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Risk Factors For Abandonment of Wilms Tumor Therapy in Kenya

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Abstract

Background—Survival from Wilms tumor (WT) in sub-Saharan Africa remains dismal as a result of on-therapy mortality and treatment abandonment. Review of patients diagnosed from 2008–2011 in our Kenyan Wilms Tumor Registry showed a loss to follow up (LTFU) rate approaching 50 percent. The purpose of this study was to trace those LTFU, estimate the survival rate, and identify risk factors for treatment abandonment.

Procedure—We administered a comprehensive survey to parents of patients with WT at the two largest referral hospitals in Kenya to identify barriers to care. We also telephoned families who had abandoned care to determine vital status and identify risk factors for treatment abandonment.

Results—Of 136 registered patients, 77 were confirmed dead (56.7%), 38 remained alive (27.9%), and the vital status of 21 patients remains unknown (15.4%). After contacting 33 of the patients who either abandoned curative treatment (n=34) or did not attend off-therapy visits (n=20), the best estimate of 2-year overall survival of patients with WT in Kenya approaches 36%.

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Conflict of Interest Statement

The authors do not have any conflicts of interest to report.

Sixty-three percent of parents misunderstood treatment plans and 55% encountered financial barriers. When asked how to increase comfort with the child's treatment, 27% of parents volunteered improving inefficient services and 26% volunteered reducing drug-unavailability.

Conclusions—Treatment abandonment remains a significant problem contributing to increased mortality from WT in developing countries. This multi-center survey identified the barriers to treatment completion from the parental perspective to be lack of education about WT and treatment, financial constraints, need for quality improvement, and drug-unavailability.

Keywords

Wilms tumor; Kenya; treatment abandonment

Introduction

Wilms tumor (WT) is the most common childhood kidney cancer worldwide and is particularly burdensome among black children of sub-Saharan Africa. [1] In 2001, our Kenyan collaborators summarized outcomes for patients with WT treated at the Kenyatta National Hospital (KNH) in Nairobi, reporting a 2-year OS from WT tragically of only 34.7%, compared with a 5-year OS of 90% in developed countries. [2–4] To monitor survival rates more accurately and to establish a sustainable platform for the biological study of WT in this at-risk population, we formed in 2012 a cooperative team of international investigators from KNH, Kijabe Hospital, Moi Teaching and Referral Hospital (Moi), and Tenwek Hospital in Kenya, and from Vanderbilt University and Meharry Medical College in the United States. Through these multidisciplinary efforts, we developed a Kenyan Wilms Tumor Registry (KWTR) and Tissue Repository to study more accurately the treatment outcomes and biology of patients in Kenya. A comprehensive analysis of this KWTR found a 52.7% 2-year OS at the time of last contact. However, the loss to follow up (LTFU) rate approached 50 percent, which tempered interpretation of any improved survival. [5]

Treatment failure in many developing countries of sub-Saharan Africa is due largely to care abandonment and therapy-related mortality. [3, 6–10] Although few analyses of factors contributing to abandonment of pediatric cancer treatment in sub-Saharan Africa have been published, most are from the perspective of health care providers or are retrospective chart reviews. Presumed causes of treatment abandonment in this region of the world most often include the patient's physical discomfort, parental fears, poor communication about and misunderstanding of the treatment plan, socio-cultural beliefs, and lack of resources to cover the expenses of full therapy regimens. [8, 11, 12] A retrospective chart review of all patients with pediatric cancers in Zambia found that due to on-therapy mortality and treatment abandonment, only 8 percent of patients completed therapy, with distance from the hospital and maternal education level to be the most important factors associated with the risk of treatment abandonment. [13] One study surveyed parents of 25 patients with Burkitt lymphoma and 7 patients with WT in Malawi prior to abandonment and found that they were motivated to adhere to therapy if they believed it would cure their child, but discussed having financial constraints, fear and questions about a cancer diagnosis that they were hesitant to ask, and concerns about blood draws weakening the child. [14] There have not been previously published studies that included the etiology of treatment abandonment for

patients with WT who actually abandoned treatment or that followed through to determine which survey respondents went on to abandon treatment.

In Kenya, we previously observed that patients enrolled in the National Hospital Insurance Fund (NHIF) completed more therapy than those not enrolled in NHIF (34.8 percent versus 23.5 percent; p=0.002). [5] However, even with enrollment in the NHIF, very few patients completed therapy, and knowledge about their ultimate vital status or the etiology of treatment abandonment remained lacking. As a result of these previous observations, we hypothesized that a poor understanding of treatment regimens and outcomes results in families abandoning WT treatment for their children. The objectives of our study were: 1) to trace the large fraction of patients with WT documented previously as LTFU, 2) to determine the most accurate 2-year OS of patients with WT enrolled in the registry through these tracing efforts, and 3) to identify risk factors for abandonment of care specific to this population using comprehensive needs assessment surveys administered to families of patients with WT. Clarifying risk factors for care abandonment in this fragile population in Kenya should afford opportunities for future interventions to improve event-free and overall survival.

Methods

Institutional Review Board (IRB) approval had previously been obtained from four collaborating hospitals (KNH, Moi, Kijabe Mission Hospital and Tenwek Mission Hospital) in Kenya to develop and maintain the Kenyan WT Registry and Tissue Repository (KWTR). [5] Amendments were made to the IRBs at both KNH and Moi, the two largest referral hospitals in Kenya that treat WT, to allow administration of the needs assessment surveys tested in this current work. Patients with WT treated at these two institutions form the basis for these analyses.

To clarify risk factors for drop-out from therapy and to determine late vital status, we called all parents of patients with WT diagnosed at these 4 collaborating hospitals between January 1, 2008 – December 31, 2011, who had abandoned care (n=54) and had available contact information in the registry (n=33) between January and February 2013. For phone numbers not in service and for any missed appointments after these initial calls, research nurses continued to make tracing calls throughout 2013, at which time all registry records were re-reviewed.

We also administered a comprehensive needs-assessment survey, developed with the assistance of the Vanderbilt Survey Core, to 39 parents of children diagnosed at KNH or Moi with WT between 2008–2013. Surveys were administered to 27 parents of the 56 patients on-therapy, 5 of whom later died, 4 of whom later abandoned treatment, and 1 who had previously abandoned therapy, but returned with relapse and was receiving salvage chemotherapy at the time of this report. Respondents also included 7 parents of patients following up for off-therapy surveillance and 5 parents who had abandoned care for their children, 2 of whom returned for off-therapy surveillance and one of whom returned to treatment after the tracing calls, as well as 2 parents who would not return to treatment, but answered the survey via telephone.

Surveys included questions about family structure, methods of emergency communication, parent-perceived understanding of WT and treatment plan, beliefs regarding the utility of chemotherapy and traditional treatment versus alternative treatment plans, the effects of the therapy on the child's health and mental status, a Life Orientation Test – Revised (LOT-R), past medical history of the child, reasons for any missed appointments, plans for continuing prescribed therapy, religious and tribal affiliations and support, home resources (toilet, trash disposal, food sources, etc.), transportation source and cost, distance to the hospital, education level of the parents, income sources and amounts, general questions, concerns and requests. Surveys were verbally administered in English or Swahili to parents in the clinic or on the ward, at a time when the child was already scheduled between January and September 2013, over a 45 minute period by the author (JL) and trained Kenyan research nurses to consenting parents. In 2 cases, parents who had abandoned care for their children were surveyed by the research nurses via telephone.

Descriptive statistics, including percentages and frequencies, were calculated for categorical parameters. Survey variables were analyzed in relation to missed visits via the Wilcoxon Rank Sum test for continuous variables and Chi square test for categorical variables.

Results

Vital Status Telephone Calls

Based on the KWTR developed previously and maintained currently by our international research team, a total of 136 patients were diagnosed with WT between January 1, 2008 through December 31, 2011 at the four collaborating Kenyan hospitals and had been entered into this comprehensive database. [5] To clarify risk factors for drop-out from therapy and to determine late vital status, we called all parents of patients who had abandoned care or opted not to return for off-therapy surveillance visits and had available contact information in the registry (n=33).

After classification of patients according to currently accepted semantic guidelines first discussed in a position statement by the Pediatric Oncology in Developing Countries (PODC) committee of the International Society of Pediatric Oncology (SIOP), we found that the true rate for all 136 registered patients to abandon curative treatment was 25 percent (n=34). [15] The loss of patient data accrual within this cohort was 16 percent (n=22): 2 after transfer to another facility, of whom one survived, and one died, and 20 after personal decision to forego off-therapy surveillance visits. Of these latter 20 patients who discontinued surveillance visits, two were confirmed to have died, seven remained alive, and the remaining 11 could not be contacted. Of the 34 patients (25%) who fully abandoned treatment with curative intent, we were able to confirm that 11 were alive, 13 died (one of whom was presumed to have died after not returning for biopsy results), and 10 were not able to be contacted.

Pathological stage, outcome, characteristics and when possible, etiology of abandonment for all patients who abandoned curative treatment (n=34) and of those who became LTFU after completion of therapy (n=20) are listed in Supplemental Table I. As above, we know that 11 patients (32%) who abandoned treatment are alive, that 7 patients (35%) who did not return

for off-therapy surveillance visits are alive, and that 19 of the total 136 patients (14%; one of whom was sent to palliative care and returned, still alive, months later) never abandoned care and are alive in off-therapy follow up. Based on our most reasonable assumption after these exhaustive tracing efforts, we estimate the actual 2-year OS to be 36%, which is effectively unchanged from 2001.

Overall, 77 patients in this cohort were found to have died, and associated causes could be broken down into either abandonment of curative care or on-therapy mortality. Thirteen patients who fully abandoned curative therapy died, two patients who did not return for off-therapy surveillance died, and one patient died after transfer to another facility. Sixty-one patients (45%) were confirmed to have died *during* therapy (n=50), after therapy (n=3), or were presumed to have died after being placed in palliative care only (n=8). One of the patients who died during therapy received only 12 doses of pre-operative chemotherapy, and further, the parents resisted resection. Parents of another patient opted for palliative care after resection only. It is implied that patients died on-therapy from either progressive disease or treatment-related complications.

Needs Assessment surveys

To evaluate parent perceptions of their child's disease and treatment, needs assessment surveys were administered to 39 parents of children having WT who were on-therapy or were contacted after abandonment. Sixty-three percent of parents expressed misunderstanding of their child's cancer and/or treatment plan through either answering "disagree a little" or "disagree a lot" with statements assessing perceived understanding of disease and treatment plan, or by asking open ended questions indicating a lack of understanding. Fifty-five percent cited financial barriers to completing care. When asked what would make the child's treatment more comfortable, 27% of parents requested more efficient services (i.e., fewer delays during admissions), and 26% expressed frustration with lack of drug availability.

Because parents were not specifically asked about drug availability, we reviewed the database and discovered that 21% of parents (n=28) had documented difficulty acquiring the prescribed drugs from the hospital pharmacy, where the drug costs are covered by NHIF. Parents were given the option to take a prescription for the chemotherapeutics to a private pharmacy not covered by NHIF. However, some parents were not able to fund this cost. As a result, dactinomycin was substituted for doxorubicin for one patient, and doxorubicin was substituted for dactinomycin in five patients. Doxorubicin was omitted for 2 patients, dactinomycin was omitted for three patients, cisplatin was omitted for one patient and vincristine was omitted for three patients. Chemotherapy was purchased by the family of four patients, doxorubicin was donated through a mission charity for two patients, chemotherapy was delayed for one patient, courses of chemotherapy were omitted for five patients, and one patient abandoned therapy after being told to return with funds for chemotherapy.

Other stressors mentioned by fewer parents included needing food of greater quantity and improved quality while on the inpatient wards. They wished for their children not to have to share beds in the often over crowded wards. They preferred smaller hospitals be equipped

with better diagnostic equipment to reduce delays in diagnosis. They also wanted books and toys to keep their children occupied while inpatient.

Characteristics of families of Kenyan patients with WT derived from survey responses are summarized in Supplemental Table II. All parents told us that they planned for their children to complete all prescribed therapy if possible, dependent on expenses and ability to pay, and that they did not believe alternative therapy (e.g., herbal treatments) would cure their children. Parents felt that potential barriers to continuing therapy would be lack of funds for transportation costs, appointment costs, costs of radiation, lack of finances in general, and time constraints. Ninety percent of parents responded that their ability to care for their family was affected by one child's WT diagnosis, either financially (57%), through time constraints (54%), emotionally (49%), or through a combination of these factors (40%). Seventy-five percent of parents received support from their tribes or communities, occasionally child-care for siblings of the patient, and assistance with transportation. Ninety-five percent of families felt that religious faith played a role in helping to cope with their child's illness. Sixty-two percent of parents reported receiving support from their church through emotional support, prayer or hospital visits

Parents were often unaware of the family's income, either because the other parent maintained the family finances solely or because income varied monthly. Income sources included farming, selling small items on the side of the road, teaching, nursing, tailoring of clothing, housekeeping, providing laundry services, car mechanics, conducting casual jobs, and working for businesses that were usually small and self-owned.

Variables including understanding of disease and treatment, the Life Orientation Test-Revised (LOT-R) statement responses, assistance from church and tribe members, transportation concerns and income were evaluated in relation to parents expressing that their child had missed at least one visit. However, likely due to the small sample size, only agreement with the statement "I rarely count on good things happening to me," was statistically significant ($p<0.05$), in direct relation to having missed a visit, with a χ^2 value of 8.94 and $p=0.03$ (Pearson chi-squared analysis). Neither transportation related variables nor income was statistically significantly correlated, although each is likely clinically significant after discussion with parents (Table I).

Discussion

Abandonment of WT treatment and loss to follow up after completion of therapy are common problems in sub-Saharan Africa, including Kenya, and contribute to a dismal overall survival, which otherwise exceeds 90% at five years in developed nations. [2, 3, 7] In order to develop an effective intervention to improve survival in this at-risk population, it was important to understand the outcomes of these patients with WT who abandoned care and the etiologies unique to this patient population having chosen to terminate curative treatment and routine follow-up. From this study, we found misunderstanding of non-standardized WT treatment plans, financial barriers, inefficient services, and drug shortages to be the most prevalent etiologies of treatment abandonment.

Many parents had questions about their children's treatment plan in addition to WT diagnosis and prognosis in general. The oncologists in Kenya appear over-burdened and admittedly do not have sufficient time to spend counseling parents about cancer and treatment plans. Patients are seen more frequently by registrars, general pediatricians, and nurses, who themselves may not be familiar with non-standardized treatment plans, in addition to complications associated with therapy. As a result, not only are families often hesitant to complete therapy that may make their child sick, they also do not understand the importance of returning for further treatment after the child appears physically well and cured.

Parents also expressed frustration with the lack of affordable and available drugs and the other costs involved with treatment and off-therapy follow up. Although we did not directly study the Kenyan medical system, conversations with families and health care providers have allowed us to understand that while cancer therapy is covered increasingly by the National Hospital Insurance Fund (NHIF), many burdensome gaps in complete coverage of all expenses persist. For example, only chemotherapy administered as an inpatient is funded by NHIF, so all patients are admitted to the hospital, even if just for a single dose of vincristine. Length of stay then resulted in complaints around inefficient services. In other circumstances, parents must pay out of pocket at a private pharmacy when drugs are not available in the public pharmacies funded by NHIF. Furthermore, NHIF does not cover radiation, radiographic imaging or consultant visits by the oncologist. Transportation costs are another important component of abandonment, and once chemotherapy has been completed, parents often do not return for off-therapy follow-up for this reason.

To overcome on-therapy mortality due to treatment complications and toxicities, international organizations have developed less toxic protocols for resource-constrained countries, beginning with WT. [3, 16] It is clear that proper support and infrastructure results in markedly improved outcomes for patients with WT in Africa. In Casablanca, Morocco, authors reported a 5-year OS of 79% from WT by following SIOP-9 treatment protocols. [17] Similarly, using National Wilms Tumor Study Group (NWTSG) protocols, the 5-year OS from WT in South Africa was 80.5%. [18] Both groups proved increased survival in impoverished communities with multidisciplinary teams, adequate therapy and supportive care. These same measures, if supported by the Kenyan government and/or nonprofit organizations, could drastically improve survival from WT and the initiative to improve life-saving therapy in this regard is crucial. However, these measures will only be successful if patients adhere to prescribed therapy. Our multi-center study was conducted to identify barriers to treatment completion from the perspective of parents of patients with Wilms tumor, including those who actually abandoned treatment. We will next aim to design an intervention that addresses these barriers.

Abandonment of care remains a significant cause of death. [8, 9, 17] Cancer registries are becoming more common in low-income countries due to expanding International Outreach Programs, which pair a developing country with a higher income institution for shared knowledge and resources. However, little research has been published to date documenting successful interventions designed to reduce treatment abandonment. In one pediatric oncology study, a social support program in India successfully reduced pediatric cancer

treatment abandonment by approximately 50 percent through tracing calls to families after missed visits. [19] In Recife, Brazil, a private foundation provided parents with transportation, housing and work opportunities in an effort to reduce abandonment, while patients were treated with a multidisciplinary team approach and standardized protocols supported through a St. Jude Children's Research Hospital twinning program, resulting in improved survival outcomes. [20] Much can also be learned from HIV and tuberculosis treatment models that have utilized outreach clinics and home visits to improve treatment compliance and patient satisfaction. [21, 22] A clear gap in published research in pediatric oncology is the impact of an educational program for parents on the rate of treatment abandonment. Our study demonstrated that an overwhelming percentage of parents did not understand their child's treatment plan or the importance of returning for further therapy once the child appeared to be cured.

We recognize several limitations of the current study. First, the study sample size was small because of the relative rarity of WT and because patients diagnosed earlier in the study period frequently had phone numbers on file that were no longer operational, and so we were forced to estimate their survival most precisely depending on the amount of therapy received. A few parents spoke local dialects that were not understandable by our research nurses, and for these patients, we did not retrieve information regarding etiology of follow-up. There was also inconsistent patient follow-up and data entry after missed visits, especially close to the time of the 2-year off-therapy anniversary for patients diagnosed later in the study, due to time constraints interfering with work productivity for one of the research nurses. For these patients, we estimated survival based on reasonable assumptions regarding the timing of when their information was lost.

Conclusions

Abandonment of care, in addition to on-therapy mortality, remains a significant problem contributing to increased mortality from WT in Kenya and other developing countries. Our findings show that it is crucial for education of both parents and hospital care providers to be included in any intervention to reduce treatment abandonment and therapy-related mortality. Future research should address the impact of an intervention including standardized therapy, provider and family education, reduced financial barriers, quality improvement and affordable drug availability, on on-therapy mortality, treatment abandonment, and EFS.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table I

Statistics by missed appointments

Descriptive Statistics by Missed Appointments: Time and Cost of Travel							
	0 (Did not miss appts) N = 30			**1 (Missed appts) N = 8**			**Test Statistic**
	a	**b**	**c**	**a**	**b**	**c**	
Time (minutes)	120	**210**	240	101	**165**	188	F1,35= 2.45, P = 0.126
Cost (shillings)	488	**1,000**	1,400	275	**900**	1,150	F1,36= 0.56, P = 0.459

Descriptive Statistics by Missed Appointments: Income								
		0 (Did not miss appts) N = 30			**1 (Missed appts) N = 8**			**Test Statistic**
		a	**b**	**c**	**a**	**b**	**c**	
Personal Income (shillings)	25	0	**2,250**	7,750	750	**1,750**	4,750	F1,22= 0.01, P = 0.927
Household Income (shillings)	24	2,000	**4,750**	7,750	2,500	**3,000**	7,000	F1,21= 0.18, P = 0.672

The Wilcoxon test was used above, with a, b, c representing the lower quartile a, the median b, and the upper quartile c for continuous variables. N is the number of values.