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

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## 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) 7,500<sup>1</sup> 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.

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<sup>1</sup> 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 handouts' 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.<sup>2</sup> 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

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<sup>2</sup> 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.