Coping with cancer and adversity: Hospital ethnography in Kenya

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Epilogue

I kept in touch with several respondents outside the hospital. Ajwang’ was very excited that I indeed visited him at home, as I had promised. He and his family strove to reciprocate by offering their best tea or lunch treats. However, they were barely able to afford meals for their own household and the special food recommended for the patient before the next hospital admission.

In July 2007, one year after my fieldwork, I took a six-week break and travelled back to Nairobi. I contacted my respondents by telephone to find out how they were faring. Mr. Ndege said he did not find it necessary to continue to attend clinical reviews at the cancer treatment centre. He said that “endless and fruitless tests” for his chronic multiple myeloma frustrated him. He did not keep the clinical appointment scheduled after his father’s funeral upcountry. Mr. Ndege decided not to return to the hospital. He was optimistic that his son Epainito, a high school leaver would find a job. Epainito had spent many months in Nairobi to help him in the hospital. He had since moved to Mombasa to live with an uncle as he looked for a job.

Mrs. Jabari answered my telephone call and said: “the pastor left us [died] in March. His blood count was too low and he needed an urgent transfusion. He passed away when we arrived at the district hospital.” Mr. Jabari had been a relatively successful rehabilitation case just like Misaka Masseyi. He had completed all his treatment sessions consecutively since he ‘qualified’ for all subsequent hospital admissions immediately. His wife had a kitchen garden to facilitate his dietary needs during treatment. Her response to my call reminded me of many telephone conversations I had had with patients during my fieldwork. Some were happy to inform me of their successful readmission for subsequent therapies. Others called to express regret that they could not be re-admitted as scheduled. Either results of their medical tests were disappointing or they lacked the money to cover hospital admission fees and drugs. Mr. Toi’s last call was to say that he would not make it back to hospital because of “unavoidable circumstances”. The following week his brother called to inform me of his death. I could not get a response when I called Ms. Nadia to confirm a home visit appointment. After recognising me as the researcher at the hospital, someone answered: “I am her mother. Nadia is no longer with us. She is gone [dead]. It has been one week since she has been gone.” I recalled some of the respondents’ funds raising events that I was able to attend. Ms. Nadia had been planning one and Ms
Souda’s did not materialise. There was an impromptu mobilisation of people to contribute some money toward ‘an education fund’ for Ms. Stella’s children at her requiem mass. There were barely one hundred fifty people, her relatives and close family friends living in Nairobi.

Nurses often looked for information about patients who left the ward. “It was even in the newspaper”, some would say, to confirm bad news of former patients’ deaths. I had attended three respondents’ funerals before the end of my fieldwork. Doctors discharged some patients “to go and rest.” We never heard about many of them again after their discharge from the ward. Physicians discharged some of them through the hospice and the others, such as Mr. Jabari, through the clinic for regular reviews. They had either completed requisite treatment or needed further investigation for chronic conditions. Some patients made many trips to the clinic because they did not qualify for subsequent admission. Any discharge implied a gradual exit from the medical gaze, or at times, an entry into a labyrinth of countless tests and clinical appointments. Ward exit paths varied. This could be from the cancer ward to regular clinics; ward-home, ward-home via a hospice, or ward-home via the nearest health facility. Some victims gave up, to “wait for God”, or tried alternative therapies at home. The journey from the hospital could lead to an infinite limbo for patients and their families. Low survival rates and beleaguered livelihood were the sad reality of daily life in the cancer ward. Relatives and staff were delighted when victims could eat and walk on their own at the end of a therapy course. A doctor’s approval for discharge elated patients too. They felt great relief upon going home again, especially when they could eat well and walk without assistance. I was happy about this too.

Before returning to the Netherlands in August 2007 to complete the monograph, I learnt of a new development at the hospital. They had initiated a palliative care unit in March to care for patients with chronic illnesses. I read that the goals of this unit were to:

- Improve pain and symptom control.
- Increase knowledge of pain and symptom control.
- Increase patient and family satisfaction with care.
- Increase communication techniques among the hospital health care workers.
- Respect and support patients’ preferences.
- Prevent inappropriate emergency department and in-patients admissions.
- Increase enrolment of patients who will benefit from hospice care.

The hospital launched the palliative unit formally in October 2007. This was about one year and a half after my fieldwork. This reminded me of some nurses’ popular idiom of hope as they talked about patient cancer care in the hospital: “Our work is to add life into their days and not days into their life.”