

## RESEARCH ARTICLE

# Health-Care Providers' Perspectives towards Childhood Cancer Treatment in Kenya

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### Abstract

**Background:** This study explored perspectives of health-care providers on childhood cancer treatment in Kenya. **Materials and Methods:** A self-administered questionnaire was completed by 104 health-care providers in January and February 2013. **Results:** Seventy six percent of the health-care providers believed cancer to be curable. More doctors than other health-care providers had this positive opinion ( $p=0.037$ ). The majority of health-care providers (92%) believed that most children with cancer will not be able to finish their treatment due to financial difficulties. They considered that prosperous highly-educated parents adhere better with treatment (88%) and that doctors adhere better with treatment for prosperous highly-educated parents (79%). According to 74% of health-care providers, quality of care is better for prosperous highly-educated parents (74%). Most health-care providers reported giving more explanation (71%), work with greater accuracy (70%) and use less difficult vocabulary (55%) to prosperous more educated families. Only 34% of health-care providers reported they feel more empathy towards patients from prosperous families. Reasons for non-adherence with the protocol according to health-care providers are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%), and financial difficulties of parents (69%). **Conclusions:** Health-care providers' health beliefs and attitudes differ for patients with families having high versus low socio-economic backgrounds.

**Keywords:** Childhood cancer - health-care providers - perspectives - low-income countries

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### Introduction

The low-income countries bear a greater burden of childhood cancer as compared to the high-income countries. Eighty per cent of all childhood cancers and 90% of the deaths occur in low-income countries (Magrath et al., 2013; Pritchard et al., 2013; Rodriguez-Galido et al., 2013; Sillivan et al. 2013).

Treatment abandonment is the leading cause of treatment failure in low-income countries. Several patient-related factors may contribute to treatment abandonment. These include low socio-economic status, low level of parental education, prolonged travel time to the hospital as well as the type of cancer. It is also recognized that health-care providers related factors may contribute to abandonment of therapy. Poor provision of information as well as poor communication skills of doctors enhances abandonment as the parents often do not understand the necessity of treatment continuation in their child. In addition, not all health-care providers may believe in the

curability of cancer and effectiveness of chemotherapy. It is not possible for the health-care providers to enforce treatment adherence when they do not believe in the treatment offered (Arora et al., 2007; Arora et al., 2010; Mostert et al., 2011; 2012).

In Kenya more than 50% of the children with cancer abandon therapy and only 20% have event-free survival (Mostert et al., 2012). The perspectives of health-care providers towards childhood cancer treatment have not been extensively studied in Africa. This study aims to provide insight into the medical team's health beliefs and attitudes towards parental financial difficulties, protocol adherence, parental education and communication in an academic hospital in Kenya.

### Materials and Methods

#### Setting

The study was carried out at the Moi Teaching and Referral Hospital (MTRH), Eldoret in Western Kenya.

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Kenya is located in the Eastern part of Africa and has a population of about 42 million people. Half of the population lives on less than 2 dollars a day (Kenya National Bureau of Statistics, 2009).

MTRH is a tertiary referral hospital that serves a catchment area of about 18 million people. The hospital takes care of about 120 new pediatric oncology patients every year (Mostert et al., 2012).

The pediatric oncology unit is housed within the pediatric wards. The pediatric wards have 72 beds of which 12 are allocated to pediatric oncology. There are 15 pediatricians of whom one is dedicated to the oncology unit. The other pediatricians are usually involved in the diagnostic process for the oncology patients, taking care of the patients during night and weekend shifts, and whenever patients cannot be transferred to the oncology unit due to lack of space. The day to day care of the patients is usually in the hands of medical and clinical officers. The nurses and other support staff (social workers, physiotherapists, occupational therapists, nutritionists, and psychological counselors) are involved in the care of the children and they rotate from one section to another every 6 months. Child life workers in the playroom provide daily activities and information about treatment to parents and children.

MTRH has two models of service provision: the public and private systems. The private system is more expensive and it serves those who are in the middle or upper socio-economic classes and those who have private health insurance schemes. Patients in the private facilities get more spacious accommodation as well as faster and more efficient services compared to the ones in the public wards (Kenya National Bureau of Statistics, 2009). In general, patients in the private systems are more prosperous and regarded as better educated than patients attending the public systems.

### Study Design

This was a cross-sectional study using a self-administered structured questionnaire. All 133 health-care providers working in the pediatric department of MTRH were requested to fill in the questionnaire at home or in the hospital.

The questionnaire covered health-care providers' health beliefs and attitudes towards parental financial difficulties, protocol adherence, parental education and communication. To evaluate the questionnaire's statements, health-care providers were able to choose from two, three or four-point rating scales.

A panel of Kenyan, Indonesian, American and Dutch doctors developed the questionnaire which was pilot-tested for its content, clarity and for cultural sensitivities on 5 Kenyan health-care providers. Small adaptations were made on basis of the pilot-test. The questionnaire was anonymous. Participants self-identified their professional title as pediatrician, medical officer, clinical officer, nurse, social worker, physiotherapist, occupational therapist, nutritionist, psychological counselor or child life worker which was the sole demographic variable noted. Participants were assured that their answers would remain confidential. This study was approved by the Institutional Research Ethics Committee of the MTRH.

### Data Analysis

Frequency distributions were calculated. Reliability of items in this study was established.. The Mann-Whitney test was used to compare differences in health beliefs between doctors and other health-care providers. Data management and analysis were accomplished with SPSS version 20.0.

## Results

During January and February 2013, questionnaires were handed out to all 133 health-care providers (HCP) of the pediatric department. Table 1 illustrates that 104 HCP (response rate 78%) returned their questionnaires. Cronbach's alpha coefficient varied between 0.71 and 0.89.

### Health Beliefs

Figure 1 illustrates causes of cancer in childhood according to HCP (n=104). Cancer is curable according to 76% of HCP, 13% are uncertain and 12% disagree. However, almost all children with cancer die according to 38% of HCP, 11% doubt this and 52% disagree. In order to cure cancer, the full length of treatment must be completed according to 99% of HCP. Ninety-two percent of HCP believe most children will not be able to complete treatment as a result of financial difficulties, 4% are uncertain and only 4% disagree. Table 2 shows health beliefs of doctors (pediatricians, medical officers, clinical officers, n=26) versus other HCP (n=78). Significantly more doctors than other HCP believe that cancer can be cured. The chance of cure increases for patients with prosperous and highly-educated parents according to 63% of HCP.

### Financial Difficulties

The vast majority of HCP (97%) asks parents about their financial situation and possible financial difficulties. Forty-three percent of the HCP ask the families whether some aspects of treatment should be postponed or withheld due to financial difficulties. Table 3 highlights the attitudes of health-care providers (n=104) towards prosperous and highly-educated parents, as compared to poor less-educated parents. Sixty-nine percent of HCP believe that the quality of care improves when a patient has prosperous and highly-educated parents. Towards

**Table 1. Health-care Providers Participating in the Questionnaire Study**

Health-Care Providers:	N	Response Rate (%)
Pediatricians	9	69
Medical officers	4	80
Clinical officers	13	81
Nurses	41	71
Social workers	4	100
Physiotherapists	4	100
Occupational therapists	3	100
Nutritionists	2	100
Psychological counselor	3	100
Child life workers	21	88
<b>Total</b>	<b>104</b>	<b>78</b>

these patients, HCP stated that they give more elaborate explanations (71%), are more accurate (70%), pay more attention (59%) and tend to show more interest (56%). Some HCP report that they have more respect (51%), pay more frequent visits (50%), and spent more time per visit (45%) towards prosperous and highly-educated parents. However, approximately half of all HCP (54%) mention that there is no difference in empathy towards prosperous highly-educated versus poor less-educated parents.

#### Protocol Adherence

The decision to start or not start cancer treatment is reported to be influenced by: type of cancer (88%), nutritional status of patient (87%), motivation of parents (72%), motivation of doctors (55%), health-insurance coverage of patient (55%), and financial situation of parents (50%). Strict doctor adherence with prescribed dosage and timing of chemotherapy administration is crucial and improves the survival of children with cancer according to 97% of HCP. In total 79% of HCP state that

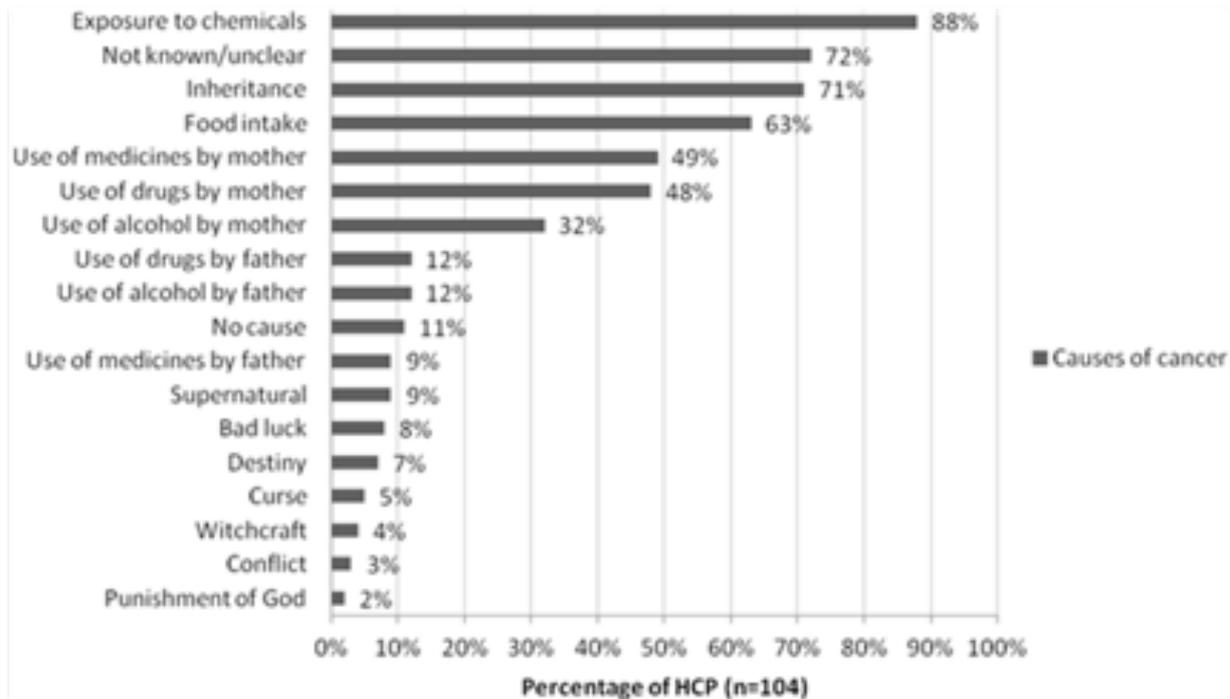


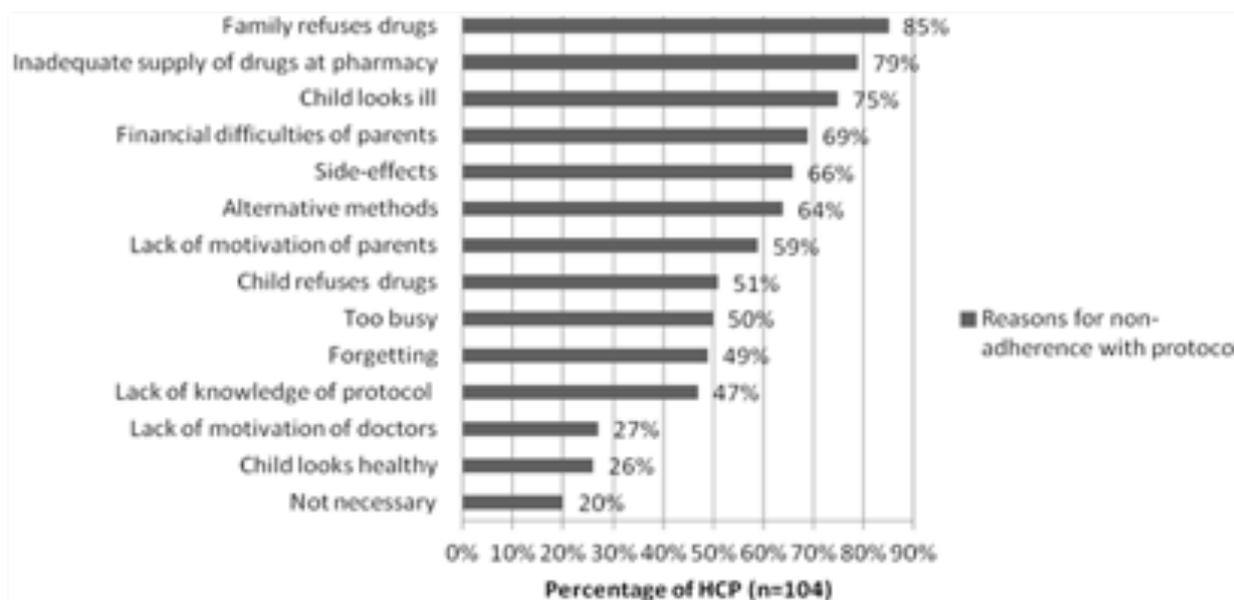
Figure 1. Causes of Childhood Cancer According to Health-Care Providers (n=104)

Table 2. Health Beliefs of Medical Doctors (n=26) versus other Health-Care Providers (n=78)

Statements:		Doctors		Other HCP		P
		Total	Count	Total	Count	
Health of children with cancer is beyond doctor's control and determined by luck, fate or God	Agree	26	0 (0%)	77	16 (21%)	ns
	Uncertain		3 (12%)		4 (5%)	
	Disagree		23 (89%)		57 (74%)	
Health of children with cancer can be influenced by health-care providers	Agree	26	25 (96%)	76	71 (93%)	ns
	Uncertain		0 (0%)		2 (3%)	
	Disagree		1 (4%)		3 (4%)	
Cancer can be cured	Agree	26	24 (92%)	78	55 (71%)	0.037
	Uncertain		0 (0%)		13 (17%)	
	Disagree		2 (8%)		10 (13%)	
Almost all children with cancer die	Agree	26	7 (27%)	78	32 (41%)	ns
	Uncertain		1 (4%)		10 (13%)	
	Disagree		18 (69%)		36 (46%)	
Cancer is cured once the children appear healthy again	Agree	26	0 (0%)	78	3 (4%)	ns
	Uncertain		4 (15%)		14 (18%)	
	Disagree		22 (85%)		61 (78%)	
In order to cure cancer, the full length of treatment must be completed	Agree	25	25 (100%)	76	75 (99%)	ns
	Uncertain		0 (0%)		0 (0%)	
	Disagree		0 (0%)		1 (1%)	
Surgery on cancer patients spreads the disease	Agree	25	0 (0%)	78	12 (16%)	ns
	Uncertain		5 (20%)		15 (19%)	
	Disagree		20 (80%)		51 (65%)	
If cancer patients receive surgery their chance of survival decreases	Agree	26	3 (12%)	77	11 (14%)	ns
	Uncertain		3 (12%)		12 (16%)	
	Disagree		20 (77%)		54 (70%)	

**Table 3. Attitude of Health-Care Providers towards Prosperous and Highly-Educated Parents, as Compared to Poor Less-Educated Parents**

Attitude towards prosperous highly-educated parents:		Total	Count	Attitude towards prosperous highly-educated parents:		Total	Count
Vocabulary	More difficult	103	18 (17%)	Expectation towards adherence of parents	Improved	101	89 (88%)
	Less difficult		57 (55%)		Worsened		2 (2%)
	No difference		28 (27%)		No difference		10 (10%)
Explanation	More elaborate	103	73 (71%)	Expectation towards adherence of doctors	Improved	103	81 (79%)
	Less elaborate		20 (19%)		Worsened		3 (3%)
	No difference		10 (10%)		No difference		19 (18%)
Respect	More respect	101	52 (51%)	Time taken per doctor visit	More time	104	47 (45%)
	Less respect		9 (9%)		Less time		28 (27%)
	No difference		40 (40%)		No difference		29 (28%)
Empathy	More empathy	104	33 (32%)	Frequency of visits	More frequent	98	49 (50%)
	Less empathy		15 (14%)		Less frequent		14 (14%)
	No difference		56 (54%)		No difference		35 (36%)
Interest	More interest	103	59 (57%)	Treatment according to protocol	More complete	104	66 (63%)
	Less interest		6 (6%)		Less complete		4 (4%)
	No difference		38 (37%)		No difference		34 (33%)
Attention	More attention	104	61 (59%)	Chemotherapy	More intense	101	49 (49%)
	Less attention		6 (6%)		Less intense		5 (5%)
	No difference		37 (36%)		No difference		47 (47%)
Accuracy	More accurate	97	68 (70%)	Side-effects	More severe	102	10 (10%)
	Less accurate		3 (3%)		Less severe		35 (33%)
	No difference		26 (27%)		No difference		57 (56%)
Expectation towards chance of cure	Increased	104	66 (63%)	Quality of care	Improved	97	72 (74%)
	Decreased		7 (7%)		Worsened		0 (0%)
	No difference		31 (30%)		No difference		25 (26%)



**Figure 2. Reasons for Non-Adherence with Protocol According to Health-Care Providers (n=104)**

doctors' adherence is improved towards children with prosperous highly-educated parents, as compared to poor less-educated parents. Figure 2 highlights the reasons for non-adherence with protocol according to health-care providers (n=104). The most frequently reported reasons for not following the prescribed schedule and dose are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%) and financial difficulties of parents (69%). Strict patient adherence with prescribed dosage and timing of medication is crucial and improves the survival of children with cancer according to 96% of HCP. Eighty-eight percent of HCP state that children with prosperous highly-educated parents adhere

better with prescribed treatment compared to poor less-educated parents. Towards children with prosperous highly-educated parents, HCP reported to provide treatment more completely as prescribed by the protocol (63%), and give more intense chemotherapy (49%).

*Parental Education and Communication*

It is crucial to give clear explanations to patients and parents to ensure cooperation and adherence to the chemotherapeutic regimen according to 99% of HCP. Medical vocabulary that patients and parents do not understand is used by 63% of HCP. Surprisingly health-care providers indicated that they use less difficult

vocabulary (55%) towards families with prosperous highly-educated parents as compared to poor less-educated parents. Some difficulties in openly discussing the illness and its treatment with patients and parents are experienced by 71% of HCP, and severe difficulties are encountered according to 18%. Poor communication between patients, parents and doctors decreases the prognosis of children with cancer, according to 73% of HCP. Education about cancer and its treatment makes parents more afraid or depressed about the future and therefore parents prefer not to know, according to 19% of HCP, 11% are uncertain, 70% disagree. There is no time to give extensive explanations about the disease and treatment to parents and patients according to 18% of HCP, 5% are uncertain and 77% disagree. Because parents can have difficulties to understand the information the health-care providers give about disease and treatment, 42% of HCP say that they always verify if parents understand the information given. Important information is always repeated by 35% of HCP.

## Discussion

This study explored the beliefs of HCP towards childhood cancer treatment in a low-income country. Significantly more doctors believed that cancer can be cured compared to the other HCP. This could be as a result of the doctors having more knowledge and experience regarding childhood cancer treatment. Nevertheless, with low survival rate observed in low-income countries, it is understandable that some Kenyan HCP have a negative perspective on the curability of cancer. The health beliefs regarding other aspects of childhood cancer were similar between the doctors versus other HCP. Similar findings were observed in Indonesia where there were also no major differences in health beliefs between doctors and other HCP. (Mostert et al., 2013)

Provision of clear information to parents is paramount in ensuring adherence to cancer treatment. (Mostert et al., 2013) This study highlights the fact that the majority of HCP use medical vocabulary when discussing with parents about the condition of their children. English is one of the official languages in Kenya, however, it is learned in school and only used as the means for communication by those who have completed up to high school level of education and are more affluent (Constitution of Kenya, 2010; What languages are spoken in Kenya, 2013). Doctors communicate among themselves in English. Most of the patients and their parents have difficulties communicating in English and are more fluent in Kiswahili and other local dialects. In our study the HCP attest to using less difficult vocabulary when dealing with prosperous highly-educated parents. This could be because the HCP are able to communicate more easily and get more relaxed when discussing with more educated parents as they can easily communicate with them in English. In order to communicate with the families on the public wards doctors need to speak Kiswahili and most of the medical terminologies are not easy to explain in Kiswahili. A similar situation was noted in Indonesia where 88% of the HCP reported using language that the parents could not understand (Mostert et al., 2013). In

Kenya 42% of the HCP verify with the parents whether they have understood the information which is important in improving the parents understanding.

The HCP reported having difficulties discussing with parents about the condition of their children while admitting that poor communication between HCP and patients leads to poorer outcomes. In Indonesia a similar situation was found where 81% of the HCP said that poor communication between parents and HCP would lead to poor outcomes and 57% stated they had difficulties discussing about cancer with the parents. (Mostert et al., 2013; Gunawan et al., 2014) Most of the HCP in Kenya may not have had adequate training on how to communicate bad news to parents or patients and this may further explain why they experience these difficulties. It could also arise from the fact that the HCP are scared of cancer or they do not understand it sufficiently enough to be able to pass on the right information to the parents.

The HCP believed that patients' and doctors' adherence with the protocol are important to achieve cure. Almost all HCP were convinced that most children will not be able to finish treatment due to financial difficulties. The vast majority of HCP believed that the children with prosperous highly-educated parents adhere better with treatment. This could be because they get more clear explanations about the disease and required treatment than the poor less-educated parents. This expected better adherence could also be because these affluent families can simply afford to complete treatment. In addition, the more educated parents are also likely to be more aware of their rights and more vigilant as well with the treatment plans. The vast majority of HCP believed that doctors' adherence with treatment is improved towards children with prosperous highly-educated parents. HCP are more likely to provide more complete treatment when dealing with these privileged families. These patients are likely to be taken care of in the private wing of the hospital where they get attention from only one specific doctor. The patients in the public wards do not get to be attended to by a specific doctor. Usually the doctor on duty on a particular day would be the one to take care of them. The doctors also earn extra money by taking care of patients in the private wing. This would have an effect on the time they spend with these patients and offer extra care. Since these patients are richer they also can afford more treatment modalities than the poorer patients.

Interestingly, we found that the most commonly reported reasons by the medical team for non-adherence with prescribed treatment schedules are beyond the control of HCP and concern patients, parents and the pharmacy. This would therefore mean that the HCP feel that they have little control over the adherence or non-adherence with protocol. In Indonesia the HCP also believed that the reasons for non-adherence had more to do with factors beyond their control (Mostert et al., 2013; Sitaresmi et al., 2008). This may indicate that the HCP have a high external health locus of control. Studies among patients previously illustrated that health locus of control can be a predictor of better adherence with cancer treatment (Iskandarsyah et al., 2014). Patients with internal health locus of control think that their health condition is determined by their

own actions. In contrast, patients with external health locus of control believe that their condition results from external situations. Patients with internal health locus of control are assumed to better adhere with treatment (Reitzal et al., 2013 ; Hiller et al., 2014; Konkoly et al., 2014). Although the health locus of control concept has previously not been extensively investigated for HCP, our study findings suggest that HCP themselves have a high external health locus of control. This may adversely affect their own attitudes and adherence with cancer treatment. It could also affect the information they give to the patients and their families. The HCP may inform the patients and their families that they have little control over the outcome of their illness and hence reduce the families adherence.

The parental financial status has an effect on many aspects of the patients' treatment. The majority of HCP agreed that the quality of provided care and chance of cure is improved towards more affluent patients and their families. This could be related to the financial benefits accrued especially by the doctors. It is interesting to note that the level of empathy does not change depending on the parents' economic status. This may mean that the more attention the prosperous patients get is based mainly on the financial gains for the HCP. The doctors employed by the government of Kenya engage in dual practice. This means they work in private hospitals although they are hired and paid on a full time basis in the public hospitals. They earn extra money for each patient they see in the private hospitals. This often leads to a situation whereby they spend more time in the private hospital to the detriment of the patients in the public hospitals (Ariadna, 2001; Chankora et al., 2009; Paulo et al., 2014).

This study had several limitations. Some of the respondents could have given socially acceptable answers. Not all HCP had worked at both the public wards and private wing. Also not all respondents had the same exposure to or training about childhood cancer.

We recommend that the HCP working with children with cancer get specific training on communication with the parents and patients. In Kenya this can be achieved through the Kenya Society of Hematology and Oncology which is the body that brings together all the health workers in the field on oncology in the country. Training on communication should be incorporated in the curricula of medical training institutes. More staff need to be added to work in this area as well and those currently working there should be encouraged to spend more time discussing the children's illness with the poorer families. The staff should also attend refresher courses on treatment and outcomes of paediatric oncology patients so that they are able to appropriately educate patients and their families.

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