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

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## 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 in-patients.

### *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.