lives. It is part of the evolution of hardship and suffering which they can link to other unpleasant daily life events. The patients reconstructed narratives of help-seeking in relation to other daily life hardships, which contributed to the deterioration of their well-being in a cumulative manner. They viewed admission to the referral hospital as the climax of daily life adversities that required comprehensive solutions. Conversely, the hospital tended to create more problems for patients than that it contributed to the improvement and protection of the quality of their lives. The onset of cancer and its protracted treatment characterised a more remarkable form of biographical disruption (Bury 1982; Radley 1993). The disruption that hospital treatment of cancer caused was more catastrophic than the hardships the patients and their families had experienced before.

Hospital treatment meant an additional strain to physical, emotional and social well-being. The experience of life in the cancer ward symbolised a biographical disruption that threatened a whole personal and family lifetime. The referral

hospital instills ambivalent feelings in a lot of cancer patients in Kenya. It is the place that low-income patients consider the ultimate source of hope for normalising the physical, social and emotional lives that serious diseases disrupt. In fact, however, the hospital turned out to be a transient place for cancer patients' persistent medical and healthcare struggles. The cancer ward was on occasion a lonely, frightening and depressing place. Hospitalisation seemed inconclusive to most patients, and each discharge served only to remind them that they 'still had to fight on'. Seeing the bodies of fellow patients who did not make it being taken out of the ward was a terrifying experience. The hospital in this sense exhausts rather than improves cancer victims' well-being and quality of life. The hospital in this sense is not necessarily a hopeful haven for cancer patients seeking restoration of their physical functioning and alleviation of suffering.

No haven for suffering patients

The adult cancer ward mainly served low-income patients. Those who have access to the referral hospital are a self-selected category from a poor socio-economic background. They are often suffering from advanced stages of cancer at the time they begin specialised treatment; for this reason, admission to the referral hospital inevitably entails radical treatment that causes additional physical and economic hardship. Treatment causes more severe side effects as patients and their families enter more expensive phases of their health-seeking struggles. The hospital thus causes more physical and emotional suffering, rather than the relief that patients and their families anticipated. In such circumstances, hospital practitioners feel morally obliged to help patients sustain hope for treatment success, and try to motivate them despite the poor prognosis most patients actually have. Depending on the type of cancer, physicians contribute to patients' high expectations through the reassurance that 'something can still be done,' even though cancer treatment specialists can predict the degree of positive and negative outcomes of current and subsequent hospital treatment – and often the outcome was negative (cf. Karla *et al.* 1985). From the physicians' perspective, disclosure of the reality of the disease and treatment outcomes in this sense would negate both the significance of hospital intervention and patients' confidence.

Physicians provided patients with authoritative validation of their hope for a cure, justifying treatment and strengthening patients' determination to endure therapy. Desperation in the ward interrupted patients' hope and medical staff's dedication. Silence during first two days of weekly chemotherapy sessions was ominous as this belied untold discomfort. Consequences of cancer and treatment side effects such as vomiting, diarrhoea and foul wounds worsened the sense of suffering in the ward. Being a patient, hospital worker or an ethnographer in the

cancer ward is therefore both distressing and upsetting. Positive thoughts about the hospital helped patients cope with the despair that resulted from personal experiences of suffering and those they witnessed. It helped patients endure the physical discomforts associated with cancer and hospitalisation when they fostered positive thoughts about the hospital, for instance the hospital as 'the place that has helped many people'. The team approach which patients perceived among healthcare professionals was an additional strength of the hospital relative to other public hospitals that attempted to ease patients' physical suffering. Although prolonged diagnostic tests, medical examinations and treatment implied uncertainty for long-term patients, they nevertheless commended the hospital for not rushing examinations and treatment decisions.

Gradual or dramatic deterioration of physical health coincided with admission to the hospital and subsequent treatment in the cancer ward, and contradicted the expectation that the hospital would necessarily improve sick people's health. There was great variation between patients' and hospital practitioners' views and expectations regarding successful hospital treatment and care. Patients' evaluation of the consequences of hospitalisation for well-being is both subjective and objective. Their physical and emotional suffering is a lived reality that resists an entirely scientific articulation (Frank 2001). Medical professionals' attempts at objective diagnoses may not capture all the aspects of suffering unique to particular patients. The patients I studied, for instance, indicated that some drugs, diagnostic and treatment procedures and food increased their physical distress. They blamed this on hospital workers who ignored their attempts to give details of their experiences. Patients who 'suffered in silence' felt that hospital workers either failed to understand them or did not have the capacity for appropriate and humane empathy.

Unremitting pain, eating difficulties and adverse treatment side effects increased with length of hospital stay. Similarly, subsequent admissions to the hospital did not always translate to better physical health. From the patients' point of view, this trend indicated the futility of hospital treatment. Their narratives indicated the connection they perceived between hospital treatment and their physical deterioration. This partly explains cases of patients' absconding from treatment, missed hospital appointments and treatment inconsistency. Owing to dissatisfaction with the hospital, patients may choose to return only when they are unable to bear their physical suffering at home any more. The hospital accelerates the deterioration of such patients due to unforeseen treatment delays and a lack of drugs and requisite treatment facilities. It is in this sense that some patients construed the hospital as a place where interventions 'interfere with' cancer, but fail to fix it well. Some attributed the onset of pain and additional physical problems to surgery, diagnostic procedures and available medi-

cines. It is, however, the lack of facilities and variety of patient care resources that constrains health professionals' efforts to relieve physical discomfort.

Shortages of resources in the study hospital constrain the provision of effective solutions to patients' physical needs. These range from pain relief to professional support through physiotherapy and occupational therapy. Physicians for instance prescribed ordinary painkillers, such as Paracetamol, which is not effective for the relief of severe pain. Morphine, the most effective painkiller, was not readily available to cancer patients. On the one hand, the Kenyan government categorises this analgesic as a narcotic, which in and of itself puts the drug almost out of poor patients' 'reach. Legislative and logistical difficulties further limited the accessibility of this drug for patients in Kenya, as in other developing countries (Kinyanjui 2006; Koshy *et al.* 1998). Morphine was only available through seven privately-owned hospices, and was not available in public health institutions. Only a few of the patients in this study could afford morphine while in the hospital and at home, and they acquired it through the Nairobi hospice.

The scarcity of effective analgesics and professional support to address physical needs accounts for the feeling among some of the patients that it was better to be an outpatient than an inpatient. While it is true that nurses and physicians may delay responding to patients' calls for help, they may also have little opportunity to meet their physical needs due to the shortage of hospital facilities and human resources. Due to these circumstances, the ward staff could offer only brief attention to patients' calls for help. On occasion, they attempted to cope through uneasy humour about patients' concerns about their physical well-being. Similarly, premature discharge from the ward without significant relief was a desperate means of coping with patients' distress and the inability of the hospital to respond effectively. Such are the circumstances in which patients may feel let down by the limitations of medical intervention and technology (Bury 1982). Disillusion also results from the realisation that the hospital may not necessarily have solutions for all physical problems. The patients in this study gradually perceived the limits of medical knowledge as precise diagnosis and treatment tended to be elusive. The hospital met their physical needs only for the short duration of the initial stay and could not guarantee this in the long run. A growing sense of general disappointment is the result of long-term hospital stays, subsequent admissions for emergencies, and the perceived low-efficacy of treatment regimes.

Discharge from the hospital does not necessarily imply an improvement in health as patients expect. Many patients made trips back to the hospital for treatment and reviews until they were physically or financially unable to continue doing so. Others gave up quickly and did not return for further treatment or review due to understated disillusionment. They evaluated hospitalisation in

terms of perceived costs relative to other needs. They may perceive a hospital stay as worthless if the costs are not commensurate with their subjective experience of physical relief. Subjective experience of physical symptoms – especially pain – influences patients' views of the value of hospitalisation (Mulemi 2008: 128). Some patients and ward staff associated the persistence of physical illness and drastic deterioration with available treatment. They feared that particular therapies were harmful and even lethal. Although such explanations may be subjective, the hospital did not provide sufficient remedies for negative treatment side effects. Complainants did not access alternatives to medicines they associated with physical discomforts. Since the hospital was not dealing with patients' physical needs effectively, it failed to be as "different from home" as they expected. However, poorer patients who did not have access to medicine and good food at home were content with whatever was available in the hospital, and may not have minded staying longer.

Patients' subjective and objective experiences of physical suffering reflected the circumstances of insufficient hospital resources. In addition, communication between patients and hospital staff about distress was inadequate. Difficulties in such communication arise from a lack of linguistic equivalents to express the reality of suffering. Patients also rightly pointed out that people who are well are unable to relate to the experience of being sick. Medical professionals may overlook or dismiss, as they often did, patients' expression of physical difficulties, including eating problems. As expected of medical professionals looking for an objective reality of pain and other physical discomforts, patients' complaints appeared to them to be insubstantial problems that existed 'only in their heads or minds'. Attempts by medical practitioners to objectify pain often negated their efforts to prescribe suitable remedies (cf. Scarry 1985: 5; Emad 2003). Cultural and language differences between patients and medical staff affected communication about the phenomena of physical suffering. Moreover, physicians may be reluctant to address issues in patients' physical well-being which may be subjective. The medical professionals may not feel comfortable initiating such talk, or language and cultural barriers may constrain the discussions (cf. Koshy *et al.* 1998: 433). These factors, coupled with lack of time to listen to the details of patients' suffering, also contribute to inadequate attention to their concerns. The patients perceived two main difficulties in seeking solutions for their physical problems: first, available medication did not relieve pain symptoms, eating difficulties or treatment side effects; second, they felt that some staff did not empathise enough to respond to their concerns appropriately. Distressed patients tended to resist therapy and hospital food, which they perceived as increasing their suffering or not improving their health. Unmet physical needs and related livelihood issues had an impact on sufferers' emotional well-being. The hospital

symbolised more emotional disruption than solace for most of the cancer inpatients.

Emotional disruption

Hospital stays become progressively more burdensome for cancer patients and their relatives. The hospital turns out to be a place where perennial illness and protracted treatment cheat the patients out the little hope they retain for the future. While they struggle to 'endure bravely' or 'cope' with the disease, it continually infringes upon their self-confidence and upsets their already precarious livelihoods. Hospitalisation entailed additional emotional suffering since it threatened social relationships as well as material and practical affairs. Hospital stays in this sense increased existential concerns and thus worsened patients' emotional suffering. The hospital environment *per se* was emotionally upsetting as it exposed patients to many unpleasant phenomena. These call for strength of personality and social support, two important coping resources in the face of life-threatening disease and emotionally taxing treatment circumstances (cf. Halim 2001; Norberg *et al.* 2005). Cancer patients in this study grappled with emotional difficulties that resulted from phenomena such frequent exposure to death and very ill fellow patients. The state of the cancer ward exposed patients to hopelessness, death, anxiety and disappointment. The hospital attempted to address patients' existential and, by extension, emotional suffering through two chaplains and two freelance religious workers who occasionally visited the cancer ward. In spite of these efforts, patients struggled to cope with perceived loss of self worth, personal identity disruption and a sense that life is meaningless.

Emotional vulnerability is recurrent with cancer patients' subsequent hospital admissions. Their overall quality of life depends on emotional stability, which is an important resource for coping with chronic illness. Emotional suffering is as significant as physical suffering, yet there was limited hospital recourse for it. Delayed treatment, delayed staff responses to calls of distress, and inadequate support from personal social networks made patients' emotional distress worse. Such circumstances prompted patients to pester hospital staff and relatives to discharge them prematurely. Ironically, it tends to be the sickest and most dependent patients who most dislike the hospital and are anxious to leave, although they are the least likely to be able to leave (cf. Roth 1972: 429). This results from the distress of dealing with the disease and confinement to the hospital environment and routines. Inpatients may withdraw from social and therapeutic interactions in the hospital as an expression of disappointment or resistance. Alternatively, they seek relationships and interactions that can ease the effects of upsetting hospital conditions. However, the as well as the patients' unfamiliarity with fellow patients or visitors limits the scope of these interactions.

Emotional disruption in the hospital may result in patients' resentment of their carers. This also shapes the trends in patients' acquiescence. Personal emotional qualities and temperament influence patients' utilisation of available material and non-material resources to cope with the emotional disruptions that medical settings cause (Halim 2001). Patients in this study acknowledged their impulsive bad moods, which they blamed on cancer and the unpleasant hospital environment. Similarly, the actual interaction between hospital workers and cancer patients is a source of stress and may lead to avoidance behaviour in doctors and nurses. This affects patient satisfaction and emotional well-being. Due to heavy workloads and a poor working environment, for instance, some nurses and physicians cannot help responding to the patients' demands at times with anger. This contradicted patients' expectation of understanding and compassion. Some respondents compared themselves to small children to describe their perceived helplessness, and the amount of care they needed and expected. Lived experiences of cancer and treatment influence patients' expectations of compassionate care (Greene & Adelman 2003). They acknowledged several nurses' efforts to meet their needs, which for them had emotional implications. Such efforts included helping patients to the toilet, bathing them, facilitating their oral medication and preventing accidents. They commended nurses who realised that 'cancer patients are like children'. They expected nurses to take on a 'mothering role' (Coser 1962). This role entails gestures and treatment which patients view as polite and humane. Appropriate treatment and care in this regard includes prompt and sympathetic responses to calls for help. From the patients' perspective, nurses demonstrated emotional support through willingness to bathe, feed, chat, run errands for and comfort patients.

Patients are often unable to talk to doctors about their emotions because doctors approach them with a series of brief, direct questions in an interview format. This hinders the ability of the healthcare providers to understand patients' psychological problems. Social and family emotional problems are usually resolved through discussion, not medication, which is the common hospital practice. This approach is typical of medicalisation at the level of doctor-patient interaction, where doctors attempt to define patients' problems as medical in order to prescribe medical treatment. In the medicalisation process, non-medical problems are classified and treated as medical problems, usually in terms of illness (Gabe *et al.* 2004; Helman 1994). This makes patients and their families too reliant on doctors' medical prescriptions. Medical remedies such as sedatives to allay psychosocial problems may be unavailable in the hospital or fail to solve patients' emotional problems. Emotional suffering may reflect more what is outside patients' bodies than what is inside. Conversely, medical practitioners may fail to recognise signs of somatisation of personal distress. Somatisation

refers to patients' expressions of personal and social distress through bodily complaints and medical help-seeking. Physicians may in turn engage in somatisation, responding to physical complaints by ordering tests and medications. They are troubled when they cannot find a biophysiological abnormality to account for a patient's distress, and they often run many tests in the hope of discovering a quantifiable abnormality (cf. Padgett & Johnson 1990: 206). However, solutions to patients' personal distress could be achieved by encouraging them to verbalise their thoughts, imaginations, fears, and feelings. Regrettably, a shortage of professional patient support staff, as indicated earlier, limited the hospital's potential to deal with patients' non-medical needs.

The expression of positive thoughts facilitated patients' coping with emotional and physical distress. Hope or adaptation idioms evolve as forms of psychological adjustment to trauma and anxiety that result from negative phenomena in the hospital. Physicians and nurses reinforced hope idioms, which strengthened patients' resilience. Both patients and hospital staff engaged in talk that promoted 'positive thinking' about the hospital and treatment outcomes (cf. Wilkinson & Kitzinger 2000; Good *et al.* 1990). Familiar and innovative hope idioms focused on concerns about debilitation, delayed healing and death. Hospital staff and other actors in the cancer ward couched encouragement in religious terms, which contributed to the resources for coping with the emotional consequences of hospitalisation and perceived limitations of medical technology. Thinking positively about the ward and treatment outcomes facilitated patients' focus on recovery. Hope idioms also helped hospital workers cope with the reality of poor outcomes of cancer treatment in Kenya. When compared to physicians in other medical specialties, oncology doctors are likely to feel more challenged by the nature of their patients' disease and especially the possibility of treatment failure. This reduces the possibility of enhanced self-image because they have to make intellectually challenging diagnoses and are unable to heal as many patients as their counterparts in the other wards. This in turn reduces the degree to which they can enjoy the gratitude of patients, their families and the community.

The hospital was a source of temporary refuge against stigma. The time that visitors and hospital staff spent with patients reduced feelings of isolation and stigma significantly. The hospital merely reduces individual isolation from fellow sufferers with whom cancer patients can share their experiences. It also minimises the magnitude of stigma they are likely to experience in the outside world. The outside world is a 'civil place' where people with cancer often encounter difficulties such as undue curiosity, uneasiness, avoidance and lack of tact (Wilson & Luker 2006). However, the present study shows that the hospital is not necessarily a place where stigmatisation is not an issue. The company of fellow cancer patients offers the opportunity for comparing experiences and how

to deal with suffering and associated stigma. However, responses of hospital carers and visitors always portray cancer patients' conditions as exceptional. Some patients felt that their problems did not receive adequate attention because the hospital isolated them as victims of an already-known fate.

The hospital not only failed to meet physical needs adequately enough for it to qualify as 'different from home', but also fell short of offering the reliable emotional support patients needed in order to 'feel at home'. The presence of compassionate hospital staff, fellow patients and visitors only rekindled hope that the hospital, as a place for a perennial medical struggle with cancer, could 'miraculously' restore the disrupted quality of life. The hospital is therefore a place in which some patients momentarily share experiences, find some points of common understanding with carers and enjoy mutual support among fellow sufferers (Kelly *et al.* 2004). Patients had opportunity to learn how to endure and manage the disease from fellow patients. The hospital was a meeting point for patients, most of whom did not have access to associations out of the hospital. The knowledge gained through such interactions varied with the patient's type and stage of cancer and relative length of hospitalisation. Fellow sufferers welcome each other into an association of mutual support that is limited to the treatment period. A patient benefits from the experience of others, who offer instructions on how to manage himself (or herself) physically and psychically (cf. Goffman 1963: 50). In this sense, patients credited hospitalisation with either helping them learn how to cope with cancer, or with providing them with a setting for mutual consolation.

While it is true that cancer patients enjoy consolation from and the company of others in the ward, the hospital limits participation of kin and other social networks. Hospital rules, procedures and relationships in Kenya inhibit the contribution of informal carers. However, kin and friends can play a positive role in meeting inpatients social and emotional needs. Roth (1972: 426-428) argues that inpatients need an informal 'agent' or 'escort' to help them better control their situations in the hospital. This would help them deal with emotionally disruptive phenomena, which include perceived treatment errors, accidents and difficulties in accessing doctors during distress. Being in hospital as an inpatient does not guarantee prompt attention for significant symptoms or discomfort. Similarly, patients find hospitals very unpleasant, entirely aside from the side effects of their illness or diagnostic and treatment procedures (Roth 1972: 428-430). Moreover, many people experience great discomfort, suffering and incapacitation resulting from cancer treatment procedures (Bond 1987). The frequency of cases in the study ward that attested to the fact that treatment outcomes and long-term survival of patients is uncertain increased the unpleasantness of the hospital. Patients therefore require more time and interaction with kin and other informal

carers to ease their emotional strain. Some patients have difficulties interacting with fellow patients and hospital staff, which isolate them further. The hospital thus embodies additional struggles in the mobilisation of non-material and material coping resources.

Mobilisation of material resources

The impact of cancer management on livelihood is progressive and cumulative. In many cases, the help-seeking process involves expenditure of social and financial capital on both biomedical and alternative therapies. This inevitably draws individuals and their families to rearrange their wider personal and community associations. The presence or absence of a supportive social network may make a significant difference in the course of hospitalisation. The disease and the hospital are often at the epicentre of the disruption of reciprocity and community involvement in daily livelihood struggles. The hospital embodies functional limitations as patients and their families experience chronic disruption in their livelihood organisation as they attempt to mobilise resources for medical treatment. The experience of cancer inpatients in this study further illustrates that the hospital increases social isolation and dependency, which flow from regular and prolonged disruptions of social interaction. The hospital increases expenditure, which threatens personal and household livelihood security.

This study shows that the referral hospital in Kenya is the place where cancer patients and their families endure the most intensive and expensive care activities. When a member of the family is affected by cancer, the hospital either facilitates or hampers the mobilisation of resources for treatment and other needs. As seen in this study, within a span of six months to one year, hospital treatment affected the livelihood of patients and healthy family members significantly and irrevocably. Hospitalisation threatened livelihood and social security as it either diverted family assets to meet medical needs or alienated productive household members from their regular livelihood activities. The chronic illness and death of a patient, especially when he or she was the breadwinner in the family, worsens livelihood insecurity and vulnerability. As medical bills escalate, destitution of poor families and dependent members increase. The ability of a household to avert the loss of production and resources due to disease depends on household size, composition and assets, as well as the type and duration of the illness (Sauerborn *et al.* 1996). Households with more dependent members and fewer disposable assets suffer more when a member is admitted to hospital. Chronic illness, incapacitation and death worsened the livelihood stagnation and insecurity of affected households.

The hospital can thus be seen to impoverish cancer patients, their families and social networks. Initial treatments in peripheral hospitals before precise diagnosis

and transfer to the national referral hospital had already caused patients' gradual asset depletion. Livelihood exhaustion is often drastic during hospitalisation sessions in the national referral hospital. Overall treatment, coping and recovery costs are frequently higher and more difficult to cope with due to the greater expense of caring for patients with advanced stage cancer. In this way, livelihood problems associated with the disease are seen to increase especially when disease prognosis is either poor or uncertain. More hardships arise from treatment expenditures and lost time and income of both the patients and the people caring for them. Hospital management of cancer in the Kenyan continually intrudes and upsets the already insecure livelihoods. Poverty and social instability characterised the lives of a significant proportion of the cancer in-patients in this study. When health problems arise, an already fragile existence is further threatened, leading many to suffer demoralisation and depression (cf. Padgett & Johnson 1990: 208). The cancer ward in this regard embodied the fate of the poor masses in Kenya. As the present study shows, the experience of the cancer patients should be understood with reference to the larger social problems.

Drawing on the critical medical anthropological perspective highlighted in Chapter One, the results of this study confirm that biomedicine may perpetuate social inequality. Victims of inadequate primary healthcare end up in an under-served public hospital ward where they find difficulties in mobilising resources to cope with advanced cancer. The hospital is both an expensive and unpleasant place particularly for low-income cancer patients due to at least three factors. First, both subsidised cancer drugs in the public hospital and those available in private pharmacies are quite costly. Frequent shortages of subsidised drugs in the hospital often cause financial crises for patients. Secondly, the fact that patients arrive at the hospital with advanced stages of the disease means that they may require more expensive treatment regimes and additional remedies. Finally cancer treatment is prolonged and requires multiple hospitalisations, even after completion of basic courses. Therefore, hospitalisation strains available financial capital and adds pressure to patients and kin. The hospital takes up most of the available personal savings, pensions, credits and remittances. This threatens future livelihood capacity as cancer patients and their kin sell their assets and postpone or fail to invest in their livelihood security in order to cover costs.

The daily lives of cancer patients in the hospital reveal their individual points of vulnerability. The disease and the hospital expose them to contingencies, stress and other difficulties incumbent in coping with them. Unexpected treatment outcomes such as adverse side effects necessitate frantic efforts to access extra material and emotional coping resources. This subjects individual patients and entire households to additional livelihood risks and shocks. Inpatients are not only unable to work, but also become a double burden to society. Chronically ill

patients are often concerned about this fact. Family assistance focuses mainly on the inpatient and he or she may feel guilty about being a burden to others. The hospital increases the problem of self-perceived burden as patients are always aware that their personal suffering and care exhausts resources available to their social networks (McPherson *et al.* 2007a). Consequently, patients tend to be bitter and keep their suffering to themselves. Friends and relatives tend to reduce their assistance gradually and this characterises the hospital as a place of increasing loneliness. Isolation increases with the frequency and length of hospitalisation, which results in guilt, distress, feelings of responsibility and diminished sense of self (McPherson *et al.* 2007b). Diversion of financial and social capital to the hospital further exposes the family to poverty and disease. Hospital treatment for cancer poses critical competition for resources against an array of other individual and family welfare needs.

The majority of cancer patients in the present study lacked formal institutional support during their hospitalisation. Either they were not in formal employment, or they earned meagre salaries. People in informal livelihood enterprises or employment and low-paying jobs did not have the benefit of private health insurance. The National Hospital Insurance Fund (NHIF) is the health insurance coverage that is accessible to most people working in the public sector. Most of the unemployed patients had not found ways of sustaining their membership to the fund. Although a monthly contribution of 30 shillings is considered affordable for unemployed people, this may be unrealistic for peasants living below the poverty line. Thus the NHIF excludes a majority of the unemployed rural masses. The fund also only covers the daily hospital bed charges and basic services at a fixed rate, leaving poor cancer patients with still-unaffordable hospital treatment bills. Cancer inpatients thus represent the masses that experience social exclusion due to inadequate health insurance coverage (Russel & Gilson 2006). The study hospital in general and the adult cancer ward in particular reflect the exclusion of the poor from decent healthcare coverage and means to safeguard the quality of their lives in times of adversity. The hospital credit system for patients does not benefit cancer patients. The patients and their families in Kenya bear the burden of healthcare costs, as medical care is not adequately subsidised (Grant *et al.* 2003). Therefore, coping strategies impose trade-offs that jeopardise either the patients' quality of life, or the livelihood security of entire families. Cancer patients, like other sick people, expect that admission to the hospital can eventually restore their lives and facilitate improvement of their quality of life. However, low-income patients experience the hospital as a place in which their general condition deteriorates rather than improves with time. The hospital in this sense increases the physical and emotional suffering and worsens their personal and family livelihood adversities.

Recommendations

This ethnography has portrayed the desperate efforts of patients, families and hospital professionals to manage cancer. Several practical and policy concerns are apparent from the preceding description and discussion.

Recommendations for hospital practitioners

This study has demonstrated that engagement of social scientists in medical research environments both as participants and as participant observers, and not only in field settings but also in medical practice and policy environments can contribute substantially to understanding the social, economic and political contexts of health (cf. Molyneux & Geissler 2008: 686). Healthcare professionals and researchers should consider incorporating ethnographic approaches in their practice. This can facilitate in-depth understanding of both medical and non-medical needs of suffering patients. The standard interaction between patients and hospital actors is formal and follows less flexible routines for healthcare and research procedures. Such approaches have very little room for patients to give a detailed account of their lived experiences. Therefore, hospital practitioners ought to allow and encourage patients to 'complain' about their treatment and care. Inclusion of hospital ethnography in hospital practice and studies is essential for the improvement of the quality of feedback on inpatient care. Medical research and practice should allow patients to express their subjective or lived illness experiences. It is important to consider the subjective experiences that have both negative and positive consequences for cancer sufferers' quality of life. Communication in this regard should enlist patients' regular participation in informative discussions. This may reduce disillusionment and desperation during extreme suffering. In addition, informal communication on an array of patients' concerns can assure them that their carers empathise with them.

Health communication in the hospital should focus on everyday symptoms and pay special attention to adverse side effects. Medical and nursing staff needs to focus on mitigating both physical and emotional suffering that arises from disease, the medical setting and from sources in the wider contexts of patients' experiences. The patient always seeks relief from symptoms, anxiety, and uncertainty, whereas the physician seeks diagnosis and intervention. Due to the different perspectives from which patients and doctors view cancer and its treatment, there is an essential failure in communication with regard to patients' deep-seated emotional issues. Physicians should, for instance, consider patients' sentiments about how cancer and treatment affect their social roles and identities. To this end, considering how patients and their family carers crave adequate disclosure about cancer and expected treatment outcomes, medical professionals should considerately balance the desire to safeguard patients' hope and self-determina-

tion with disclosure of 'bad news'. This is important for gradual preparation of patients and their families for the ultimate outcome of their treatment. Similarly, appropriate advice to patients and their carers about hospitalisation can enable them to make informed decisions on whether to continue or terminate therapy. Without this advice, many patients remain in hospital until they are physically, materially and emotionally too devastated to go on. This negates the desire to improve their quality of life through hospitalisation.

Most cancer patients arrive at the referral hospital after radical interventions such as surgery and mastectomy, which they complain about. However, admission for further hospital treatment should consider the rights of patients to accept or refuse treatment. Since cancer treatment options are generally few in Kenya, physicians and nurses have to take time to explain the diagnosis and available treatment options to patients. Similarly, patients need time to synthesise information regarding their treatment in order to understand its possible outcomes. While the patient has a right to available treatment, he or she also has the right to express his or her personal experiences with the treatment. Patients should have access to any cheap alternative treatments that can enhance their objective and subjective quality of life. Unfortunately, a large proportion of patients cannot avoid radiotherapy and chemotherapy owing to the nature of their diseases. However, they still should be granted the right to accept or decline treatment after an explanation of the advantages and disadvantages of their decisions. This requires clear guidelines for the implementation of informed treatment consent among patients. Patients' full awareness of the implications of treatment and their right to refuse treatment may reduce their tendencies towards self blame or holding hospital practitioners responsible for their suffering.

Hospital practitioners also need discretion in decisions about patients' admission and hospital stay. While it is true that patients have confidence in the hospital as a source of solutions to physical suffering, it is also true that they perceive hospital stay as fruitless at some point. Therefore, medical staff can advise against hospitalisation, which worsen patients' quality of life rather than improving it. Patients develop mixed feelings about the hospital when they perceive the inadequacy of biomedicine and medical professionals in effecting a cure. In recognition of the limitation of hospital intervention in particular cases, medical practitioners can ease patients' suffering by reducing their hospital admissions and their lengths of stay. However, adequate advice about the management of adverse symptoms at home or in nearest health facilities is essential.

Recognising and strengthening the roles of different patient care actors in the hospital is necessary, and more attention should be given to improving the discussion of cases and coordination of patient care activities among different hospital professionals. This is important for communication and professional

feedback on patients' progress. Detailed discussions among the hospital staff, especially after ward rounds, can facilitate useful exchanges of ideas about particular cases. The adult cancer ward in the present study requires more support from medical consultants dealing with different aspects of cancer management. The plight of cancer patients also requires the hospital to recognise and integrate the role of informal carers in its activities. Informal caregivers have the potential to bridge the communication gap between healthcare professionals and patients. Since nurses and doctors may not have adequate time to address non-medical concerns, they should encourage informal carers and auxiliary staff to spend more time with patients. Hospital staff should also encourage patients to support and give information about the needs of others. Recognising and strengthening the participation of patients' informal agents and families can complement hospital efforts to address their social and physical needs.

Hospital practitioners and researchers should appreciate and include the supportive work that visitors and patients offer. The role of visitors in supportive interaction with cancer patients in the hospital was invisible. Visitors have the potential to supplement the work of hospital staff whose medical and technical routines take up all the time they have for patient care. This implies that hospital actors should strive to provide a supportive environment that acknowledges patients' wider social and emotional needs. Inclusion of informal carers should extend to the work undertaken by freelance religious workers in the hospital to complement the work of hospital chaplains. A few patients enjoyed spiritual support in the ward, but more religious workers are required to reflect the religious diversity of the inpatients in Kenya. Promotion of both formal and informal hospital support activities, such as professional counselling and religious fellowships, can make the hospital environment more responsive to cancer patients' emotional needs.

The living conditions of patients in the hospital also deserve attention. This relates to the general ward layout, patients' daily subsistence, and sanitary facilities. Repair and maintenance of physical facilities would protect patients from extra physical discomfort and anxiety about their safety and contracting additional illnesses. The hospital management should also strive to protect patients from emotional disruptions that result from witnessing the suffering of others. The ward staff, for instance, should isolate very ill patients from the rest, as most respondents suggested. Expansion of the ward would also guarantee patients more privacy, which they desire on occasion. It is important to note that the location of the 'private room' (Appendix 2) intensifies fear, anxiety, uncertainty and emotional distress in the ward. The hospital management can reduce anxiety about death among patients by finding an alternative room in which to keep the deceased, ideally outside the ward. Cancer is always associated with fear and

helplessness, and many who have witnessed suffering due to cancer are apt to associate it with looming death. Therefore, it is important to minimise inpatients' chances to witness death. Relocation of the 'private room' and quick, discreet removal of those who succumb to the disease can facilitate this. While this may be inevitable, ward attendants can make death in the ward less obvious, for example by reducing the length of stay of the deceased in the ward. Similarly, an improvement in the meals served in the cancer ward can contribute to making hospitalisation more favourable for patients. This is essential because only a few patients are fortunate enough to receive visitors to who supply home-cooked meals.

Policy implications

This study highlights the necessity of a major commitment to training more cancer management professionals. The hospital was facing great challenges stemming from understaffing. More pathologists are required in peripheral hospitals to facilitate early detection and treatment of cancer. There is a need to increase the scope of learning about cancer and its management in basic medical and nursing training. After basic training, physicians need incentives to pursue a specialisation in cancer management. This implies the need for policy guidelines to provide due attention to preventive and palliative care in medical training. Balancing the training in curative medicine and preventive and palliative care can motivate medical professionals to change their attitudes about serving patients with poor prognoses. Arguably, medical scientists perceive cancer management as an unattractive specialisation due to the low probability that treatment interventions will cure patients. This translates to the attitude that the cancer ward is of low status in the hospital. This is a challenge to the Kenyan hospital and healthcare system to create incentives that can make a specialisation in oncology more attractive.

The shortage of oncologists and other cancer care professionals may also be a result of low political commitment to training in this field. Healthcare trainees require both incentives and funding to train in cancer management. The hospital needs to make specialist training for nurses working on the cancer ward mandatory. After this, the hospital can seek support from the government and international organisations for such training programmes. This will not only benefit patients, but also will equip nurses with the skills for patient-centred care. Improvement of working conditions can also encourage nurses and other carers to tolerate the challenge of taking care of very ill patients. In order for nurses to get a meaningful break from the physical and emotional strain related to taking care of cancer patients, there should be guidelines on engaging additional nurses on a part-time basis. More nurses with training in nursing oncology, counselling and

general palliative care are required in the national referral hospital and regional hospitals.

This study furthermore indicates an urgent need for some kind of centralisation of cancer management in the hospital. At the time of this study, informants reported that cancer patients were 'scattered' throughout different units of the hospital, and that specialists tended to work autonomously. This reduced interdisciplinary interaction and discussion of patient care. The establishment of a proper cancer treatment centre to bring specialists together was long overdue. Such a centre is required for the harmonisation of cancer management in the hospital. Policy for the establishment and actual operation of a cancer treatment centre can facilitate centralisation of cancer management, thereby improving multidisciplinary communication. Centralised management of cancer in the hospital would enhance the all patients' access to consultants with experience in the management of different cancers and related conditions. This requires guidelines for interaction among the specialists and the discussion of treatment decisions. If available cancer treatment experts attend to patients in one unit, the experts can discuss their needs together. This may increase interdependence among hospital professionals to provide patients with optimal care. While it is true that the cancer ward received most of the adult cancer patients, the unit where they first arrived for consultation determined the department or ward in which they were admitted. Therefore, some patients got their referral to the cancer ward after a prolonged stay in other wards in which they felt that they had received little or no assistance. This calls for improved coordination of cancer treatment in the hospital.

The social, economic and emotional plight of cancer inpatients calls for policy on the frequency and duration of their hospitalisation. Appropriate guidelines can help in minimising treatment interventions and hospital stays that increase patients' suffering. A programme to promote home nursing, for instance, can help reduce hospital admission to only those patients who urgently need it. This should also take into consideration the availability of necessary facilities and resources outside the referral hospital. As this study had shown, it may be unavoidable that ward staff discharges a patient because they feel that they are not helping him or her. In such cases, both patients and their relatives become bitter that hospital stay has either negative or no impact on the quality of their lives. Similarly, patients may deem hospital treatment and some interventions such as surgery to be unnecessary. Hospital management should therefore reduce patients' length of stay for investigations that do not result in fruitful diagnosis and treatment. Hospitalisation in such cases frustrates both patients and their caregivers, especially when it becomes obvious that nothing can be done for patients after all. With the possibility of increasing trained health personnel for cancer

management, the national and regional hospitals can invest in home-care programmes. Not all patients need professional medical attendance for the great majority of their time (cf. Roth 1972: 432). Family members and occasional visits by medical personnel can serve as an alternative for patients to travelling long distances to the (referral) hospital.

An adequate pool of trained nurses, nurse aides, physicians' assistants and professional patient support staff is essential for both hospital and home-care initiatives for cancer patients. A mechanism to monitor home-care through the use of mobile phones for discussions, for instance, can reduce unnecessary transport fare costs to the hospital. Some patients and their carers travelled many times for subsequent admission only to be told that they did not qualify for the next course of treatment. Patients and their families could read the diagnostic results from their local facilities to oncology consultants over the phone before their travel for admission. Unnecessary travel to the hospital also relates to instances of over-booking patients for the very few hospital beds.

Cancer management in Kenya also requires efforts to strengthen the capacity of patients, families, community members and religious organisations to contribute to sufferers' quality of life both at home and in hospital. The community in Kenya with its networks of health and local informal insurance systems has the capacity to care for patients at home but lacks adequate resources (cf. Murray *et al.* 2003). Establishment and strengthening of informal and formal support groups outside the hospital can offer patients the opportunity to share their experiences and meet their needs. Post-discharge cancer patients require such associations to help them cope with their concerns about reintegration into society. Hospital care should in this sense facilitate identification of psychosocial difficulties and offer post-discharge support for patients and their carers.

This study highlights inequalities in health and wealth and inadequate attention to cancer in Kenya. This is a policy concern for Kenya, as well as for other developing countries, and the world as a whole. Cancer is and has been relatively neglected in developing countries, a consequence of the complexity of the health problems cancer causes. In addition, cancer is an expensive disease to manage and consumes extensive human and financial resources. This discourages national policymakers in resource-poor countries and international agencies from addressing it (The International Network for Cancer Treatment and Research 2008). Public health funding prioritises communicable diseases, reproductive health, and child healthcare services, leaving very meagre funds to deal with the growing cancer crisis. Therefore, cancer care initiatives in Kenya, like in most sub-Saharan Africa, take place in a context of inadequate health funding, poor infrastructure and extreme poverty. A poor resource base, low priority to cancer and other non-communicable diseases, and little education devoted to prevention,

early detection and treatment define the overall situation of cancer care management in the study hospital. In spite of these circumstances, efforts to decentralise essential cancer management activities from the national referral hospital and private facilities in the capital city of Kenya would ease the cost of the disease for low income families. This requires social and political investment in cancer detection and treatment facilities in the main public hospitals. Similarly the health sector needs to partner with developed countries to scale up local cancer management programmes. This should include funding and a public campaign for prevention, early detection and treatment of cancer. Policy to increase universal access to and the affordability of morphine would help improve patients' quality of life. The government and non-governmental organisations should collaborate to facilitate drug dispensing, distribution and payment mechanisms and support for poor patients.

Cancer in-patients in this study received minimal formal support in the long run. After catastrophic expenditure on treatment and the resultant impoverishment of families, a majority of the patients succumb to the disease. The hospital in this sense is a place where inpatients and families reach the acme of cancer treatment in the context of a wider spectrum of misfortunes. The cancer ward provides the requisite yet transient setting for collective efforts for patient rehabilitation. This monograph underscores the need for ongoing support for cancer patients and their family carers. Comprehensive cancer management requires constant assessment of sufferers' needs inside and outside the hospital. Cancer management is a continuous process, involving oscillation between hospital and home. This ethnography further illustrates that the hospital becomes increasingly unpleasant for both patients and their caregivers as patients draw closer to either the end of their lives or subsequent therapy sessions. Discharges from the hospital and additional admissions to the ward prior to the final exit are numerous, depleting social, economic and emotional coping resources, and posing significant threats to the present and future family livelihood. Patients and their families need more support and information to facilitate each of their transitions from the hospital to their homes. However, post-discharge needs of victims and their families often go unrecognised (cf. Wilson *et al.* 2002). Each discharge of a cancer patient from the hospital constitutes a new phase in the patient's life, and patients and their families require constant material, social and emotional support to adapt to their new conditions. The immediate circumstances of patient care in this study suggest larger issues of social and economic inequality. The plight of cancer patients in Kenya indicates the need for social and healthcare policies that address the needs of the poor.

Appendix 1: Patients quoted in the ethnography

Mr Ader, 53 years old, was a married primary school teacher with five children. His wife helped in the management of family subsistence farming. He was a long-term in-patient suffering from Squamous cell carcinoma with a chronic wound on his thigh. He believed that his disease was unknown to the doctors as they were not providing a cure, especially for the wound. He was discharged “to go and rest” and return if the illness became more severe.

*Ajwang** was a 21-year-old single high school leaver. He was diagnosed with osteogenic sarcoma during his final year of school. This resulted in the amputation of his leg. He lived with his parents and four siblings. Their source of livelihood was subsistence farming and his father’s wages from masonry. At the end of the fieldwork he had completed chemotherapy sessions and had been discharged.

Mr. Bedokufa was a 45 year old long-term patient suffering from multiple myeloma. He worked as a warden/caretaker of rental houses and had five dependents. His wife also worked as an agent for rental houses and supplemented their meager family income. He was anxious about his health as the diagnosis was not yet definite and he felt that physicians did not explain his condition adequately. They discharged him to the hospice to await readmission pending the presentation of recommended diagnostic results.

Mr Chepia was 39 years old, married with one child and expecting a second at the time of his hospitalisation. Before he was diagnosed with melanoma of the bone marrow, he had enrolled as an undergraduate in a theology programme. He worked as an electrical technician and supplemented his earnings through subsistence farming. His wife was not employed. He was among the patients who openly expressed bitterness due to the disease and its social and economic implications for them. He did not return for treatment after the second course of chemotherapy. Both nurses and fellow patients indicated that he intended to abscond from hospital treatment.

Mrs Gatoro, 40 years of age, was a primary school leaver and a victim of breast cancer. She had six children and a husband, and she earned a living from subsistence farming and small businesses. She was a long-term patient due the complication of the spreading disease. Doctors indicated that she was experiencing

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These are respondents I visited at home for data on livelihood contexts in the hospitalisation of cancer patients. This is further described in Chapter 7.

metastasis of the disease to her brain. In the second month of the fieldwork she collapsed and died in the ward bathroom.

*Mr Jabari** was 49 years old and was married with four children. He was diagnosed with colon cancer after prolonged illness. He was a high school leaver trained as a technician/"mechanical engineer". Both his wife and he were in stable employment. Apart from owning rental houses they also engaged in subsistence farming and raised a few dairy cows. His wife and children visited at least once during his short hospitalisation sessions. His treatment process was relatively successful. He always had adequate blood counts and other diagnostic results. In addition, he never was turned down for admission and raised the requisite hospitalisation and treatment funds promptly. As an active member of his church at home, he served fellow in-patients as a religious counselor. At the end of the fieldwork, he had completed the first-line chemotherapy sessions and was attending clinical reviews regularly. He died in a hospital in his home district seven months after the fieldwork.

Mr. Johana was a 34-year-old married male patient diagnosed with nasopharyngeal carcinoma. He held a diploma in mechanical engineering after high school. He had four dependents and received support from kin during the hospitalisation period. He completed five courses of chemotherapy and by the end of the fieldwork was discharged pending the final course. This respondent had documented the details in a diary about his experience with cancer illness.

*Mr. Kabba**, 19 years old, was a high school student. He was diagnosed with osteogenic sarcoma after protracted illness. His left hand was amputated in a district hospital before referral to the present hospital for 25 radiotherapy sessions as an outpatient. He was later admitted to the cancer ward for chemotherapy and had completed the first line courses before the fieldwork. He lived with his married sister and other relatives in a one-bedroom apartment during his hospital treatment period. His parents lived in the remote areas of a arid district in North-Eastern Kenya. He had completed second-line chemotherapy by the end of the fieldwork and visited the clinic regularly for reviews.

Mr. Kassi, 64 years old, was a retired primary school teacher. He was married and had nine dependents. He earned a living from a maize farm and a few dairy cows. He was admitted to treat a tumour in the chest which was not diagnosed until after about five years. He attended radiotherapy sessions as an outpatient in the hospital before admission to the cancer ward for chemotherapy. He had a few relatives in Nairobi who supported him during the hospitalisation process. At the

end of the fieldwork he was waiting for the diagnostic results needed in order to be hospitalised again.

Mr. Makamo suffered from nasopharyngeal carcinoma. He was 36 years old, single, and was engaged in small-scale business. He documented his experience in a diary and hoped to discover the meaning of his suffering from this exercise. He referred to the book of Daniel in the Bible and hoped to publish his personal memoir. This respondent informed some fellow patients that he was getting tired of fruitless hospitalisation. He did not turn up for subsequent treatment after the fourth course of chemotherapy.

Ms. Marina was 24 years old, single, and diagnosed with nasopharyngeal carcinoma. She was a medical laboratory assistant before her illness. She was not able to go back to work due to frequent hospitalisation, and resigned from her job with a private doctor. Close family members assisted her during the hospital treatment process. She was pessimistic about treatment outcomes and was bitter about the opportunities to work and study that she had lost due to the disease. Her closest family carer was her brother who lived in the Nairobi. At the end of the fieldwork she was discharged and attending treatment and review as an out-patient.

Mr. Mati was a 38-year-old widower suffering from colon cancer. He was referred to the current hospital after diagnosis and first operation in a district hospital. He worked as a primary school teacher, ran small business and did subsistence farming. He had three dependants. He underwent second operation at the current hospital. At the end of the fieldwork he was discharged, awaiting subsequent admission

Mr. Mamba, 65 years old, was a married farmer. He was a primary school dropout and earned a living from growing food crops and raising livestock. He had one dependent in tertiary college training. He was on radiotherapy for six weeks to treat throat cancer. He had relatives with whom he stayed in the city during his short-term discharge from the ward. At the end of the fieldwork he was discharged pending hospitalisation for chemotherapy sessions.

Mr. Misaka Masseyi, 55 years old, was diagnosed with breast cancer. Mastectomy was carried out in a district hospital before referral to the cancer ward for further treatment. He had retired from his job as a clerical officer in a housing corporation and used his retirement benefits to pay for his treatment. He had seven dependents, and received support from his family, which also depended on subsistence farming and small scale tea production for cash. He was hospitalised

for second-line chemotherapy. The outcome was relatively successful and he was discharged pending regular reviews at the cancer treatment centre clinic. He died in the ward following an emergency readmission after the first scheduled clinic.

*Mr. Mukuru**, 22 years old, was a single primary school leaver. He had been a self-employed fruit vendor in the coast province before his undiagnosed illness became severe. Diagnosis at a district hospital revealed nasopharyngeal carcinoma. He was admitted to the cancer ward for radiotherapy after an operation at the district hospital. He lived with his elderly widowed mother during the hospital treatment process. They earned a living from subsistence farming and kin support. By the end of the fieldwork he was seeking readmission on credit to start chemotherapy.

Ms. Nadia was a single divorced mother of three children. She lived in a single room in a nearby slum area with her children. She earned her living from a small second hand clothes business. Before conversations with her began, she had been on the ward for two months to treat nasopharyngeal carcinoma. She was discharged after being retained in the ward for two weeks due to a lack of money to clear her bills. She died at home one week after discharge, before I could visit her at home as we had agreed.

*Mr. Ndege** was a 54-year-old primary school teacher suffering from multiple myeloma. The diagnosis was, however, not entirely clear and investigations were still underway. He had seven dependents and supplemented his income with subsistence farming. He lived alternately with two relatives during the treatment period while he was not in hospital. Doctors recommended further clinical investigations and reviews after he completed radiotherapy sessions. The funeral of his father in a rural area interrupted his clinical reviews.

Mrs. Ndunduri, 56 years of age, was a married long-term inpatient. She was a primary school drop-out and a subsistence farmer. Her husband and she had two dependent grandchildren who were orphans. She suffered from squamous cell carcinoma of which the primary cause was unknown. Metastasis of the disease affected the upper oesophagus and oral cavity and lungs. Her son who worked in a town near the hospital provided financial support, but she did not have relatives in the city. She was often delirious and experienced insomnia. The doctor sedated her several times and nurses on occasion tied her to the bed using sheets to restrain her. She died in the ward before the end of the fieldwork.

Mrs. Omari, 49 years of age, was married with eight children. She was diagnosed with breast cancer and was undergoing second-line chemotherapy. She was a

primary school teacher, and her husband managed the family's sugarcane farm, from which they got extra income. They also did some subsistence farming. Her experience typified that of other patients who required stronger analgesics to relieve their pain. She did not have relatives in Nairobi and relied on her husband, who was over 350 km away, for emotional support. By the end of the fieldwork she had been discharged awaiting the fourth course of (second-line) chemotherapy.

*Mrs. Pakot** was 49 years of age and a primary school teacher. She suffered from breast cancer. She was married with three children, and her husband was unemployed. Subsistence and small scale cash crop farming supplemented their income. She was admitted for recurrence a few years after she had a mastectomy and relatively successful treatment. The disease spread, and doctors confirmed that she now had Stage I cancer of the uterus. She resisted physicians' recommendations for discharge through the hospice, and was transferred to another ward where surgery was done. She was finally discharged and accepted referral to a local hospice for home-based palliative care. She passed away at home before the end of the fieldwork.

Mr. Saulo, 43 years of age, was a primary school leaver and a married father of three. He suffered from colorectal cancer and was admitted for a combination of chemotherapy and radiotherapy. He earned a living from subsistence and cash crop (wheat and maize) farming. His wife was not formally employed and participated in the management of the family farm and livestock rearing. He was involved in the sale and use of patented food supplements and alternative medicine, which he tried to market to fellow in-patients. He relied on his aunt who lived in Nairobi to supply him with home-prepared food while he was in hospital.

*Ms. Souda** was a 39-year-old single mother of four children. Her first born son and a daughter had completed high school, whereas two sons had dropped out of school due to a lack of school fees. She separated from her husband around the time she became ill, before being diagnosed with cervical cancer. She lived in Nairobi in a two-bedroom apartment and depended on relatives and well wishers for her livelihood. Due to the illness she lost her job as a bank clerk and worked as a volunteer in a local non-governmental organisation when she felt well.

*Ms. Stella** was a 47-year-old widow suffering from breast cancer. She was referred to the cancer ward for chemotherapy after a successful mastectomy in the present hospital. Her husband fell ill and died in a district hospital while she was taking treatment in the cancer ward. She had seven dependants and only two had completed high school. A daughter who housed her while she waited for subse-

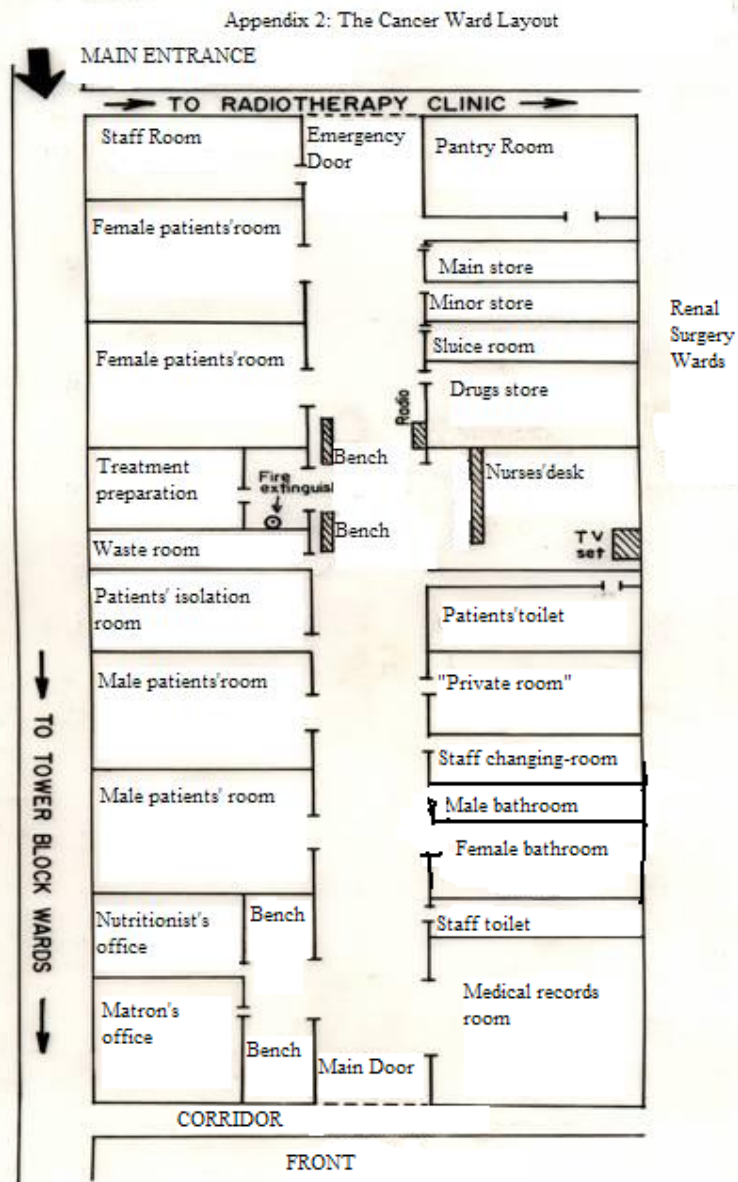
quent hospitalisations had a low paying job. Ms. Stella worked as a school bursar and managed a small subsistence farm before her prolonged illness and hospitalisations. At the time of the fieldwork she was undergoing second-line courses of chemotherapy. She refused to go back for the last course of chemotherapy as she claimed that it was futile. She resorted to alternative Chinese medicine at home, and died in the ward after her relatives brought her in as an emergency case.

*Mr. Tarus**, 28 years of age, was a married businessman. He had been admitted for chemotherapy to treat bone marrow/spinal cancer. He had started his treatment in a nearby private hospital, which he realized was becoming too expensive. He was a primary school leaver and had five dependents. He supplemented his income with subsistence farming. This respondent had rented a room in Nairobi where he lived during the hospitalisation period. He died in the ward before the end of the fieldwork.

*Mr. Toi** was a 26-year-old high school leaver. He was diagnosed with osteogenic sarcoma and had his leg amputated in a district hospital. Before this he used to do petty business for his own maintenance and the support of his parents who were both unemployed subsistence farmers. He relied on funds from kin and especially the fundraising event for his benefit organised by clan members. He was a victim of delayed readmission for chemotherapy due to low blood count and extra infections. His condition worsened after the fifth course of treatment, and he postponed his readmission many times. He died at home before the end of the fieldwork and before he could be readmitted for a sixth chemotherapy course.

Mrs. Vyakawa, a 43-year-old long-term inpatient, suffered from fibrosarcoma. Her left leg was amputated due to the disease. She was childless and married as a second wife. She was the main breadwinner for her deceased co-wife's five children and her poor parents, providing for them through petty business and subsistence farming before her illness became severe. She had also been diagnosed with the HIV/AIDS virus and this interrupted her chemotherapy sessions. She did not have relatives living near the hospital. Her sister, the only caregiver from the family lived about 170 kilometers from the hospital and was unable to visit regularly. She died in the ward before the end of the fieldwork.

Appendix 2: The cancer ward layout



Appendix 3: In-patient statistics (January 2005-July 2006)

2005 Month	<i>Admissions</i>		<i>Discharges</i>		<i>Deaths</i>		%Occ*	ALOS†
	Male	Female	Male	Female	Male	Female		
January	36	36	19	22	5	5	52.2	9.7
February	30	30	24	25	5	4	67.6	9.8
March	23	37	30	44	1	3	67.6	8.1
April	37	28	30	23	1	4	74	11.5
May	17	29	11	27	2	2	83.8	18.5
June	33	24	36	17	2	0	76.8	12.6
July	22	24	23	24	5	6	74.5	11.9
August	47	31	30	26	3	9	63.8	8.7
September	30	31	34	24	1	8	59.9	8
October	29	31	19	26	4	2	69.9	12.7
November	29	27	23	25	4	5	69.2	10.9
December	15	24	22	31	5	4	51.6	7.7
<i>Total</i>	<i>347</i>	<i>352</i>	<i>301</i>	<i>314</i>	<i>38</i>	<i>52</i>		
2006								
January	16	36	18	25	3	5	50.1	9.1
February	21	29	20	21	2	1	73.8	14.1
March	26	21	25	26	4	3	79.5	12.7
April	26	26	23	23	4	1	62.7	11.1
May	34	24	16	21	2	6	75.7	15.6
June	27	22	26	18	6	4	82.2	13.7
July	25	27	17	16	3	10	83.0	15.0
<i>Total</i>	<i>175</i>	<i>185</i>	<i>145</i>	<i>150</i>	<i>24</i>	<i>30</i>		

* Percentage bed occupancy †Average length of stay in days

Source: Medical Records department, 23rd March and 7th August 2006

Appendix 4: Nutrition counselling guide for cancer patients

Counselling session for Mr and Mrs. Jabari

Monday, 13th February 2006

The nutritionist invites Mr. Jabari and his wife for a counselling session. Mr. Jabari (49) is taking the second course of chemotherapy for cancer of the colon. Mr. Jabari's wife is a teacher by profession and is able to follow the counselling in English. The nutritionist often talks to patients and relatives separately and together in *ad hoc* or arranged sessions. The nutritionist advises relatives and patients about the appropriate diet during treatment. During the fieldwork, there was a handout, which the nutritionist went through together with the clients during the counselling sessions. Apart from the talk on balanced diet and the side effects of cancer therapies the nutritionist attempt counselling on how patients and relative should cope with the reality of the disease. The nutritionist explains what food to eat or avoid in case of particular side treatment side effects. A balanced diet chart and a nutrition handout, which the nutritionist signs and gives to a patient or his/her a family member, are handy during the session.

Below is the main handout the nutritionist goes through with some patients and/or their relatives.

Due to the treatment you are receiving, you may experience some of these symptoms:

1. Nausea and vomiting
2. Loss of appetite and weight
3. Loss of taste and/or taste changes
4. Soreness of the mouth
5. Diarrhoea
6. Constipation

To relieve the symptoms, do the following:

- 1.) Nausea and vomiting
 - a) Have small frequent meals, alternating dry and fluid feedings.
 - b) Eat promptly when hunger is first felt.
 - c) Keep away from cooking smells-where possible let some one else cook for you.
 - d) Avoid fatty and sugary foods (may add in moderation for extra energy if underweight).
 - e) Avoid liquids at meal times. Take liquids 30-60 minutes after or before meals.
 - f) For early morning nausea, try unbuttered bread or plain biscuits.
 - g) Try cold foods-they have less smells.
 - h) Avoid lying flat and at least two hours after eating.
 - i) Use anti-emetics before meals (but a doctor must prescribe them for you).

- 2.) Loss of appetite and weight.
 - a) Use seasonings and herbs e.g. *muchuzi* mix, *knorr* cubes spices etc (do not increase salt).
 - b) Avoid very hot foods- foods taste better at room temperature.
 - c) Eliminate foods that taste bad.

- 3.) Soreness of mouth.
 - a) Use moist foods.
 - b) Avoid always salty and spicy foods e.g. curried foods, chillies, instead use a bland diet.
 - c) Use nourishing drinks, e.g. special *uji*, milk, *mala*, soups.
 - d) Avoid carbonated drinks like sodas and beers.
 - e) Avoid hot foods, use cold foods.
 - f) Use a straw if necessary.
 - g) Avoid rough and very dry foods.
 - h) Avoid highly acidic foods like oranges and pineapples.

- 4.) Dry mouth.
 - a) Have frequent drinks.
 - b) Suck ice cubes-if available
 - c) Suck lemon slices
 - d) Do mouth wash regularly

- 5.) Diarrhoea
 - a) Have a low fibre diet with plenty of fluids e.g. eat white bread instead of brown bread, meat, eggs, poultry instead of beans and lentils-until diarrhoea subsides
 - b) Eat cooked vegetables and fruit juices in order to reduce fibre as opposed to raw vegetables and whole fruits.
 - c) Take as much fruit juices as possible to replace potassium lost during diarrhoea.
 - d) Increase fluid intake to prevent losses.
 - e) If lactose is a problem, stop using milk, use *maziwa mala*, Soya milk, or Soya-based milk products such as Alsoy or prosobee.
 - f) Avoid gassy foods like beans, cabbage, and cauliflower if not tolerated.
 - g) Omit foods with seeds, like tomatoes, however tomatoes may be pre-cooked, mashed, and sieved before use in food preparation.
 - h) If fat is a suspected cause of diarrhoea then do not fry or deep fry foods. Instead, boil, bake, or steam. Use skim milk instead of whole milk.

- 6.) Constipation
 - a) Have a diet high in fibre e.g. brown bread, beans, peas, lentils, fruit, and vegetables.
 - b) Drink plenty fluids-at least a glass a day

- 7.) Loss of weight and appetite
 - a) Have small attractive meals daily
 - b) Have snacks e.g. biscuits, cakes, *mandazi*, peanuts and nourishing drinks in between meals e.g. special *uji*, milk and soups
 - c) Serve protein containing foods cold or at room temperature
 - d) Eat your favourite foods when your appetite is particularly poor
 - e) Eat slowly in a relaxed atmosphere
 - f) Use spices and seasonings to improve food aroma and taste
 - g) Enrich your meals with eggs, butter/oil and milk
 - h) Minimize food odours by placing lids on cooking pots

Try some of the following recipes:

- 1.) Enriched *uji*; 2 cups (250ml each)
 2 cups *uji-wimbi* or maize meal made with KCC milk
 One-tablespoon corn oil or margarine
 2-4 tablespoons sugar
 One egg

Preparation method: Beat corn/margarine, sugar, and egg together, mix in cooked porridge.

- 2.) Enriched milk 2 cups (250 ml each)
 2 cups KCC milk
 Corn oil- 2 tablespoons
 Four table spoons sugar
 One egg

Preparation method:

Beat egg, sugar, and corn oil together and add to milk.

- 3.) Enriched mashed potatoes.
 Add Blue Band and corn oil, milk and egg to mashed potatoes o increase nutritional value.

Signed..... Date.....

NUTRITIONIST.....

Appendix 5: Tables

Table 1 Estimated monthly expenditure (in Ksh) in 'dependent' patients' households

Cases	Medical costs	Other costs	Hospital costs	Total costs	Household income
Mr. Toi	4,100	14,920	12,250	31,770	7,000
Ajwang	3,800	4,900	16,350	25,050	6,500
Mr. Mukuru	6,000	3,000	7,440	16,440	3,000

Table 2 Estimated monthly expenditure (in Ksh) in households of formally employed and unsalaried breadwinners

Cases	Medical costs	Other costs	Hospital costs	Total costs	Household income
Ms. Souda	7,793	16,746	7,500	32,039	12,000
Mrs Pakot	8,000	17, 240	18,150	43,390	6,000
Mr. Jabari	3,100	41, 388	8,000	51,988	50,888

Table 3 Cancer drug prices (in Ksh) inside and outside the hospital

<i>Drugs</i>	Hospital	Pharmacy A.	pharmacy B [†]	pharmacy C&D ⁺	pharmacy E	Pharmacy F.
Cyclophosphamide 500mg	500	300	350	350; 759	287	----
Cyclophosphamide 200mg	200	200	200	175; 200; 250; 321; 350	200 @40	----
Doxorubicin 50mg	1,000	1,300	1,800	1,620; 1,800; 2,261; 5, 301	1,887	----
Doxorubicin 10mg	200	480	555	495; 550; 779	----	----
Bleomycin 15 IV	1,300	1,400	1,500	2,000;2662;3,450	----	----
Vinblastine 10mg	1,200	1,000	1,150	2,590	----	----
Vincristine 1mg	200	180	150	180; 250;317	----	---
Methotrexate 50mg	200	180	1,602	380; 400;650	287	1,600
Actinomycin-D 0.5mg	1,000	400	1,094	1,094	----	----
Etoposide 100mg	900	500	900	900; 2,240; 2,804	1,220	----
Docetaxel 80mg	20,000	18,500	-----	18,000; 25,097; 40,000	----	40,000
Docetaxel 20mg	6,000	5,000	----	11,000; 5,400; 7,843	----	11,000
Gemcitabine 200mg	2, 970	----	-----	3,295	-----	----
Gemcitabine 1gm	14,850	----	-----	15,758	-----	----
5-Fluorouracil 250mg(5FU)	200	250	300	350; 481; 1000	353	----
Granulocyte colony Stimulating Factor (Neupogen) 300mg	9,700	(Roche) 11,400	-----	(Roche)		
10,071	-----	----				
Cisplatin 50mg	500	650	1,100	1,271; 1,458; 1,689; 2,478	1,463	----
Carboplatin 150mg	2,000	1,500	1,700	3,500	----	----
Dacarbazine 200mg	1,680	1,300	1,500	1,800	----	----

Source: Hospital Pharmacy and interviews in selected private pharmacies/ chemists, Nairobi June 2006

[†] Private pharmacy B was a key distributor of anticancer medicines at wholesale prices to all buyers.

⁺ From these pharmacies, prices vary as indicated; according to the company supplying the drugs. This was the popular pricing criterion for pharmacies in the central business district and adjacent streets. Most private pharmacists referred to the price guide in a Textbook: Kimotho, J.H. (ed) 2006/2007 (Seventh Edition) *East African Pharmaceutical Loci: A regional drug index for Medical Practitioners*. Nairobi: Pharmaceutical Loci publishers.

Table 4 Estimated subsidised cost (in Ksh) of some cancer regimes in the ward

Cancer type	Option	Regimen	Cost
Breast cancer	Opt. 1, 1 st line	(option 1) 1gm Cyclophosphamide and 80-100gm doxorubicin	3,800
	Opt.2, 1 st line	1gm Cyclophosphamide, 100gm methotrexate, 1gm Flourouracil	2,200
	Opt.1 2 nd line	1.6gm Gemcetabine and 100gm Cisplatin	25,000
	Opt.2 2 nd line	1.6gm Gemcetabine and 450gm carboplatin	30,000
	Opt 3. 2 nd line	1000mg doxorubicin and 100gm docetaxel	40,000
Colorectal (colon)	Opt 1	5-Fluorouracil 250 mg (5-FU) and leucovorin	5,500-6,000
Head and neck	Opt. 1	100gm Cisplatin 5-FU-1000mg& radiotherapy	2,000
	Opt 2	5FU, leucovorin	5,500-6,000
Gastric/Stomach		Etopisode 120mg, doxorubicin 20mg, cisplatin 40mg	1,800
Esophageal		5FU 1000mg and cisplatin 75 mg	1,500
Multiple Myeloma		Doxorubicin 50mg, Vincristine 1mg	1,200
Cervical		1mg Vinscristine, cisplatin 50mg, beleomycin 15IV	2,000

Source: Interview with cancer ward pharmacist 2006

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Epilogue

I kept in touch with several respondents outside the hospital. Ajwang' was very excited that I indeed visited him at home, as I had promised. He and his family strove to reciprocate by offering their best tea or lunch treats. However, they were barely able to afford meals for their own household and the special food recommended for the patient before the next hospital admission.

In July 2007, one year after my fieldwork, I took a six-week break and travelled back to Nairobi. I contacted my respondents by telephone to find out how they were faring. Mr. Ndege said he did not find it necessary to continue to attend clinical reviews at the cancer treatment centre. He said that "endless and fruitless tests" for his chronic multiple myeloma frustrated him. He did not keep the clinical appointment scheduled after his father's funeral upcountry. Mr. Ndege decided not to return to the hospital. He was optimistic that his son Epainito, a high school leaver would find a job. Epainito had spent many months in Nairobi to help him in the hospital. He had since moved to Mombasa to live with an uncle as he looked for a job.

Mrs. Jabari answered my telephone call and said: "the pastor left us [died] in March. His blood count was too low and he needed an urgent transfusion. He passed away when we arrived at the district hospital." Mr. Jabari had been a relatively successful rehabilitation case just like Misaka Masseyi. He had completed all his treatment sessions consecutively since he 'qualified' for all subsequent hospital admissions immediately. His wife had a kitchen garden to facilitate his dietary needs during treatment. Her response to my call reminded me of many telephone conversations I had had with patients during my fieldwork. Some were happy to inform me of their successful readmission for subsequent therapies. Others called to express regret that they could not be re-admitted as scheduled. Either results of their medical tests were disappointing or they lacked the money to cover hospital admission fees and drugs. Mr. Toi's last call was to say that he would not make it back to hospital because of "unavoidable circumstances". The following week his brother called to inform me of his death. I could not get a response when I called Ms. Nadia to confirm a home visit appointment. After recognising me as the researcher at the hospital, someone answered: "I am her mother. Nadia is no longer with us. She is gone [dead]. It has been one week since she has been gone." I recalled some of the respondents' funds raising events that I was able to attend. Ms. Nadia had been planning one and Ms

Souda's did not materialise. There was an impromptu mobilisation of people to contribute some money toward 'an education fund' for Ms. Stella's children at her requiem mass. There were barely one hundred fifty people, her relatives and close family friends living in Nairobi.

Nurses often looked for information about patients who left the ward. "It was even in the newspaper", some would say, to confirm bad news of former patients' deaths. I had attended three respondents' funerals before the end of my fieldwork. Doctors discharged some patients "to go and rest." We never heard about many of them again after their discharge from the ward. Physicians discharged some of them through the hospice and the others, such as Mr. Jabari, through the clinic for regular reviews. They had either completed requisite treatment or needed further investigation for chronic conditions. Some patients made many trips to the clinic because they did not qualify for subsequent admission. Any discharge implied a gradual exit from the medical gaze, or at times, an entry into a labyrinth of countless tests and clinical appointments. Ward exit paths varied. This could be from the cancer ward to regular clinics; ward-home, ward-home via a hospice, or ward-home via the nearest health facility. Some victims gave up, to "wait for God", or tried alternative therapies at home. The journey from the hospital could lead to an infinite limbo for patients and their families. Low survival rates and beleaguered livelihood were the sad reality of daily life in the cancer ward. Relatives and staff were delighted when victims could eat and walk on their own at the end of a therapy course. A doctor's approval for discharge elated patients too. They felt great relief upon going home again, especially when they could eat well and walk without assistance. I was happy about this too.

Before returning to the Netherlands in August 2007 to complete the monograph, I learnt of a new development at the hospital. They had initiated a palliative care unit in March to care for patients with chronic illnesses. I read that the goals of this unit were to:

- Improve pain and symptom control.
- Increase knowledge of pain and symptom control.
- Increase patient and family satisfaction with care.
- Increase communication techniques among the hospital health care workers.
- Respect and support patients' preferences.
- Prevent inappropriate emergency department and in-patients admissions.
- Increase enrolment of patients who will benefit from hospice care.

The hospital launched the palliative unit formally in October 2007. This was about one year and a half after my fieldwork. This reminded me of some nurses' popular idiom of hope as they talked about patient cancer care in the hospital: "Our work is to add life into their days and not days into their life."

Summary

This monograph describes the experiences of patients, families and hospital staff in a cancer ward in Kenya. It shows how circumstances of cancer treatment in a national referral hospital ward reflect insufficient services in the country's healthcare system. The physical, social and healthcare circumstances in the ward further shape patients' experiences of cancer. These aspects of hospitalisation, coupled with other factors within and beyond the hospital, influence patients' expressions of physical and emotional satisfaction and discomfort.

Chapter 1 introduces the book with a glimpse at typical experiences of patients and carers in the cancer ward. It represents a significant scene of continuity in the perennial struggle of patients and caregivers to ease the suffering that cancer and its treatment cause. The cancer ward is a scene of climax in the fight against cancer where a majority of the patients either do not pull through or fail to restore their physical, emotional and social lives as adequately as they expect. The onset of cancer illness ushers in relentless help-seeking and arduous hospital treatment processes which tend to dominate the remainder of patients' lives.

The central question of the study follows a brief depiction of the ethnographic scene: how do the lives and experiences of cancer inpatients in a Kenyan referral hospital relate to their needs, and what aspects of the experience characterise their hospitalisation? I then present the primary goal of the study, which is to contribute to hospital ethnography, in developing countries. Specifically, the purpose of the study is to show how hospital and family circumstances in Kenya shape patients' experiences of cancer management. I then present an overview of the critical medical anthropological conceptual framework for understanding and describing daily life experiences in the cancer ward. Experiences of individual sufferers in a local hospital ward depict subjective perspectives, therapeutic and care relationships, caregiver interdependence and broader socio-economic contexts encompassing patients' well-being and quality of life. Chapter One ends with an historical overview of the study hospital, the cancer problem in Kenya, and the nature of existing research on cancer management in Kenya. Previous hospital studies focus on quantitative biomedical aspects and tend to ignore ethnographic dimensions, which are equally important for patient care initiatives.

Chapter 2 describes the ethnographic methodology of this study. I explain the scope of the present hospital ethnography and my purpose in selecting the cancer ward as the fieldwork site. I then explain how I collected my data as an ethno-

grapher in the cancer ward and treatment centre clinic of Kenyatta National Hospital (KNH) between August 2005 and July 2006. I did the fieldwork as a direct non-participant observer; my participation was limited to activities and conversations that a lay (non-medical) person can generally engage in. I transcribed in-depth conversations with 42 patients, eleven relatives, three doctors and eleven nurses. Continuous informal conversations and observations were the hallmark of this study. This chapter further describes and analyses issues in the processes of my admission to the hospital as a researcher without a biomedical identity and training. I show that accessing the hospital as an ethnographer may be difficult because it is an 'unusual fieldwork site' for anthropological research. Hospital professionals may also view the presence of an anthropologist as threatening their autonomy. The study included an exploration of patients' treatment contexts beyond the clinical setting, which shape ongoing hospital care experiences and outcomes. Collection of data beyond the hospital highlighted the contextual issues in hospital treatment of cancer. These included low affordability of medicines and patient care services, difficulties in accessing adequate amounts of food, let alone appropriate food, and social support. Transient hospital stay does not allow most other researchers and hospital workers enough time to understand and deal with matters in the wider contexts of cancer inpatients' expressed suffering.

Chapter 3 describes the cancer ward as both a study and a treatment site that constitutes the physical and emotional space for cancer patients. This chapter further highlights patients' expectations of the ward and what it means to them. In the initial stages of hospitalisation, the cancer ward is a place they associate with full recovery and restoration of their disrupted lives. Since KNH generally offers better technology and expertise than other public healthcare facilities, admission to the cancer ward renews hopes for a cure and a return to normal life. However, the chapter also highlights the hospital staff's underlying perceptions of the low status of the cancer ward and its insignificant contribution to the overall improvement of patients' well-being. The description of the ward's physical layout and its human and non-human resources reveal the limitations of the ward in meeting patients' physical and emotional needs. The second part of the chapter deals with patients' experiences of treatment in the prevailing 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 interactions among various actors in the cancer ward. It situates patients' experiences and roles in treatment within the social and medical hierarchies in the hospital, and shows how issues in social and medical hierarchy in the cancer treatment centre have implications for patient care interactions, communication and interdependence. In this chapter I

present the hospital ward as a microcosm of social interactions of different actors which shape the outcome of hospital treatment and patient care efforts. The hierarchical, social and power relations in this ward influence different actors' participation in attempts to improve patients' quality of life. The chapter shows that shortage of hospital staff, ward space and facilities constrain the participation of key patient support professionals. Similarly, routine activities in the cancer ward and treatment centre marginalise other professionals and prevent them from giving the maximum of their input in patient care discussions and communication. In addition, the role of patients' relatives (visitors) and ward assistants is ambiguous, though they can contribute to the effort to ease patients' suffering during hospitalisation, thereby improving patients' quality of life and satisfaction.

Chapter 5 is about the patients' experience of pain and eating difficulties as the main physical symptoms of suffering due to cancer and hospital treatment. I describe and analyse difficulties associated with patients' attempts to express their suffering. Insufficient hospital resources and time constraints affected the responses of ward staff to patients' explicit or implicit communications of pain and eating difficulties. The chapter highlights patients' disillusionment as the responses they receive and available medicines do not meet their expectations of hospital treatment in relieving pain and other kinds of physical suffering. As medical professionals and patients alike noted, persistent pain results from either cancer or treatment procedures. However, pain and eating difficulties are also iatrogenic, resulting from treatment procedures, unpleasant hospital circumstances and a lack of appropriate empathy and support in the ward. Persistence of these phenomena may further interfere with a patients' ability to eat, concentrate, sleep, or interact with other people. This results in a series of psychological and social consequences, including depression and anxiety, which worsen inpatients' suffering. Chapter 5 concludes with a description of patients' discreet recourse to alternative aetiologies as part of their desperate attempts to make sense of their suffering and supplement hospital treatment.

Chapter 6 describes cancer patients' emotional and social concerns that result from the disease and hospital treatment. It depicts patients' worries about social support, experiences of stigma, and some moral ideas about cancer. The chapter shows how subjective feelings about physical symptoms and disease progression can shape sufferers' existential and emotional concerns. In this chapter, I describe a scenario in which medical professionals may ignore inpatients' emotional and social concerns. They relegate patients' non-medical or non-technical issues to the category of 'extra baggage', which they do not consider important aspects of their routine patient care responsibilities.

Chapter 7 explores phenomena that link treatment outcomes to patients' lives outside the hospital. It describes the wider social, economic and livelihood realities manifested in patients' experiences in the ward. This chapter examines how patients experience treatment and hospitalisation in relation to their livelihood circumstances. It describes the social and economic issues behind patients' experiences of cancer treatment and hospitalisation. The chapter examines the implications of individual and family strategies for coping with cancer and hospitalisation for livelihood organisation and security. I explore and describe the implications of cancer inpatients' and their families' inadequate access to formal and informal sources of support.

Chapter 8 concludes this book by revisiting the main aspects of the life of cancer patients in Kenyatta National Hospital. Recommendations for hospital workers and policy makers follow the conclusions. The book closes with an epilogue tracing some of the patients' exits from the hospital and my own as an ethnographer. Chapter 8 emphasises the relevance of hospital ethnography to comprehensive patient-centred hospital care and studies. The conclusions and practical implications of the ethnography further problematise the role of the hospital in offering solutions to cancer patients' physical and emotional adversity. A wide array of hardships shape cancer inpatients' daily experiences in Kenyatta National Hospital. Ambiguity characterises their hospital stay and treatment, while the hospital both alleviates as well as increases the human suffering of cancer patients. Their experiences of hospital treatment, as in other resource-poor countries constitute part of a wider spectrum of misfortune that afflicts cancer inpatients. A shortage of hospital resources and competent cancer healthcare staff worsens poor patients' physical, social and emotional adversity. The national referral hospital turns out to be the place where cancer patients and their families endure the most intensive, expensive distressing experiences. Lack of resources and poverty among the population in general, and among these patients in particular, hamper mobilisation of resources for treatment and other needs. Destitution of poor families and dependent members increase with the frequency of hospital admission and escalation of treatment bills. In addition, their current hospital stays reveal only a small part of the cancer patients' long and cumulative experiences of interrupted lives. The onset of cancer and management of chronic illness entails the catastrophic disruption of normal rhythms of life and a serious threat to patients' lifeworlds.

This study illustrates the plight of cancer patients in a context of inadequate access to affordable and effective cancer treatment drugs and analgesics at both local and national levels. The suffering of individual patients indicates the urgent need for the government to accelerate efforts to improve cancer management in peripheral hospitals and revitalise treatment facilities and services at the national

referral hospital. This calls for the government's commitment to the establishment and sustainable funding of cancer management services in both national and regional hospitals. Cancer patients in Kenya would benefit not only from more material and emotional support, but also from a reduction in the frequency of hospital admission and duration of stay. This can be achieved through improvement of outpatient services and facilities for palliative care in peripheral hospitals and hospices. A programme for home care and accessible hospice services would also contribute to the improvement of patients' quality of life during and after hospitalisation.

Samenvatting (Dutch summary)

Deze dissertatie gaat over de ervaringen van patiënten, families en ziekenhuispersoneel op een afdeling voor kankerpatiënten in Kenya. Het beschrijft de behandeling van kankerpatiënten in het Kenyatta National Hospital in de context van ontoereikende zorgfaciliteiten. Zowel factoren binnen het ziekenhuis als externe factoren beïnvloeden het welbevinden van kankerpatiënten.

Hoofdstuk 1 leidt het boek in met een korte beschrijving van de ervaringen van patiënten. Het laat de voortdurende strijd zien van patiënten en zorgverleners om het lijden te verlichten dat ziekte en behandeling met zich meebrengen. Het verblijf op de afdeling is voor veel patiënten een dieptepunt in het gevecht tegen kanker. De meeste patiënten verliezen dit gevecht of kunnen hun fysieke, emotionele en sociale leven niet meer oppakken. De aanvang van de ziekte kanker luidt voor veel patiënten een onverbiddelijke fase in van het zoeken en regelen van hulp en van zware behandelingsprocessen die de rest van hun leven beheersen.

De centrale vraag van het onderzoek vloeit voort uit een korte etnografische schets. Hoe verhouden de ervaringen van kankerpatiënten in een Kenyaans academisch ziekenhuis zich tot hun behoeften? En welke aspecten van hun ervaring kenmerken hun verblijf in het ziekenhuis? Vervolgens wordt het voornaamste doel van het onderzoek gepresenteerd: een bijdrage leveren aan ziekenhuis-etnografie in ontwikkelingslanden. Het onderzoek laat vooral zien hoe ziekenhuis- en familie-omstandigheden de ervaringen van patiënten met behandeling van kanker bepalen. De dagelijkse ervaringen van mensen in de onderzochte afdeling worden beschreven en begrepen met behulp van het conceptuele schema van kritische medische antropologie. Opvattingen en zorg-relaties worden beschreven vanuit het perspectief van de individuele zieke. De ervaring van patiënten is gekoppeld aan de onderlinge afhankelijkheid tussen zorgverleners en bredere sociaal-economische omstandigheden. Hoofdstuk 1 eindigt met een historisch overzicht van de ontwikkeling van het ziekenhuis, van de kankerproblematiek in Kenia en van de stand van zaken rond bestaand onderzoek op het gebied van kanker bestrijding in Kenia. Eerder onderzoek naar ziekenhuizen richt zich vooral op kwantitatieve biomedische aspecten en negeerde de etnografische dimensie, die net zo belangrijk is voor de zorg van patiënten.

Hoofdstuk 2 beschrijft de etnografische methodologie van het veldwerk. De participatie van de onderzoeker was beperkt tot activiteiten en gesprekken waarin

een persoon zonder kennis van medische zaken normaal gesproken betrokken kan worden. Er zijn diepte-interviews gehouden met 42 patiënten, elf familieleden, drie artsen en elf verpleegkundigen. Dit hoofdstuk beschrijft en analyseert de kwesties die voortvloeiden uit de positie van de onderzoeker zonder biomedische identiteit of training. Het toont aan dat het moeilijk is om als etnograaf binnen een ziekenhuis te werken; het ziekenhuis is een ongebruikelijk terrein voor antropologisch onderzoek. Ziekenhuispersoneel kan de aanwezigheid van een antropoloog als een bedreiging ervaren van hun autonomie.

Om de problemen van kanker in een bredere context te plaatsen zijn ook buiten het ziekenhuis data verzameld. Dit omvatte aspecten als de (on)betaalbaarheid van medicijnen en services, de moeite om voldoende en kwalitatief goed voedsel te krijgen, en het gebrek aan sociale ondersteuning. Doordat ziekenhuisbezoek tijdelijk is hebben onderzoekers en ziekenhuispersoneel meestal onvoldoende gelegenheid om het lijden van kankerpatiënten in die wijdere context te begrijpen en hier naar te handelen.

Hoofdstuk 3 beschrijft de kankerafdeling als een plaats van wetenschappelijk onderzoek naar de behandeling van kanker. Het beschrijft de verwachtingen van patiënten ten aanzien van de afdeling. In de eerste fase van de ziekenhuisopname associëren patiënten de afdeling met volledig herstel van hun ziekte en van hun verstoorde leven. Aangezien het Kenyatta Hospital bekend staat als een ziekenhuis dat betere technologie en expertise biedt dan andere publieke gezondheidsinstellingen, geeft een opname in dit ziekenhuis patiënten nieuwe hoop op genezing en een terugkeer naar het normale leven. Het hoofdstuk beschrijft echter ook dat ziekenhuispersoneel zich bewust is van de lage status van de afdeling en van de geringe bijdrage die hun zorg levert aan de verbetering van het welbevinden van patiënten. De locatie en de gebrekkige voorzieningen tonen de beperkingen van de afdeling om aan de fysieke en emotionele behoeften van patiënten tegemoet te komen. Het tweede deel van het hoofdstuk laat de vasthoudendheid van patiënten zien om zich te concentreren op de behandeling ondanks de potentieel stressvolle omgeving waarin deze behandeling plaatsvindt.

Hoofdstuk 4 beschrijft en analyseert de interacties van verschillende actoren op het gebied van zorg. Het plaatst de ervaringen van patiënten en de rollen die zij vervullen in het behandelingsproces binnen de sociale en medische hiërarchie in het ziekenhuis en laat zien hoe die medische hiërarchie de interactie en communicatie tussen patiënt en zorgverleners beïnvloedt. Het hoofdstuk toont de ziekenhuisafdeling als een microkosmos van sociale interacties van verschillende actoren die de resultaten van behandeling en zorg bepalen. De machtsverhoudingen beïnvloeden ook de pogingen van de diverse actoren om de kwaliteit van leven van patiënten te verbeteren. Tekort aan personeel, onvoldoende ruimte op de afdeling, en gebrekkige faciliteiten beperken de ondersteuning die professio-

nals kunnen bieden. Daarnaast hebben bezoekers en ‘ward assistants’ een tweeslachtige invloed. Hoewel ze het lijden van patiënten enigszins kunnen verlichten, hebben ze slechts beperkte invloed in de ziekenhuishiërarchie, en durven patiënten hen niet voortdurend lastig te vallen.

Hoofdstuk 5 gaat in op de pijn die kankerpatiënten lijden en op de problemen die zij ondervinden bij het eten. Het beschrijft en analyseert de moeilijkheden van patiënten om hun pijn tot uitdrukking te brengen. Als gevolg van ontoereikende voorzieningen en de beperkte tijd van verplegend personeel, wordt niet altijd goed ingegaan op de expliciete en impliciete uitingen van pijn en moeilijkheden bij het eten van patiënten. Dit leidt tot frustratie bij patiënten. Zowel patiënten als medische professionals geven aan dat kanker en de behandeling ervan hardnekkige pijn veroorzaken. Pijn en moeilijkheden bij het eten worden echter ook veroorzaakt door de behandelingsprocedures, onprettige omstandigheden in het ziekenhuis en een gebrek aan empathie en ondersteuning binnen de afdeling. Het langer voortduren van deze fenomenen kan vervolgens weer invloed hebben op de mogelijkheden van patiënten om te eten, zich te concentreren, te slapen of te communiceren met anderen. Dit leidt tot een reeks van psychologische en sociale complicaties, waaronder depressie en angst. Patiënten gaan zelfs heel voorzichtig en discreet over tot het toepassen van alternatieve geneeswijzen naast hun ziekenhuisbehandeling als deel van hun wanhopige pogingen hun lijden zin te geven.

Hoofdstuk 6 beschrijft de emotionele en sociale bezorgdheid van kankerpatiënten die het gevolg is van de ziekte en de behandeling in het ziekenhuis. Het toont hun zorg over sociale ondersteuning, stigma, en morele oordelen over kanker. Het hoofdstuk laat zien dat subjectieve gevoelens over fysieke symptomen en de progressie van de ziekte de existentiële en emotionele zorgen van patiënten kan bepalen. Verder blijkt dat medische professionals deze zorgen van patiënten soms negeren. Zij hebben de neiging om niet-medische en niet-technische kwesties te scharen onder de categorie van ‘extra bagage’ die zij niet beschouwen als een belangrijk onderdeel van hun routinematige dagelijkse zorg activiteiten.

Hoofdstuk 7 onderzoekt aspecten die de ziekenhuisbehandeling verbinden met het leven van patiënten buiten het ziekenhuis. Het bestudeert hoe patiënten het verblijf en de behandeling in het ziekenhuis relateren aan hun levensomstandigheden en het levensonderhoud van het gezin. Dit omvat sociale en economische problemen in en rond de familie. Het hoofdstuk onderzoekt de consequenties van kanker en ziekenhuisopname van een gezinslid voor het levensonderhoud en de bestaanszekerheid van de gehele familie.

Hoofdstuk 8 presenteert de conclusie. De belangrijkste aspecten van het leven van kankerpatiënten in het Kenyatta National Hospital passeren kort de revue. Verder worden aanbevelingen voor ziekenhuispersoneel en beleidsmakers gege-

ven. Het boek sluit af met een epiloog waarbij een aantal patiënten gevolgd wordt die eerder waren ontslagen uit het ziekenhuis en daarna door de etnograaf uit het oog waren verloren. Dit hoofdstuk benadrukt het belang van etnografisch onderzoek bij het opzetten en begrijpen van patiënt-gerichte zorg. De conclusies en praktische implicaties van de etnografie problematiseren de rol van het ziekenhuis in het bieden van oplossingen voor fysieke en emotionele tegenslag van patiënten. Hun ziekenhuisopname en behandeling worden gekenmerkt door tweestrijdigheid waarbij het ziekenhuis het lijden van patiënten en hun families zowel verlicht als verergert. Hun ervaringen staan in een wijder verband van tegenslag dat, net als in veel andere ontwikkelingslanden, samenvalt met problemen in de aanpak van kanker. Een gebrek aan middelen en competent personeel verergert het lot van patiënten, fysiek, sociaal en emotioneel. Het ziekenhuis blijkt de plek te zijn waar kankerpatiënten en hun families de meest intensieve, dure en verontrustende ervaringen opdoen. Algemene armoede onder de bevolking en specifiek onder deze patiënten belemmert het mobiliseren van hulpbronnen voor de behandeling van kanker en het oplossen van andere gerelateerde problemen. Het hier beschreven ziekenhuisverblijf laat slechts een klein deel van de lange opeenstapeling van ervaringen in het verstoorte leven van kankerpatiënten zien.

Dit onderzoek illustreert de moeizame situatie waarin kankerpatiënten zich bevinden in een context van ontoereikende toegang tot betaalbare en effectieve medicijnen en pijnstillers voor de behandeling van kanker op lokaal en nationaal niveau. De beschrijving van het lijden van kankerpatiënten toont de overheid dat het noodzakelijk is om meer te investeren in de behandeling van kanker in regionale ziekenhuizen. De faciliteiten om kanker in een vroeg stadium te behandelen alsmede de voorzieningen in het centrale ziekenhuis moeten verbeteren. Dit vraagt om betrokkenheid en toewijding voor het tot stand komen van duurzame financiering van deze voorzieningen. Kankerpatiënten in Kenia zouden niet alleen profijt hebben van materiële en emotionele steun, maar ook van een vermindering van het aantal ziekenhuisopnamen en van de lengte van hun opname. Dit kan mede bereikt worden door het verbeteren van de faciliteiten en voorzieningen om patiënten buiten het ziekenhuis te behandelen, en van pijnbestrijding in het algemeen.

About the author

Benson A Mulemi completed basic and primary school education in 1982 in Western Kenya and pursued his Secondary School ('O-level') and High School ('A-level') education from 1983 to 1988. He graduated with Bachelor of Arts degree in Anthropology (major) and Kiswahili language (minor) from Moi University, Kenya in 1993. In 1998 he obtained a Master of Arts degree in Anthropology from the Institute of African Studies, University of Nairobi. He took the position of PhD researcher at the Amsterdam institute for Metropolitan and International Development Studies (AMIDSt); University of Amsterdam in September 2004. He has worked on several projects as a researcher and lecturer at the Catholic University of Eastern Africa, and visiting lecturer at the Institute of African Studies; University of Nairobi. He has also worked as visiting lecturer at Christ the Teacher Institute for Education, Tangaza College (affiliated to St. Mary's University Minnesota, USA), Theological Centre for Religious; Tangaza College and the Jesuit School of Theology; Hekima College, both constituent colleges of the Catholic University of Eastern Africa in Nairobi. He also worked as a field and graduate assistant at the Maryknoll Institute of African studies of St. Mary's University of Minnesota, U.S.A and Tangaza College, in Nairobi. His research interests are in hospital ethnography, culture and health, social and cultural issues in end of life care, African belief systems and thought, and ethnographies of health and health care in Africa.

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