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Coping with cancer and adversity : Hospital ethnography in Kenya

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Appendix 1: Patients quoted in the ethnography

Mr Ader, 53 years old, was a married primary school teacher with five children. His wife helped in the management of family subsistence farming. He was a long-term in-patient suffering from Squamous cell carcinoma with a chronic wound on his thigh. He believed that his disease was unknown to the doctors as they were not providing a cure, especially for the wound. He was discharged “to go and rest” and return if the illness became more severe.

*Ajwang** was a 21-year-old single high school leaver. He was diagnosed with osteogenic sarcoma during his final year of school. This resulted in the amputation of his leg. He lived with his parents and four siblings. Their source of livelihood was subsistence farming and his father’s wages from masonry. At the end of the fieldwork he had completed chemotherapy sessions and had been discharged.

Mr. Bedokufa was a 45 year old long-term patient suffering from multiple myeloma. He worked as a warden/caretaker of rental houses and had five dependents. His wife also worked as an agent for rental houses and supplemented their meager family income. He was anxious about his health as the diagnosis was not yet definite and he felt that physicians did not explain his condition adequately. They discharged him to the hospice to await readmission pending the presentation of recommended diagnostic results.

Mr Chepia was 39 years old, married with one child and expecting a second at the time of his hospitalisation. Before he was diagnosed with melanoma of the bone marrow, he had enrolled as an undergraduate in a theology programme. He worked as an electrical technician and supplemented his earnings through subsistence farming. His wife was not employed. He was among the patients who openly expressed bitterness due to the disease and its social and economic implications for them. He did not return for treatment after the second course of chemotherapy. Both nurses and fellow patients indicated that he intended to abscond from hospital treatment.

Mrs Gatoro, 40 years of age, was a primary school leaver and a victim of breast cancer. She had six children and a husband, and she earned a living from subsistence farming and small businesses. She was a long-term patient due the complication of the spreading disease. Doctors indicated that she was experiencing

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These are respondents I visited at home for data on livelihood contexts in the hospitalisation of cancer patients. This is further described in Chapter 7.

metastasis of the disease to her brain. In the second month of the fieldwork she collapsed and died in the ward bathroom.

*Mr Jabari** was 49 years old and was married with four children. He was diagnosed with colon cancer after prolonged illness. He was a high school leaver trained as a technician/"mechanical engineer". Both his wife and he were in stable employment. Apart from owning rental houses they also engaged in subsistence farming and raised a few dairy cows. His wife and children visited at least once during his short hospitalisation sessions. His treatment process was relatively successful. He always had adequate blood counts and other diagnostic results. In addition, he never was turned down for admission and raised the requisite hospitalisation and treatment funds promptly. As an active member of his church at home, he served fellow in-patients as a religious counselor. At the end of the fieldwork, he had completed the first-line chemotherapy sessions and was attending clinical reviews regularly. He died in a hospital in his home district seven months after the fieldwork.

Mr. Johana was a 34-year-old married male patient diagnosed with nasopharyngeal carcinoma. He held a diploma in mechanical engineering after high school. He had four dependents and received support from kin during the hospitalisation period. He completed five courses of chemotherapy and by the end of the fieldwork was discharged pending the final course. This respondent had documented the details in a diary about his experience with cancer illness.

*Mr. Kabba**, 19 years old, was a high school student. He was diagnosed with osteogenic sarcoma after protracted illness. His left hand was amputated in a district hospital before referral to the present hospital for 25 radiotherapy sessions as an outpatient. He was later admitted to the cancer ward for chemotherapy and had completed the first line courses before the fieldwork. He lived with his married sister and other relatives in a one-bedroom apartment during his hospital treatment period. His parents lived in the remote areas of a arid district in North-Eastern Kenya. He had completed second-line chemotherapy by the end of the fieldwork and visited the clinic regularly for reviews.

Mr. Kassi, 64 years old, was a retired primary school teacher. He was married and had nine dependents. He earned a living from a maize farm and a few dairy cows. He was admitted to treat a tumour in the chest which was not diagnosed until after about five years. He attended radiotherapy sessions as an outpatient in the hospital before admission to the cancer ward for chemotherapy. He had a few relatives in Nairobi who supported him during the hospitalisation process. At the

end of the fieldwork he was waiting for the diagnostic results needed in order to be hospitalised again.

Mr. Makamo suffered from nasopharyngeal carcinoma. He was 36 years old, single, and was engaged in small-scale business. He documented his experience in a diary and hoped to discover the meaning of his suffering from this exercise. He referred to the book of Daniel in the Bible and hoped to publish his personal memoir. This respondent informed some fellow patients that he was getting tired of fruitless hospitalisation. He did not turn up for subsequent treatment after the fourth course of chemotherapy.

Ms. Marina was 24 years old, single, and diagnosed with nasopharyngeal carcinoma. She was a medical laboratory assistant before her illness. She was not able to go back to work due to frequent hospitalisation, and resigned from her job with a private doctor. Close family members assisted her during the hospital treatment process. She was pessimistic about treatment outcomes and was bitter about the opportunities to work and study that she had lost due to the disease. Her closest family carer was her bother who lived in the Nairobi. At the end of the fieldwork she was discharged and attending treatment and review as an out-patient.

Mr. Mati was a 38-year-old widower suffering from colon cancer. He was referred to the current hospital after diagnosis and first operation in a district hospital. He worked as a primary school teacher, ran small business and did subsistence farming. He had three dependants. He underwent second operation at the current hospital. At the end of the fieldwork he was discharged, awaiting subsequent admission

Mr. Memba, 65 years old, was a married farmer. He was a primary school dropout and earned a living from growing food crops and raising livestock. He had one dependent in tertiary college training. He was on radiotherapy for six weeks to treat throat cancer. He had relatives with whom he stayed in the city during his short-term discharge from the ward. At the end of the fieldwork he was discharged pending hospitalisation for chemotherapy sessions.

Mr. Misaka Masseyi, 55 years old, was diagnosed with breast cancer. Mastectomy was carried out in a district hospital before referral to the cancer ward for further treatment. He had retired from his job as a clerical officer in a housing corporation and used his retirement benefits to pay for his treatment. He had seven dependents, and received support from his family, which also depended on subsistence farming and small scale tea production for cash. He was hospitalised

for second-line chemotherapy. The outcome was relatively successful and he was discharged pending regular reviews at the cancer treatment centre clinic. He died in the ward following an emergency readmission after the first scheduled clinic.

*Mr. Mukuru**, 22 years old, was a single primary school leaver. He had been a self-employed fruit vendor in the coast province before his undiagnosed illness became severe. Diagnosis at a district hospital revealed nasopharyngeal carcinoma. He was admitted to the cancer ward for radiotherapy after an operation at the district hospital. He lived with his elderly widowed mother during the hospital treatment process. They earned a living from subsistence farming and kin support. By the end of the fieldwork he was seeking readmission on credit to start chemotherapy.

Ms. Nadia was a single divorced mother of three children. She lived in a single room in a nearby slum area with her children. She earned her living from a small second hand clothes business. Before conversations with her began, she had been on the ward for two months to treat nasopharyngeal carcinoma. She was discharged after being retained in the ward for two weeks due to a lack of money to clear her bills. She died at home one week after discharge, before I could visit her at home as we had agreed.

*Mr. Ndege** was a 54-year-old primary school teacher suffering from multiple myeloma. The diagnosis was, however, not entirely clear and investigations were still underway. He had seven dependents and supplemented his income with subsistence farming. He lived alternately with two relatives during the treatment period while he was not in hospital. Doctors recommended further clinical investigations and reviews after he completed radiotherapy sessions. The funeral of his father in a rural area interrupted his clinical reviews.

Mrs. Ndunduri, 56 years of age, was a married long-term inpatient. She was a primary school drop-out and a subsistence farmer. Her husband and she had two dependent grandchildren who were orphans. She suffered from squamous cell carcinoma of which the primary cause was unknown. Metastasis of the disease affected the upper oesophagus and oral cavity and lungs. Her son who worked in a town near the hospital provided financial support, but she did not have relatives in the city. She was often delirious and experienced insomnia. The doctor sedated her several times and nurses on occasion tied her to the bed using sheets to restrain her. She died in the ward before the end of the fieldwork.

Mrs. Omari, 49 years of age, was married with eight children. She was diagnosed with breast cancer and was undergoing second-line chemotherapy. She was a

primary school teacher, and her husband managed the family's sugarcane farm, from which they got extra income. They also did some subsistence farming. Her experience typified that of other patients who required stronger analgesics to relieve their pain. She did not have relatives in Nairobi and relied on her husband, who was over 350 km away, for emotional support. By the end of the fieldwork she had been discharged awaiting the fourth course of (second-line) chemotherapy.

*Mrs. Pakot** was 49 years of age and a primary school teacher. She suffered from breast cancer. She was married with three children, and her husband was unemployed. Subsistence and small scale cash crop farming supplemented their income. She was admitted for recurrence a few years after she had a mastectomy and relatively successful treatment. The disease spread, and doctors confirmed that she now had Stage I cancer of the uterus. She resisted physicians' recommendations for discharge through the hospice, and was transferred to another ward where surgery was done. She was finally discharged and accepted referral to a local hospice for home-based palliative care. She passed away at home before the end of the fieldwork.

Mr. Saulo, 43 years of age, was a primary school leaver and a married father of three. He suffered from colorectal cancer and was admitted for a combination of chemotherapy and radiotherapy. He earned a living from subsistence and cash crop (wheat and maize) farming. His wife was not formally employed and participated in the management of the family farm and livestock rearing. He was involved in the sale and use of patented food supplements and alternative medicine, which he tried to market to fellow in-patients. He relied on his aunt who lived in Nairobi to supply him with home-prepared food while he was in hospital.

*Ms. Souda** was a 39-year-old single mother of four children. Her first born son and a daughter had completed high school, whereas two sons had dropped out of school due to a lack of school fees. She separated from her husband around the time she became ill, before being diagnosed with cervical cancer. She lived in Nairobi in a two-bedroom apartment and depended on relatives and well wishers for her livelihood. Due to the illness she lost her job as a bank clerk and worked as a volunteer in a local non-governmental organisation when she felt well.

*Ms. Stella** was a 47-year-old widow suffering from breast cancer. She was referred to the cancer ward for chemotherapy after a successful mastectomy in the present hospital. Her husband fell ill and died in a district hospital while she was taking treatment in the cancer ward. She had seven dependants and only two had completed high school. A daughter who housed her while she waited for subse-

quent hospitalisations had a low paying job. Ms. Stella worked as a school bursar and managed a small subsistence farm before her prolonged illness and hospitalisations. At the time of the fieldwork she was undergoing second-line courses of chemotherapy. She refused to go back for the last course of chemotherapy as she claimed that it was futile. She resorted to alternative Chinese medicine at home, and died in the ward after her relatives brought her in as an emergency case.

*Mr. Tarus**, 28 years of age, was a married businessman. He had been admitted for chemotherapy to treat bone marrow/spinal cancer. He had started his treatment in a nearby private hospital, which he realized was becoming too expensive. He was a primary school leaver and had five dependents. He supplemented his income with subsistence farming. This respondent had rented a room in Nairobi where he lived during the hospitalisation period. He died in the ward before the end of the fieldwork.

*Mr. Toi** was a 26-year-old high school leaver. He was diagnosed with osteogenic sarcoma and had his leg amputated in a district hospital. Before this he used to do petty business for his own maintenance and the support of his parents who were both unemployed subsistence farmers. He relied on funds from kin and especially the fundraising event for his benefit organised by clan members. He was a victim of delayed readmission for chemotherapy due to low blood count and extra infections. His condition worsened after the fifth course of treatment, and he postponed his readmission many times. He died at home before the end of the fieldwork and before he could be readmitted for a sixth chemotherapy course.

Mrs. Vyakawa, a 43-year-old long-term inpatient, suffered from fibrosarcoma. Her left leg was amputated due to the disease. She was childless and married as a second wife. She was the main breadwinner for her deceased co-wife's five children and her poor parents, providing for them through petty business and subsistence farming before her illness became severe. She had also been diagnosed with the HIV/AIDS virus and this interrupted her chemotherapy sessions. She did not have relatives living near the hospital. Her sister, the only caregiver from the family lived about 170 kilometers from the hospital and was unable to visit regularly. She died in the ward before the end of the fieldwork.