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

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## Struggle with pain and eating difficulties

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

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

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

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

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

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

Dr. Wario: Are you feeling any pain?

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

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

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

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

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

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

## Unspoken pain

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

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

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

### Expression of pain and quest for relief

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

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

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

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

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

### *Elusive reality*

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

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

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

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

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

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

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

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

### 'Missing chances to eat'

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

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

### *Meal times and treatment schedules*

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

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

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

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

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

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

#### *Unpleasant ward surroundings*

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

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

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

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

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

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

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

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

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

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

#### *Food ‘defeats’ me*

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

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

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

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

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

*'Inappropriate' food*

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

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

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

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

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

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

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

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

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

## Caregiver responses and patient satisfaction

### *Routine casual responses*

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

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

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

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

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

### *Medicines*

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

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

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

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

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

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

### *Disclosure*

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

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

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

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

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

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

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

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

## Resistance

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

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

*'Refusing to eat'*

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

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

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

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

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

#### *Refusing treatment and care*

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

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

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

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

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

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

## Patient inputs

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

*Patient-centred aetiologies*

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

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

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

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

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

#### *Alternative medicines*

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

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

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

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

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

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

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

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

## Summary and discussion

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

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

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

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

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

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

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

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

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

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

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