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

Mulemi, B.A.

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## Patient care interactions

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

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

The major ward round was in effect the ‘main event’ that brought key patient care participants<sup>1</sup> together. The composition of the group varied from time to time, with medical and paramedical staff, pharmacy and nutrition students, and some ward assistants forming a full team. An oncology consultant led the ‘major ward round’ on Fridays, and attendance was compulsory for the main cancer management actors assigned to the ward. The major ward round represented the ideal picture of professional collaboration in cancer management. The ‘minor round’, in contrast, was held by a ward physician (also known as the Medical Officer of Health) on Tuesdays. This was a less flamboyant event, obligatory for the matron or her representative, a records clerk, porter and a pharmacist. There was more laxity in the timing and attendance of the ward physician’s than the consultant’s round.

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

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

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

## Hierarchy and participation

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

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

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

## Consultant and ward physician

### *Chief and subordinate medical authority*

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

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

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

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

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

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

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

#### *Discharge and treatment decisions*

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

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

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

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

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

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

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

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

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

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

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

#### *Unpopular decisions*

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

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



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

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

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

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

### *Help from lower ranks*

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

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

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

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

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

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

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

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

## Pharmacists

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

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

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

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

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

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

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

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

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

## Nurses

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

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

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

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

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

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

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

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

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

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

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

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

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

### Marginal professionals

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

#### *Radiotherapists*

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

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



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

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

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

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

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

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

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

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

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

### *Physiotherapist*

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

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

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

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

#### *Medical social worker*

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

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

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

#### *Occupational therapist*

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

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

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

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

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

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

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

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

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

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

*'The small people'*

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

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

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

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

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

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

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

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

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

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

### Patients' participation

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

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

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



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

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

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

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

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

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

## Relatives: ‘Visitors’ or care partners?

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

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

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

*'Boasting' relatives*

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

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

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

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

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

## Summary and discussion

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

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

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

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

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

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

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

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

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

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