

Two overlooked contributors to abandonment of childhood cancer treatment in Kenya: parents' social network and experiences with hospital retention policies

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Abstract

Background: The principal reason for childhood cancer treatment failure in low-income countries is treatment abandonment, the most severe form of nonadherence. Two often neglected factors that may contribute to treatment abandonment are as follows: (a) lack of information and guidance by doctors, along with the negative beliefs of family and friends advising parents, which contributes to misconceptions regarding cancer and its treatment, and (b) a widespread policy in public hospitals by which children are retained after doctor's discharge until medical bills are settled.

Objective: This study explored parents' experiences with hospital retention policies in a Kenyan academic hospital and the impact of attitudes of family and friends on parents' decisions about continuing cancer treatment for their child.

Methods: Home visits were conducted to interview parents of childhood cancer patients who had been diagnosed between 2007 and 2009 and who had abandoned cancer treatment.

Results: Retrospective chart review revealed 98 children diagnosed between 2007 and 2009 whose parents had made the decisions to abandon treatment. During 2011–2012, 53 families (54%) could be reached, and 46 (87%) of these agreed to be interviewed. Parents reported the attitudes of community members (grandparents, relatives, friends, villagers, and church members); 61% believed that the child had been bewitched by some individual, and 74% advised parents to seek alternative treatment or advised them to stop medical treatment (54%). Parents also reported that they were influenced by discussions with other parents who had a child being treated, including that their child's life 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%). These discussions influenced their perceptions of cancer treatment and its usefulness (65%). Thirty-six families (78%) had no health insurance, and 19 of these parents (53%) could not pay their medical bills and were not allowed to take their child home when treatment ended. Parents reported feelings of desperation (95%), powerlessness (95%), and sadness (84%) and that their child has been imprisoned (80%), during the period of retention. The majority of parents (87%) felt that hospital retention of children must cease.

Conclusions: The attitudes and beliefs of parents of children with cancer are impacted by those close to them and their community and may influence their perceptions of cancer treatment and decisions to stop treatment. Hospital retention policies are highly distressing for parents and may contribute to both treatment delays and treatment abandonment. These factors jeopardize treatment outcomes for young patients and require attention and modification.

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Introduction

The vast majority of children with cancer live in low-income countries and have little chance of survival [1,2]. A principal reason for treatment failure in these countries may be nonadherence to recommended therapies. Nonadherence, which forms a continuum from sporadic

lapses to total withdrawal or abandonment, can be influenced by both the characteristics of a child, their parents, and their disease and treatment, as well as broader hospital policies and health-care provider attitudes. Treatment abandonment, defined as the failure to initiate or sustain treatment during four or more successive weeks, is the most severe form of nonadherence and is ubiquitous throughout these regions [1–5].

The Moi Teaching and Referral Hospital (MTRH) in Kenya serves as a prime example of this critical issue. Fifty-four percent of childhood cancer patients abandon treatment and thus jeopardize treatment outcomes [6]. In recent qualitative research evaluating families' experiences in this setting, we identified two often overlooked factors that may play an important role in families' decision to abandon cancer treatment at MTRH. First, a lack of information and guidance by doctors may contribute to misconceptions held by parents of childhood cancer patients. These misconceptions may stem from beliefs and attitudes of those surrounding parents (family, community members at home, and other parents on the ward) and adversely impact parents' decisions regarding their child's treatment (results from unpublished study). Second, widespread policies that direct public hospitals to retain children after their doctor's discharge until their parents pay their medical bills [6] sometimes result in patients being retained for months [7–9]. Hospital retention can be traumatic for both parents and children and thus may prompt parents to abandon their child's treatment in order to avoid such a scenario [6–9].

Various studies in low-income countries illustrate that doctors treating children with cancer provide insufficient information and guidance to poor families [4,10–12]. In the absence of clear evidence-based information, the influence of a families' social network, both inside and outside of the hospital, becomes increasingly important in parents' treatment decisions. For instance, 87% of parents whose child received treatment at MTRH stated that they would not have understood their child's disease and the treatment required if they had not talked with other parents on the ward (results from unpublished study). If parents rely on each other for information, these discussions may affect not only their understanding of the disease but also their level of adherence to their child's treatment. Likewise, when guidance and support from medical staff is lacking, those in the parents' home community may also be significant in guiding attitudes toward treatment.

The retention of either living patients or bodies of deceased patients over unpaid medical bills is a critical issue and has been reported in numerous countries in addition to Kenya [7,13–21]. The current mean retention period of children treated for malignancies at MTRH is 5 weeks (results from unpublished study). Forced stays in the hospital due to retention may not only be traumatizing for the children and families involved [6–9] but also further corrodes potential treatment adherence and increases likelihood that children will not be brought back after a period of forced retention.

Treatment abandonment is thus an important contributor to the poor outcomes noted in the treatment of childhood cancer in low-income countries. Misconceptions regarding treatment and hospital retention policies may detrimentally affect the well-being of patients and their

families and possess consequences for treatment adherence and ultimately abandonment.

Methods

Setting

Kenya is a low-income country, and 50% of its population lives below the poverty line [22]. Our study was conducted at MTRH, a tertiary care referral hospital. MTRH is the only hospital in Western Kenya providing curative childhood cancer treatment. Although an estimated 700 childhood cancer patients younger than 15 years are expected in the service area of MTRH, only 110 children are diagnosed with a malignancy per annum, suggesting that many are not coming for treatment [23–25]. The pediatric oncology ward contains 12 beds supervised by one to two pediatricians. Treatment options are limited to chemotherapy and surgery. Radiotherapy is not available. In Kenya, the costs to enroll in national health insurance are low (1.4 Euro per month covers inpatient service for the whole family) and affordable for the poor [26]. Despite its affordability however, less than 10% of Kenyan citizens have health insurance because of lack of information, complexity of applications, and poverty, which demands funds be directed to immediate needs [27,28].

Hospital retention policies

If doctors discharge a patient from the hospital and their family cannot pay the medical bill, the parents are not allowed to take their child home. The child is retained in the hospital until the parents can cover the medical bill or until their medical bill is waived, which is a procedure not readily made available [11–13]. For every additional day that the child is retained in the hospital, further charges are added to the bill. The children may be left alone as parents cannot easily visit because of the need to seek funds from family and friends to pay their bill. To enforce this policy, security guards are placed at an iron gate at the entrance of the pediatric ward, thus preventing parents from leaving with their child before their medical bills are settled. In cases where parents do escape with their child, the medical bill will be demanded to be paid by the security guard, social worker, and sometimes by the nurse who took care of the child on the ward [6].

Waiving procedure

Procedures exist for families who have problems paying for their child's treatment to seek partial or complete payment forgiveness [7–9]; however, written procedures and guidelines do not exist. Social workers assemble information on the families' financial situation and submit it to a waiver committee that comprised the hospital's

legal and security officers. This procedure by which social workers, patients, and their families may apply is not made widely known, and there are no transparent rules or regulations that govern committee decisions [6].

Study design

This exploratory, descriptive study used home-based, informant interviews to explore the influence of parents' social network on their decisions about treatment and their experiences with the hospital retention of their children. These interviews were conducted with parents of children who had been diagnosed with a malignancy at MTRH between January 2007 and January 2009, who subsequently abandoned treatment, and whose whereabouts could be determined. These investigations were part of a more extensive research study on abandonment of childhood cancer treatment in Western Kenya [29].

Home visits were made between December 2011 and August 2012 by an independent experienced interviewer and assistant. Parents' contact information (addresses and phone numbers) was extracted from medical records, and contact was made by phone or through the assistance of the regional chief (usually an older wise man with high status and the recognized leader of a village or several villages).

The interviews utilized a semi-structured questionnaire and were administered orally in Kiswahili. Most questions were evaluated by parents on two-point, three-point, or four-point rating scales. These questions focused on the parents' reaction to their child's cancer, and the reactions of their family members, friends, villagers, and church members, as well as the information they recalled obtaining from other parents at the hospital, and their experiences with hospital retention policies and the fee waiver procedure. An open-ended question assessed the parental perspectives on hospital retention policies. A panel of doctors and psychologists designed the questionnaire, which was consecutively pilot tested for its content, clarity, and cultural sensitivities with five families who had abandoned treatment for their child. The questionnaire is a modification of one used by the authors in Indonesia [3]. Participants were assured of anonymity and confidentiality, and informed consent was obtained. The Institutional Research and Ethics Committee of MTRH approved the study.

Data analysis

SPSS (IBM Corporation, Armonk, NY, USA) was used to conduct data management and analysis. For each variable, frequency distributions, median, means, and standard deviations were calculated. Differences in socio-demographic and clinical characteristics between respondents and nonrespondents were compared using chi-square, Fisher's

exact, and *t*-tests. Fisher's exact test for variables with over two categories was executed in R version 2.15.0.

Results

Patient and parent characteristics

At MTRH, 222 children were newly diagnosed with a malignancy between January 2007 and January 2009. Treatment outcomes were recorded in the medical records of 180 children. Among these 180 cases with recorded outcomes, 98 children (54%) had abandoned treatment [6].

Families of 53 children (54%) were contacted between December 2011 and August 2012. Families of 34 children (64%) could be reached by phone and families of 19 children (36%) through the assistance of the regional chief. Families of 45 children could not be contacted because contact information was missing in their medical records. Of the 53 contacted families, 46 (87%) consented to participate in the study. Parents declining consent noted that their children had passed away and reminiscing was too painful. No significant differences existed in age, gender, or type of cancer between the group of children whose caretakers could or could not be contacted. The time span between abandonment and when the home visit occurred ranged from 25 to 64 months (median 44 months).

The respondents included the following caretakers: both parents (35%), mothers (33%), fathers (20%), siblings (7%), grandmother (2%), both uncle and aunt (2%), and uncle (2%). All families had a Christian religious background. Tribal origin was Kalenjin (48%), Luhya (26%), Luo (11%), and others (15%). The distance between the families' residence and MTRH was as follows: <50 km (22%), 50–100 km (30%), and >100 km (48%).

The majority of the 46 children were male (72%). Patients' age range at diagnosis was 0–18 years, with a mean of 9.2 years (SD = 5.0) and median 9 years. Cancer diagnoses were hematological (63%), composed of non-Hodgkin lymphoma (52%) and acute lymphoblastic leukemia (28%). The remainder consisted of solid tumors (22%), rare tumors (11%), and unconfirmed tumors (4%). During the home visits, we found that 80% of the children had died [29].

Social network

Nuclear family

The marital status of parents at the time of interview was as follows: married (70%), widowed (15%), separated (7%), divorced (2%), and single mother (4%). Of the married couples, husbands had one wife (81%), two wives (16%), or three wives (3%). Mothers of children with cancer were either the first wife (97%) or the second wife (3%). Marital problems caused by the child's disease were experienced by 25% of couples, and 3% divorced because

of these marital problems. Several parents reported that their spouses believed that the child was bewitched (12%), and they advised stopping treatment (9%) and consulting a traditional healer (21%). Witchcraft is surrounded by secrecy and taboos [30,31]. In this context, it implies that a malicious magic user or witch had put a curse or spell on the child and caused the development of cancer. The witch is either a person close to the family or consulted by a person closer to the family to impose the curse. It is believed that the family must attend a witch doctor to cure the child. The witch doctor subsequently goes into a trance to make contact with ancestors, who will point out the person who was responsible for bewitching the child. The witch doctor then prescribes a remedy to rid the child from the bewitching spirit.

Community at home

All parents reported receiving social support from their home community, including grandparents, relatives, friends, villagers, and church members. However, this social support did not necessarily mean support for their decision to seeking conventional cancer treatment for their child. Many parents reported that community members believed that their child was bewitched (61%), advised them to seek alternative treatment (74%), or advised them to stop attending MTRH (54%). Seventeen percent of parents reported that their family had been socially isolated after their child had been diagnosed with cancer. This isolation included, for instance, that families were not spoken to, ignored, excluded from communal activities, and cut off from resources of the farming land. Out of fear for the reaction of the community, 20% of families chose not to disclose their child's cancer. Table 1 illustrates the reaction to child's cancer subdivided by various community members at home.

Despite this, the community of family and friends were a frequent source of financial support for parents. Most parents reported receiving financial support to pay for

medical bills from the following: friends (59%), relatives (54%), religious community (50%), village community (48%), and grandparents (37%). In this setting, hospital staff had often asked relatives to pay for medical bills (21%). A house visit to check the families' financial situation was sometimes made by a social worker and security guard from the hospital (5%). In addition, community members would also assist with childcare needs. During periods of hospitalization, the patients' siblings were taken care of primarily by spouses (74%), in addition to grandparents (14%), relatives (14%), villagers (7%), or a housekeeper (2%). A minority (11%) of families reported that siblings took care of themselves.

Other parents on the ward

Many parents recalled that they had shared their experiences, feelings, and beliefs with parents of other children with cancer when their child was hospitalized (67%). Caretakers reported that other parents offered emotional support (97%) and that these interactions became 'a world of its own inside hospital walls' and one that was 'out of sight from doctors'. Table 2 illustrates the topics that parents discussed together. The majority of parents interviewed reported that these discussions with other parents influenced their perception of the utility of their child's cancer treatment (65%).

Hospital retention

Parental experiences

Before coming to MTRH, 10 families (22%) had health insurance. In these cases, health insurance covered their medical bills, and none of these children were retained in the hospital. The majority of families (78%) however did not have health insurance. After their children had been discharged from the hospital by doctors' orders, parents of 19 children (53%) could not pay the medical bills owed and were not allowed to take their child home.

Table 1. Reaction of community members at home to the child's cancer according to parents (*n* = 46)

Reaction	Spouse ^a (<i>n</i> = 34) (%)	Grandparents ^b (<i>n</i> = 28) (%)	Relatives ^c (<i>n</i> = 42) (%)	Friends ^c (<i>n</i> = 41) (%)	Village community ^c (<i>n</i> = 40) (%)	Religious community ^c (<i>n</i> = 40) (%)
Gives social support	97	93	86	98	98	98
Acceptance	97	93	83	95	95	95
Left/isolate the family	3	7	10	0	5	0
Disappointing	0	4	12	0	5	0
Believes disease is caused by inheritance	41	18	48	39	45	25
Believes child is bewitched	12	11	36	41	50	3
Advises to seek alternative treatment	21	25	38	63	63	18
Advises not to attend public hospital	9	11	19	29	38	10

^aTwelve parents had no spouse.

^bGrandparents of 18 children had deceased.

^cParents did not disclose their child's cancer to relatives (*n* = 4), friends (*n* = 5), village community (*n* = 6), and religious community (*n* = 6).

Table 2. Topics discussed with other parents on the ward according to parents ($n = 31$)

Topics	
The life of your child is in God's hands	27 (87%)
Forced stay in hospital and separation from family is traumatizing	26 (84%)
It is important to complete the whole treatment	25 (81%)
The financial burden of treatment is too much	24 (77%)
Cancer is not curable	23 (74%)
Hospital procedure to waive medical bill is traumatizing	21 (68%)
Surgery spreads cancer	20 (65%)
All children with cancer die	19 (61%)
Child is traumatized with medical procedures	18 (58%)
Feelings of guilt toward siblings	18 (58%)
The health of your child is beyond doctor's control	15 (48%)
It is better to seek alternative treatment	15 (48%)
Children should not suffer from such severe side effects	10 (32%)
Children should live a normal life or die in peace at home	10 (32%)
If your child appears healthy again, you can stop treatment	7 (23%)
Cancer treatment at public hospital kills your child	6 (19%)
Dissatisfaction with health-care providers	3 (10%)

During hospital retention, cancer treatment was continued according to the prescribed treatment protocol in 79% of cases. Hospital retention ranged between 2 and 21 days, with mean 8.4 days ($SD = 5.4$ days) and median 7 days. Parents of one child reported that they were not allowed to take the body of their child home after the child had died at MTRH, because medical bills were not paid yet. Several parents described the hospital retention policy as particularly painful because it deprived parents of the opportunity to give their children a dignified funeral and burial in the soil where relatives and ancestors were buried.

Waiving procedure

The possibility of medical bills being waived was communicated by health-care providers to 63% of families whose children were retained. Of these families, the majority (75%) received a partial waiver, whereas the others received complete waivers. The remaining 37% of families with retained children reported that they had not been informed of the possibility of medical costs being waived. These families indicated that, in retrospect, they would have wanted to be informed of this possibility and were unsure why they had not been told. Ultimately, 15 families had to render their national identity card as collateral in order to take their child home; all these families had to first pay part of the medical bill themselves. In Kenya, national identity cards are the primary form of legal identification and are mandatory for all citizens older than 17 years. National identity cards are required, for instance, for employment, to open a bank account, to acquire a driving license, to transact mobile phone banking, to vote during elections, and to register a business [32].

Child left alone

When children were retained in the hospital, 53% of parents reported that they had to leave their child alone inside the hospital because the parents needed to search for money, go to work, or take care of siblings left at home. Retained children were then either accompanied by grandparents, siblings, and other relatives (60%), or completely left alone inside the hospital (40%).

Parental feelings

Table 3 illustrates parental feelings during the hospital retention of their children. Most commonly reported feelings were as follows: desperation (95%), powerlessness (95%), sadness (84%), and perceiving the hospital as like a prison (80%). For some (16%), hospital retention policies made them wish that they had never come to MTRH with their child.

Prior awareness of hospital retention policies

Among all 46 families interviewed, 33% had heard about hospital retention policies in public hospitals before they came to MTRH. Twenty-seven percent of those who had heard of the retention policies reported that this caused them to delay coming to MTRH.

Parental criticism of hospital retention policies

The majority of parents ($n = 40$, 87%) felt that retention of children in public hospitals needed to cease and provided multiple reasons for this belief (Table 4). Only six families (13%) believed that hospital retention policies should continue, of which four had had their child retained. These parents acknowledged that retention of patients was a problem but believed that the hospital needed money to provide care. They felt that the alternative would be that

Table 3. Parental feelings during hospital retention of their children ($n = 19$)

Parental feelings	
Desperate	18 (95%)
Powerless	18 (95%)
Sad	16 (84%)
Imprisoned	15 (80%)
Depressed	13 (68%)
Alone	12 (63%)
Ashamed	8 (42%)
Unfair	8 (42%)
Guilt	7 (37%)
Afraid	6 (32%)
Fine	6 (32%)
Good	3 (16%)
Relaxed	3 (16%)
Happy	2 (11%)
Crying	1 (5%)
Indifferent	1 (5%)

Table 4. Parental criticism of hospital retention policies: reasons why hospital retention of children after doctor's discharge must stop according to parents ($n = 40$)

Reasons why hospital retention must stop
Forced hospital stays are unfair and traumatizing to children and their families.
It is not the fault of parents that they are poor.
It is not the fault of children that they are sick.
Medical bills continue to accumulate while families go out searching for money to clear medical bills. When parents come back to pay their balance and take their child home, the total bill has increased again and parents still cannot take their child home.
Parents become desperate and feel that there is no way out.
Forced hospital stays stimulate treatment abandonment after their child has been released, which will lead to the child's death due to disease progression or relapse.
The child may be left behind, alone inside hospital, either temporarily or permanently. Separation from their family harms children. In particular, when children are sick, they need the comfort of their parents. Children become depressed because of separation from their family.
Retained children are exposed to infections inside hospital.
Protests of community members at home to high treatment costs can lead to social isolation or excommunication.
Retained children are denied the opportunity to attend school.

no children would receive cancer treatment, which was an even greater problem.

Discussion

Widely held misconceptions of cancer, along with widespread hospital policies, may adversely affect the welfare of patients and families in low-income countries and may have implications for consequent treatment adherence and abandonment. In the absence of clear advice from medical providers, parents' attitudes and beliefs regarding treatment may be influenced by members of their community and parents of other children with cancer whom they met in the context of treatment. This study illustrated that families' social network and parental experiences with hospital retention policies may contribute to nonadherence and abandonment of cancer treatment.

Various studies from high-income countries underline that treatment adherence is related to available social support [33–35]. A close family bond, the presence of local help, and the encouragement of others can improve adherence to medical regimens. For example, supportive family members may remind patients to take medication or attend hospital appointments and thus enhance treatment compliance. Emotional support can also reduce distress among parents and consequently their children and thus improve treatment adherence [33–36].

In the current study, we found that all caretakers of children with cancer received social support from community members at home, including spouses, grandparents, relatives, villagers, and church members. However, members of parents' social network did not always encourage adherence to conventional cancer treatment and may have enhanced misconceptions of cancer. For example, many

parents reported that community members believed that their child was bewitched and consequently advised them to seek out traditional healers. In fact, half of all parents were strongly advised by community members to stop treatment at MTRH. This illustrates the possible role of public awareness campaigns that are needed to educate people about cancer and that witches and witchcraft do not cause illness, which may in turn reduce the communities' fear of witches and bewitched children and enhance their access to timely curative treatment [29,30]. Booklets about childhood cancer for parents of newly diagnosed children would help them to educate others and reduce the ignorance and social isolation. Communities in Kenya are characterized by a collectivist mentality and typically offer financial support to families in need [37]. Many community members had indeed offered financial support to the family; however, when they then saw no improvement of the child's condition, they concluded that treatment at MTRH was a futile waste of money. Because most Kenyan communities live in great poverty, the family's decision to continue expensive cancer treatment aroused strong negative sentiments among community members. We learned that some families had decided not to disclose their child's condition to various community members out of fear of being stigmatized, isolated, or excommunicated.

Previous research in low-income countries illustrates that doctors' delivery of information and guidance to poor families is meager [4,10–12]. In this vacuum of support and education, the role of a social network can become increasingly significant to families, both outside and inside the hospital. For example, 87% of caretakers of children treated for cancer in MTRH mentioned that they would not have understood cancer and its treatment if they had not been able to consult other parents on the ward (results from unpublished study). If parents depend on one another for information, it is essential to know what parents discuss and how this may impact their decision to adhere to or abandon treatment. Our study illustrated that although they learned more about cancer and felt supported by others, some discussion topics may have undermined treatment adherence, such as fostering beliefs that their child's life was in God's hands alone, that the financial burden of treatment was too great, and that the cancer was incurable. Optimistic attitudes, a sense of control, and words of hope are important in increasing families' motivation for treatment, whereas feelings of helplessness, powerlessness, and despair undermine adherence and may ultimately lead to abandonment [6,38].

This study showed that half of all families without health insurance faced retention of their children because of hospital policy. About one-third of these families were not informed by hospital staff that a waiver could be sought for their medical bills. The nature of hospital retention may contribute to nonadherence to treatment in

a number of ways. First, hospital retention policies may scare and prevent poor families from coming to public hospitals at all, thereby contributing to the lower-than-expected childhood cancer incidence in the service area of MTRH [23–25]. In addition, parents may be reluctant to bring children in after a period of retention because of fear of it happening again. Critically, one-third of families who knew about hospital retention policies beforehand reported delaying in coming to MTRH because they feared forced separation from their children. Hospital retention was associated with feelings of powerlessness among parents affected. The fact that the process by which medical bill waiver requests are submitted and adjudicated lacks written guidelines or criteria, and transparency further exacerbates this sense of powerlessness among families. Evidence suggests that the less control families may feel they have, the less they may adhere to treatment recommendations [33,39]. Finally, hospital retention policies were perceived as a traumatizing experience. Parents described feelings of despair and sadness and that their child's hospital retention felt like a form of imprisonment. The forced separation from their sick child may be sufficiently traumatic for parents and children that they decide it is better to abandon treatment than to return to the hospital to complete treatment. This is particularly worrying in the context of pediatric oncology care, as many types of cancer can be cured despite the limited resources and lack of available radiotherapy.

When parents were asked during the interview if hospital retention policies should stop, the vast majority of parents strongly condemned 'the imprisonment of innocent children'. Parents were able to note numerous reasons why hospital retention policies should cease. This study shows their willingness to report their experience and suggests the need for international pediatric oncology organizations to raise awareness in the global community regarding hospital retention policies in low-income countries and their negative impact on families and patients treatment adherence.

Although health-insurance coverage is affordable and covers the cost of care, only 22% of families had health insurance. This is quite remarkable as insurance costs in Kenya are low even by Kenyan standards and benefits are high [25–27]. Greater efforts are needed on a national level to raise awareness and increase enrollment in health-insurance coverage and in turn reduce financially related distress. Kenyan residents should be actively encouraged or obliged to enroll in health insurance, whereas basic health insurance should be provided to citizens who cannot afford national health insurance. A better organized, taxpayer-funded system could enable equal access to health-care services for all Kenyans [6].

Our study has several limitations. Tracing families was particularly difficult because the study was conducted

several years after the children had been treated for cancer. Many medical records were completely missing, whereas medical records that were located frequently lacked contact information. Even if contact information was available, the information was often not up to date as families had moved or changed phone numbers. As a consequence, we could only reach half of all intended families. In addition, some families declined participation, which may also have influenced our study results.

On the basis of this exploratory study, and despite these limitations, we recommend that the following steps should be taken in the interest of caring for children with cancer. First, although social networks often provide important tangible support (e.g., child care), misconceptions regarding cancer causes and treatment need to be addressed so that families are encouraged to adhere to potentially life-saving treatment. Our study identified several potential mechanisms that could facilitate this transition: providing a structure to the social network inside the hospital and organizing parental supportive meetings to be supervised by a doctor and psychological counselor to ensure that accurate information is disseminated. This will create an outlet for parents to express needs and share experiences in a manner that is constructive instead of destructive. It will also create an opportunity for health-care providers to improve their delivery of information and guidance and clarify any sources of misunderstanding.

Second, in regard to community-based social networks, we believe it would be advisable to distribute educational materials that parents can show community members at home. For instance, an information booklet about cancer, its curability, and the type of treatment required would not only provide parents with a better understanding of their child's disease but also aid parents in their discussions with community members. This information could also serve to challenge widely held beliefs regarding cancer and witchcraft and reduce the stigma and isolation that often result. Doctors are advised to proactively ask parents about their social network at home and its contribution to their perceptions of treatment and its importance. If necessary, doctors can invite community members to come and discuss their concerns inside the hospital.

On a national level, hospital retention policies in public hospitals violate basic principles of international law and must end. The Kenyan Parliament should respect its ratification of the United Nations Human Rights Declaration in 1963 [40]. Legislation needs to be introduced that makes it illegal to hold patients who are unable to pay their medical bills [20]. These measures would go far in ameliorating issues of treatment adherence, decrease abandonment, and ultimately enhance the survival outcomes of children diagnosed with cancer.

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Conflict of interest

The authors have declared no conflicts of interest.

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