CHAPTER 12

SUMMARY

Chapter 1 describes the challenges faced in treatment of childhood cancer in low-income countries. Globally there are about 200,000 new cases of childhood cancer annually of which 80% occur in low and middle-income countries. Eighty per cent of deaths due to childhood cancer occur in low and middle-income countries. The survival is more than 75% in high-income countries while it is less than 35% in low and middle-income countries. There are a variety of reasons that explain this huge difference in survival. These include inadequate financial and human resource, and treatment related mortality. However, the most important reason for this difference in survival is abandonment of treatment, which is almost never seen in high-income countries.

The aims of this study are:

i) To investigate the epidemiology of childhood cancer at MTRH

ii) To explore treatment outcomes and survival of childhood cancer at MTRH

iii) To assess the magnitude and the factors which contribute to childhood cancer treatment abandonment in Kenya.

iv) To investigate the barriers to accessing health care for childhood cancers in Kenya

Chapter 2 describes the epidemiology of diagnosed childhood cancer in Western Kenya. This was done through a retrospective medical records study performed at the Moi Teaching and Referral Hospital (MTRH) located in Eldoret, Kenya. All children aged less than 19 years who presented to the hospital between January 2006 and January 2010 with a newly diagnosed malignancy were included. Three databases were used to identify these children and we found a total of 436 children with 59% being male. Non-Hodgkin lymphoma was the most common type of cancer (34%) followed by acute lymphoblastic leukemia (15%), Hodgkin lymphoma (8%), and nephroblastoma (8%). Majority of the children were between 6-10 years (29%). We found that the distribution of childhood cancers in Western Kenya is the same as what has been described in other Sub-Saharan Africa countries, but differs markedly from those in high-income countries.
Chapter 3 focuses on the problem of treatment abandonment in the Kenyan set-up. Between January 2007 and January 2009 treatment abandonment was the leading cause of childhood cancer treatment failure at MTRH. We had found an abandonment rate of 54% among the 180 patients diagnosed during this period. The aim of this study was to assess the reasons for treatment abandonment and the clinical condition of these children. This was a descriptive study using semi-structured questionnaires. Home visits were conducted to interview the families of children with cancer, diagnosed between January 2007 and January 2009, who had abandoned treatment at MTRH. Due to lack of contact information, only 53 families could be traced. In total, 46 families (87%) agreed to be interviewed. The most common reasons for abandonment were financial difficulties (46%), inadequate access to health insurance (27%) and transportation difficulties (23%). Most patients (72%) abandoned treatment after the first 3 months had been completed. Twenty per cent of the children who abandoned treatment were still alive at the time of conducting the interviews.

In Chapter 4 we looked at two unique factors that might be contributing to the high abandonment rate in this setup. These were hospital retention policies and access to health insurance. This study explores whether childhood cancer treatment outcomes in Kenya are influenced by health-insurance status and hospital retention policies. We reviewed the medical records of children diagnosed with malignancy in the years 2007 to 2009 and used a case report to illustrate the contribution of these two factors to abandonment. Among the 222 children diagnosed during this time frame, 180 had documented outcomes. The majority (54%) abandoned treatment, 19% had event-free survival with the rest having progressive/relapsed disease or death. Health-insurance status at diagnosis was recorded in 148 children: 23% had health-insurance, and 77% had not. For those with health-insurance compared to those without, the relative risk for treatment abandonment relative to event-free survival was significantly smaller (relative-risk ratio=0.31, 95% CI 0.12-0.81, P=0.016). The case reported was on a child diagnosed with acute lymphoblastic leukemia whose family did not have health-insurance at diagnosis and the boy was retained in the hospital as the family could not pay the hospital bill.

In Chapter five we looked at the effect of parents’ social network and hospital retention policies on parents’ decisions to abandon cancer treatment of their child. We did this by conducting home visits to families that had abandoned childhood cancer treatment at MTRH in the years
2007-2009. We managed to interview 46 of those families. Their social network comprised the grandparents, relatives, friends, villagers and church members. Majority (74%) of the families were advised by those in their social network to seek alternative treatment, while 54% were advised to stop the hospital treatment. Parents also reported that they were influenced by discussions with other parents who had children with cancer as they told them the life of the child was in God’s hands (87%), the trauma to the child and family of forced hospital stays (84%), the importance of completing treatment (81%), the financial burden of treatment (77%), and the incurability of cancer (74%). Seventy-eight percent of the families had no health-insurance and 53% of them had their children detained in the hospital due to non-payment of hospital bills. The families had a lot of negative feelings about the detention: desperation (95%), powerlessness (95%), and sadness (84%). The majority of parents (87%) felt that hospital retention of children must stop.

Chapter 6 describes the experiences parents go through as their children undergo cancer treatment at MTRH. This was done by conducting face to face interviews with parents whose children with cancer came for treatment between November 2012 and April 2013. Semi-structured questionnaires were used. We assessed the socio-economic, psychological and treatment related experiences. We had a response rate of 65% and were able to interview 75 parents. Cancer treatment resulted in financial difficulties (89%). Most families (63%) had no regular source of income while 66% reported that the income reduced while the child was undergoing treatment. Most of the families felt that they needed more information about cancer (88%) and more contact with doctors (83%). At diagnosis, cancer was perceived as curable (63%). Yet, parents were told by health-care providers that most children with cancer die (49%). Most parents reported using complementary alternative medicine (95%) although they found it difficult to discuss the same with the doctors (88%). They had varied reasons for using complementary medicine: hope for cure (53%), hope for improvement of child’s condition (47%), and recommendation by others (37%). Community members advised to use complementary alternative treatment (61%), believed that the child was bewitched (57%), and isolated families because their child had cancer. Parents shared experiences with other parents at the ward (97%) and would otherwise not understand cancer and its treatment (87%).
In Chapter 7 we evaluated the health-care providers’ perspectives on childhood cancer. Using a self-administered questionnaire which was filled out by 104 staff who work in the Department of Pediatrics at MTRH. Seventy-six percent of the health-care providers believed that cancer is curable. More doctors than other health-care workers believed that cancer is curable (P=0.037). Majority of health-care providers (92%) believe most children with cancer will not be able to finish their treatment due to financial difficulties. They believe that prosperous highly-educated parents adhere better with treatment (88%) and that doctors adhere better with treatment for prosperous highly-educated parents (79%).

According to 74% of health-care providers, quality of care is improved towards prosperous highly-educated parents (74%). Most health-care providers report to give more explanation (71%), work with greater accuracy (70%) to prosperous more educated families. Only 34% of health-care providers reported they feel more empathy towards patients from prosperous families. Reasons for non-adherence with the protocol according to health-care providers are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%), and financial difficulties of parents (69%). Health-care providers’ health beliefs and attitudes differ between families with high versus low socio-economic backgrounds.

Chapter 8 is a review of the problem of corruption and how it affects cancer care in Africa. We searched Pubmed and Google for relevant articles published between January 1990 and February 2015. We included articles with the terms “corruption” and “low-income countries” or “Africa”. Corruption is the use of entrusted power for private gain. The corruption perception index, a scale ranking countries from 0 (very corrupt) to 100 (very clean), is currently lower than 50 in 91% of the African counties. The health-care system is vulnerable to corruption since there are many players involved at different levels and there is an imbalance of medical knowledge among the different players. At the government level, misallocation of resources, diversion of resources, nepotism and poor monitoring systems are major components of corruption. This is replicated at the hospital level, as well as poor maintenance of equipment and diversion of supplies to private facilities. At the health-care provider level there are many doctors involved in dual physician practices and absenteeism. Some health-care providers also ask for informal payments before they provide services to staff and some are involved in diversion of supplies to their private clinics. Corruption therefore leads to delays in cancer patients seeking care as they avoid the public health facilities. It also leads to
abandonment of treatment as the patients incur high costs due to unavailability of drugs and the demands for bribes. There are delays in making and implementing decisions on patient care due to absence of the senior doctors. This leads to prolonged hospital stays among other effects. We have suggested several recommendations to international financial institutions, health organizations, donors, the United Nations, governments in high-income countries, African governments, and to the hospitals and health-care workers which we hope can reduce the magnitude of the problem.

In Chapter 9 we explored the factors that influence the time to diagnosis and treatment among pediatric oncology patients in Kenya. We conducted a study among parents of childhood cancer patients diagnosed between August 2013 and July 2014 at the MTRH in Eldoret, Kenya. Patient, physician, diagnosis, treatment, health-care system, and total delay were explored using a questionnaire. Demographic and medical data were collected from the patients' medical records. Parents of 99 childhood cancer patients were interviewed (response rate: 80%). Median total delay was 102 (9–1021) days. Patient delay (4 days) was significantly shorter than health-care system delay (median 87 days; \( P < 0.001 \)). Diagnosis delay (median 94 days) was significantly longer than treatment delay (median 6 days; \( P < 0.001 \)). Lack of health insurance at diagnosis and use of alternative medicine before attending conventional health services were associated with a significantly longer patient delay (\( P = 0.041 \) and \( P = 0.017 \), respectively). The type of cancer had a significant effect on treatment delay (\( P = 0.020 \)). The type of health facility attended affected only patient delay (\( P = 0.030 \)). Gender, age at diagnosis, stage of disease, parents' education level or income, and distance from hospital did not have a significant effect on the length of any type of delay.

In Chapter 10 we report on the outcomes of Wilms' tumor treatment in Western Kenya. This was a retrospective medical records review of all children diagnosed with Wilms' tumor between 2010 and 2012. Data on treatment outcomes and various socio-demographic and clinical characteristics was collected. Of all 39 Wilms' tumor patients, 41% had event-free survival, 31% abandoned treatment, 23% died, 5% had progressive or relapsed disease. Most patients presented at advanced stages: stage I (0%), stage II (7%), stage III (43%), stage IV (40%), stage V (10%). The most likely treatment outcome in patients with low (I-III) stage disease was event-free survival (67%), whereas in high (IV-V) stage disease it was death (40%). Stage of disease significantly
impacted treatment outcomes (P=0.014) and event-free survival estimates (P<0.001). Age at diagnosis, gender, duration of symptoms, distance to hospital, and health-insurance status did not statistically significantly influence treatment outcomes and event-free survival estimates. Survival of Wilms’ tumor patients in Kenya is lower compared to high-income countries. Treatment abandonment is the most common cause of treatment failure. Stage of disease at diagnosis statistically significantly affects treatment outcomes and survival.

Chapter 11 is a position statement from the International Society of Paediatric Oncology Global Taskforce on hospital detention practices. It recommends and defines the terms “hospital detention practices” and “detained patients.” It calls on professionals and advocates to report hospital detention in scientific journals, media and public venues. Recognition of adverse consequences is crucial. Progressive or relapsed disease and unnecessary death often result. Hospital detention is often the result of mismanagement, corruption, dysfunctional health-care system structures, inadequate health-insurance coverage, and unfair waiver procedures, warranting attention. Advocacy by stakeholders, such as international financial institutions, health organisations, donor countries, United Nations, national governments, civil society organisations, and scientific journals, is urgently needed.