

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/267757745>

Parental experiences of childhood cancer treatment in Kenya

Article in *Supportive Care in Cancer* · October 2014

DOI: 10.1007/s00520-014-2475-x · Source: PubMed

CITATIONS

36

READS

190

10 authors, including:



Joyce Musimbi

Independent Researcher

12 PUBLICATIONS 313 CITATIONS

[SEE PROFILE](#)



Sharon Langat

University of Nairobi

6 PUBLICATIONS 208 CITATIONS

[SEE PROFILE](#)



Jodi Skiles

Indiana University School of Medicine

41 PUBLICATIONS 1,129 CITATIONS

[SEE PROFILE](#)



Mei Neni Sitaresmi

Universitas Gadjah Mada

44 PUBLICATIONS 1,293 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



TOURISM AND ECONOMIC GROWTH IN KENYA [View project](#)



Research Study for Treatment of Children and Adolescents With Acute Myeloid Leukaemia 0-18 Years [View project](#)

Parental experiences of childhood cancer treatment in Kenya

F. Njuguna · S. Mostert · A. Seijffert · J. Musimbi · S. Langat ·
R. H. M. van der Burgt · J. Skiles · M. N. Sitaresmi ·
P. M. van de Ven · G. J. L. Kaspers

Received: 16 March 2014 / Accepted: 6 October 2014 / Published online: 17 October 2014
© Springer-Verlag Berlin Heidelberg 2014

Abstract

Purpose Our study explores socioeconomic, treatment-related, and psychological experiences of parents during cancer treatment of their children at an academic hospital in Kenya.

Methods This cross-sectional study used semi-structured questionnaires. Parents whose children came for cancer treatment consecutively between November 2012 and April 2013 were interviewed.

Results Between 2012 and 2013, 115 oncology patients attended the hospital and 75 families (response rate 65 %) were interviewed. Cancer treatment resulted in financial difficulties (89 %). More information about cancer and treatment was required (88 %). More contact with doctors was needed (83 %). At diagnosis, cancer was perceived as curable (63 %). However, parents were told by health-care providers that most children with cancer die (49 %). Parents had difficulties with understanding doctors' vocabulary (48 %). Common reasons to miss hospital appointments were travel costs (52 %) and

hospital costs (28 %). Parents (95 %) used complementary alternative treatment (CAM) for their children. Health-care providers told parents not to use CAM (49 %). Parents had not discussed their CAM use with doctors (71 %). Community members isolated families because their child had cancer (25 %), believed that child was bewitched (57 %), advised to use CAM (61 %), and stopped conventional treatment (45 %). Some families (15 %) never disclosed the child's illness to community members. Parents shared experiences with other parents at the ward (97 %) and would otherwise not understand the disease and its treatment (87 %).

Conclusions Parents suffer financial hardships and are dissatisfied with doctors' communication regarding their children's condition. CAM is very commonly used. Doctors need to improve their communication skills and discuss CAM more openly. Cancer programs should include more support for parents: financial assistance, a facility where parents and children can stay during the course of therapy, and parent support groups.

F. Njuguna (✉) · J. Musimbi · S. Langat
Department of Child Health and Pediatrics, Moi Teaching and Referral Hospital, Eldoret, Kenya
e-mail: muigaifes2000@yahoo.com

S. Mostert · A. Seijffert · R. H. M. van der Burgt · G. J. L. Kaspers
Department of Pediatric Oncology-Hematology and Doctor 2 Doctor program, VU University Medical Center, Amsterdam, The Netherlands

J. Skiles
Department of Pediatrics, Division of Hemato-Oncology, Indiana University School of Medicine, Indianapolis, USA

M. N. Sitaresmi
Department of Pediatrics, Dr Sardjito Hospital, Yogyakarta, Indonesia

P. M. van de Ven
Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

Keywords Childhood cancer · Treatment-related experiences · Socioeconomic experiences · Psychological experiences · Physician communication · Complementary alternative treatment

Abbreviations

MTRH Moi Teaching and Referral Hospital
CAM Complementary alternative treatment

Introduction

The burden of childhood cancer is disproportionately greater in low-income countries as compared to high-income countries. More than 90 % of deaths among children aged below 15 years worldwide occur in low-income countries [1–5].

Africa is greatly underserved in terms of providing care for pediatric oncology patients. More than 80 % of the children with cancer die without access to adequate treatment. This is mainly due to inadequate health-care budgets, scarce diagnostic facilities, and paucity of appropriately trained personnel. Hospitals generally serve a large number of pediatric oncology patients in proportion to the doctors available. In addition, doctors do not prioritize communication with patients and their families [6, 7]. As a result, families may not fully understand their child's illness and the need to adhere with cancer treatment. Abandonment of cancer treatment, the most severe type of nonadherence, is the most common reason for cancer treatment failure in Africa and other low-income countries [3, 6].

In low- and high-income countries, childhood cancer has devastating effects on both the child and family. Having a child with cancer is one of the most distressing life experiences for families. Parents experience numerous socioeconomic, treatment-related, and psychological challenges. Families are unable to resume a normal life during the treatment of their children [8–12].

There is a paucity of information regarding the effects of childhood cancer treatment on parents, especially in Africa. This study explores socioeconomic, treatment-related, and psychological experiences of parents during cancer treatment of their children at an academic hospital in Kenya.

Methods

Setting

This study was conducted at Moi Teaching and Referral Hospital (MTRH) which is located in Eldoret, western Kenya. It is the second largest public tertiary hospital in the country with a catchment area of 18 million people. About 110 new pediatric oncology patients are seen in MTRH per year [13–15]. Patients are taken care of in an inpatient unit within pediatric wards and an outpatient clinic that runs once per week. The pediatric wards include 72 beds, of which 12 beds are reserved for cancer patients often with more than 100 % occupancy. The pediatric oncology ward is supervised by one to two pediatricians.

Study design

This cross-sectional study was conducted using a semi-structured questionnaire, which focused on assessing socioeconomic, treatment-related, and psychological experiences of parents during the treatment of their child with cancer. All consecutive parents of childhood cancer patients who attended MTRH between November 2012 and April 2013 were requested to be interviewed. Parents were interviewed by two independent interviewers. The questionnaire contained statements that could be answered on two-, three-, or four-point

rating scales. There was an English and Kiswahili version of the questionnaire. A pilot test was done by interviewing five parents of childhood cancer patients to detect questions that were unclear or too complicated. Small adaptations were made based on the pilot test. The interviews were held in a private area, where only the interviewers and parents were present. Each of the interviews took about 30 min. Confidentiality was maintained. The questionnaire was approved by the Institutional Research and Ethics Committee of MTRH.

Data analysis

Frequency distributions, median, means, and standard deviations were calculated. Differences in sociodemographic and clinical characteristics between respondents and nonrespondents were compared using chi-square and Fisher's exact tests. Fisher's exact tests for variables with more than two categories were performed in R version 2.15.0. Data management and analysis were performed by using SPSS for Windows version 20.0.

Results

Patient characteristics

Between November 2012 and April 2013, 115 oncology patients attended MTRH. Parents of 75 children were interviewed (response rate 65 %). Parents of 40 patients (35 %) were not interviewed for different reasons: parents only briefly attended outpatient clinic (67 %), parents did not give consent (10 %), parents could not communicate in any of the languages understood by interviewers (language barrier, 8 %), patients either deceased (8 %) or abandoned treatment (5 %) before the interview took place, or patients came to appointments unaccompanied by parents (2 %). There were no significant differences in the children's age at diagnosis, gender, or type of cancer between respondents ($n=75$) and nonrespondents ($n=40$). Table 1 illustrates sociodemographic characteristics of parents of childhood cancer patients ($n=75$).

Of 75 childhood oncology patients whose parents were interviewed, 43 (57 %) were male. Patients were between 0 and 14 years old at diagnosis. Figure 1 illustrates their distribution of diagnoses. At the time of interviewing, children were at the phase of diagnosis and staging (5 %), undergoing treatment (82 %), or had completed treatment (13 %).

Socioeconomic experiences

Financial situation and transportation

Most families had no regular income (63 %). A total of 64 % of families owned land. This land was either taken care of

Table 1 Sociodemographic characteristics of parents of childhood cancer patients ($n=75$)

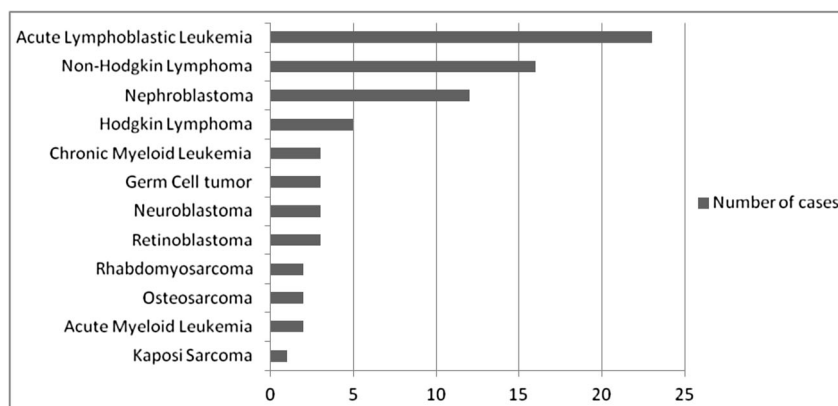
Sociodemographic characteristics	Percent	Percent
Respondents		
Mothers	70	
Fathers	15	
Grandparents	5	
Uncles	4	
Aunts	4	
Sibling	1	
Orphanage employee	1	
Marital status		
Married	67	
Widowed	12	
Single	10	
Separated	7	
Divorced	3	
Deceased	1	
Parental educational status	Fathers ($n=59$) ^a	Mothers ($n=69$) ^b
Low (no education, primary school)	45	61
Intermediate (high school)	28	24
High (university, other tertiary institute)	5	7
Parental occupation	Fathers ($n=59$) ^a	Mothers ($n=69$) ^b
Housewife	0	35
Regular job	37	27
Farmer	29	25
Laborer/irregular job	15	6
Unemployed	9	4
Student	0	3
Family's monthly income ($n=65$) ^c		
<US\$12	5	
US\$12–60	63	
US\$60–100	12	
>US\$100	7	
Main economic provider		
Father	48	
Mother	28	
Both parents	15	
Other caregiver	9	
Distance to MTRH		
<50 km	13	
50–100 km	23	
>100 km	64	
Transportation mode to MTRH		
Public transport	83	
Walking and public transport	13	
Private vehicle	3	
Walking	1	
Travel time to MTRH		
<1 h	4	
1–3 h	37	
>3 h	59	

^a Educational level of father was unknown according to the mother in 16 children: nine fathers had died and seven had left the family

^b Educational level of mother was unknown in six children: two mothers had died and four had left the family. Mothers had low (61 %), intermediate (24 %), or high education (7 %)

^c Ten families (13 %) could not report their monthly income

Fig. 1 Diagnosis of children whose parents were interviewed ($n=75$)



during hospitalization (85 %) or neglected (15 %). The majority of families reported a decrease in income since the start of treatment (66 %). Cancer treatment resulted in financial difficulties (89 %) and debts (64 %). Financial struggles were perceived as a great burden (83 %). Parents had to sell valuables (76 %), like livestock (60 %), land (9 %), or other possessions (23 %). Families received financial support from friends (47 %), relatives (41 %), religious community (36 %), or grandparents (29 %). Families experienced difficulties in providing food for their child at home (47 %). Treatment costs forced families to withhold their child from certain aspects of prescribed treatment (28 %). Some families (29 %) expected not to be able to complete treatment due to financial problems, and 23 % were uncertain about this. Traveling to the hospital was considered to be expensive (84 %), time consuming (77 %), and difficult (45 %). Reasons not to attend appointments in hospital were travel costs (52 %), inadequate transport facilities (20 %), and distance from clinic (20 %).

Treatment-related experiences

Parental education and communication with doctors

The information at diagnosis about cancer and its treatment was given by doctor (74 %), nurse (11 %), counselor (11 %), social worker (4 %), and another parent at ward (1 %). Parents were either aware of the specific diagnosis of their child (74 %) or knew that their child had cancer (26 %). Parents felt that more information about cancer and its treatment was required (88 %). More contact with doctors was needed (83 %). Parents were told by health-care providers that most children with cancer die (49 %) and that their child's fate is in God's hands (56 %). Parents had difficulties with understanding doctors' vocabulary (48 %) and the information provided (36 %). Parents hesitated to ask questions or attention from doctors (51 %) because of the following: families did not get a chance to ask questions or attention (58 %), doctors seemed too busy (58 %), fear that doctors become irritated (42 %) and this irritation may harm their child's treatment (32 %), and

doctors had high status (18 %). The parents disagreed (86 %) or were uncertain (7 %) that getting more information about cancer will make them afraid or depressed.

Health beliefs

Parents had some prior knowledge about cancer before the diagnosis of their child was made (75 %). At diagnosis, cancer was perceived as curable (63 %). Table 2 illustrates the causes of childhood cancer according to parents. The use of surgery in cancer may be helpful (85 %) and necessary (80 %), but is also believed to be frightening (61 %), causing death (45 %), and spreading cancer (30 %). Cancer can be cured according to 88 % of parents, 9 % were uncertain, and 3 % disagreed. The health of their child was beyond doctor's control and determined by luck, fate, or God according to 27 % of parents, 5 % were uncertain, and 68 % disagreed. Once their child appears healthy again, cancer is cured according to 40 % of parents, 13 % were uncertain, and 47 % disagreed. Most children with cancer die according to 55 % of parents, 20 % were uncertain, and 25 % disagreed. Chemotherapy can only cure cancer, if total treatment is completed according to 81 % of parents, 14 % were uncertain, and 5 % disagreed.

Adherence with hospital appointments and medication

Strict patient adherence with the prescribed dosage and timing of medication is crucial and improves the chances of survival of the children according to all 75 parents. Table 3 presents reasons for nonadherence with medication administration and hospital appointments according to parents. An accumulation of unused tablets at home was reported by 15 % of parents.

Complementary alternative treatment

Parents (95 %) used complementary alternative treatment (CAM): spiritual or religious help (89 %), herbalist (43 %), special food intake (9 %), and traditional healer (5 %). None of the parents reported to have used witchcraft. Table 4 shows

Table 2 Causes of childhood cancer according to parents ($n=75$); more than one answer was allowed

Causes of childhood cancer	Percent
Exposure to chemicals	80
Not known/unclear	67
Food intake	63
Inheritance ^a	58
Bad luck	40
Supernatural	32
Destiny	23
No cause	20
Curse	13
Witchcraft	8
Conflict	5
Environmental factors	4
Punishment by God	1
Exposure to plastic bags and other plastics	1
Uncleanliness/lack of hygiene	1
Missing childhood immunization	1
Getting kick in the chest	1
Sleeping with open mouth and breathing in dust	1
Same cause as any other disease	1
Contagious	1

^a Inheritance in this context does not refer to genes but rather it means parents pass on the disease to their children because of curse that has been subjected to the family by a supernatural being

the reasons why parents used CAM. Parents believe that doctors have negative perspectives of CAM (75 %). Health-care providers told 49 % of parents not to use CAM. Families find it difficult to discuss CAM with doctors (88 %), and parents had also not discussed their use of CAM with doctors themselves (71 %). Parents feared that they would receive less care from doctors if they expressed doubts about the effectiveness of conventional treatment or authority of doctors (25 %).

Psychological experiences

Coping

The emotional state of their child was described as somewhat unhappy (17 %), very unhappy (19 %), and so unhappy that life was not worthwhile (1 %). The parents' own emotional state was described as somewhat unhappy (28 %) and very unhappy (7 %). The feelings most parents experienced toward the disease of their child were acceptance (100 %), optimism (92 %), sadness (68 %), worrying (65 %), preoccupation with the progress of disease (60 %), hopelessness (39 %), fear (39 %), preoccupation with physical functions (39 %), preoccupation with fatal return of cancer (33 %), depression (21 %),

Table 3 Reasons for nonadherence with medication administration ($n=71$) and hospital appointments ($n=75$) according to parents of childhood cancer patients; more than one answer was allowed

	Percent
Reasons for nonadherence with medication administration ($n=71$) ^a	
Financial difficulties of parents	38
Inadequate drug supply at pharmacy	30
Forgetting	20
Too busy	18
No food available for child	11
Lack of motivation of parents	11
Alternative treatment	10
Side effects	10
Child is in pain	10
Lack of motivation of doctors	8
Child looks healthy	7
Lack of knowledge protocol	6
Child refuses drugs	4
Child looks ill	3
Not necessary	1
Reasons for nonadherence with hospital appointments ($n=75$)	
Travel costs	52
Hospital costs	28
Loss of daily wages	24
Distance to the clinic	20
Inadequate transport facilities	20
Retention of child in the hospital	15
Hospital procedure to clear hospital bill	15
Not satisfied with provided care	11
Time of clinic appointment is inconvenient	11
Forget appointments	9
Going to work	9
Do not see benefit of hospital appointment	8
Nobody to look after other children	8
Too busy	8
Child appears healthy	9
Nobody to look after land	7
Child is in pain	5
Child appears ill	4

^a Parents of all 71 children who were either on treatment or had completed treatment

and shame (3 %). Marital problems caused by disease and treatment of their child were reported by 13 % of parents.

Siblings

Sixty-seven parents had more than one child. Parents reported to have less time and energy for siblings (79 %). Parents were afraid for siblings' well-being (52 %). Siblings felt neglected by their parents (45 %). Parents said to be overprotective of

Table 4 Reasons for using complementary alternative treatment according to parents of childhood cancer patients ($n=75$); more than one answer was allowed

Reasons for complementary alternative treatment	Percent
Hope for cure	53
Hope for improvement of the child's condition	47
Helpful	43
Recommended by others	37
Certainty of cure	36
Other patients look healthy after taking it	27
Recommended by parents of other patients	25
Cheap	23
Easily accessible	23
At short distance available	20
No side effects	13
Child can stay inside the family	13
Child will not be retained in the hospital	12
No painful medical procedures	12
No discomfort	11
Fear of surgery in the hospital	9
Conventional treatment has no certainty of cure	8
Chemotherapy has side effects	5

siblings (36 %) and to have feelings of guilt toward siblings (34 %). During treatment of their child in the hospital, siblings were taken care of by the father (30 %), older sibling (19 %), mother (18 %), grandmother (13 %), relatives (13 %), neighbors (7 %), house helper (4 %), or orphanage worker (1 %). In two families, the children were considered to be old enough to take care of themselves (3 %).

Social network

Table 5 illustrates the reaction of social network to child's cancer. Social support from community members was received by almost all parents (96 %): spouses, grandparents, relatives, villagers, and church members. However, community members isolated families because their child had cancer (25 %), believed that the child was bewitched (57 %), advised to use alternative treatment (61 %), and advised to stop treatment at MTRH (45 %). Totally, 15 % of families decided not to disclose their child's cancer to community members at home.

Interaction with other parents at the hospital ward

Parents shared experiences with other parents of children with cancer at the ward (97 %) and received emotional support from them (95 %). Parents explained that they feel they have a close bond with other parents because they face similar difficulties (93 %). This emotional support from other parents was

described as very important (90 %). Experiences shared with other parents were as follows: progress of disease (96 %), management of side effects (88 %), adverse effects of disease (88 %), and alternative therapies (20 %). It was good to learn from the experiences of other parents, because parents otherwise would not understand the disease and its treatment (87 %). Health-care providers were busy and therefore could not provide them with sufficient information, advice, or emotional support (53 %). However, advice from emotionally close parents was not considered to be more valuable than the opinions of health-care providers (88 %).

Discussion

This study reveals that parents of children with cancer in Kenya, Africa, undergo a wide variety of socioeconomic, treatment-related, and psychological experiences.

The majority of parents reported financial difficulties (89 %) and a reduction in family's income (66 %). This results from the fact that parents take time off their jobs to be with their sick child in the hospital. Since a big proportion of parents work as casual laborers, any absence from their workplace results in loss of a day's wages. Among parents of Indonesian children with acute lymphoblastic leukemia, 69 % of parents reported a reduction in their income [11]. Despite their financial difficulties, only one third of Kenyan parents expected not to be able to complete cancer treatment. Potential solutions to financial problems would include lobbying for more government and donor funding which can help cover some of the expenses the parents incur.

Transport to the hospital was described as expensive, time consuming, and difficult. It was also cited as the most common reason why parents miss hospital appointments. Majority of parents have low socioeconomic backgrounds and use public transportation which is rather disorganized in Kenya [16, 17]. This, coupled with long distances to the hospital, could explain the reason why transport was described as expensive and time consuming. Some ways of alleviating transport problems would include providing financial support to parents or having a house near the hospital where families could stay in between treatment courses.

Majority of parents (88 %) felt that they required more information to understand the diagnosis and treatment of their child. In Indonesia, 86 % of parents with children with acute lymphoblastic leukemia also felt that they needed more information about their child's condition from doctors. Likewise, majority of Kenyan parents (83 %) felt that they needed more contact with doctors similar to what was reported in Indonesia (77 %) [11]. Parents had difficulties approaching doctors to ask them questions regarding their children. This could be due to a combination of the fact that there are relatively few

Table 5 Reaction of social network to the child's cancer according to parents of childhood cancer patients ($n=75$)

Reaction	Spouse ^a ($n=55$)	Grandparents ^b ($n=59$)	Relatives ^c ($n=72$)	Friends ^c ($n=72$)	Village community ^c ($n=71$)	Religious community ^c ($n=67$)
Gives social support	91 %	81 %	72 %	72 %	59 %	87 %
Acceptance	91 %	81 %	83 %	83 %	83 %	87 %
Left/isolate the family	4 %	3 %	14 %	17 %	14 %	6 %
Disappointing	15 %	17 %	26 %	28 %	18 %	10 %
Believes disease is caused by inheritance	25 %	17 %	25 %	26 %	21 %	10 %
Believes child is bewitched	16 %	17 %	33 %	39 %	34 %	13 %
Advises to seek alternative treatment	22 %	25 %	36 %	36 %	39 %	7 %
Advises not to attend public hospital	16 %	14 %	28 %	22 %	25 %	6 %

^a Twenty parents had no spouse^b Grandparents of 16 children had deceased^c Parents did not disclose their child's cancer to relatives ($n=3$), friends ($n=3$), village community ($n=4$), and religious community ($n=8$)

doctors in MTRH and that doctors are regarded as members of higher social status. In Kenya, it is culturally not accepted to question somebody of a higher status. Parents also had difficulties understanding the language used by doctors. As a legacy of British colonization, English is Kenya's official language. However, English is learnt in school and is hardly the first language for the vast majority of low-educated poor Kenyans. Kenya harbors many different tribes with their own ethnic languages or dialects. Also, in our study, more than half of parents had low education levels, and consequently, problems understanding English can be expected. Most of our parents would be more fluent in Kiswahili which is the national language. A minority of Kenyans belongs to high socioeconomic strata and use English as a means for communication [18, 19]. In hospitals, doctors communicate among themselves in English. Maybe unintended, the use of English emphasizes the difference in social hierarchy between doctors and families. This will hinder communication further. All these coupled with the fact that health-care providers also use medical terminologies, which are difficult to translate in Kiswahili, make it difficult for parents to understand. The doctors also spend very minimal time with the patients during daily ward rounds due to the high number of patients. This calls for more training among doctors regarding proper communication skills. Other staff especially nurses and counselors should be given more training about the various childhood cancers so that they are able to provide more information to parents.

At diagnosis, most parents (63 %) perceived childhood cancer to be curable. However, half of the parents were subsequently informed by health-care providers that children with cancer are likely to die. The latter may be understandable as cancer survival is low at MTRH [20] and health-care providers could have come across many children with cancer who have died, but negative comments are certainly not advisable. Parents were still hopeful of a cure, and such

pessimism from medical staff may discourage families to adhere with treatment and opt out. At MTRH, 54 % of children abandon cancer treatment [20]. This will result in poorer cancer survival.

Almost all parents (95 %) had used complementary alternative medicine in the course of the illness of their children with the commonest forms being spiritual help and traditional healers. Other studies have reported high rates of use of CAM among children with cancer both in low- and high-income countries: Jordan (65 %), Turkey (49 %), Netherlands (42 %), Indonesia (37 %), and Germany (35 %) [11, 21–24]. However, different types of CAM are used in Kenya compared to other countries in the world. The majority of the parents in this study report using spiritual help which could be explained by the fact that most people are deeply religious. Communities living in Kenya still strongly follow their traditional practices, and this may explain why many of them seek traditional healers as a way of improving the condition of their children. It is also interesting to note that no parents reported use of witchcraft despite being advised by community members that their children had been bewitched. In most cultures, if an individual is believed to be bewitched, they need to consult a witchdoctor to remove the curse. The witchdoctor blames the illness on a curse from a community member, and this is often a person close to those who are seeking his services. One would therefore not publicly admit to have visited a witchdoctor as this means they are blaming somebody in their close social network for the child's cancer [25, 26].

Despite a large number of families using CAM, most parents never discussed its use with doctors (71 %). Also, in the Netherlands, only 33 % of parents discussed the issue with doctors [24]. Half of our parents were told not to use CAM by doctors. This means that there is a great disconnect between doctors and parents on this subject. Parents have valid reasons to use CAM, and it would be helpful if the doctors became

more open and discuss the subject with parents. For doctors to do this in a useful manner, they will require more knowledge about CAM.

The communal way of living in Kenya is exemplified by the fact that families received financial and social support from the community [18, 19]. However, community members believed that the children with cancer were bewitched. The parents were advised to stop treatment at MTRH and seek necessary CAM care. This may imply that the level of knowledge and understanding of childhood cancer in the community is quite low. It also implies that, in contradiction to what is reported in the western world where social support helps to improve adherence with conventional treatment, in Kenya, social support may result in nonadherence [26, 27]. In Indonesia, 39 % of parents with children with acute lymphoblastic leukemia felt that they did not get support from the community [11].

Stigma against cancer is still prevalent in the Kenyan community as demonstrated by the fact that 15 % of families did not disclose the diagnosis. Community education about childhood cancer would be useful in providing correct information to community members so as to enhance positive support to affected families. This can be achieved through mass media, schools, or churches.

The parents interviewed received a lot of information and support from other parents in the ward. Eighty-seven percent of parents said that they would not have understood their child's disease without the explanation they received from other parents. This could be mainly because fellow parents are able to express themselves in a language they can easily understand. Since they are also going through the same experiences, parents can associate with one another more easily. This is an aspect that should encourage the formation of a parent support group in this setting.

In conclusion, this study reveals that families in Kenya suffer a lot of economic turmoil when they have children undergoing treatment for cancer. It also reveals that CAM use is very widespread in these patients and that parents are not satisfied with the amount and manner of receiving information from doctors.

There were several limitations in this study. Parents could have given socially acceptable answers during interviews as the culture in Kenya does not encourage criticism. Parents were interviewed at different phases of their child's treatment, and this means that they could have undergone different experiences. The perceptions of a parent whose child is just starting treatment are likely to be different from those of a parent whose child has finished treatment and is in remission. There could also have been a recall bias among those who had completed treatment.

Based on the findings of our cross-sectional study, we would like to make the following recommendations:

The national government through the ministry of health should provide more funds for the care of pediatric oncology patients. The government should focus on setting up satellite pediatric oncology clinics so that the burden of traveling long distances by the patients is minimized. There should be focus on training more doctors in the field of pediatric oncology to reduce the patient to doctor ratio to allow more time for interaction between doctors, patients, and their guardians.

The hospital should work on getting a facility near the hospital where patients and their guardians can stay in between cycles of chemotherapy. The hospital can partner with local and international charities to raise money for running the facility. The money raised through such collaborations can be used to help offset transport costs for very poor patients. The hospital should also ensure health workers undergo refresher courses on patient communication.

Doctors should work toward having a set out time for discussing with families about their child's illness especially at the time of diagnosis and start of treatment. Doctors should also ensure they equip themselves with proper communication skills and use easy and appropriate language when talking to patients and families. They should also discuss CAM more openly with families as majority of them use it at some point during their child's illness. Doctors, in conjunction with other help workers like social workers and psychologists, should help parents in forming a support group that meets regularly.

Acknowledgments We wish to acknowledge the Doctor 2 Doctor program for their logistical support. The funding for this study was through a grant from the International Society of Pediatric Oncology (SIOP).

Conflict of interest The authors have no relationship with the organization that funded the study. All the authors have no conflicts to declare.

References

1. Sullivan R, Kowalczyk JR, Agarwal B et al (2013) New policies to address the global burden of childhood cancer. *Lancet Oncol* 3:125–135
2. Mehta PS, Wiernikowski JT, Perrilli JA et al (2013) Essential medicines for paediatric oncology in developing world. *Pediatr Blood Cancer* 60:889–891
3. Magrath I, Steliarora-Foucher E, Epelman S et al (2013) Paediatric cancer in low- and middle-income countries. *Lancet Oncol* 14:104–116
4. Masera G (2009) Bridging the childhood cancer mortality gap between economically developed and low income countries. *J Paediatr Hematol Oncol* 31:710–712
5. Rodriguez-Galido C, Friedrich P, Morrissey L et al (2013) Global challenges in paediatric oncology. *Curr Opin Paediatr* 25:3–15
6. Hadley LG, Rouma BS, Saad EY (2012) Challenges of pediatric oncology in Africa. *Semin Paediatr Surg* 21:136–141

7. Harif M, Traore F, Hesseissen L, Moreira C et al (2013) Challenges for paediatric oncology in Africa. *Lancet Oncol* 14:279–281
8. Abum G, Gott M (2001) Education given to parents of children newly diagnosed with acute lymphoblastic leukaemia. *J Pediatr Oncol Nurs* 28:300–305
9. Khoury MN, Huijter HA, Doumil MA (2013) Lebanese parents experiences with a child with cancer. *Eur J Oncol Nurs* 17:16–21
10. Dockerty JD, Skegg DC, William SM et al (2003) Economic effects of childhood cancer on families. *J Pediatr Child Health* 39:254–258
11. Mostert S, Sitaresmi MN, Gundy CM et al (2008) Parental experiences of childhood leukaemia treatment in Indonesia. *J Pediatr Hematol Oncol* 30:738–743
12. Stam H, Grootenhuis MA, Brons PP (2006) Health related quality of life in children and emotional reactions of parents following completion of cancer treatment. *Pediatr Blood Cancer* 47:312–319
13. Kenya National Bureau of Statistics (2014) 2009 population and housing census results. www.knbs.or.ke. Accessed 11 Oct 2013
14. Mostert S, Njuguna F, Kamps L (2012) Epidemiology of diagnosed childhood cancer in Western Kenya. *Arch Dis Child* 97:508–512
15. Kenya National Bureau of Statistics (2010) Kenya demographic and health survey 2008–9. www.knbs.or.ke. Accessed 11 Oct 2013
16. Kolossa K (2014) The Kenyan transport system. www.uni-koeln.de/phil-fak. Accessed 11 Oct 2013
17. Ministry of Transport and Communications (2009) Integrated national transport policy; moving a working nation. Government of Kenya 2004. www.marsgroupkenya.org. Accessed 11 Oct 2013
18. Advameg, Inc. (2014) Culture of Kenya. www.everyculture.com. Accessed 11 Oct 2013
19. The Africa Guide (2013) People and culture of Kenya. www.africaguide.com/country/kenya/culture.htm. Accessed 11 Oct 2013
20. Mostert S, Njuguna F, van de Ven PM et al (2013) Influence of health-insurance access and hospital retention policies on childhood cancer treatment in Kenya. *Paediatr Blood Cancer* 61:913–918
21. Al Quidimat MR, Rozmus CL, Farhan N (2011) Family strategies for managing childhood cancer: using complementary and alternative medicine in Jordan. *J Adv Nurs* 67:591–597
22. Gozun S, Arikan D, Buyukavci M (2007) Complementary and alternative medicine use in pediatric oncology in eastern Turkey. *Cancer Nurs* 30:38–44
23. Laengler A, Spix C, Seiffert G et al (2008) Complementary and alternative treatment methods in children with cancer: a population based retrospective survey on the prevalence of use in Germany. *Eur J Cancer* 44:2233–2240
24. Singendonk M, Kaspers GJ, Naafs-Wilstra M et al (2013) High prevalence of complementary and alternative medicine use in the Dutch pediatric oncology population: a multicenter survey. *Eur J Pediatr* 172:31–37
25. Bussman RW (2006) Ethnobotany of the Samburu of Mt. Nyiru, South Turkana, Kenya. *J Ethnobiol Ethnomed* 6:35
26. Gona JK, Hartley S, Newton CR (2006) Using participatory rural appraisal (PRA) in the identification of children with disabilities in rural Kilifi Kenya. *Rural Remote Health* 6:553
27. Mostert S, Njuguna F, Langat S et al (2014) Two overlooked contributors to abandonment of childhood cancer treatment in Kenya: parents' social network and experiences with hospital retention policies. *Psychooncology* 23:700–707