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

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## The ‘extra baggage’: Unmet psychosocial concerns

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

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

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

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

### Disintegrating bodies

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

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

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

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

### *Being 'half-dead'*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## Fear and information flow

### *Increasing fear*

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

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

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

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

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

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



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

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

#### *Unempathetic revelations*

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

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

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

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

## Unfolding misfortune

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

### *Social history*

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

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

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

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

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

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

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

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

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

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

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

*Medical history and silent grief*

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

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

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

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

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

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

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

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

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

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

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

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

## Stigma and hospital refuge

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

### *Social reproach*

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



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

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

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

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

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

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

#### *Uneasy personal and observer curiosity*

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

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

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

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

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

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

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

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

## Dimensions of isolation

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

### *Experiential isolation*

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

*Precautionary isolation*

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

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

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

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

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

*Social exclusion*

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

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

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

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

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

## Daily living and the future

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

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

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

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

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

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

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

#### *A Glimmer of hope against a diminishing future*

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



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

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

## Summary and discussion

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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