"SOME PSYCHOSOCIAL ASPECTS OF CHILDHOOD CANCER AS SEEN AT KENYATTA NATIONAL HOSPITAL"

A DISSERTATION SUBMITTED IN PART FULFILMENT FOR THE DEGREE OF MASTER OF MEDICINE (PAEDIATRICS AND CHILD HEALTH) OF THE UNIVERSITY OF NAIROBI

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1987

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DEDICATION

To my late father

DECLARATION

I certify that this thesis is my own original work and has not been presented for a Degree in any other University.

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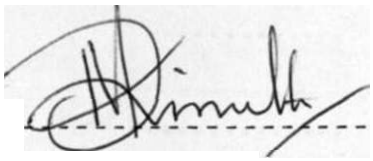
This Dissertation has been submitted for the examination with our approval as University Supervisors.

Signed: 

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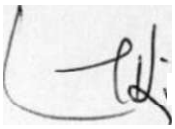
Signed: 

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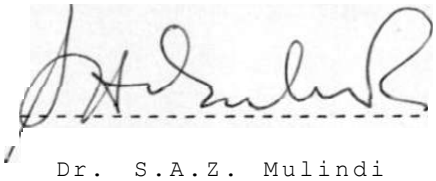
Signed: 

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TABLE OF CONTENTS

LIST OF TABLES PAGE NO.

LIST OF TABLES (Cont'd)

LIST OF FIGURES

SUMMARY

The knowledge, attitude and practice of relatives of 50 children with cancer, the effects of the child's disease on the affected family from the point of view of parent's marital status, the parent-patient relationship and behavioural disturbances in out-patients are presented.

A total of 67 adults were interviewed including 30 mothers, 28 fathers, 4 uncles, 4 aunts and one brother. Twenty eight (41.8%) of them had good know-ledge of the child's disease, 20 (29.85%) of them despite explanation from a doctor did not understand the disease well and 19 (28.35%) had no knowledge of the child's disease and had also not benefited from a doctor's explanation. Good knowledge of the disease was related to better level of education and socio-economic status. Duration of treatment, however, had no influence on knowledge of the disease by relatives.

Most relatives thought the disease was like any other God's wish, however, a small number thought their families were cursed or undergoing temptations (trials). Relative's knowledge on disease, and duration of treatment of affected children had no bearing on their beliefs and thoughts but their level of education had.

The majority of the parents had overprotective attitude towards their sick children and most of the affected children being followed up as out-patients had behavioural disturbances.

INTRODUCTION

The terms cancer, neoplasia and malignancy are usually used interchangeably to apply to all malignant neoplasms of characteristically grave prognosis (1,2). Cancer is a worldwide scourge that respects no boundaries, class or creed. It accounts for 4.3 million deaths annually in the whole world (3). Cancer in childhood is a relatively rare phenomenon and it was only a little more than a century ago that it became generally accepted that children could suffer from malignant disease (4).

Historically, the diagnosis of cancer in children meant an almost uniformly fatal outcome. The family had to cope with the acceptance of poor prognosis and prepare for rapid deterioration and death of the child. With the complex up-to-date management today, most children with cancer enter remission (disease-free stage) and a significant proportion is expected to be cured (3,4,5,6,7,8,9). The intense intrapsychic and interpersonal problems, the effects of available treatment, and the chronicity of the process are all complex and difficult. The patient, their family members and the health workers change as they go through this disease's process (10).

The improved prognosis due to management of cancer in paediatrics means that the families are faced with new issues in their tasks to provide help for the child and function for a prolonged period with an uncertain prospect for cure. Management usually last for several months or years and has side effects. The patient and family have to adjust to the psycho-social problems that arise from a chronic illness, a tiring and demanding treatment schedule; varied

levels of disability like lost limb in osteogenic sarcoma, and lost eye in retinoblastoma, a threat of relapse and death. There is however, a possibility of cure when patients are in remission whereby the children can have a quality of life approaching that of normal children.

Three decades ago, childhood cancer was considered rare in Tropical Africa. This was largely due to lack of statistics possibly as a result of under-diagnosis or early deaths (3). As medical services improve and death from infectious, nutritional and metabolic disorders decrease in incidence malignant disorders hitherto masked assume relatively greater significance in the practice of the Paediatrician (11). Bwibo (12), in an article reviewing activities in the field of Paediatrics and Child Helath in East Africa in the decade 1970 to 1979 and prospects for the next decade, noted that chronic disorders like asthma, rheumatic heart disease, neurological disorders and neoplasms were increasingly being seen in many clinics and hospitals. This means a new look at measures to deal and cope with these problems are necessary. In the developed countries, cancer ranks among the top causes of death. In Scandinavia, cancer ranks second only to accidents today as a cause of death in children between the ages of one to fourteen years (4). In the USA, 1978 mortality figures show that between one and four years, malignant diseases rank third after accidents and congenital anomalies but second only to accidents in the age group five to fourteen years (13).

During the period 1975 to 1981, a total of 435 cases of childhood malignancies were seen and managed at Kenyatta National Hospital, a referral hospital to a significant scale in Kenya. The quality and duration of survival of children with cancer has shown some improvement over the years but the overall survival results are still poor in comparison to those currently achieved in Europe and America. Inadequate physical support to combat complications, lack of psychosocial care, negative health care workers' attitudes and shortage of key cytotoxic agents are the main reasons given for the unsatisfactory results (5). As a result of treatment of childhood cancer today, 40-50% of children suffering from acute leukaemia in Europe and America survive over 10 years meaning they are probably cured. A look at Kenyatta National Hospital indicates that where no child previously survived over six months after diagnosis, there is now 20% survival at 5 years and over. Similarly, two years survival in childhood cancer of the kidney in America has improved from mere 30% in the early fifties to 80% today. Corresponding local figures are 10% in the early seventies and 50% now (3).

The patients' psychosocial reactions especially as the disease state worsens need to be understood and respected. Some appropriate action need to be considered so as to provide hope, the will to act and develop interpersonal and community attitudes to possibly accepting this as just one of the many diseases with varied outcome. The above observation in the improved survival rate is a further driving force to encourage redoubling of efforts in the field of paediatric oncology.

The complexity of care requires that other well trained individuals besides the physician have a part to play in the care offered the patient's family. A major determinant of early detection and management of cancer within an early curable stage is the attitude of patient and of the family, the physician and the public. Negative attitudes on the part of the patients and in paediatrics, parents or guardians can lead to denial and delay in seeking medical attention (14,15).

One of the most painful and difficult responsibilities that a physician encounters in the practice of medicine is to inform parents that their child has a potentially fatal illness. The initial encounter with a member of the family of a child recently diagnosed as having a malignant disease establishes the basis for ongoing supportive care. How the initial discussion is conducted will significantly influence further therapy of the child and his family (16,17).

As new services for treatment of neoplasms and other illnesses develop, it would seem particularly important to ascertain the personal and social effects of treatment. Whatever the reasons for admission of cancer patients, mental health services are essential to minimise trauma and maximise the ability of the family to develop and to maintain productive coping patterns (18). Health education of the public will play a major role in early detection of cancer. Failure of follow up is also a major-stumbling block in our set up because awareness by the patient, patients' parents or guardians of the importance of clinic attendance for maintenance therapy is one of the key factors to successful

cancer management. Good health education and improved socio-economic standards will all contribute to improved results and prognosis (9).

Treatment for childhood malignancy means repeated, prolonged hospital admissions with aggressive regimens of chemotherapy, radiotherapy and sometimes surgery. Serious side-effects and treatment complications are common. These considerable burdens put on the patients and their families make it obvious that the improved survival statistics in childhood malignancies must be complemented with knowledge not only of medical complications but also of the socio-economic consequences of malignancy and its treatment and psychological adoption.

Most work done on childhood cancers in East and West Africa concentrate on specific therapy and follow up of patients (5,7, 8,9,19,20,21). Little work seem to have been done in psycholosocial aspects of those engaged in childhood cancer as parents, relatives and health care workers. It is with this view in mind that the author was motivated to find out some psychosocial factors of childhood cancer especially to gain knowledge on how much is understood about the disease and their everyday effect on families concerned.

Background Information

Kenyatta National Hospital (KNH) serves as the national referral hospital for all health institutions in Kenya, and is the teaching hospital for the medical school, University of Nairobi and all paramedical courses. It therefore serves the entire Kenyan population of about twenty million. The study covered paediatrics patients with confirmed diagnosis of cancer.

Paediatric patients from Nairobi are usually refered to KNH from city council dispensaries, private hospitals and private practitioners within Nairobi. At the hospital, they are first seen at the Paediatric Filter Clinic or Casualty department. From these two points they are referred to appropriate units after initial examination. The units include Paediatric Surgical, Paediatric Emergency Ward (PEW), ENT wards, Paediatric In-Patient wards and Paediatric oncology ward. Patients found not to require immediate admission or those discharged are referred to Out-patient clinics for investigations or follow up and admissions or re-admissions as their condition dictate. Patients referred from outside Nairobi are also seen at the two points and referred to the appropriate units.

Paediatric patients referred with or suspected to have any malignancy are promptly admitted and appropriate investigations started. Paediatric cancer management at KNH takes the form of teamwork work among specialists involving oncologists, paediatricians, radiologists, paediatric surgeons, pathologists, radiotherapists, physiotherapists, social workers and nurses. Psychiatrists are not yet fully involved. Initial investigations are usually started

in Paediatric Emergency ward or other in-patients wards and necessary consultations made. KNH is the only centre in Kenya managing Paediatric malignancies currently.

Childhood malignancies seen at KNH fall into three main categoires; Leukaemias (mainly Acute Lymphoblastic and Acute myeloblastic), Lymphomas (Hodgkin's and Non-Hodgkin's) and solid tumours (Nephroblastoma, Neuroblastoma, Rhabdomyosarcoma, Kaposi's sarcoma and others).

Initial management of Acute Leukamemia consist of initial patient work up, improvement of nutritional status, treatment of any intercurrent infection and any other necessary supportive care. Once the diagnosis is confirmed from Full Blood Counts, peripheral blood film, Bone marrow aspirate examination and sometimes cytochemical studies, aggressive chemotherapy is started. Acute leukaemia therapy is divided into four major phases:

(i) Remission Induction with the goal of eradicating measurable disease.

(ii) Consolidation or Cytoreduction is the administration of high dose chemotherapy to patients in remission to eradicate clinically undetectable leukaemia (Intensification is a similar approach generally used after remissions of one or -mor-e— years).

(iii) Central Nervous System prophylaxis with intrathecal methotrexate or cytosine arabinoside and cranial irradiation.

(iv) Remission maintenance with the objective of preventing reccurrence and this therefore includes close follow up and continual drug therapy after discharge.

The details of the standard protocol used at KNH is shown in appendix I.

Malignant lymphomas are managed broadly as Hodgkins or Non-Hodgkin[1]s lymphomas. At KNH, this involves clinical assessment and diagnostic procedures for staging the disease, supportive treatment, chemotherapy, monitoring progress of treatment and follow-up as outpatients. The details of these are shown in Appendix II (Hodgkin's lymphoma) and Appendix III (Non-Hodgkin*s Lymphoma).

Childhood solid tumours (including nephroblastoma, neuroblastoma, Kaposi's sarcoma, embryonic sarcoma, rhabdomyosarcoma and others) are also managed using standard protocols at KNH. Childhood brain tumours are sometimes managed with adjuvant chemotherapy to surgery and radiotherapy. The details of these are shown in appendices IVa, IVb, IVc, IVd, IVe and IVf.

The above therapy protocols were initially adopted from those used in the United States or Europe. They have however, been modified, re-designed, revised and adapted through trial and error to suit the local situation (5).

AIMS AND OBJECTIVES

AIM: To study some psychosocial aspects of childhood cancer as seen at Kenyatta National Hospital.

OBJECTIVES:

1. To study the Knowledge, Attitude and Practice of parents and relatives of children with cancer.

2. To study the effects of disease on the family of a child with cancer with respect to:

    (a) Parent's marital status

    (b) Parent-patient relationship

    (c) Emotional status of patients in remission.

MATERIALS AND METHODS

Place and Period of Study

The study was carried out at the Kenyatta National Hospital (KNH) Teaching and Referral Hospital, Nairobi, Kenya. The areas of study included Paediatric In-Patient Wards, Paediatric Oncology Ward, Paediatric Surgical Ward, Paediatric Haematology/Oncology outpatient clinics, ENT and Eye wards. The study period was from October 1986 to January 1987.

Inclusion Criteria

Patients with confirmed diagnosis of a childhood malignancy such as acute leukaemia, lymphoma, nephroblastoma, neuroblastoma, rhabdomyosarcome etc. having been treated as in-patients and now being followed up in Out-patient clinics and those as in-patients on treatment for more than one month were included in the study. At the out-patient clinic every third patient being seen with a confirmed diagnosis of paediatric malignancy was selected and the accompanying parent or other relative interviewed. In the wards where patients with different diagnosis were present, the oncology patients were randomly picked from different cubicles of the wards. In the paediatric oncology ward where all the patients have a paediatric canceryevery fourth bed was selected and visiting parents or relatives interviewed.

Collection of Data

A Questionnaire (Appendix V) was filled by taking history from the parents or other relatives of children with cancer. The history was supplemented with the patient's notes. A second questionnaire (Appendix VI) was filled by interviewing patients' parents and other relatives. The details of these questionnaires are in the respective appendices.

Data Analysis

Data was analysed using the above described questionnaires.

Analysis of the knowledge of parents and other relatives on their child's disease was done by dividing them into three categories, A,B, and C. Category A were those parents and relatives with good knowledge of their child's disease, had had some explanation from a doctor and were satisfied with the information. Category B were those parents and relatives with some idea of the child's disease, had had some explanation from a doctor and still required more information. Category C were those parents and relatives with no knowledge of their child's disease and had not benefited from a doctor's explanation.

Soci-economic status of the families the patients in the study came from were determined by the use of the Republic of Kenya Economic Survey of 1986 by the Central Bureau of Statistics, Ministry of Planning and national Development (Appendix VII).

R E S U L T S

A total of 50 children with confirmed diagnosis of various paediatric malignancies were included in the study.

The average age of patients in the study was 6.5 years. There were 32(64%) males and 18(36%) females. The age and sex distribution of the patients is shown in Table 1 below.

Table 1: Age and Sex Distribution of Children in the Study

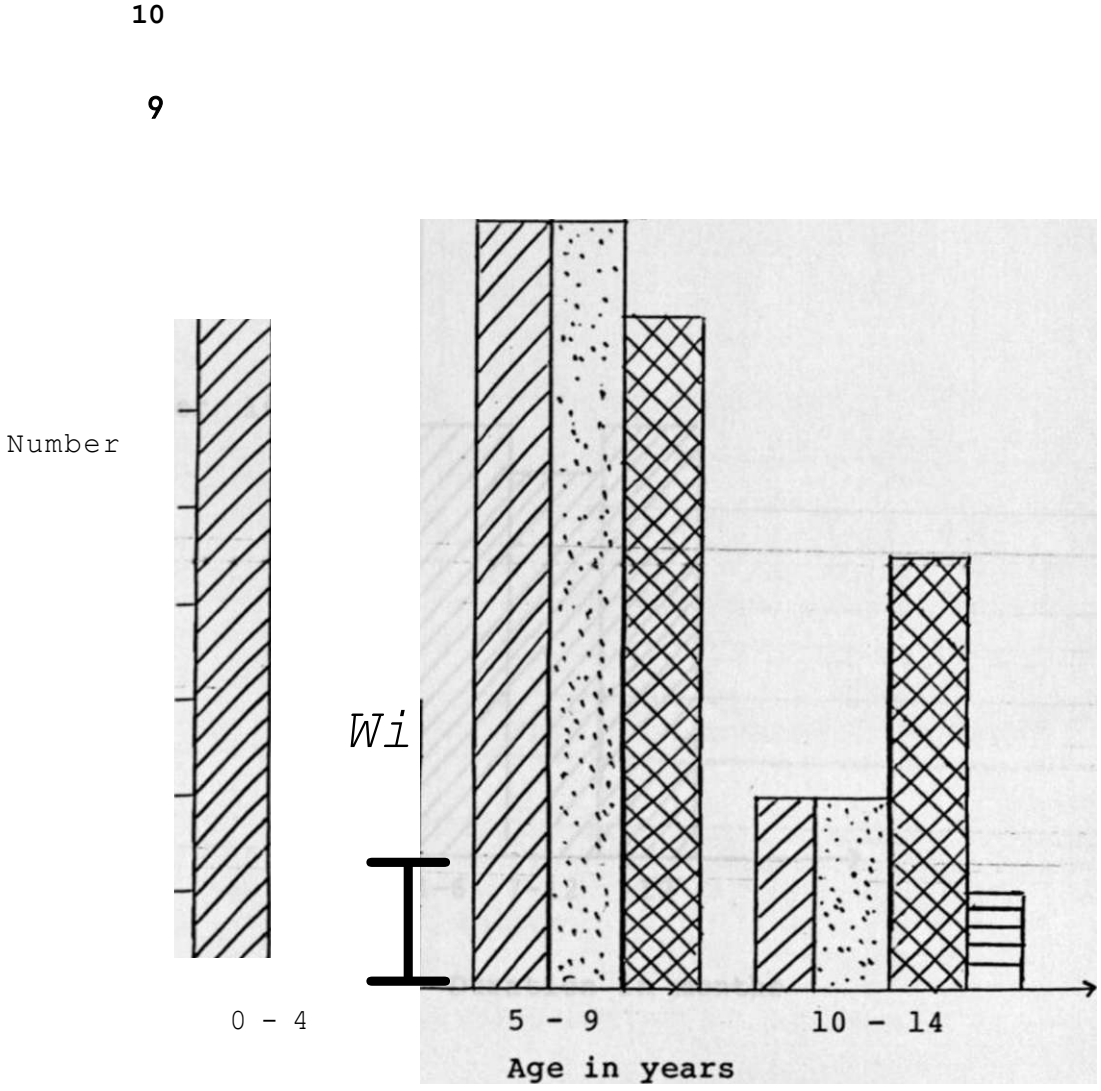
Age Group in years	Sex		Total	Percentage
	Males	Females		
0 - 4	10	8	18	36
5 - 9	17	6	23	46
10 - 14	5	4	9	18
Total	32	18	50	100

The peak age group in the study was 5-9 years.

Malignancies

Acute leukaemia accounted for 17 (34%), solid tumours (nephroblastoma, osteogenic sarcoma, neuroblastoma, rhabdomyosarcoma and retinoblastoma) 18 (36%) lymphomas 14(28%) and chronic leukaemia 1 (2%). The distribution of these various malignancies is shown in figure 1 below:

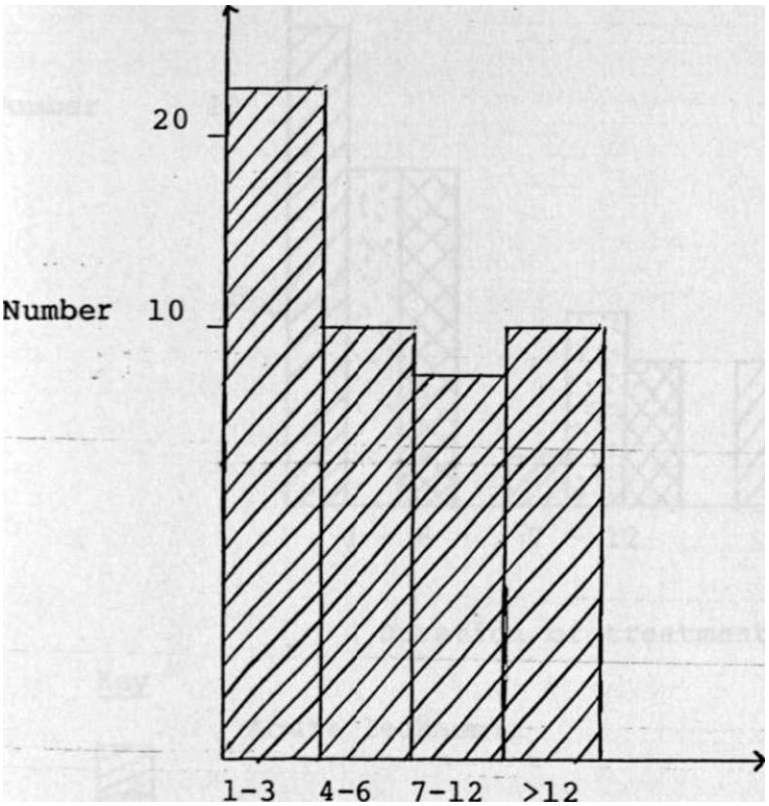
Figure 1 : Age and various childhood cancers in the study



Duration of Treatment

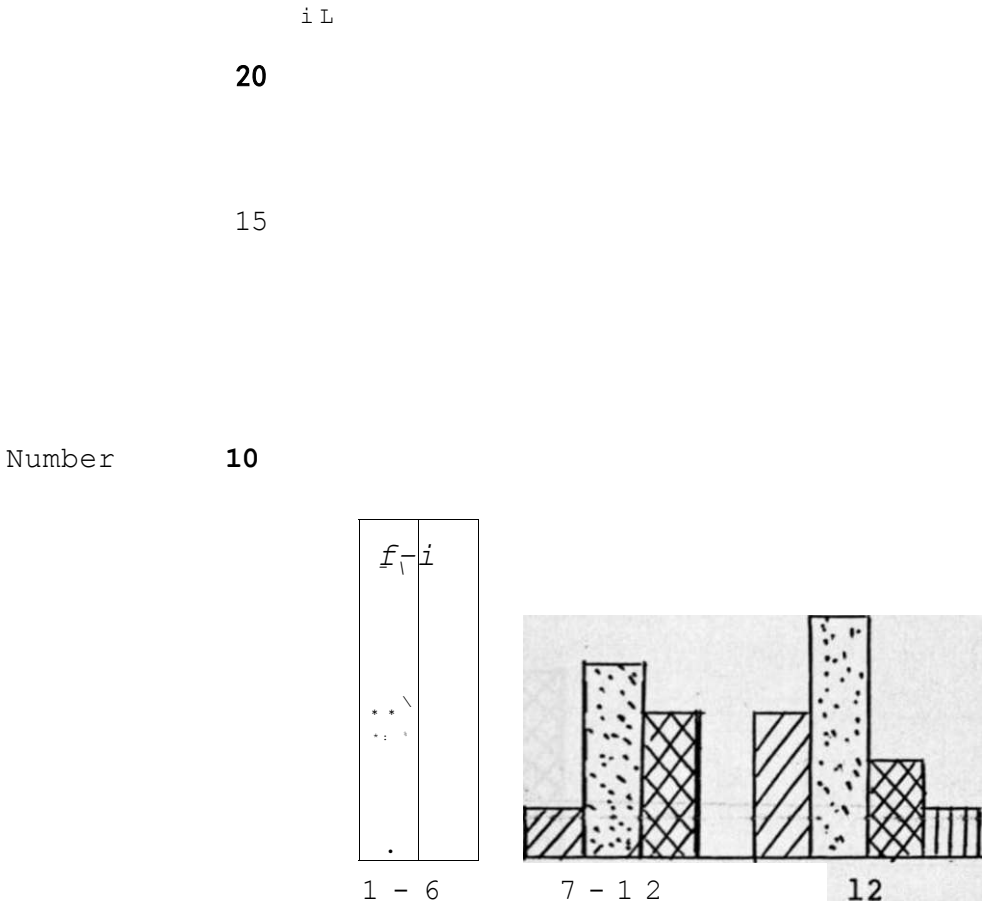
The patients were in various stages of treatment when their parents and relatives were interviewed. Nineteen (38%) were seen as out-patients in the outpatient follow up clinics. These were patients who had entered remission and after discharge were in continued remission. Thirty-one (62%) were in-patients in various wards mainly in the initial stages of treatment. The duration of treatment after diagnosis is shown in figure 2 below:

Figure 2: Distribution of patients in the study by duration of treatment



The various diagnosis (acute leukaemia, solid tumours, lymphoma and chronic leukaemia) and duration of treatment at time of interview is shown in figure 3 below:

Figure 3: Diagnosis and duration of treatment of the 50 patients studies

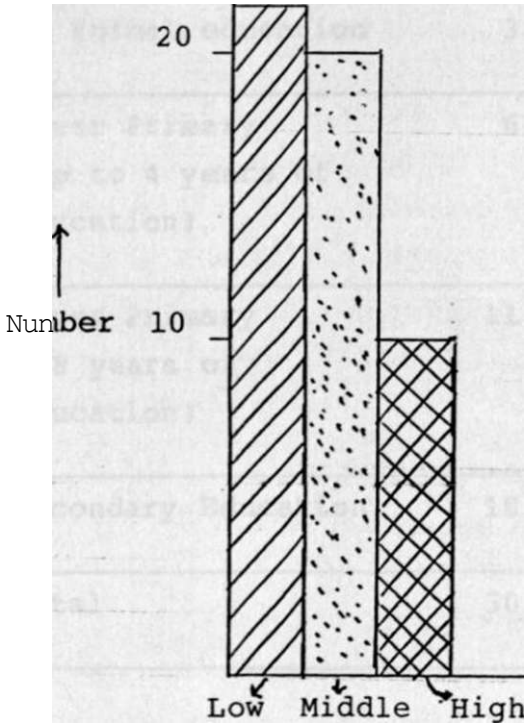


Most patients (31(62%) were in the first six months of treatment when their parents and relatives were interviewed.

Socio-economic status

Most children in the study came from low or middle socio-economic backgrounds. Twenty one (42%) of the families studied were of low socio-economic status, 20 (40%) were of middle socio-economic status and 9 (18%) were of high socio-economic status. The socio-economic status of the families studied is shown in figure 4 below.

Figure 4 : Socio-economic status of the fifty families studied



Parents and other relatives

A total of 30 mothers, 28 fathers, 4 aunts, 4 auncles and one brother were interviewed. The level of education of the parents is shown in table 2 below.

Table 2 : Level of education of the 58 parents interviewed

Level of Education	Number of parents		Total
	Mothers	Fathers	
No formal education	3	2	5(8.6%)
Lower Primary (up to 4 years of education)	6	1	7(12.0%)
Upper Primary 5-8 years of education)	11	12	23(39.7%)
Secondary Education	10	13	23(39.7%)
Total	30	28	58(100%)

All the four uncles, three aunts, and the one brother in the study had secondary education. The fourth aunt had upper primary education.

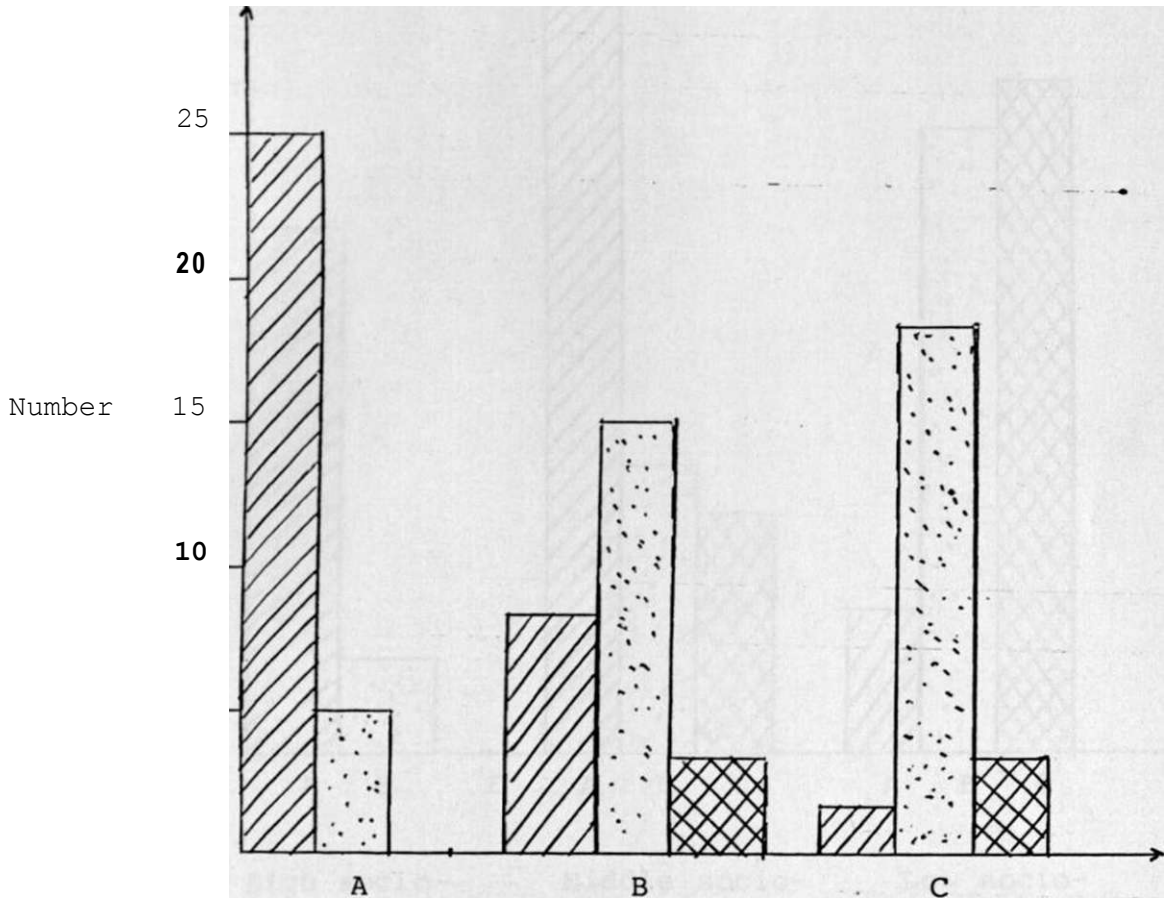
Table 3: Education and Socio-economic status of the 58 parents interviewed in the study.

Socio-Economic status	Education			Total
	Nil	Primary	Secondary	
High	-	-	13	13
Middle	1	11	10	22
Low	4	19	-	23
Total	5	30	23	58

There was a significant difference between the level of education and socio-economic status ($x^2(4)= 33.47$, $p<0.01$). All the parents from high socio-economic backgrounds had secondary education while none of the parents from low socio-economic background had secondary education.

Knowledge

Figure 5: Relative's knowledge on disease and their level of education



Secondary Education

/'A Primary education

No education

Better understanding of the disease was related to higher level of education.

Figure 6: The knowledge of the disease and socio-economic background of the 50 families studies

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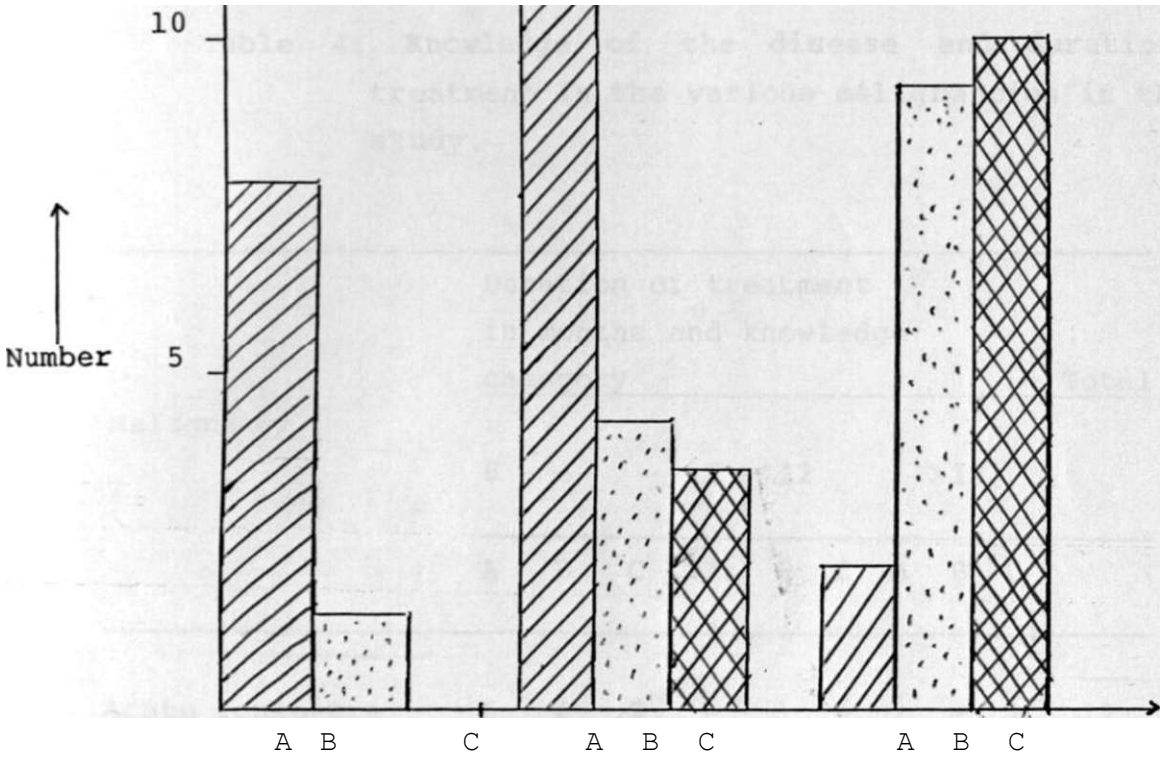


High socio economic homes | Middle socio-economic homes | Low socio-economic homes

Knowledge categories A,B,C and Socio-Economic status. ^

In 8(88.9%) of the 9 high socio-economic homes the disease was well understood and, some idea of the disease was present in the remaining one (11.1%)."

In middle socio-economic homes, 11(55%) of the 20 homes knew the disease well, 5(25%) had some idea of the disease and 4(20%) had no knowledge of the disease.

In the 21 low socio-economic homes, it was only in 2(9.5%) that the disease was well understood, 9(42.9%) had some idea of the disease and 10(47.6%) had no knowledge of the disease.

Table 4: Knowledge of the disease and duration of treatment in the various malignancies in the study.

Malignancy	Duration of treatment in months and knowledge category									Total
	0 - 6			7 - 12			>12			
	A	B	C	A	B	C	A	B	C	
Acute leukaemia	6	4	3	-	1	-	2	-	1	17
Solid tumours	5	3	1	2	3		1	2	1	18
Lymphoma	2	2	5	1		2	2			12
Chronic leukaemia									1	1
Total	13	9	9	3	4	2	5	2	3	50

Duration of treatment had no influence on the knowledge the relatives had on the disease. No statistical difference was found between various malignancies and within various malignancies with respect to duration of treatment, ($p > 0.1$);

Thoughts and beliefs on child's disease

The thoughts and beliefs about the chronic nature the disease was assuming were varied from the parents and other relatives interviewed as shown in table 5 below.

Table 5: Thoughts and beliefs of parents and other relatives on child's disease

Thought and Feelings about the disease	Number of Relatives: Mothers	Fathers	Other Relatives	Total %
Like any other disease, god's	15	20	8	43(64%)
Don't know	8	5	1	14(20.9%)
Family cursed/ Bewitched	3	2	-	5(7.5%)
Temptations Trials	4	1	-	5(7.5%)
Total	30	28	9	67(100%)

Most relatives 43(64.1%) thought the disease was like any other, god's wish, 5(7.5%) thought they were cursed or bewitched and another 5(7.5%) thought the families were undergoing temptations (trials).

Table 6: Number of patients' relatives with various beliefs and thoughts and their level of education

Beliefs and Thoughts on disease	Education			
	Nil	Primary	Secondary	Total
Like any other, God's wish	3	12	28	43
Don't Know	1	12	1	14
Family Cursed/ Bewitched	-	3	2	5
Temptations (Trials)	-	1	4	5
Total	4	28	35	67

The level of education of parents and other relatives seemed to influence their thoughts and beliefs on the disease ($x2_{(6)}=15.90$; $p < 0.025$ Significant at 5% level)

Table 7 : Number of parents and relatives with different beliefs and thoughts and their knowledge on disease

Beliefs and Thoughts on disease	Knowledge of Parents and relatives			Total
	A	B	C	
Like any other, God's wish	23	16	4	43
Don't know			14	14
Family Cursed/ Bewitched	2	2	1	5
Temptations (Trials)	5			5
Total	30	18	19	67

Comparison was made between beliefs and thought of disease and knowledge. There was no significant statistical difference.

($X^2(2) = 0.66$ p > 0.5).

Table 8: Number of parents and other relatives with various thoughts and beliefs and duration of treatment of patients.

Thoughts and Beliefs on disease	Duration of treatment in months			Total
	0 - 6	7 - 12	>12	
Like any other, God's wish	24	12	7	43
Don't know	8	3	3	14
Family Cursed/ Bewitched	2		3	5
Temptations (Trials)	4	1		5
Total	38	16	13	67

Duration of treatment of the child's disease had no influence on thoughts and beliefs on the disease by parents and other relatives. There was no significant statistical difference. ($x^2(g) = 5.89$ $p > 0.25$)-

Immediate medical attention was sought by parents once the patient's symptoms were noticed. None of the parents admitted to having consulted a traditional doctor (healer).

All the parents and guardians interviewed were satisfied with the care given to their patients while in hospital.

Most of the 50 families studied had large number of siblings. The average number of siblings per family was five. Fourty-four (88%) of the children studied came from monogamous marriages. Three (6%) were from polygamous marriages and one (2%) was from a single mother. One child had lost a mother and another a father. The marital status of the fifty families studied is shown in table 9 below.

Table 9: Marital status of the fifty families in the study.

Marital Status	Number of Families	Percentage
Monogamous	44	88
Polygamous	3	6
Widow/Widower	2	4
Single parent	1	2
Total	50	**100**

Marital Status

Marital status was assessed in the 47 families since the child became sick. In 3(6%) the marital status could not be assessed since in one, a mother was deceased, in another a father and in the third the mother was a single parent.

Twenty-four (51%) of the families reported no change in marital status. In 19 (40.5%) of the families the marriage bond was reported to have strengthened as most attention was being given to the sick child. In 4 (8.5%) of the families, frequent quarrels and misunderstandings were reported.

In the 3 polygamous marriages the father gave more attention to the household of the affected child and incidentally all three patients were from the first wives.

Table 10 : Marital status since onset of child's disease in 47 families:

Marital status	Number	Percentage
No change	24	51.0
Stronger	19	40.5
Frequent Quarrels	4	8.5
Total	47	-100.0

Parent-Patient Relationship

The parent-patient relationship was found from interviews with parents. This was possible in 48 of the 50 patients in the study since in 2 patients, only other relatives were interviewed and therefore parents' relationship to the sick child was not assessed. The various parent-patient relationships are shown in table 11 below.

Table 11: Parent-Patient Relationship

Relationship	Number of Parents			
	Mothers	Fathers	Total	(%)
Overprotecting attitude Impatience, Low self-control	18	18	36	(62.1%)
Lost interest in the child	7	3	10	(17.2%)
Good co-operation high self control	3	3	6	(10.35%)
Bad co-operation Impatient attitude low self control	2	4	6	(10.35%)
Total	30	28	58	(100%)

Table 12 : Parent-patient relationship and parents' education

	Education			
Relationship to Sick Child	Nil	Primary	Secondary	Total
Overprotecting attitude	2	15	19	36
Lost interest in child	1	8	1	10
Good co-operation	1	3	2	6
Bad co-operation		3	3	6
Total	4	29	25	58

The parents level of education had no bearing on the type of relationship with the sick child ($x2^{gj} = 6.6$ $p > 0.25$).

Table 13 : Parent-patient relationship and parents' knowledge on disease

	Knowledge			
Parent-sick child Relationship	A	B	C	Total
Overprotecting attitude	17	7	12	36
Lost interest in child	1	6	3	10
Good co-operation	2	3	1	6
Bad co-operation	2	3	1	6
Total	22	19	17	58

The paremt's knowledge on the child's disease had no influence on the relationship with the sick child. $lx^2(6) = 9.08$ $p > 0.1$).

Table 14 : Parent-patient relationship and socio-economic background of 48 families.

Relationship	Socio--Economic Status			Total
	Low	Middle	High	
Overprotective attitude	12	9	9	30
Lost interest in child	5	2	-	7
Good co-operation	2	3	1	6
Bad co-operation	1	4		5
Total	20	18	10	48

The different socio-economic backgrounds had no bearing on the various parent-patient relationships. j = p > **o . 1)**

Emotional Status of Patients in Remission

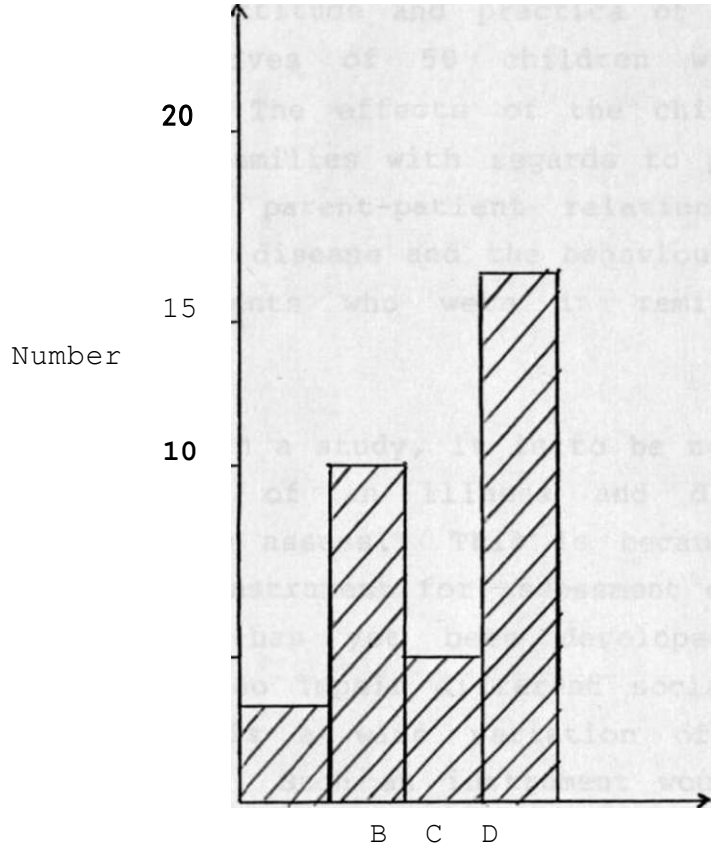
The effects of the disease and treatment on the behavioural patterns of the affected children in remission and staying with their families was assessed in 19 patients being followed up as out patients. Four of the patients had acute leukaemia, 10 had solid tumours, 4 had lymphoma and one had chronic leukaemia. Four of the patients were in the first 6 months of treatment, 7 were in the next six months and 8 had had treatment for more than a year.

In 15 (78.9%) patients at least one behavioural disturbance was reported by parents as being more frequent than prior to disease onset. It was only in 4 (21.1%) patients that no behavioural problem was reported.

Three (75%) of the patients who had no behavioural problems had their disease well understood by parents and in one (25%), some idea of the disease was known to the parents. In 5 (33.3%) of the patients with behavioural problems, the parents had good knowledge of the disease. In another 5 (33.3%) some idea of the disease was known to parents and in 5 (33.3%) the parents had no knowledge of the disease their child had.

The frequency of the various behavioural disturbances of the 19 patients is shown in figure 7 overleaf.

Figure 7 : Behavioural disturbances in 19 patients in disease remission



*Key_*

A Anxiety
B Depression
C Aggression
D Psychosomatic Disturbances

Most of the patients had psychosomatic disturbances followed by depression.

DISCUSSION

No local study is available on psychosocial aspects of cancer in childhood. In this study, the knowledge, attitude and practice of 67 patients and other relatives of 50 children with cancer are presented. The effects of the child's disease on respective families with regards to parent's marital status, the parent-patient relationship since the onset of the disease and the behavioural disturbances in out-patients who were in remission are also presented.

In doing such a study, it is to be noted that social consequences of an illness and disabilities are difficult to assess. This is because no generally applicable instrument for assessment of social impact of illness has yet been developed. Particular illnesses also impair different social relationships and there is a wide variation of normal social interaction. Such an instrument would therefore be difficult to standardise (22).

The 50 children with various childhood cancers in this study were of average age 6.5 years and their peak age group was 5-9 years. There was a male preponderance in the study with 32 (64%) males and 18 (36%) females. The peak age group and sex differences are different from other studies done locally since this was a descriptive study and the patients were selected randomly and hence the incidence was not being sought. In a study on solid tumours by Kasili et al (9), the peak age group was 2-4 years and equal sex incidence was reported. In a

study of 582 children with cancer covering a five year period in Enugu Nigeria, the peak age group was between 7 and 11 years. The male to female ratio was 1.5:1 with preponderance of boys during the first two years of life but more girls during the 9th to 14th year (19). This particular study covered all paediatric malignancies seen. In the study presented, several paediatric malignancies were also included. These were acute leukaemias, solid tumours (nephroblastoma, neuroblastoma, osteogenic sarcoma, rhabdomyosarcoma, retinoblastoma), lymphomas (Hodgkin's and Non-Hodgkin's) and chronic luekaemia. The picture of psychosocial factors evaluated is thus representative of childhood cancers as a whole.

The patients were in various stages of treatment when their parents and relatives were interviewed. Most patients, 31 (62%) were in the first 6 months of treatment, 8 (16%) were in the next six months and 11 (22%) had had varied lengths of treatment for more than one year. As was evident from the study, however, the duration of treatment had no bearing on knowledge of child's disease by the parents and other relatives or attitudes on the disease. Initial explanation about the disease may therefore be very useful.

Most children in the study came from low or middle socio- economic backgrounds. Only 9 (18%) came from high socio- economic families. This is further compounded by the fact that most families were large with an average number of siblings per family in the study of five. This factor would probably further downgrade the poor socio-economic outlook and with the added financial burden of caring for the child with cancer more psychosocial stress to the affected family is a real possibility.

Twenty eight (41.8%) of the 67 parents and other relatives studied had good knowledge of their child's disease. They knew the nature, course, complications of treatment and prognosis of the respective diseases. Most of them had had an explanation from a doctor and understood, and they also had good level of education. In some relatives, however, prior knowledge of the disease was present. Two relatives had had friends whose children had died of leukaemia and one parent's former teacher had lost a child with leukaemia. When these relatives then realised what the disease their child had, they needed little explanation to understand what to expect of their child's disease.

Twenty (29.85%) of the relatives had some idea of their child's disease, but did not understand the disease and would have still liked more explanation from a doctor. This was despite earlier explanation by a doctor .

In 19 (28.35%) of those interviewed, the knowledge of the child's disease was found lacking. The main reason for this was that no doctor had given any explanation on the disease and during hospital visiting hours no doctor was available and the nurses were not offering any explanation. The parents of some patients being followed up as out-patients after initial admission still did not know what disease their child was having. With the opening of the paediatric oncology ward, however, most parents and other relatives, it is hoped will know their patient is having cancer and will only perhaps seek details of the particular malignancy. It can be said that doctors reviewing especially out-patients assumed the parents understood and knew what disease their child

had. It would appear that parents' silence or inability to ask do not necessarily mean understanding but could be a question for the doctor to explain the disease of the child. This would also allay the anxiety probably present in the parents.

Since a significant number, 19 (28.35%) of adults interviewed lacked knowledge about their child's disease, health education would therefore be very important for successful total management of a paediatric patient with cancer. In the study presented, fine knowledge on the disease depended on better level of education. High socio-economic status was also related to better understanding of the disease. This was perhaps due to better education correlating with higher socio-economic status and hence better comprehension of the disease.

"Adult patients and parents of sick children are becoming increasingly aware of the rights of a patient. With this awareness, patients will no longer accept to suffer penalties of bad science. Ligitation is therefore likely to become more common. Regardless of the legal implications, it is vital that the increasing gravity of the cancer problem in paediatric practice is appreciated at all levels of medical practice in tropical Africa" (11).

The diagnosis of a malignant disease in a child is an emergency - not necessarily only a medical emergency but also an emotional one (23). In many centres in the developed world, oncology teams consisting of a health visitor, a haematologist, hospital chaplain, nurses, paediatrician, psychiatrist, social worker, paediatric surgeon, pharmacist all work together towards optimal care of a child with cancer (4,23).

This team work is only emerging in our setting and it is hoped that it will grow from strength to strength. This multi-disciplinary approach must be emphasized as it is the key to optimal management of childhood cancer.

Forty three (64.1%) parents and relatives interviewed thought the disease was like any other, god's wish. Forty (93%) of them had some education and 39 (90.7%) had at least some knowledge of the disease. The duration of treatment and knowledge of the disease had no influence on these thoughts and beliefs but the level of education had.

All the 5(7.5%) parents who thought the family was undergoing temptations had good knowledge of the disease, good education but were christians with strong convictions ('saved'). Five (7.5%) other parents thought the disease was due to a curse to the family. All were christians and one came from a polygamous family. The thoughts and beliefs were thus varied and the only variable which affected this was level of education. The duration of treatment however had no influence on the beliefs and thoughts of the relatives. Health education to the public would therefore be useful in instillin gthe right attitudes towards the various childhood cancers.

Forty seven families were assessed for marital status. In 24 (51%) no change was reported in marital status. In 19 (40.5%) the marriage bond grew stronger and in 4 (8.5%) there were frequent quarrels. The information obtained was not necessarily correct as parents would perhaps say how everything was going on well while they were not.

More probing questions and several interviews would be necessary as these parents were interviewed only once.

The parent-patient relationship was found from the interviews with parents. This was possible in 48 (96%) of the 50 patients studied since only other relatives were interviewed in two. Thirty six (62.1%) of the 58 parents interviewed had overprotective attitude towards their children. This represented 30 (62 .5%) of the 48 patients in the study whose relationships with the parents were assessed. Twenty four (66.7%) of the 36 parents with overprotective attitude knew something about the child's disease and most of them had been to school. It is important that proper counselling is done to parents with respect to the nature of the disease so that normal co-operation with the sick child is achieved. This large number of parents with overprotective attitude could be due to the fact that most patients in the study were in the first six months of treatment and parents had not gotten rid of any guilt feelings that they may have had. In a study in Scandinavia, parents were found to experience a particular attachment and protectiveness towards the patient. Parents recognised their protectiveness towards the child and attempted to master it when the health of the children improved (4).

Six (10.35&) parents had good co-operation with their affected children. One (16.7%) was illiterate, 3 (50%) had primary education and 2 (33.3%) had secondary level education. Most of them had some knowledge of the disease and all came from middle or low socio-economic status. Another 6 (10.35%)

parents had bad co-operation with their sick children even regarding them as a bother, 3 (50%) of them had primary and another 3 (50%) had secondary education. Most of them had some knowledge of the disease and all families were either of low or middle socio-economic status. The parent's education, knowledge of the child's disease, and socio-economic backgrounds all had no bearing on the parent-patient relationship. The duration of treatment also appeared to have no influence, on the relationship of the parent and the patient.

In a study by Magni et al (24) in Padua, Italy, psychosocial distress in 41 parents of children with acute lymphocytic leukaemia or Hodgkin's disease was evaluated using the Symptom Distress Checklist (SCL-90) (25). At the first evaluation the experimental group had higher mean scores than the controls for obsession, depression, anxiety and sleep disturbances. The 8 month and 20 month follow-ups confirmed the presence of high scores of psychosocial distress particularly in the sleep disturbances and depression subscales. The study shows that most parents of children with cancer suffer some form of psychological distress. This might explain the various parent-patient relationships found in the study presented.

Emotional status of children in disease remission staying with their families was evaluated. In 15 (78.9%) of 19 patients being followed up as out-patients, at least one behavioural disturbance was reported as being more freguent than prior to disease onset. It was only in 4(21.1%) of these patients that no behavioural problem was reported.

The parents' knowledge on the child's disease was better in those with no problems compared to the patients with problems. Behavioural disturbances such as anxiety, depression and sleeping difficulties have been reported in children with cancer during the first two years of the disease (4).

There is overwhelming evidence that even small children understand the seriousness of their disease and can tolerate knowledge about it. It is also known that failure to discuss the disease contributes to behavioural problems (26). Although this was not carried out in this study it is important and therefore should be done in future similar studies. Since the attitude of health care workers is also known to influence care of patients with cancer, this should be assessed in subsequent studies as it was not done here.

From the foregoing, it is important to have a well stream-lined therapeutic approach to paediatric cancer patients. Once the child is discharged back to the family, he or she has to adjust to the re-joining of the previous environment including school if of school age. A rehabilitation protocol is therefore necessary. The society and the school have all to be given enough knowledge to be able to cope with the problem (27). Levels of intervention by health workers and hence multidisciplinary approach to paediatric cancer patient can't therefore be overemphasised.

Various groups of workers have developed protocols for difficult situations. In one at Massachusets hospital, honesty about prognosis at all times, periodic meetings with the family members and entire staff and specific discussions in rounds about the status of family members and what can be done to help them were emphasised (28).

Interventions recommended included:-

(i) decrease in uncertainty as much as possible by disseminating all available information among physicians, staff and the family.

(ii) Every effort to be made to decrease conflict between groups - nurses, physicians, different specialists, family.

(iii) Specifically emphasising increasing tolerance of uncertainties especially since the patients' condition can change.

The above protocol can be modified like the treatment protocols have been to suit the local situation.

CONCLUSIONS

1. More than fifty percent of parents of children with cancer either know nothing about their child's illness or have only a vague idea.

2. A large number of parents of children with cancer, did not understand the disease of their children despite explanation from doctors.

3. Childhood cancer has a great effect on the family of affected children in terms of financial burden, weakening of marriage bonds and behavioural disturbances inthe affected child.

4. Health care workers looking after paediatric cancer patients tend to concentrate on the medical care of the patients and give little if any psychosocial support to the family of the affected child.

RECOMMENDATIONS

1. The patient's family members should be well informed about his disease, with regards to progress, prognosis at all stages of treatment and counselling done where appropriate. Information should be in simple terms, and understandable by the subjects concerned. The public should also be informed about cancer.

2. Psychosocial aspects of cancer should be incorporated into the current treatment protocols for childhood cancer.

3. Multidisciplinary approach to the management of childhood cancer must be more emphasised and a psychiatrist should be involved in the management of childhood cancer from the time of diagnosis.

4. A follow up study to involve the medical personnel and the patients themselves is desirable.

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REFERENCES

1. Mendelsohn, J.: Principles of Neoplasia in Harrison's Principles of Internal Medicine. 11th Ed. McGraw-Hill Inc. pp. 421, 1987.

2. Oken, D.: What to tell cancer patients. A study of Medical Attitudes. J.A.M.A. 175, 86-94, 1961.

3. Kasili, E.G.: Children's Cancer Ward at Kenyatta National Hospital. Medicus 5 No. 8, 3-5, 1986.

4. Marky, Ildiko: Children with Malignant Disorders And Their Families. A study of the Implications of the Disease and Its Treatment on Everyday life. Acta. Paediatr. Scand. Suppl. No. 302; 3-81, 1982.

5. Kasili, E.G., Kyambi, J.M., Onyango, J.N.: A seven year (1975-1981) experience in the treatment of childhood malignancies in Kenya - Proceedings to the Kenya Paediatrics Association Scientific Seminar, Nairobi. lOth-llth March 1983.

6. Schuler, D.: Psychosocial problems in Families of A child With Cancer. Med. Ped. One. 13:173-179, 1985.

7. Kasili, E.G.: management of Leukamemia in a Developing Country (Kenya). E.Afr. Med. J. 55: 417-419, 1978.

8. Padmini Urs, R.A.: Acute Leukaemia in Children observed in Muhimbili Hospital, Dar-es-Salaam, E. Afr. Med. J. 53:33-35, 1978-

9. Kasili, E.G., Onyango, J.N., Awori, N.W. Bwibo, N.O., Oduori, M.L.:$_f$ The management of some childhood solid tumours in Kenya: Preliminary results. E. Afr. Med. J. 55:550-557, 1978.

10. Abrahams, R.C.: Not Alone With Cancer. Charles C. Thomas, Springfield, Illnois, 1974.

11. Kasili, E.G.: Paediatric malignancy in Tropical Africa - A growing concern. (Editorial). E. Afr. med. J. 63:685-686, 1986.

12. Bwibo, N.O.: The practice of Paediatrics and Child Health in East Africa (1970-1979) and Prospects for the Next Decade. E. Afr. Med. J. 57:515-552, 1980.

13. Nelson Textbook of Paediatrics. 12th Edition. W.B. Saunders Company, pp. 5: 1983.

14. Lebovits, A.H. Croen, L.G. Goetzel, R.Z.: Attitudes Towards Cancer. Development of the Cancer Attitude Questionnaire. Cancer 54:1124-1129, 1984.

15. De Wys, W.: Changing Attitudes Towards Cancer. (Editorial). J. Chron. Dis. 29:545-548, 1976.

16. Greenberg, L.W.: Giving information for a life threatening Diagnosis: Parents' and Oncologists' perceptions. Am.J. Dis. Child. 138:649-653, 1984.

17. Ablin, A.R.: A conference with the family of a Leukaemic Child. Am. J. Dis. Child. 122:362, 1971.

18. Friedman, S., Chodoft, P., Mason, J. and Hamburg, D.: Behavioural Observations on parents anticipating the death of a child. Paediatrics 32:610, 1963.

19. Agugua, N.E.N, and Okeahialam, T.: Malignant Diseases of childhood seen at the University of Nigeria Teaching Hospital (UNTH), Enugu, Nigeria. E. Afr. med. J. 63:717-723, 1986.

20. Kasili, E.G.: Leukaemia And Lymphoma in Kenya. Leuk. Res.: 9:747-752, 1985.

21. Olweny, C.L.M.: Lymphomas And Leukaemias in Tropical Africa. Clin. Haemat. 10:873, 1981.

22. McCarthy, M.: Social Aspects of Treatment in Childhood Leukaemia. Soc. Sci. med. 9:263-269, 1975.

23. Barbor, P.: Emotional aspects of malignant disease in children. Family medicine, pp. 320-327, August 1983.

24. Magni, G.M., Carli, D., De Leo, D., Tshilolo, M., and Zanesco, L.: Longitudinal Evaluations of Psychological Distress in Parents of children with malignancies. Acta. Paediatr. Scand. 75:283-288, 1986.

25. Deragatis, C.R., Rickel, K., Rock, A.F.: The SCL-90 and the MMPI. A step in the validation of a self-report scale. Br. J. Psychiatry 126:280-287, 1976.

26. Vernick, J., Karon, M.: Who's afraid of death on a leukaemic ward? Am. J. Dis. Child 77:571-578, 1965.

27. Henning, J.R.N., Fritz, G.K.: School Re-entry in childhood cancer: Psychosomatics 24:261-269, 1983.

28. Cassem, N.H.: In Massachusetts General Hospital Handbook of General Hospital Psychiatry. Edited by Hackelt and Cassem N.H. pp. 570-571. The C.V. Mosby Co. Saint Louis, 1978.

APPENDIX I

PROTOCOL FOR MANAGEMENT OF ACUTE LEUKAEMIA AT KNH

DIAGNOSIS

1. Clinical Evaluation

(a) Age: duration of illness

(b) Clinical features of anaemia, fever, haemorrhagic tendency, infection and organomegaly.

(c) Other clinical features: Bone pain, gum hypertrophy, arthritis, chloromas, jaundice and respiratory distress.

Laboratory Evaluation

(a) Peripheral Blood Examination

i. Haemogram (coulter indices)

ii. Blood film morphology
May Grunwald Giemsa
Cytochemistry (Sudan Black, P.A.S., Acid phosphatase, Feulgem, serum muramidase estimation).

iii. Platelet count.

Blood to be taken for leukaemic cell marker studies and HTLV I antibodies.

(b) Bone marrow Examination

i. Both smears and squashes prepared

ii. Cytological and cytochemical procedures as in 2, (a) (ii) noting the degree of blast cell count infiltration.

iii. Bone marrow trephine where indicated.

(Histological Sections stained with H/E).

(c) Radiological Examination

i. Chest X-ray (PA and lateral)

ii. Skeletal survey when indicated (Phalangeal joints and lower end of tibia and fibula).

(d) Biochemical evaluation of Renal and Liver Function.

i. Liver function tests (including Immuno-electrophoresis if indicated).

ii. Serum electrolytes, urea, calcium and uric acid determinations.

(e) Bacteriological investigations.

Blood culture, pus culture, throat swab culture, stool or sputum culture are done whenever there is indication.

(f) Lumbar puncture - CSF for cytology to evaluate meningeal involvement.

MANAGEMENT

1. Supportive Therapy

(a) Anaemia:- Aim at maintaining haemoglobin concentration above 8.0 g/dl by packed cell transfusions.

(b) Haemorrhage:- Platelet concentrates given when platelet count fall below 20,000/ul and there is evidence of active bleeding.

(c) Infections:- Any patient with persistent fever for over 24 hours to be started on I.V. gentamicin with large doses of penicillin pending culture and sensitivity results of any relevant bacteriological specimen. The antibiotic of choice is accordingly instituted as soon as the results are available. All localised infections are treated similarly. (Note that there are no facilities for isolation).

(d) Hyperuricaemia:- Allopurinol (50-100mg TDS) for 3 weeks.

(e) Rehydration with 5% dextrose in normal saline during the first 24 hours of cytotoxic therapy.

SPECIAL THERAPY

Note: I. The currently accepted standard practice of INDUCTION CYTOREDUCTION AND MAINTENANCE PHASES is followed.

II. In view of the preliminary obsevations, (in particular for the acute leukaemias) that African patients tend to have advanced disease at present-ation with poorer prognosis and that they tolerate cytotoxic drugs very well, the dosages have been scaled upwards.

III. Due to poor and irregular suppy of drugs, protocols are often changed or modified.

ACUTE LYMPOCYTIC LEUKAEMIAS (Including FAB L1-L3) (AL KNH/4 1985)

Induction

Vincristine - 2mg/m^2, I.V. Weekly x 4.
prednisone - 40mg/m2, p.o. in 3 doses daily, tailing off in week 6.

Bone marrow done at the end of week 4 to assess the remission status, and if not in remission a further dose of V.C.R. is given or start on the cytoreduction phase.

ONE WEEK'S REST THEN,

Cytoreduction

Two courses: To start one week after the last injection of vincristine; OMIT Adriamycin during the second course.

Adriamycin 30mg/m^2, I.V. (day 1-3)
Cyclophosphamide - 1200mg/m^2, I.V. given in saline infusion on day 1.
Cytosine arabinoside - 100mg/m^2, I.V. O.D. as I.V. push on day 1-5. (Or Methotrexate 20mg/m^2, OD day 1-5).

iii. MAINTENANCE: (to start after one week's rest and continue for 24 months)

6 - Mercaptopurine - 75mg/m^2, P.O. daily
Methotrexate; - 15mg/m^2, P.O. weekly
Vincristine - lmg., I.V. monthly
Prednisone - 40mg/m^2, P.O., in 3 doses daily x 7 days monthly.
Adriamycin - 40mg/m^2, I.V. every 3 months.
Cyclophosphamide - 400mg/m^2, I.V., every 3 months.

B. ACUTE NON-LYMPHOCYTIC LEUKAEMIA (ANLL) AL KNH/4-DAT

(comprising FAB Ml to M6 and including Accelerated CGL and juvenile CGL).

i. Induction Cytoreduction

- Daunorubicin - 40mg/m^2, I.V., day 1-3
  Cytosine Arabinoside - 100mg/m^2, I.V., twice daily day 1-6
  Thioguanine - 80mg/m^2 (or 6-Mercaptopurine - 100mg/m^2), P.O., day 1-6.
- Cyclophosphamide - 1200mg/m^2, I.V. in saline infusion, day 6 only.

* The pulse is repeated after a rest period determined by the recovery of haematological parameters until complete remission is achieved.

ii. Maintenance (For 24 Months)

- Cytosine Arabinoside - 100mg/m^2 i.v. (max. lOOmg) monthly.
  6 - mercaptopurine 100mg/m^2 (or 6-Thioguanine 80mg/m^2 P.O. daily.

MANAGEMENT OF MENINGEAL LEUKAEMIA

(a) Treatment if there is involvement at the time of diagnosis.

Intrathecal methotrexate - lOmg.m^2 (max 12mg) daily for 5 doses.

Rest for 2 days.

Intrathecal cytosine arabinoside 100mg/m^2 (Maximum 150 mg) daily for 5 days

Repeat lumbar puyncture to assess the response.

(b) CNS prophylaxis, if no involvement at the time of diagnosis and when there is complete haematological remission at the beginning of maintenance therapy.

Intrathecal methotrexate 10mg/m^2 five doses in three weeks. (or cytosine arabinoside 100mg/m^2)

Cranial radiation, 2500 rads in three weeks after IT drugs.

The technique of intrathecal administration of cytotoxic drugs.

1. Prepare sterile trolley as for lumbar puncture.
2. Wash up and wear the gloves.
3. Dilute I.T methotrexate or cytosine arabinoside as follows: Draw the required quantity of the drug and make up to 10ml in normal saline in a 20ml syringe and place on the trolley.
4. Draw the requisite amount of the local anaesthetic into 5ml syringe and place on the trolley.
5. The aid should then position the patient, properly as for lumbar puncture.
6. Clean and then drape the site of operation.
7. Infiltrate the site with the local.
8. Do a lumbar puncture in the usual way and let off 7-10ml of CSF in to two specimen bottles, one for cytology and the other for biochemistry.
9. Slowly, and cautiously but firmly attach the drug containing syringe on to the lumbar puncture needle.
10. Aspirate the CSF in to the syringe to ascertain that the needle is still in position (subarachnoid space), then slowly push the drug into the intrathecal space.
11. On finishing, quickly withdraw the needle to avoid tracking back by the drug.

12. It is advisable for the patients to remain in bed over the next 6-8 hours as they may have some headaches.

APPENDIX Illb

STANDARD PROTOCOL FOR THE MANAGEMENT OF HODGKIN'SDISEASE

Historical Note

Thomas Hodkin 1832 - Gross description.
Wilks 1865 - More cases and start of eponym Greenfield 1878, more cases and pointed to fibrosis and Reticulum Cells.

Goldman 1892 - Histological features and described the occurrence of eosinophils.

Reed & Sternberg 1901 & 1898 - Description of R-S cells.

Histological Criterion

Reed - Sternberg cells must be present in the correct setting of the cellular environment for the diagnosis to be made. Note the Rye classification of L.P., M.C., N.S., and L.D. (Lymphocyte predominance, mixed cellularity, Nodular Sclerosis and Lymphocyte depleted).

Clinical Staging

Ann - Arbor (1971)
I^A, II^A, III^A, IVA - Without systemic symptoms.
IB, IlB, HlB^ivB - with systemic symptoms
+E - Extra nodal -
+S - With splenic involvement.

Staging Procedures

1. Clinical examination. (40% accurate).
2. Radiological examination. (Chest X-Ray, I.V.P., skeletal survey, G.I.T. series, Lymphangiography).
3. Bone marrow (or Trephine).
4. Laparotomy (Biopsy and splenectomy).
5. Ultrasonic scans or radioisotope scintiscans.
6. F.B.C. (Note Halie Cells in W.B.C. concentrates).

Aetiology and Natural History

Neoplastic process of probable multifactorial aetiology. There is mixed immunological disturbance, but C.M.I. is affected more profoundly, particularly in the advanced forms of the disease. There is total lymphocytic depletion. The origin of the disease in the childhood form is thought to be unicentric, whereas multicentric in the form that occurs after 50 years of age. In the unicentric variety, the spread is predictable and progression is to contiguous lymphnodes. Prognosis; Fatal disease, if untreated the life expectancy from time to diagnosis depends on the extensiveness of the disease. Other prognostic features include age, sex, histological grading and skill of treatment, and previous treatment.

Years of Survival	5	10
Stage I	90%	80%
Stage II	70%	20%
Stage III	10%	0%

Rates of Remission:- L P & N S - More than 90%
M.C. - 70%
L.D. - 50%

Principles of Management

1. Curative or Palliative? (AFTER STAGING)
2. Supportive care.
3. Chemotherapy (MOPP, COAP, MOMP, etc.)
4. Radiotherapy.
5. Place of Surgery and Splenectomy.

RADIOTHERAPY: Extended nodal DXT for stages I - IlA.

CHEMOTHERAPY PROTOCOL

Induction for Stages I - IV

Induction - 6 Pulses with 4-6 weeks rest intervals between pulses.
Mustine - 6mg/m^2, I.V., Day 1 and 8 (or Cyclophosphamide 600mg/m2).
VCR - 1.5mg/m^2, I.V., Day 1 and 8.
FRED - 40mg/m^2, p.O. Daily in 3 or 4 divided doses x 14.
Procarbazine - 100mg/m^2, P.O., Daily x 14.

Note: No maintenance therapy for staging I - IlA.

Maintenance for Stages IlB - iyB

The same protocol of drugs.
1st year - 3 monthly pulses.
2nd year - 6 monthly pulses.

APPENDIX Ilia

PROTOCOL FOR THE MANAGEMENT OF NON-HODGKIN'S MALIGNANT LYMPHOMAS AT KNH (KNH/NHML/3/1981)

Diagnosis and Staging

i. Physical examination, noting the site of lymphadenopathy.

ii. Lymphnode biopsy or biopsy of the mass - histological classification.

iii. Radiological investigations.

- Chest X-ray (and tomography as indicated)
- Abdominal X-ray
- X-ray spine and long bones
- Lymphangiography
- I.V.P.

iv. Full blood count, ESR and platelet count; blood film report.

v. Bone marrow for evaluation of marrow involvement.

vi. Biochemical investigations.

- L.F.T.S., L.D.H.
- Renal function tests including uric acid determination
- Serum proteins and immunoglobulin electrophoresis.

vii. Lumbar Puncture for CSF cytology.

viii. Staging I - IV depending on the degree of dissemination.

2. Treatment

Supportive

i. Treat any intercurrent infections; using most appropriate antibiotic regimen.

ii. Transfuse with packed cells if anaemic (i.e. less than 6 g/dl).

iii. Platelet therapy when and if indicated.

iv. Allopurinol, according to indication by uric acid level.

Therapy

i. Stage 1 (Nodal and Extanodal). Radiotherapy and Chemotherapy. (CHOP)

a) Extended nodal radiation (3500 - 4000 r) followed by the following drug therapy.

b) Adriamycin 60mg/m^2 I.V. on days 1 and 22.

c) Cyclophosphamide 600 g/m^2 i.v. weekly x 6 courses.

d) Vincristine 1.5 mg/m^2 I.V. weekly x 6 courses.

e) Prednisone 60 mg/m2 $_P$.o. daily in 4 doses for 4 weeks - tailing off from the 4th week.

f) No maintenance treatment, but,only three monthly follow up.

Stages II - IV

a) Chemotherapy course as in (i) above followed by (b) and (c) below.

b) Cytoreduction

Cyclophosphamide - 1200 mg/m^2, I.v., given in saline infusion on day 1 and 8.
Cystosine Arabinoside - 100mg/m^2, I.V., twice daily as I.V. push on day 1 - 4 . (Or Metho-trexate 30mg/m^2, I.V. ond ay 1 - 4) Repeat on days 8-12.
- BCUNU - 60 mg/m^2, I.V. on day 5 only

OR

* High Dose methotrexate 300-600mg/m^2 followed by Folinic acid tabs 15mg QDS x 3/7 after 24 hours of Methotrexate.

c) Maintenance (To **start after one week's rest** following consolidation).

6 - Mercaptopurine - 75 mg/m^2, P.O., daily.
Methotrexate - 15 mg/m^2, P.O., weekly.
Vincristine - lmg. I.V., monthly.
Cyclophosphamide - 600 mg/m^2, I.V., every 3 months.
Adriamycin 50 mg/m^2, I.V., every 3 months.

d) Treatment of CNS Disease

i) Cranial radiation 2400r in 2 - 3 weeks,
ii) I.T. Methotrexate 12.0 mg/m2 for 5 doses in 3 weeks.

Record and Monitoring of Assessment Parameters

i) Physical parameters: lymphadenopathy, hepatomegaly, splenomegaly, systemic symptoms, assessed every two weeks.

ii) Twice weekly full blood counts and platelet counts as long as the patient is on the ward. Then full blood counts and platelet counts at every visit.

iii) Liver funciton tests every 4 weeks.

iv) Renal function tests (Blood urea and creatinine).

v) Diagnostic lumbar puncture at week 10 for meningeal involvement which would be treated accordingly.

vi) Radiological assessment as appropriately indicated from the initial findings.

vii) Re-biopsy of tumour if there is recurrence.

ALTERNATIVE TO CHOP (When I.V. cyclophosphamide is not available).

- Vincristine - 1.5mg/m^2 i.v. Day 1 and 8
  Adriamycin - 60mg/m^2 I.V. Day 1
  Cyclophosphamide 1200mg/m^2 P.O. divided into daily doses from day 1 through to day 14
  Two weeks rest after above treatment
- Six courses of therapy given
  Prednisone (given as before) 60 mg/m^2 P.O. Daily in 4 doses for 4 weeks tailing off from the 4th week

APPENDIX Illb

PROTOCOL FOR THE MANAGEMENT OF BURKITT'S LYMPHOMA
(KNH/BT/1/87)

1. Diagnosis and Staging

i. Physical examination, noting the site of tumour,
ii. Biopsy of the mass for histological diagnosis,
iii. Tumour imprints for cytology,
iv. Radiological investigations

- Chest X-ray (and tomography as indicated)
- Abdominal X-ray
- X-ray spine and long bones
- IVP
- Abdominal ultrasonography

v. Full blood count, ESR and platelet count; blood film report,
vi. Bone marrow evaluation of involvement,
vii. Biochemical investigations

Liver Function Test, Lactate Dehydrogenase
Renal Function Tests including uric acid determination
Serum protein and immunoglobulin electrophoresis

viii. Lumbar Puncture for CSF cytology
ix. Staging I - IV (A -D) depending on the degree of dissemination.

2. Treatment

a. Supportive

i. Treat any intercurrent infections; using most appropriate antibiotic,
ii. Transfuse with packed cells if anaemia (i.e. HB concentration less than 6 g/dl)
iii. Platelet therapy when and if indicated,
iv. Allopurinol, as indicated by uric acid levels or tumour load
v. Rehydration during the 24-48 hours of indication

b. Induction

- Cyclophosphamide 1500mg/m^2 I.V. infusion, (3 hours) on day 1 and 36.
- Vincristine 1.5 mg/m^2 IV ond ays 1,8,15,22.
  Prednisone 60mg/m2, daily in divided doses for four weeks, tail off during fifth and sixth weeks.
  Methotrexate 200mg/m^2 IV infusion for one hour (followed by Folinic Acid 15 mg QDS starting 24 hours after infusion for 72 hours) on days 15 and 22.

c. CNS prophylaxis

Intrathecal (IT) Methotrexate 12 mg/m^2, 5 doses to be administered between weeks 23 and 36.

d. Consolidation

Methotrexate 300 mg/m^2, IV infusion for one hour during weeks 11 and 12.

e. Maintenance (To start after one week after the second course of consolidation)

6-Mercaptopurine - 75 mg/m^2 P.O. daily
- Methotrexate - 15 mg/m^2, P.O. weekly
Vincristine - lmg I.V., monthly
Cyclophosphamide - 600 mg/m^2, I.V. every 3 months

f. Treatment of manifest CNS disease

i. Cranial Spinal Radiation
ii. I.T. Methotrexate 12.0 mg/m^2 daily for 5 doses repeat cycle after four days rest.

Record and Monitoring of Assessment Parameters

i. Physical parameter: Lymphadenopathy, hepatomegaly, splenomegaly, systemic symptoms.

ii. Once weekly full blood counts and platelet counts as long as the patient is on the ward. Then full blood counts and platelet counts as every clinic visit.

iii. Liver function test every 4 weeks

iv. Renal function Tests (Blood Urea and creatinine)

v. Diagnostic lumbar puncture for meningeal involvement as appropriately indicated.

- vi. Radiological assessment as appropriately indicated from the initial findings.

vii. Re-biopsy of tumour if there is recurrence.

APPENDIX Ilia

STANDARD MANAGEMENT OF SOLID TUMOURS AT KNH
(INCLUDING NEUROBLASTOMA, EMBRYONIC SARCOMA,
RHABDOMYOSARCOMA AND OTHERS)

A. Assessment

i. - Clinical-Extent of disease (staging)
ii. - Haematological - FBC and Bone Marrow,
iii. - Radiological-CXR and I.V.P. (Skeletal survey)
iv. - Biochemical LFT and Renal F.T. catecholamine (VMA) La Brosse test and calcium levels,
v. - Alphafetoprotein (AFP) levels.

B. Management

a) Localised - Surgery, Radiotherapy and Chemotherapy.
b) Disseminated - Chemotherapy plus surgery if feasible.

Triple Therapy for the Disseminated Tumours

1. Cytotoxic agents used: To be given as IV push, all on the same day.

a) Cyclophosphamide (CYCLO): 450 mg/m^2, I.V. weekly (max 450) on day 1.

b) Vincristine (VCR) - 2 mg/m^2 I.V. weekly (max 2mg) on day 1.

c) Adriamycin (ADRIA) -60 mg/m^2 I.V. Every three weeks on day 1 and 43.

d) Actinomycin - D - 0.5mg/m2 Every three weeks for day 1-3 starting on day 22 alternate with ADRIA.

e) Prednisone - 40 mg/m^2 P.O. daily x 4 weeks.

In disseminated neuroblastoma only. Tailed off.

Induction: Two cycles of six, one - weekly courses are given.

Maintenance;

•i) Monthly courses of cyclophosphamide and vincristine with three monthly courses of Adriamycin alternate with Actinomycin - D for six months.

ii) Three-monthly courses of all the three drugs for one year (VCR, CYCLO, ADRIA or ACD).

iii) Follow up and re-induce if there is recurrence.

Parameters to be monitored:

i) Full blood count - twice weekly during induction and at every visit during the maintenance period.

ii) Liver function test

iii) Blood urea and electrolytes

iv) Uric acid

v) E.C.G.

vi) Any useful parameter such as I.V.P., CXR, VMA or HVA and AFP to be done as indicated.

vii) Any clinical land mark to be followed up by measuring it.

APPENDIX Illb

STANDARD TREATMENT FOR NEPHROBLASTOMA AT KNH (KNH/STT/3 '81)

Assessment: i) Clinical - Extent of disease.
ii) Haematological - Haemogram and Bone marrow.
iii) Radiological - CXR and I.V.P.
iv) Biochemical LFT and Renal F.T. and Catecholamines (VMA).

Management:

a) Localised - Surgery, R Px to tumour bed and Chemotherapy (Stage I - III).

b) Disseminated - Chemotherapy plus surgery if feasible (Stage IV - V)

Triple Therapy for the Disseminated Tumours

1. Cytotoxic agents used

a) Cyclophosphamide: 450 mg/m^2 I.V. weekly (Max 450).
b) Vincristine : 2mg/m^2 I.V. weekly (Max 2mg).
c) Actinomycin-D : 0.5 mg/m^2 I.V. day 1-3 then repeat during the fourth week.
All the I.V. drugs are given as a bolus on the same day.

2. Induction:

A total of six weekly courses of VCR and cyclo is given. Depending on the response, which should be evident by the third course, additional courses may be given up to eight.

3. Maintenance:

i) Monthly courses of cyclophosphamide and vincristine with Actinomycin D alternate with Adriamycin ($60mg/m^2$), every three months for six months.

ii) Three-monthly courses of the three drugs for one year. Actinomycin - D to alternate with adriamycin.

iii) Follow up and re-induce if there is recurrence.

4. Parameters to be monitored

i) Full blood count - twice weeekly during induction and at every visit during the maintenance period.

ii) Liver function tests every three months.

iii) Blood urea and electrolytes every three months.

iv) uric acid.

v) E.C.G. every six months.

vi) Any useful parameter such as I.V.P., CXR, VMA or HVA to be done as indicated.

vii) Any clinical land mark to be followed up.

APPENDIX IIIb

CYTOTOXIC THERAPY FOR OSTEOGENIC SARCOMA
(POST-SURGICAL)

Induction (vac)

a. Adriamycin 60 mg/m^2 I.V. day 1 q 21-28 days x 3
b. Vincristine 2 mg/m^2 I.V. day 1 q 21-28 days x 3
c. Cyclophosphamide 600mg/m^2 I.V. day 1, q 21-28 days x 3.

Intensification

Methotrexate 200mg/m^2 I.V. day 1 three weeks after last cause of (VAC).
Folinic Acid 15mg ODS x 72 hours, 24 hours after Methotrexate. Give two courses with one week's rest in between.

Maintenance

I.V. Adriamycin 60 mg/m^2
I.V. Vincristine 2 mg/m^2
I.V. Cyclophosphamide 600 mg/m^2
I.V. Methotrexate 20 mg/m^2

Repeated every 3 months for 18 months.

APPENDIX IVd

CHEMOTHERAPY PROTOCOL FOR TESTICULAR TUMOURS IN CHILDREN AT KNH

Introduction

Rehydrate the patient with 1.5 - 2 litres of 5% dextrose in saline 24 hours prior to chemotherapy. Continue rehydration during Cis-platinum administration (1 - 1.5 litres daily) also giving Lasix 40mg to induce diuresis.

Drug Schedule

a. Cyclophosphamide 750 mg (max. lOOOmg) I.V. on day 1.

b. Actinomycin D 0.5mg (max. 1mg) I.V. on day 1.

c. Cis-platinum 20mg (max. 30mg) I.V. infusion lasting 4 hours on days 2 - 5

d. Give Stemetil, one tablet 2 hours prior to starting treatment then 1 TDS for one week.

APPENDIX IIIb

CHEMOTHERAPY SCHEDULE FOR
DISSEMINATED KAPOSI'S SARCOMA

1st Course (A)

Adriamycin - 60 mg/m^2 I.V. Day 1.
Vincristine - 1.5 mg/m^2 I.V. Day 1 and 8
Cyclophosphamide - 600 mg/m^2 I.V. Day and 8.

2nd Course after three weeks (B)

Actinomycin-D lmg/m^2 I.V. Day 1.
Vincristine 1.5mg/m^2 I.V. Day a and 8.
Cyclophosphamide 600mg/m^2 I.V. Day 1 and 8.

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Subsequent Courses

Alternate A and B up to a total of three courses each.

APPENDIX IVf

CHEMOTHERAPY FOR LOCALISED BRAIN TUMOURS

This is adjuvant to surgery and radiotherapy.
Patients undergo curative or palliative surgery as the tumour presents. As soon as possible after surgery, begin Radiotherapy - 3500 - 5500 rads in 3 to 6 weeks to the tumour, cranium and spinal column. On completion of radiotherapy, begin chemotherapy.

Methotrexate: lOmg/day intrathecally, daily doses for 5 consecutive days. 5-day courses are repeated q 4 weeks for 12 weeks.

Vincristine; 1.5mg/m^2 (maximum dose 2 mg) I.V. on day 1 q 14 days for 3 months. Then q 28 days for the next 12 months. Then q 3 months for 9 months.

PCB - 50mg/m^2 P.O. day **1** thought 5, repeat q **14** days for 6 months, then q 28 days for 9 months.

CCNU - 130mg/m^2 P.O. on day 1 q 6 weeks. Continue therapy **for** all **patients for 18** months if possible.

APPENDIX V

1. Date . . . . . 2. Name
3. I.P. No . . . . . 4. Age . . . . . 5. Sex
6. Tribe . . . . . 7. Place of Birth ....
8. Present Residence (Duration)
9. Birth order . . . . . 10. Birth Weight
11. Maternal Age at Birth of patients
12. Date of 1st admission
13. Presenting complaints and duration

- Non specific tiredness
- Cough
- Fever
- Bone pains
- Swelling (specify anatomical region)
- Bruises/purpara/bleeding
- Others.

14. Past medical History

15. Operations

16. Clinical Assessment at Presentation

17. How Diagnosis Reached

18. Stage of Disease At Diagnosis (Duration of Symptoms)

    Early
    Intermediate
    Advanced

19. Treatment and Side effects

20. Position of Patient presently

APPENDIX VI

Date 2. Patient's Name

Patient Hospital Number

Relationship to child (specify)

Age 6. Sex

Place of Birth 8. Tribe

Residence .... 10. Occupation

Total Income/Month

Level of Education

Religion

Duration of child's illness since diagnosis

How did you feel when this child got affected by this illness

What steps did you take when the child got sick?

(i) Gave medicines bought from the shop

(ii) Took to hospital

(iii) Took to a traditional healer

(iv) Others (specify)

(a) Do you know the disease your child is having (parents only) Yes/No

(b) If yes, who told you?

Doctor

Nurse

Relative

- Other

(c) Has a doctor ever explained to you what your child is suffering from? Yes/No

If yes, briefly explain from the doctor's explanation your understanding of the disease.

(d) is there anything else you would have liked to be told? Yes/No
If yes, explain briefly

17. (a)^(For In Patients) Has the hospital care of the patient been adequate as far as you are concerned? If No, what would you like to see done in addition?

(b) (For Out Patients) Was the hospital care of the patient adequate as far as you are concerned? Yes/No
If No, what would you have liked to be done in addition?

18. (a) (i) Do you drink alcohol? Yes/No
(ii) If Yes for how long?_
and what type?_ . .....
(iii) What was the quantity before onset of the child's illness
(iv) What is the quantity now_
(b) (i) Do you smoke? Yes/No
(ii) If yes, for how long?_
and what type?
(iii) What was the quantity before onset of child's illness?
(iv) What is the quantity now?_

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(c) Is there any change in your marital relationship since the child got sick. Yes/No.

(i) Frequent quarrels
(ii) Separation
(iii) Divorce
(iv) Others (specify)

(d) How is your occupational situation since the child got sick?

(i) Irregular, confilicts in work place
(ii) Lost interest in work
(iii) No change
(iv) Others (specify)

(e) How is your sleep pattern now?
(f) How is your appetite?
(g) What is your relationship to your child since she/he got sick?

(i) Same as before
(ii) More loving
(iii) Lost interest
(iv) Others (specify)

(h) What is your relationship with other healthy siblings?

(i) No change
(ii) Given attention since patient "since up"
(iii) Others (specify)

(a) What is the relationship between the patient and other siblings since he/she got sick?

(i) Good loving
(ii) Lack of understanding quarrel
(iii) Others (specify)

(b) Since the child got sick?

(i) Does he/she get difficulty in getting off to sleep? Yes/No
(ii) Does he/she wake up at night more often than before? Yes/No
(iii) Does he/she have frightenging dreams (nightmares)? Yes/No
(iv) Does he/she have reluctance for school? Yes/No

(c) (i) Is she/he easily upset and crying unnecessarily? Yes/No
(ii) Does he/she have poor concentration? Yes/No
(iii) Is he/she withdrawn ("Difficult to get to")? Yes/No

(d) (i) .Is he/she rude and shouting at times? Yes/No
(ii) Is he/she banging or breaking things? Yes/No
(ill) Does he/she have excessive fighting? Yes/No
(iv) Is he/she have temper tantrams? Yes/No

(e) Is he/she complaining of the following more often than before?

(i) Headaches Yes/No
(ii) Body pains Yes/No
(iii) Tiredness Yes/No
(iv) Loss of appetite. Yes/No

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APPENDIX VII

PERCENTAGE INCREASES IN NAIROBI CONSUMER PRICES
1982 - MARCH 1986

INCOME GROUP	1982/81	1983/82	1984/83	1985/84	MARCH 1985 to 1986
NAIROBI LOWER INCOME INDEX	20.6	14.4	• 10.3	13.0	3.4
NAIROBI MIDDLE INCOME INDEX	25.9	15.2	8.9	11.1	8.9
NAIROBI UPPER INCOME INDEX	20.3	16.9	8.0	8.0	6.0
AVERAGE INCREASE FOR 12 MONTHS	22.3	14.5	9.1	10.7	6.3

Republic of Kenya Economic Survey 1986. Central Bureau of Statistics. Ministry of Ministry of Planning and National Development, Nairobi May 1986.

FOR THE PURPOSE OF THE INDEX

1. The lower income group comprised households with monthly earnings below KSh. 699.

2. The middle income group comprises households with monthly earnings between KSh, 700 - KSh. 2,499.

3. The upper income group comprises households with monthly earnings of KSh. 2,500 and above.