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

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## Summary

This monograph describes the experiences of patients, families and hospital staff in a cancer ward in Kenya. It shows how circumstances of cancer treatment in a national referral hospital ward reflect insufficient services in the country's healthcare system. The physical, social and healthcare circumstances in the ward further shape patients' experiences of cancer. These aspects of hospitalisation, coupled with other factors within and beyond the hospital, influence patients' expressions of physical and emotional satisfaction and discomfort.

Chapter 1 introduces the book with a glimpse at typical experiences of patients and carers in the cancer ward. It represents a significant scene of continuity in the perennial struggle of patients and caregivers to ease the suffering that cancer and its treatment cause. The cancer ward is a scene of climax in the fight against cancer where a majority of the patients either do not pull through or fail to restore their physical, emotional and social lives as adequately as they expect. The onset of cancer illness ushers in relentless help-seeking and arduous hospital treatment processes which tend to dominate the remainder of patients' lives.

The central question of the study follows a brief depiction of the ethnographic scene: how do the lives and experiences of cancer inpatients in a Kenyan referral hospital relate to their needs, and what aspects of the experience characterise their hospitalisation? I then present the primary goal of the study, which is to contribute to hospital ethnography, in developing countries. Specifically, the purpose of the study is to show how hospital and family circumstances in Kenya shape patients' experiences of cancer management. I then present an overview of the critical medical anthropological conceptual framework for understanding and describing daily life experiences in the cancer ward. Experiences of individual sufferers in a local hospital ward depict subjective perspectives, therapeutic and care relationships, caregiver interdependence and broader socio-economic contexts encompassing patients' well-being and quality of life. Chapter One ends with an historical overview of the study hospital, the cancer problem in Kenya, and the nature of existing research on cancer management in Kenya. Previous hospital studies focus on quantitative biomedical aspects and tend to ignore ethnographic dimensions, which are equally important for patient care initiatives.

Chapter 2 describes the ethnographic methodology of this study. I explain the scope of the present hospital ethnography and my purpose in selecting the cancer ward as the fieldwork site. I then explain how I collected my data as an ethno-

grapher in the cancer ward and treatment centre clinic of Kenyatta National Hospital (KNH) between August 2005 and July 2006. I did the fieldwork as a direct non-participant observer; my participation was limited to activities and conversations that a lay (non-medical) person can generally engage in. I transcribed in-depth conversations with 42 patients, eleven relatives, three doctors and eleven nurses. Continuous informal conversations and observations were the hallmark of this study. This chapter further describes and analyses issues in the processes of my admission to the hospital as a researcher without a biomedical identity and training. I show that accessing the hospital as an ethnographer may be difficult because it is an 'unusual fieldwork site' for anthropological research. Hospital professionals may also view the presence of an anthropologist as threatening their autonomy. The study included an exploration of patients' treatment contexts beyond the clinical setting, which shape ongoing hospital care experiences and outcomes. Collection of data beyond the hospital highlighted the contextual issues in hospital treatment of cancer. These included low affordability of medicines and patient care services, difficulties in accessing adequate amounts of food, let alone appropriate food, and social support. Transient hospital stay does not allow most other researchers and hospital workers enough time to understand and deal with matters in the wider contexts of cancer inpatients' expressed suffering.

Chapter 3 describes the cancer ward as both a study and a treatment site that constitutes the physical and emotional space for cancer patients. This chapter further highlights patients' expectations of the ward and what it means to them. In the initial stages of hospitalisation, the cancer ward is a place they associate with full recovery and restoration of their disrupted lives. Since KNH generally offers better technology and expertise than other public healthcare facilities, admission to the cancer ward renews hopes for a cure and a return to normal life. However, the chapter also highlights the hospital staff's underlying perceptions of the low status of the cancer ward and its insignificant contribution to the overall improvement of patients' well-being. The description of the ward's physical layout and its human and non-human resources reveal the limitations of the ward in meeting patients' physical and emotional needs. The second part of the chapter deals with patients' experiences of treatment in the prevailing ward circumstances. It points out patients' determination to focus their minds on treatment in spite of a potentially stressful treatment environment.

Chapter 4 describes and analyses patient care interactions among various actors in the cancer ward. It situates patients' experiences and roles in treatment within the social and medical hierarchies in the hospital, and shows how issues in social and medical hierarchy in the cancer treatment centre have implications for patient care interactions, communication and interdependence. In this chapter I

present the hospital ward as a microcosm of social interactions of different actors which shape the outcome of hospital treatment and patient care efforts. The hierarchical, social and power relations in this ward influence different actors' participation in attempts to improve patients' quality of life. The chapter shows that shortage of hospital staff, ward space and facilities constrain the participation of key patient support professionals. Similarly, routine activities in the cancer ward and treatment centre marginalise other professionals and prevent them from giving the maximum of their input in patient care discussions and communication. In addition, the role of patients' relatives (visitors) and ward assistants is ambiguous, though they can contribute to the effort to ease patients' suffering during hospitalisation, thereby improving patients' quality of life and satisfaction.

Chapter 5 is about the patients' experience of pain and eating difficulties as the main physical symptoms of suffering due to cancer and hospital treatment. I describe and analyse difficulties associated with patients' attempts to express their suffering. Insufficient hospital resources and time constraints affected the responses of ward staff to patients' explicit or implicit communications of pain and eating difficulties. The chapter highlights patients' disillusionment as the responses they receive and available medicines do not meet their expectations of hospital treatment in relieving pain and other kinds of physical suffering. As medical professionals and patients alike noted, persistent pain results from either cancer or treatment procedures. However, pain and eating difficulties are also iatrogenic, resulting from treatment procedures, unpleasant hospital circumstances and a lack of appropriate empathy and support in the ward. Persistence of these phenomena may further interfere with a patients' ability to eat, concentrate, sleep, or interact with other people. This results in a series of psychological and social consequences, including depression and anxiety, which worsen inpatients' suffering. Chapter 5 concludes with a description of patients' discreet recourse to alternative aetiologies as part of their desperate attempts to make sense of their suffering and supplement hospital treatment.

Chapter 6 describes cancer patients' emotional and social concerns that result from the disease and hospital treatment. It depicts patients' worries about social support, experiences of stigma, and some moral ideas about cancer. The chapter shows how subjective feelings about physical symptoms and disease progression can shape sufferers' existential and emotional concerns. In this chapter, I describe a scenario in which medical professionals may ignore inpatients' emotional and social concerns. They relegate patients' non-medical or non-technical issues to the category of 'extra baggage', which they do not consider important aspects of their routine patient care responsibilities.

Chapter 7 explores phenomena that link treatment outcomes to patients' lives outside the hospital. It describes the wider social, economic and livelihood realities manifested in patients' experiences in the ward. This chapter examines how patients experience treatment and hospitalisation in relation to their livelihood circumstances. It describes the social and economic issues behind patients' experiences of cancer treatment and hospitalisation. The chapter examines the implications of individual and family strategies for coping with cancer and hospitalisation for livelihood organisation and security. I explore and describe the implications of cancer inpatients' and their families' inadequate access to formal and informal sources of support.

Chapter 8 concludes this book by revisiting the main aspects of the life of cancer patients in Kenyatta National Hospital. Recommendations for hospital workers and policy makers follow the conclusions. The book closes with an epilogue tracing some of the patients' exits from the hospital and my own as an ethnographer. Chapter 8 emphasises the relevance of hospital ethnography to comprehensive patient-centred hospital care and studies. The conclusions and practical implications of the ethnography further problematise the role of the hospital in offering solutions to cancer patients' physical and emotional adversity. A wide array of hardships shape cancer inpatients' daily experiences in Kenyatta National Hospital. Ambiguity characterises their hospital stay and treatment, while the hospital both alleviates as well as increases the human suffering of cancer patients. Their experiences of hospital treatment, as in other resource-poor countries constitute part of a wider spectrum of misfortune that afflicts cancer inpatients. A shortage of hospital resources and competent cancer healthcare staff worsens poor patients' physical, social and emotional adversity. The national referral hospital turns out to be the place where cancer patients and their families endure the most intensive, expensive distressing experiences. Lack of resources and poverty among the population in general, and among these patients in particular, hamper mobilisation of resources for treatment and other needs. Destitution of poor families and dependent members increase with the frequency of hospital admission and escalation of treatment bills. In addition, their current hospital stays reveal only a small part of the cancer patients' long and cumulative experiences of interrupted lives. The onset of cancer and management of chronic illness entails the catastrophic disruption of normal rhythms of life and a serious threat to patients' lifeworlds.

This study illustrates the plight of cancer patients in a context of inadequate access to affordable and effective cancer treatment drugs and analgesics at both local and national levels. The suffering of individual patients indicates the urgent need for the government to accelerate efforts to improve cancer management in peripheral hospitals and revitalise treatment facilities and services at the national

referral hospital. This calls for the government's commitment to the establishment and sustainable funding of cancer management services in both national and regional hospitals. Cancer patients in Kenya would benefit not only from more material and emotional support, but also from a reduction in the frequency of hospital admission and duration of stay. This can be achieved through improvement of outpatient services and facilities for palliative care in peripheral hospitals and hospices. A programme for home care and accessible hospice services would also contribute to the improvement of patients' quality of life during and after hospitalisation.