Chapter 2a

The Guardians’ Perspective on Paediatric Cancer Treatment in Malawi and Factors Affecting Adherence

Trijn Israëls MD1,2*, Chawanangwa Chirambo Bsoc1, Huib Caron MD PhD2, Jan de Kraker MD PhD2, Elizabeth Molyneux FRCPCH FCEM1, Ria Reis MSc PhD.3

1  Department of Paediatrics, College of Medicine, University of Malawi, Blantyre, Malawi
2  Department of Paediatric Oncology, Emma Children’s Hospital/AMC, Amsterdam, The Netherlands
3  Department of Sociology and anthropology, University of Amsterdam, The Netherlands
Abstract

**Background:** Abandonment of paediatric cancer treatment is a common problem in developing countries. Little is known about the guardians’ perspective on cancer treatment in these countries, especially the factors that affect adherence.

**Methods:** Following a pilot study enquiring into the possible causes of abandonment, a problem analysis diagram was drawn which helped to develop the questionnaires. Semi-structured interviews (n=83) and focus group discussions (n=8) were held with the guardians of 25 Burkitt lymphoma patients and 7 Wilms tumour patients at different phases of therapy in Malawi.

**Results:** Parents in Malawi are very motivated to continue treatment if they think that it will cure their child. Financial costs are important concerns. Not all tasks at home are assumed by other household members. The diagnosis of cancer was unknown before being told about it in hospital and caused fear of recurrence and death. Guardians are reluctant to ask the health personnel questions. They worry that taking frequent blood samples will weaken their child. The side effects of the chemotherapy are seen as a proof of efficacy.

**Conclusion:** It is important to appreciate the guardians’ concerns when offering treatment that requires their sustained commitment. It is necessary to provide not only medical treatment, but also travel allowances and adequate nutritional support during long hospital stays to impoverished families. Information should be given proactively.
Introduction

Abandonment of paediatric cancer treatment is a common problem in developing countries. It is important to try to prevent this as failure to complete treatment generally increases the risk of relapse. This is especially important in a resource limited setting where the allocation of health resources has to be carefully considered.

In a Wilms tumour study in Morocco 15% of patients (n=17/86) abandoned treatment. (1) In Nigeria, where parents had to pay for diagnostic tests and medicines to treat their children for Burkitt lymphoma, 20% of parents (n=8/41) could not afford to start chemotherapy and a further 32% (n=13/41) did not finish treatment due to financial constraints. (2)

Arora et al recently presented a literature review on the abandonment of treatment in this journal. (3) They found that failure to complete therapy in developing countries was related to the socio-economic and educational status of parents, distance from treatment centres, and affordable, locally available treatment. They also found that the abandonment of treatment seemed to be greater in cancers with a poorer prognosis.

The motivation of parents to have their child with cancer treated has been questioned. Chandy for example, states that there is a group of patient whose ‘Illiterate parents working as labourers with a monthly family income of less than U.S. $ 20, have little motivation to treat a child with cancer.’ (4) It has been shown in other settings, for example in Recife, Brazil, that abandonment can be decreased. Rates of abandonment of leukaemia treatment decreased from 16 % to 0.5 % over an 8 year period. In this period, a twinning programme with St. Jude Children’s Research Hospital was established, availability of medicines, standardized medical care and social services (including accommodation and money for transportation) greatly improved. (5)

The Queen Elizabeth Central Hospital (QECH) in Blantyre is a large, public referral and teaching government hospital in southern Malawi. The paediatric oncology ward admits about 160 new patients a year. Over half of the patients have Burkitt lymphoma and about 15 patients per year are diagnosed with Wilms tumour. Medical treatment is free and the hospital supplies two meals a day for the patient and one guardian. Money for transportation is given to the patients by the staff when it is felt necessary.

The objective of our study was to gain insight into the guardians’ perspective on cancer treatment, especially concerning factors which could influence abandonment of treatment.
Patients and methods

We first did a pilot study enquiring into the causes of abandonment of treatment. In this exploratory phase we discussed cancer treatment and possible reasons for not completing it with 4 nurses and a clinical officer working on the ward and with five guardians. From this information, a focussed problem analysis diagram was developed. This diagram (Figure 1) included all the factors that may affect the decision to abandon therapy.

![Figure 1. Problem analysis of factors involved in and affecting adherence to therapy.](image)

The questionnaires included structured questions about demographic and socioeconomic factors and a semi-structured portion with mostly open questions addressing the disease history, care seeking history, experiences in the hospital, and concerns while in the hospital and contact with home. The interviews usually took 40 - 50 minutes.

Twenty five guardians of patients with Burkitt lymphoma patients and 7 guardians of patients with Wilms tumour were interviewed between November 1st 2006 and 2007. The interviews with all the guardians were held at different phases of therapy, i.e. at diagnosis and after three weeks of treatment. The guardians of patients with Wilms tumour had additional interviews after surgery and during a home visit after the second post operative chemotherapy course. Eight focus group discussions (FGDs) were held with small groups of parents (4-6 parents) on the ward when issues such as decision making, religion and understanding of the
disease were discussed. These were non-structured discussions about a topic; led by one of the researchers. The parents involved were the same as those individually interviewed. Other FGDs were conducted with neighbours and relatives during the home visits of patients with Wilms tumour on issues such as community support and task allocations at home.

Following a grounded framework approach for health research we developed an analytical framework as described by Pope et al. which helped to classify, label, code, and organise our findings and facilitated interpretation. The interviews were in (Chichewa) the local language and led either by TI, a female Dutch paediatrician (with a translator) or by CC, a male Malawian social scientist. Privacy was maintained. Guardians were asked for verbal informed consent at which time it was made clear that they would not be financially rewarded for taking part in the study.

The treatment protocol for Burkitt lymphoma took a minimum of 28 days. (Day 1: intravenous cyclophosphamide 40 mg/kg + intrathecal methotrexate 12.5 mg and hydrocortisone 12.5 mg Day 8, 18 and 28: oral cyclophosphamide 60 mg/kg + intrathecal therapy). Treatment for Wilms tumour, (chemotherapy and surgery), required an initial in-patient period of at least 7 weeks, with return visits for post-operative chemotherapy. For localized tumours the therapy consisted of vincristine 1.5 mg/m² week 1-4 with actinomycin 45 μg/kg on week 1 and 3. For metastatic tumours doxorubicin (50 mg/m²) was added and the preoperative treatment prolonged to a minimum of 6 weeks.

Results

Care seeking history
All guardians had been to several other health providers before coming to QECH, e.g., a dispensary, health centre, traditional healer, private clinic and/or a district hospital. Many had received anti-malarial medications. Twenty seven of the 32 (84%) guardians said they had gone first to see a traditional healer. The traditional healer would put small scratches on any obvious lump and sometimes gave oral medicines. All but one had been referred by ambulance within one or 2 days from the district hospital to QECH and guardians had had no opportunity to notify family members and/or organize their absence from home.

Decision making
Twenty three of 32 parents had discussed together where to seek care. In 7 cases their own parents (especially their mothers) had also given them advice. Only 2
guardians had asked advice from other relatives, this was because the patient’s guardians were economically dependent on them. No one had asked advice or support from non-related elders in the community or ancestors. Some guardians mentioned how decisions are made has changed. In the past these types of problems were discussed with the extended family and with the community, now this happens rarely. Three of 32 guardians spontaneously said that these sort of problems now remain within the immediate family.

Concepts concerning disease

Guardians and medical personnel in the district hospital simply call the disease a swelling, without stating the type of swelling or its cause. Three of 32 guardians had first suspected witchcraft to be the cause of the disease either because of their economic status in the community leading to envy or out of evil intent. No guardian suspected that his/her child had cancer until they were told in hospital. Parents fear that the diagnosis cancer (‘khansa’) means that the disease will recur after treatment and their child will die. (See supplemental Table I examples of responses) Six of 32 guardians mentioned this fear of recurrence or death spontaneously. They have known only adult cancer patients who have almost invariably died from it.
Costs during treatment / absence from home

One of the main concerns of the guardians during their hospital stay is financial costs. One of the major costs is transportation, both for seeking health care and for returning to the hospital for further chemotherapy courses or follow up. (Table I) Secondly, guardians usually lack money to buy additional food while staying in hospital. Costs also include loss of normal daily income. Income generating activities are affected, farm work is left undone, and even jobs are lost. One household breadwinner lost her job (at a tea estate) after staying longer than the leave granted by her employer when she had found the patient (her grandchild) and his mother unwell at the hospital. Six out of 7 guardians of a patient with a Wilms tumour reported that their income generating activities had been affected during the hospital stay.

There may also be non-monetary ‘social costs’ to being absent from home. Six mothers expressed their concern about not being able to take care of their other

<table>
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<th>Table I. Demographic and socio-economic characteristics of the guardians</th>
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<td>Water supply*</td>
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<td>Assets; chicken, goat, radio or bicycle*</td>
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* A description of the living conditions (housing, water supply, electricity supply and assets) is a standard way of assessing socio-economic status in developing countries. All are in order of increasing wealth.
children themselves. 4 of 32 guardians had lost close relatives (brother/granny) at home while still at the hospital and could not attend the funeral. One mother expressed her fear of her husband’s infidelity in her absence.

Support

About one third of the guardians were visited by relatives during their stay in the hospital, the frequency depended on distances, length of hospital stay and financial means. They would bring maize flour with them and sometimes money. The basic tasks in the home (taking care of the other children, cooking, cleaning and washing) are taken over by the immediate female family members. (Table I) In one case the father took over the house chores with help of other ladies nearby. In the focus group discussions three quarter of the guardians thought that the work in the field was neglected, though in three cases an elder son or the husband had taken over this responsibility. (Supplemental Table I Examples of responses) Income generating activities (selling charcoal, selling banana fat cakes, and ‘piece work’) were never taken over. No guardians received support from the community as a whole. Guardians mentioned that community responsibility for issues such as a sick child has lessened in recent times.

Religion

All guardians consider themselves religious and their religious beliefs help them to stay hopeful. (Table I) Every morning all parents/guardians on the ward conduct prayers together with the nurse on duty, regardless of their religion. All guardians also pray individually for the well being of their child. Seven parents spontaneously expressed their trust in God ‘making a way’.

Only one guardian had been visited by members of his own religious group at home, though some (four of 32) mentioned that they had hoped to be visited and supported with money or materials. Almost every other Saturday religious groups without a personal relationship with one of the guardians visit the ward. They conduct prayers and sometimes bring soap, sugar, soft drinks or small presents for the children.

Perception of Hospital Care

During the interviews seven guardians expresses that they would like to know more about their child’s illness and the treatment (especially how long treatment will take, when they will be able to go home). These guardians said they felt reluctant to ask the nurses and doctors these questions, because they were afraid that they would be told off or they were shy of them. All guardians worry that drawing blood (frequently) will weaken their child, especially when they do not understand why it is necessary. Four of the 7 guardians of patients with a Wilms tumour, but only after being asked, expressed their fear of the operation their child had to undergo. Three
of them expressed their fear by saying: ‘anything can happen’. The side effects of the chemotherapy (nausea, vomiting) did not cause concern to any of the guardians, since they are seen as proof that the treatment is with ‘strong medicines’.

Only 5 out of 128 patients abandoned in patient treatment last year. Of these 4 were not improving on therapy. One was forcibly removed by his father during a family squabble. On our daily rounds we note that parents are dishearted when their children do not improve on therapy. The nurses are reluctant to tell parents about a poor prognosis, thinking that they will then lose hope, abscond and try traditional medicine.

Toxic deaths / abandonment

None of these 32 patients died from treatment related toxicity. One patient with a Wilms tumour showed progressive disease and was sent home after preoperative chemotherapy without being operated upon (with palliative care). Of these 32 patients one patient with a Wilms tumour did not return for the third post operative chemotherapy. His mother was HIV positive, had lost her husband 3 months
previously and was dependant on the salary of her mother who had moved to the north of Malawi. All other patients completed their chemotherapy course.

Discussion

This study of African children with cancer and their families demonstrates their perspectives on treatment and factors related to adherence.

We found that financial issues related to the treatment are major concerns for the guardians. The guardians in our study specifically mentioned the financial burden of transportation, food in the hospital and loss of income. It is necessary to provide not only medical treatment, but also travel allowances and adequate nutritional support when offering prolonged treatment that needs several journeys and long hospital stays in resource poor settings like Malawi.

People are often supported only by their first degree family members and not anymore by the community as a whole. Family members will sometimes help financially and some tasks at home are taken over, usually by female family members, though the work on the field is rarely and income generating activities never taken over.
Our findings show that it is important to inform parents about the duration of treatment, the reason for and frequency of drawing blood samples and the positive outcome in many cases of common childhood cancers. Abandonment of treatment is a common cause of treatment failure in many developing countries. It is important to know what the reasons for abandonment are to be able to develop preventive strategies. Arora et al. already stated that abandonment seems to be associated with cancers with a poorer prognosis. (3) Our impressions that guardians need hope of recovery to continue treatment confirm this. In this respect one needs to realize that Burkitt lymphoma and Wilms tumour are curable malignancies in Malawi whereas many others are not. The findings may have been biased by the interviewers; one was a physician on the ward and the other one a co-worker. Possibly guardians were reluctant to express negative things about the medical care or hoping to get financial support. Nevertheless, the mothers were discussing issues, including questions on income and costs, openly. The guardians who were interviewed were in hospital with children who had cancer. This biases the selection to those who were able to reach hospital whereas others may have been unable to attend. Ideally, in a further study, one would also want to interview guardians who have abandoned treatment to analyze their reasons for doing so. In Malawi, with a lack of addresses, it would be extremely difficult to find such guardians after they have left hospital. The findings and conclusions in this study cannot easily be applied to patients needing much longer treatment including outpatient treatment that is prolonged such as ALL. To remain motivated in such a situation is probably much more difficult.
Reference List


