PSYCHOLOGICAL ASPECTS OF PAEDIATRIC CANCER PATIENTS AT THE KENYATTA NATIONAL HOSPITAL

A DISSERTATION SUBMITTED IN PART FULFILMENT FOR THE DEGREE OF MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY OF THE UNIVERSITY OF NAIROBI

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DECLARATION

I Gerald Kirimi Ibari hereby declare that this dissertation is my original work carried out in part fulfilment of requirements for the degree of Master of Science in Clinical Psychology of the University of Nairobi and has not been presented for a degree in any other university.

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Lastly I thank my friends who gave support and encouragement in the time of need.

DEDICATION

To my wife Lisper Kirimi and daughter Brenda Kinya for their endurance as I worked on this study.

CONTENTS

LIST OF TABLES

Page

LIST OF FIGURES

Page

DEFINITION OF TERMS

Instrument	:	Standardized tests administered for clinical or research purpose
Normal Level	:	Non- Pathological total behaviour score indicating normal or non-deviant level of behaviour as defined by the scoring manual
Pathological Level	:	Level of total behaviour problem score deviant from the normal as a indicated by the scoring manual
Psychological Aspects	:	Psychiatric morbidity and other psychological characteristics.
Residence	:	Place of abode (home) of patient and family

ABBREVIATIONS

1. ALL	-	Acute Lymphoblastic leukaemia
2. ANLL	-	Acute Non-lymphoblastic leukaemia
3. CBCL	-	Child Behaviour Checklist.
4. CNS	-	Central Nervous System
5. CR	-	Clinical Range
6. CVS	-	Cardiovascular System
7. DMS IV		Diagnostic and Statistical Manual of Mental Disorders, 4th Edition
8. ENT	-	Ear, Nose and Throat
9. GAF	-	Global Assessment of Functioning
10. GIT	-	Gastro – Intestinal Tract
11. KNH	-	Kenyatta National Hospital
12. MS	-	Musculo- Skeletal
13. NHL	-	No-Hodgkin's lymphoma
14. NR	-	Normal Range
15. P.A	-	Psychological Aspects
16. PTSD	-	Post Traumatic Stress Disorder
17. RS	-	Respiratory System
18. SES	-	Social Economic Status
19. SDQ	-	Socio – Demographic Questionnaire

ABSTRACT

Objective: To establish the psychological status of paediatric cancer patients at Kenyatta National Hospital

Study design: A cross sectional descriptive study of children with cancer at Kenyatta National Hospital. The study duration was from 27th April 2005 to 26th April 2006.

Setting: Kenyatta National Hospital; Kenya's largest referral and teaching hospital.

Methodology: The parents of 63 study cases and who gave consent were interviewed using a prepared questionnaire. The inclusion criteria consisted of tissue confirmed diagnosis of patients, admitted in the oncology unit and paediatric wards of Kenyatta National Hospital having children with cancer. The exclusion criteria were patients with diagnosed primary mental disorder. Those cases younger and older than the 4-16 years age category were also excluded from the study. The variables documented included sex, age, place of residence, family characteristics, cancer and treatment (s) modalities. Screening for psychological aspects was done using the child behaviour Checklist and behaviour profile which were scored using manual developed for that purpose and subjected to DSM – IV TR. Data analysis was done using the non-parametric chi-square test procedure. The analysis of the overall data was done using SPSS and the findings reported in the form of tables, diagrams, charts, and percentages.

Results: According to age categories of the child behaviour checklist the study showed that 76% of cases were aged between 6 and 11 years while 18% were 4 and5 years old. Only 6% were in the 12-13 years age group. A mean age of 8 years was found. Of these 62% were males while 38% were females with male to female (M:F) ratio of 1:6:1. The

significant finding from the study was that the older children were more likely to have higher psychological morbidity, which was positively associated with low SES, unlike other socio-demographic factors. Lack of religious affiliation in the family and single parenthood were not found to be risk factors for developing child psychopathology. The current study found majority (98%) of the study cases as having come from families practising religion and parents staying together. Other than age and low SES, the other factors studied including family type level of formal education and alcohol use of parents and history of mental illness in the family did not show a statistically significant relation with psychological morbidity (PM). Chemotherapy causing alopecia and surgery leading to visible scars was found to increase morbidity (P=0.01). A high positive correlation (r=0.84) was found between the neoplasia and the severity of psychological morbidity. The prevalence was found to be 84% as identified with the use of child behaviour checklist and the behaviour profile. It was also found that 16% of the study cases did not show clinical psychological morbidity.

Conclusion: The study showed that there was PM of 84% of psychological disorders in children with cancer, with severity as being slight (10%), mild (30%) and moderate (40%).

The morbidity observed in the study cases was in the clinical level warranting therapeutic intervention. The morbidity was positively correlated with low SES of families of the study cases. Also older cases in the age group 6 – 11 years appeared to show increased morbidity as captured in the behaviour checklist.

Recommendation: The results of this study highly suggest that further study be carried out involving more centres, hospitals and cases so as to avail more information needed by psycho-oncology health staff to manage paediatric psychopathology in hospitals or clinics caring for children with cancer. Research is also necessary to identify exacerbating and ameliorating factors of the psychopathology in children suffering from cancer. Parents of such children with cancer should also be involved so as to equip them with skills enabling them and their children to cope with cancer.

CHAPTER ONE: INTRODUCTION

1.1 Background

The assessment of psychological profile of paediatric cancer patients can avail information that can be used to help such children discuss their illness with caretakers. This could lead to lessening the abnormal behavioural and emotional problems, enhance self-esteem, bring closer to their families of sick children and perhaps also lead to better adaptation to the rigors of disease (1).

An emotional or behavioural sign or symptom manifested by a child in paediatric setting has all along stimulated interest towards thorough evaluation for psychopathology and other related factors.

Also chronically ill children suspected to be having distress, worries and fears should be evaluated for such paediatric psychopathology (2).

Furthermore it is also noted that the associations of cancer such as hair loss, weight gain or loss and physical disfigurement, and repeated absences from school and peers interact to impact negatively on psychological status and may lead to generation of psychopathology (3).

Therefore incidence and prevalence of paediatric oncology psychopathology currently in Kenya is a challenge that this study addresses.

In the Western World studies that have been done in the area of child psychiatry centred around the pattern of childhood cancer psychiatric morbidity at paediatric clinics in hospitals (4), primary health care facility and among young persons (5).

These studies have identified psychological disorders such as depression, conduct disorders, anxiety and others, but no such study which focused on children with cancer with regards to psycho-oncology had been done in this country.

1.2 Statement of the Problem

Living with cancer leads to serious psychological distress in children as the young patients have to confront the effects of disease and treatment procedures. Attending the issue also opens new frontiers such as pain, more dependence on others, disability, disfiguring changes in the body and loss of function. All these may jeopardize the child's relationship with others, in the family, and the limitations the disease imposes on environmental exploration (5).

Although the specific psychopathologies among children related to cancer depend on the characteristics of the disease presentation, the age of the child and premorbid functioning, it can be expected that the child will manifest various aspects of psychopathology (6). Shock, fear, anger and mourning of the loss of the once normal, healthy body and possible death can compound the child in his / her everyday relation to others and environment (7).

Although the clinical manifestation of the stress and neoplasia also changes as the child changes physically over time, the emotional and behavioural symptomatology is presented (8,9,10). Therefore a thorough evaluation in the paediatric oncology cases for psychopathology was done to establish the psychological morbidity in the patients in the Paediatric Oncology Unit (KNH) in this study.

Research regarding the effects of cancer and cancer treatment and how that affect the child's ability to carry on a normal life has become increasingly important especially in the area of physical, psychological and social effects, all of which impact on a child's experience in the environment (11).

Thus it was interesting to study the psychological disorders and related factors in these cancer patients. This study contributes to decision making concerning children with cancer in Kenyatta National Hospital and the Kenya Ministry of health in general. Equally important it will provide new insights into the psychological research in this category of clinical population towards gaining additional knowledge and improvement of diagnostic and therapeutic services in the management of the patients.

CHAPTER TWO: LITERATURE REVIEW

The literature focusing mostly on the psychological disorders and related factors in paediatric patients arising out of neoplasia is accumulating and giving insight into this hitherto ignored aspect of patient management, A paediatric patient with cancer may undergo a range of psychological disorders which may not be overt from the clinical history taking to start with (11).

Most of the studies (12 - 13) observe that as a consequence of the cancer disease per se, hospitalization and discomfort, the patient may suffer emotional problem during the major phase of the illness. In a study of 629 cancer patients in Pennsylvania cancer Registry (15) it was found that 59% of the paediatric patients had at least one psychological disorder. In another study (16) 25% of the patients were reported to have emotional disorders. Also in a study (17) of patients with advanced cancer disease and receiving chemotherapy at Memorial Sloan Kettering Cancer Centre, 62% of patients were reported to be suffering loneliness as parental contact was minimized by hospitalization and distress due to restricted play and socialization.

A number of studies (18) have shown that changes in physical appearance have psychological implications for youths and children who have undergone cancer treatment which include poor body image, psychological impairment, low self -esteem and symptoms of depression.

In another study (19) these aspects were found to be true in children with cancer, where 30 children aged 8-13 year with varying types of cancer showed that a more positive perception of one's physical appearance was significantly correlated with fewer depressive symptoms, less social anxiety and a higher self esteem.

Further support for these results comes from results in a study of 21 cancer patients aged 12-21 years (20) which shows that the more the subject perceived that his or her appearance was affected by cancer, the worse he or she tended to rate adjustments which included feeling of loneliness and social anxiety.

Psychological aspects related to physical appearance are significant issues that a child with cancer may experience. This was evident in a study (21) which found a variety of psychological disorders which include anxiety and panic, both chronic and acute (21) in children affected by cancer. Inhibited and withdrawn behaviour, fear of trying new things and low emotional expressiveness are other pathologies (22). Another study (23) reports behaviour problems and others (24), identified an excessive number of unfounded somatic symptoms in these paediatric patients.

Other reported disorders include intense stress (22), posttraumatic stress disorder (26) frustration and discouragement related to school difficulties (27) and peer relationship difficulties (28). Some illnesses directly cause lethargy and social withdrawal, whereas other problems such as depression may be by-products of an illness or reaction to the constraints of medical treatments or physical handicaps (28). Other psychological problems reported from studies are loss of independence and worries (29).

In addition, another study has concluded (30) that the chronic strain of childhood cancer such as treatment, pain, nausea and vomiting; visible side - effects such as alopecia, weight gain or loss and physical disfigurement, interact to negatively impact on the social and psychological adjustment.

Furthermore, having a brain tumour in certain vulnerable parts of the brain and receving some chemotherapeutic agents may cause neurological impairments which may be difficult to differentiate from the psychopathology. One study (31) reports specific neuropsychological difficulties in paediatric patients who have received these treatments as including problems in higher conceptual abilities, memory functioning, visual motor functioning, visuo graphic abilities and fine motor skills. Other studies (32) report these difficulties in their review of literature as well as various signs of attention- deficit hyperactivity disorder such as distractibility, impulsivity and concentration problems.

Other investigations (33) also report that children with brain tumours, acute lymphoblastic leukaemia and solid tumours who have received chemotherapy show fatigue, decreased energy, motor weakness, hearing impairment and irritability. Thought behavioural and emotional disorders occur frequently in the general population of children in varying degrees, it appears that childhood cancer psychopathology rates are similar in developed and developing, countries (34). The level of psychological morbidity in children with cancer varies with age, with higher rates in older children (35) higher rates of such morbidity are also noted in males compared to females (36).

Another study has shown that there is significant relationship between SES and psychopathology of childhood cancer (37). This study shows that : psychopathology is higher in lower SES groups (37).

In other studies rates of psychiatric morbidity are reported to vary in different areas being higher in urban areas (25%) and lower in rural areas (12%) (42). A poor body and low self esteem in those children who have undergone amputation and others with scars arising from cancer suffer symptoms of depression (18). Unstable

families and parental conflicts identified as risk factors for developing cancer related psychopathology (19). The physical appearance also raises risk for psychological maladjustment if caused by cancer or cancer treatment, such as a alopecia (20). It has also been noted in another study that lack of empathy and psychosocial support from siblings and parents compromises the young patients' mental health (21). Poor performance and low level of the formal education has also been found to significantly correlate with higher ratings of behavioural problems in the patients (22), feelings of loneliness, distress and low elf-esteem in the parents have also been found to raise level of psychological morbidity in the children with neoplasia (23).

Age and sex have been found to also affect the level of cancer related psychopathology (21 -24). The older children in the middle and late childhood have been found to have higher levels of psychopathology, with higher rates in the males (41). It has also been reported from other studies (41) that the children from lower SES and less formal education parents show more behavioural problems and that age affects the kind of behavioural problems manifested by these children. Another study (41) has shown increase of cancer-related psychopathology in older children for boys and girls. It was therefore expected that such results would be found in a similar study.

In general it appears from this literature review that psychological disorders are associated with paediatric forms of cancer including leukemia, brain tumours, lymphomas, Wilms' tumour, neuroblastoma, oteogenic sarcoma, Ewing's sarcoma and retinoblastoma (34 - 35). This study on psychological disorders in paediatric oncology patients sheds light on their clinical status and thus assists in planning for possible psychological and other interventions in order to improve their well being, besides guiding further research in area.

CHAPTER THREE: *METHODOLOGY*

Aim

This research was carried out with the aim of identifying the major psychological aspects in paediatric cancer patients at Kenyatta National Hospital.

Hypotheses

H_0 There is no significant level of psychological morbidity in children with cancer at the Kenyatta National Hospital as found in other studies (62%) of the similar population in Western World (17)

H_1 There is significant level of psychological morbidity in children with cancer at Kenyatta National Hospital as found in similar studies in Western World.

Objectives

To establish the psychological status in paediatric cancer patients at the Oncology Unit of Kenyatta National Hospital.

Specific Objectives

1. To identify various types of psychological aspects of children with cancer at Kenyatta National Hospital.
2. To establish prevalence of psychological aspects of children with cancer at the Oncology Unit of Kenyatta National Hospital.
3. To determine the factors associated with the psychological aspects of the children with cancer at Kenyatta National Hospital.

Study Design

This was a cross sectional descriptive study conducted in the Paediatric Oncology Wards at the Kenyatta National Hospital. The duration of the study was a 12 month period from 27th April 2005to 26th April 2006.

Study Area.

Kenyatta National Hospital is situated approximately five kilometres from Nairobi City Centre. It is the only hospital with oncology unit in the republic.

Being the first national referral hospital as well the teaching hospital for the University of Nairobi, it harbours the highest concentration of health personnel in the country and the best facilities and equipment for diagnostic and therapeutic purposes among the national health institutions in Kenya.

For these reasons, patients are referred to the hospital from all over the country for purposes of expert diagnosis and management .

The oncology unit at the Kenyatta National Hospital was the site of this study it is located within the hospital.

The treatment approaches in this unit include:

- Chemotherapy
- Radiotherapy
- Surgery
- Supportive and palliative care.

The staff in the unit is multidisciplinary consisting

- Hematologists
- Pediatricians
- Rad

- Pharmacists
- Nurses
- Physiotherapist
- Clinical nutrionists

This is the staff that provides diagnostic, curative and rehabilitative services in the unit in their respective functions.

Study Instruments

The instruments used in the study were the following:-

a) Socio-demographic questionnaire designed for the research was administered to collect data on the study cases on family quality of life, system involved by neoplasm, clinical diagnosis and treatment administered. It was also used for getting data on other factors related to the psychological aspects.

b) Child Behaviour Checklist (CBCL) and profile (41)

This instrument was developed in 1983 and has been used together with its manual. It is designed to record in a standardized format children's problems as reported by their parents or parent surrogates. It can be self-administered or administered by an interviewer. The 113 items obtain parent's reports of the quality of how well their child gets along with others and specific problem items and open – ended problem items are scored according to its manual (41).

The checklist was developed to cover a broad range of symptoms. It presents items related to mood, frustration, tolerance, hyperactivity, oppositional behaviour, anxiety and depression plus various other behaviour of children of ages 4 and up to 16 years.

Such a checklist identified specific problem areas that may otherwise be overlooked and it may point out areas in which the child's behaviour is deviant compared with normal children of the same age group. A list of studies done using the instrument is provided in appendix D.

It is used by clinicians for the following purposes:

- Assessing main symptoms of depression such as a child's feelings of worthlessness and loss of interest in activities.
- Aid in diagnosis and treatment planning and conducting clinical research.

In terms of reliability, the mean correlations for the CBCL scales are in the 0.60s for all sex / age groups over a 6 month follow up. Test retest correlation over a 3-month period averages 0.74 for parents' ratings. The content validity of CBCL is that 116 of the 118 behaviour problems items are significantly ($P< 0.01$) associated with clinical status as established independently by CBCL. Significant correlations with other behaviour by rating scales give evidence of its construct validity. It has criterion related validity at ($P<.001$).

The CBCL helps in assessing various areas of psychopathology and thus it can facilitate the multifaceted evaluation of children or adolescent for:

- Depression
- Mood Disorders
- Conduct / Behaviour problems
- Inter personal difficulties
- Negative self-esteem
- Ineffectiveness

- Anhedonia
- Anxiety

The CBCL (41) was systematically scored with the guide of a manual developed for the checklist.(41) The CBCL was translated in to Kiswahili for those respondents who were not conversant in English.

C) Diagnostic and Statistical Manual for Mental Disorders 4th Edition(DSM IV) TR. The psychological disorders found were finally subjected to a multixial presentation with the use of DSM IV TR.

Study Population

The national annual estimate of cancer patients is 158 and about 105 of these are in Kenyatta National Hospital. The paediatric cancer patient population in Kenyatta National Hospital has annual turnover of about 135 patients. Thus in this study all the subjects who met the entry criteria were included in the study.

Population Sample

All the patients admitted to Paediatric Oncology Unit of Kenyatta National Hospital and who met the inclusion criteria were subjects of the study. These were drawn from the patients reporting to the paediatric oncology wards over a period of 12 months.

Data Analysis

Data was mainly in the form of tables, diagrams, charts, figures and percentages. Descriptive and inferential statistics were used in the analysis including standard deviation, chi-square and correlations. The data was systematically presented.

Procedure

The study was designed to elicit socio-demographic factors of the study cases. Thereafter there was an appraisal of the socio-demographic correlates to the psychological aspects of the subjects based on standard instruments administered to the study cases. The data collected in the use of the questionnaire also included aspects related to CVS, RS, GIT, CNS, ENT, MS and SDQ.

The CBCL administered to the study cases in screening psychopathology and other psychological aspects was interpreted and scored with a manual. The scores on the CBCL and CBP are the index of the psychological status of the patients. The proportion of clinical psychological morbidity generally increases as the total behaviour problem score on the CBCL increases.

The CBCL and CBP are standard instruments for describing and quantifying children's behavioural problems. The profile reflects an overall behavioural pattern. It provides a basis for descriptive taxonomy that is more comprehensive than classification according to individual syndromes or diagnoses. It has been used in similar studies before (41) in the west.

As the total behaviour problem score on the CBCL included all the items of the other behaviour problems scales on the CBP, it was likely to be superior to any of the more specific profile scales in a comprehensive assessment of the psychological status of the patients. CBCL and CBP were comprehensively competent. The instrument objectively measured and described behaviour besides aiding in formulation of diagnosis and planning for therapeutic interventions.

All the symptoms and other psychological and socio-demographic correlates were recorded, analyzed and subjected to multiaxal presentation using DSM IV.

Inclusion Criteria

The entry criteria into the study was tissue confirmed (histology) diagnosis of a malignancy, admitted in the Paediatric Oncology Unit and wards of Kenyatta National Hospital, aged 4 -16 years and the patient's parent gave informed consent.

Exclusion Criteria

The exclusion criteria were patients who had diagnosed primary mental disorder and those who did not meet the other inclusion criteria and those who died before the completion of the interview.

Ethical Considerations

Approval to conduct the research was obtained from the Kenyatta National Hospital Ethics and Research Committee.

All the parents or guardians of the study cases were requested to give written consent after the purpose and procedure of the study was explained to them.

In addition it was clarified to them that participation was voluntary and they were free to withdraw from the study at any stage without penalty or harm.

Having thus sought and obtained permission and informed consent the research was embarked upon.

CHAPTER FOUR: RESULTS

4.1 Introduction

The analysis of data and presentation of findings from the study cases was presented in the form of tables, charts, frequencies and percentages where applicable. Besides descriptive analysis, some statistical techniques such as correlation, cross tabulations and Chi-square have also been applied in the analysis.

The first part of the data processing and analysis consists of socio demographic characteristics of the studied cases. This includes analysis of gender, age, parents' marital status, level of formal education of the parents, residence of the patient, religion of the respondents, family history of mental illness and current substance use among others. The second part covers the analysis of the behavioural scores from the checklist and profile, which mainly show the psychological aspects of the subjects. The findings were further subjected to DSM –IV multiracial presentation to show the level of severity of the psychological disorders in relation to the significant factors.

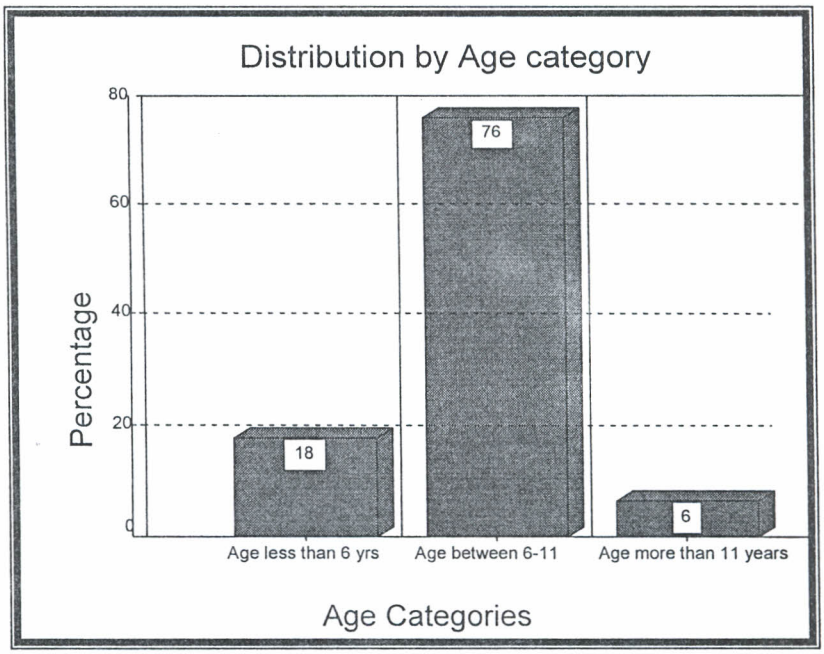
Distribution of Age

The youngest patient was 4 years old while the oldest was 13 years. Mean age was 8 years and mode was 6 years. The median age was also 8 years. The range in the distribution of ages was 9 years. The standard deviation was 1.70.

The age groups were set according to the requirements and procedures determined by the manual for scoring the child behaviour checklist and the behaviour profile. The rules and regulations of the manual required the age categories to be set as such for distinguishing distinct behavioural symptomatology in different developmental stages.

Figure 4.1 shows study cases' age distribution categories. Seventy Six percent (76%) of the respondents were aged between 6-11 years, 18% were aged between 4-5 years while only 6% were aged between 12-16 years. This shows that all target age group were represented in the study with the category of 6-11 years being the majority of the study cases.

Figure 4.1: Age Category Distribution of Study Cases (Age in Years)



Explanation:

Age category: age was categorised according to the scoring instructions of the child behaviour checklist.

Gender Distribution of the Study Cases

About sixty two per cent (62%) of the respondents were male while 38% were female. The age category of 6-12 years has the highest percentage of male respondents (51%). The same category has 24% female. This shows that both sexes were represented in the study.

The distribution on table 4.1 shows the age categories of the respondent against gender.

Table 4.1: Age and Gender Distribution of the study cases.

Age category (in years)	Male		Female		Total	
	n	(%)	n	(%)	n	(%)
Age 4-5 years	6	10	6	10	12	19.0
Age 6-11	32	50.8	15	24	47	75
Age between 12-16	1	2	3	5	4	7
Total	39	62	24	38	63	100.0

Explanation.

Age category – age was categorized according to the child behaviours checklist scoring manual.

Marital Status of Parents of the study cases

The study established that 78% of the patients had both parents staying together, 3% separated, 8% single parent, 2% living away from each other due to work, while 6% were windowed as shown in table 4.2. This shows that majority of patients' parents were staying together and very few were separated or living away from each other due to work.

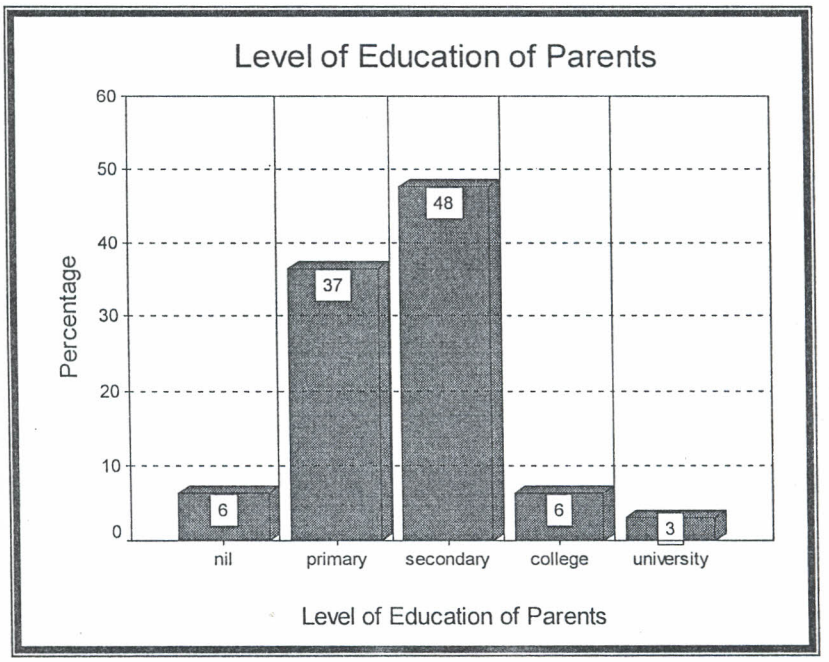
Table 4.2: Marital Status of Parents of the study cases.

Parent's Marital Status	**n**	**(%)**
Married	49	78
Separated	2	3
Single	5	8
Living away from each other due to work	1	2
Widowed	4	6
Total	**63**	**100.0**

Level of Formal Education of Parents, Occupation and Income

Majority of patients' parent had secondary education. This is represented by the 37% of primary and 48% of secondary education of respondents respectively. College and university levels accounted for 6% and 3% respectively as shown in figure 4.2. Majority (67%) had informal employment with a mean monthly income of 2000 (kshs) while the rest (20%) were semi-skilled learning 4,000 (Kshs.) and 13% in the formal employment and having a monthly mean income of 6,000 (Kshs.)

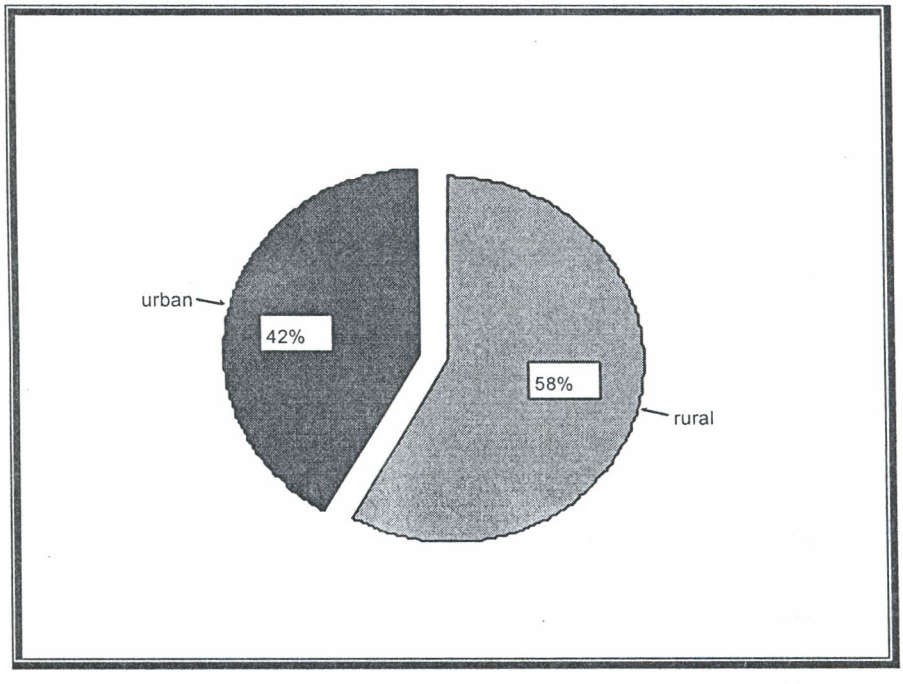
Figure 4.2: Level of Formal Education of Parents of the study cases.



Catchment Area of the Study Cases (Rural and Urban)

The study findings established that majority of the patients lived in rural areas which represents 58% of the total study cases while less lived in urban areas (42%). This is shown in figure 4.3. This shows that most patients resided in the rural areas.

Figure 4.3: Catchment Area of the Study Cases.



Religion of the Families of study cases

Table 4.3: Study Cases' Religion (N=63)

Religion	n	%
Christian	58	92
Muslim	4	6
Traditional African Belief	1	2
Total	63	100.0

The study established that 92% of the respondents were Christians, 6% were Muslim while 2% Traditional African Belief. This shows that majority of patients were Christians. It was found that other than SES the socio-demographic factors did not have statistically significant association with psychological morbidity as measured by total behaviour score and profile scales (r=0.203, p=0.420).

Mental illness and Current Alcohol Use by Parents

Table 4.4: Mental illness and Substance Use (N =63)

Mental Illness and Alcohol use	Yes	
	(n)	(%)
Past History of Mental illness in the family	2	3
Alcohol use by parents	15	24

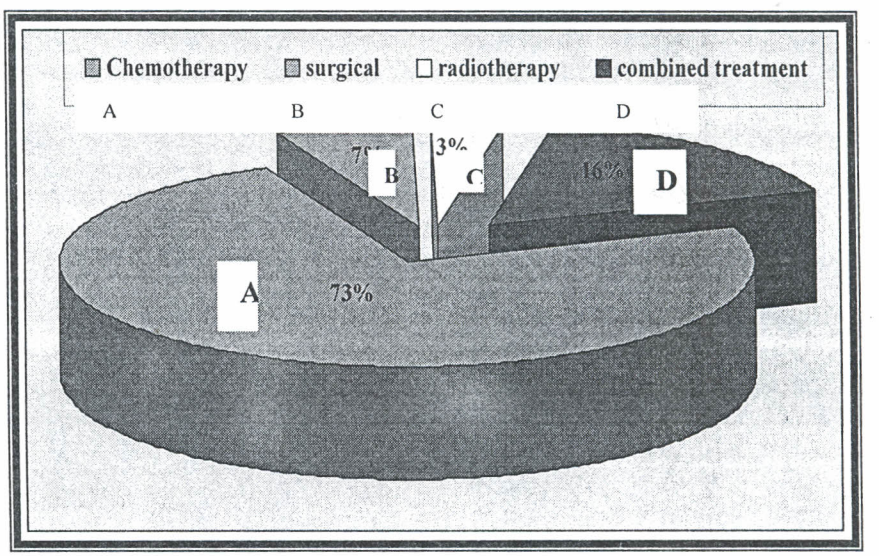
Table 4.4 shows the status of Mental illness and psychoactive substance use of their parents. Majority of the patients' parent had no Past History of Mental illness as represented by a yes response of 3%. There was a positive response (yes response) from 24% of parents, who said they used alcohol. However none of them was ever treated or sought clinical help for alcohol use.

Current Treatment Modalities and Neoplastic Conditions of the study cases.

The study established that 73% of the patients were receiving chemotherapy treatment, 7% received Surgical treatment, 3% received Radiotherapy treatment while 16% received combined treatment. (more than one treatment modality)

as shown in figure 4.4

Figure 4.4: Current Treatment modalities of the study cases.



Majority of the patients had Acute Lymphoblastic Leukemia and non-Hodgkin's lymphoma which accounted for 30% and 21% respectively. Burkitt's Lymphoma and Wilms' tumour accounted for 16% and 18% respectively of the study cases. The rest of the neoplastic conditions which include Retinoblastoma, Osteogenic sarcoma, Testicular Embryonal sarcoma, Benign cystic teratoma and Rhabdomyosarcoma accounted each for less than 10% of the patients as shown in table 4.5

Table 4.5: Neoplastic Conditions found in study cases

	Neoplastic Conditions	**n**	**%**
1.	Acute Lymphoblastic Leukemia	22	30
2.	non-Hodgkin's lymphoma	12	21.1
3.	Burkitt's Lymphoma	10	18
4.	Wilms' tumour	9	15.8
5.	Rhabdomyosarcoma	3	5
6.	Retinoblastoma	3	5
7.	Osteogenic sarcoma	2	4
8.	Testicular Embryonal sarcoma	1	1.8
9.	Benign Cystic Teratoma	1	1.8
Total		**63**	**100.0**

Psychological Aspects of the Study Cases

This part contains the analysis of the scores on children behaviour. This was obtained from the checklist and profile of children above four years. The parent was asked to indicate the child's behaviour now or within six months, by scoring the items in the two instruments. The interpretation of scores based on the scoring manual and profile scales were used to identify the psychological aspects of the study cases and presented in the multiaxial system of DSM IV.

Total Behavior Problem Score

The total behaviour score for the children behavior was found to be in the pathological level for some children and normal level for others. The pathological levels of scores was a measure of behaviour pathology and was used to indicate behaviours which were deviant from those of normal children of the same age. The level of psychological morbidity increases as the score increases. Normal level indicates behavior that was not deviant from normal behavior per age group. The results arising from the assessment based on the cutoffs as provided in the scoring manual are presented in table 4.6 below.

Total Behaviour Problem (TBP) Score, Age Group and Gender

The total behaviour scores for the study cases were categorized with gender of patient and age category. The study established that the study cases in the age group of 4-5 years, all the females in this age category were in the pathological level (47.3 %). Fifty seven percent (57%) of the males were in the pathological level.. In the age category of 6-11 years 80.6% of the male were in the pathological level as compare to the females who were 59.1% in the study case. None of the study cases in the age category

of 12-16 years was in the normal level. Three percent (3.2%) of the males were in the pathological level as compare to females who were 13.6% in the same level. This is shown in table 4.6

Table 4.6: Age Category and Total Behaviour problem scores and Gender

Age Categories	**Total Behavior Problem Score**							
	Pathological Level				Normal level			
	Male		Female		Male		Female	
	n	%	n	%	n	%	n	%
Age less than 6 yrs	5	57	6	47.3	5	16.1	0	0
Age between 6-11	25	80.6	13	59	7	18	2	4
Age ≥ 12 yrs	1	3.2	3	13.6	0	0	0	0

Explanation:

Age category: age was categorised according to the scoring instructions of the child behaviour checklist.

Behaviour Profile Scale Scores

Table 4.7: Profile Scale Scores of Study Cases (N=63)

BEHAVIOUR PROFILE SCALE OF PATIENTS				
	Pathological Level $n_1 = 53$		**Normal Level $n_2 = 10$**	
Profile Scale	**n_3**	**%**	**n_4**	**%**
Depressed	23	36.5	40	63.5
Socially Withdrawn	53	84.1	10	15.9
Somatic Complaints	16	25.4	47	74.6
Schizoid Obsessive	1	1.6	62	98.4
Hyperactive	2	3.2	61	96.8
Sex Problems	1	1.6	62	98.4
Delinquent	1	1.6	62	98.4
Aggressive	2	3.2	61	96.8
Cruel	1	1.6	62	98.4

Explanations: n_1 =Total number of study cases with pathological behavioural profiles.

n_2 = Total number of study cases with normal behavioural profiles.

n_3 = Total number of study cases with pathological level on each profile scale.

n_4 = Total number of study cases with normal level on each profile scale.

The study finding established that 36.5% of the patients were in the pathological level of depressed scale while 63.5% of the study cases were in depressed scale within thenormal level. Those socially withdrawn accounted for 84.1% in the pathological level and 15.9% in the normal level.

Somatic Complaints, Schizoid Obsessive and Hyperactive accounted for 25.4%, 1.6% and 3.2% of the study cases in the pathological level respectively. Sex Problems, Delinquent, Aggressive and Cruel all of these profile types accounted for about 98% in the normal level as shown in table 4.8. This shows that most of the disorders in the behaviour pathology were in the profile scales of Social Withdrawal, Depression and Somatic Complaints. These findings are also presented in a cross tabulation of socio-demographic variables and psychological morbidity in table 4.9 and figure 4.5.

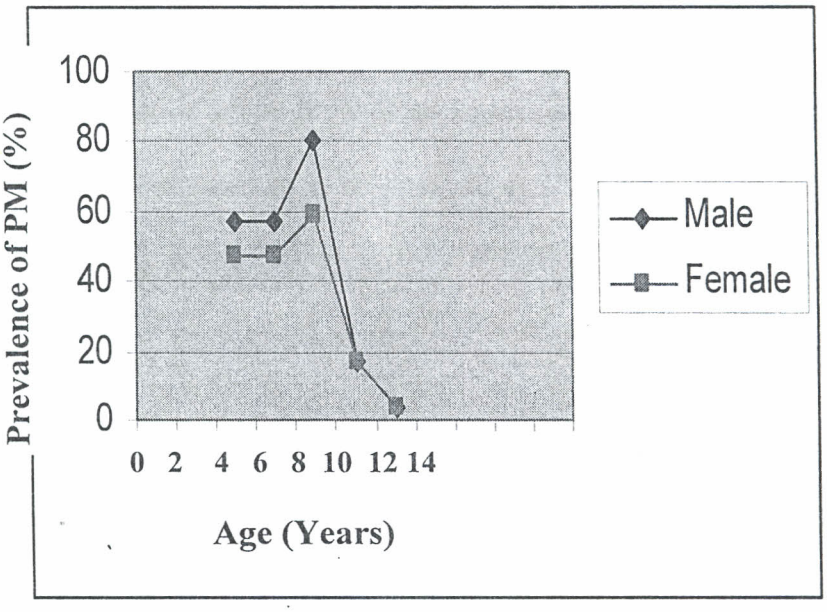
Table 4.8 Socio-demographic Variables versus Psychological status. (N=63)

Variable	Risk Factors	PM	NPM	P Value
Age Category	4-5 yrs , n=12 (19%) 6-11yrs, n =47 (75%) 12-13yrs, n =4 (7%)	9 40 4	3 7 0	0.89
Sex	Male, n= 39 (62%) Female, n =24 (38%)	3 21	7 3	0.99
Years of Formal Education of Parents	Nil, n = 3 (6%) Primary, n=25 (37%) Secondary, n =30 (48%) Post secondary, n =5 (9%)	3 22 46 7	0 3 4 2	0.701
Catchment Area	Rural, n=40 (58%) Urban, n= 4 (6%)	36 20	4 3	0.581
Religion	Christian, n=58 (92%) Muslim, n=4 (6%) Traditional African belief, n=1 (2%)	49 3 1	9 1 0	1.21
Socio-Economic Status of Parents	Monthly earnings <6000 Kshs. n=52 (87%) Monthly earnings >600 Kshs, n= 11 (13%)	42 11	10 0	0.0238
Principal System Involved by Neoplasm	Haematogical, n=23 (39%) Lymph Node & Immune, n=22 (30%) Musculo- Skeletal, n=17 (29%) Genito –Urinary, n=1 (2%)	18 19 15 1	5 3 2 0	0.01

Explanation.

Age category – age was categorized according to child behaviour checklist scoring manual

Figure 4.5 Level of Psychological Morbidity versus Age and Sex.



Note:

The figure above represents age in years of the study cases. The oldest patient was 13 years old whereas the youngest was 4 years. The graph shows the level of psychological morbidity in relation to age and sex of the study cases. It was found that morbidity increased in the older children in the age group 6-11 years with a drop in the oldest cases of 12 -13 years. A slightly higher level of morbidity was noted with the males.

Main Psychological Disorders Found in the Study Cases

The disorders were picked through a factor analysis of the child behaviour checklist with the aid of the diagnostic and scoring manual (41).

The diagnostic scales having the largest factor loadings were used to identify the disorders picked through the behaviour checklist and profile.

The psychological aspects were finally subjected to the scoring manual to determine whether they were normal or pathological in terms of their levels. The levels were determined on the basis of the total behaviour score of the checklist. The severity of dysfunctions of the study cases were also assessed using the DSM-IV Axis V. The DSM-IV Axis 1 diagnoses and Axis V results were shown as in tables 4.9 and 4.10 respectively.

Table 4.9 DSM-IV Axis V (GAF) Scale Found in the Study Cases (N=63)

AxisV Scale	Severityof dysfunction	n	%
90	Good Functioning	13	20
80	Slight	6	10
70	Mild	19	30
60	Moderate	25	40

Explanation (as per DSM-IV Instructions)

GAF – Global assessment of functioning.

Good functioning – minimal symptoms present

Slight – slight impairment in psychosocial functioning; transient symptoms if present.

Mild – mild symptoms but functioning pretty well in psychosocial areas.

Moderate – moderate symptoms/moderate difficulty in psychosocial functioning e.g

Few friends and conflict with peers.

Table 4.10 DSM –IV Diagnoses Found in the Study Cases (N= 63)

DSM – IV Code	DSM – IV descriptions		
	Disorder	n	%
309.28	Adjustment disorder with Mixed Anxiety and Depressed Mood	25	40
311	Depressive disorder NOS	19	30
300.82	Undifferentiated Somatoform Disorder	6	10
-Ve	NAD	13	20

Explanation:

NAD – Nothing abnormal diagnosed

NOS – Not otherwise specified

-Ve - symbol indicates no code was given for study cases with no diagnosis as they were found normal on DSM – IV Axis 1 criteria.

From table 4.10 it can be established from the study that 30% of patients had depressive disorder not otherwise specified, 40% had adjustment disorder with mixed anxiety and depressive mood. Ten percent (10%) had undifferentiated Somatoform disorder. Thus it was found that most of the patients suffered adjustment disorder with mixed anxiety and depressed mood and undifferentiated somatoform disorder. These were identified and recorded as the main DSM IV Axis 1 clinical disorders found in the study cases. There were no Axis II (personality disorders/ mental retardation) diagnoses found in the study cases.

Various neoplastic conditions (table 4.5) were the general medical conditions found affecting the patients. These were found to be in different prevalent rates as presented above from the findings of the study.

It was also found from the study results based on the checklist that there were no statistically significant environmental stressors. Other than SES, factors studied (table 4.9) were found not to be statistically significant in increasing risk to psychological morbidity.

The findings also showed that 53 study cases (84%) obtained a total behaviour mean score of 62 which was an index of pathological level of psychopathology while 10 cases (16%) had a mean score of 38 in the normal level. The lowest score was 15 and the highest was 97. This means majority of the patients showed psychological morbidity that could warrant clinical intervention and was serious enough to impair some of their levels of functioning which were assessed using the DSM IV Global Assessment of Functioning (GAF) scale. These results therefore showed that the study cases had moderate, mild and slight psychological dysfunctions. The total behaviour problem scores and the GAF scales indicated that the study cases suffered clinical psychological morbidity. The PM prevalence of 84% was based on behavioural scores obtained from the checklist.

Binomial Test of Hypothesis

Ho : There is no statistically significant rate of psychological disorders in the paediatric cancer patients at Kenyatta National Hospital compared to the average rate found in studies done in the western world

H_1 : There is statistically significant rate of psychological disorders in the paediatric cancer patients at Kenyatta National Hospital as compared to average rate found in studies done in the western world.

The non-parametric tests for two independent samples are useful for determining whether the values of a particular variable differ between two groups. The test of the above hypothesis involved establishment of whether there were any significant differences in the number of study cases in the normal and pathological levels across each of the nine psychological profile types namely: Depression, social withdrawal and inhibited behaviour, somatic complaints, anxiety, hyperactivity, sex problems, cruel, aggressive and delinquency. This was performed using the non-parametric Chi-square test procedure. The Chi-Square test procedure tabulates a variable into categories and tests the hypothesis that the observed frequencies do not differ from the expected values. The decision rule is to reject the null hypothesis when the p-value is less than the level of significance (in this case 0.05), and accept the null hypothesis otherwise. The calculated P-value was found to be 0.151 which is greater than 0.05 (level of significance). This leads to rejection of the null hypothesis Ho and accepting the alternative hypothesis (H_1). This therefore led to the conclusion that there were significant psychological disorders in the paediatric cancer patients of Kenyatta National Hospital.

The minimum TBP score for patients within the normal level was 15 while the maximum score was 40. The minimum TBP score for patients within the pathological level was 44 while the maximum score was 97.

The normal level indicates the number of the study cases found not to be suffering clinical psychological morbidity. The pathological level indicates the cases found suffering clinical morbidity. The determination of these levels were based on scores provided in the manual of the child behaviour checklist cutoff points as shown on page 69.

CHAPTER FIVE: DISCUSSION

In this study the main focus on the results was the psychological aspects of the children with cancer. Apart from the psychiatric morbidity other aspects of the findings were the behavioural profile and other non-pathological aspects of the psychological characteristics of the study cases. The socio-demographic parameters and risk factors for the psychological morbidity were evaluated.

A total of 63 cases were studied out of which 53 (84%) showed clinical psychological morbidity and10 (16%) were normal as screened using the child behaviour checklist and behaviour profile. These cases were aged 4 – 16 years with the prevalence rate of psychiatric morbidity (PM) being 84%. The prevalence was found to be higher than results of studies done in the western world where prevalence rates of 59% and 62% respectively were found. Onyango (40) studying only adults and using Leeds Scale for Assessment of Anxiety and Depression found a prevalence of 47.8% of PM in the adult cancer patients in the same hospital which was a lower rate compared with that of children (84%) found in the current study but somewhat higher than some results of PM of adults in Western Countries.

Variables such as age, sex, education, marital status of parents, history of mental illness in the family and substance use by parents were found not to have a statistically significant association with PM. However socio-economic status (SES) was found to be significant (P=0.0238).

Types Of Psychological Disorders Found.

Disorders were found on the basis of scores obtained from the factor analysis using the manual for the child behaviour checklist, profile and the DSM-IV. Axis 1 findings were: adjustment disorder with mixed anxiety and depressed mood (40%), Depressive

Disorder Not Otherwise Specified (30%) and Undifferentiated Somatoform Disorder (10%). Other Study Cases were found to a greater extent to be normal as per DSM-IV Axis 1.

The psychological disorders found in table 4.9 in this study also resembled those found in other studies done elsewhere. Rae Grant in a study of psychological implications of cancer in children found 61% of, psychological impairment to be common (2). In another study of 30 children with cancer Varni and Colegrore found 25% of depression to be associated with the childhood neoplasia (4). Also in a study of 21 children with cancer, Pendley and Dreyer found strong association of anxiety and neoplasia at 30% (20). Kazak (21) found 42% of social withdrawal and inhibited behaviour, Mulhern noted 48% of somatoform disorder (24) and Kazak (21) also found 38% of post-traumatic stress disorder (PTSD). Other studies found 60% of behavioural and antisocial behaviour (24, 8) and adjustment disorder (19) at rate of 42%.

In the present study the most common psychological impairments were adjustment disorder with anxiety and depressed mood, depressive disorder Not Otherwise Specified and somatoform disorders and this reflects a similar trend in types of disorders in the other studies with a higher prevalence rate of 79% in the current study. In a study of children with cancer of similar age group in Pennysylvania Cancer Registry and Memorial Sloan Kettering Cancer Centre, 59% and 62% prevalence rates respectively of psychological morbidity were found (15,17), where these were lower than that found in the current study.

The current study used a researcher designed questionnaire to pick socio-demographic variables and the kind of neoplastic conditions and their treatment modalities of the

study cases while the checklist and DSM – IV were used to screen for the psychological aspects. However there were no study cases with DSM IV Axis II diagnoses considered in this study other than cancer.

Many studies (12 – 13) have shown that as a consequence of cancer per se and the hospitalization in the absence of other physical pathology, the patient suffers psychological problems and impairment which include depression (18).

Studies by Kazak and Varni (19.21) show that poor support from the family raises the risk of developing psychological disorders in the children with cancer. Christakis and Kazak found that coming from a single-parent home was a risk factor highly associated with psychological morbidity in such children (4,12) but in the current study majority (78%) of the parents were staying together (married) and only a minority (7.9%) were single and this may explain the difference in findings from the studies by Kazak, Christakis and Varni. Stressors such as physical disability, and disfigurement resulting from cancer have also been found to be risk factors in other studies (18). In the current study such stressors as physical effects of cancer were studied in general as part of cancer and not as specific variables meaning that those other studies went a step further in assessing the risk factors directly emanating from specific type of cancer per se.

By using DSM-IV Axis IV (GAF) majority of the study cases (80%) were found to have levels of dysfunction warranting clinical intervention. These findings showed that whereas a subset of the study cases showed clinical levels of psychological morbidity, with the dysfunction as being slight (10%), mild (30%) and moderate (40%), this was not diagnosed by the medical staff and hence it persisted without intervention. A notable finding in a similar study showed that primary health care workers did not

diagnose or manage 80-90% of childhood cancer psychiatric morbidity(19). This is a significant finding relevant to the provision of preventive and curative aspects of clinical management of psychological pathology emanating from cancer (tables 4.8 and 4.9). It is a significant finding that while majority (79%) of the study cases were found to have DSM-IV Axis 1 diagnoses, only 25(20%) of the 63 cases had levels of dysfunction not warranting clinical psychological intervention. This implied that minority (20%) of the cases psychologically functioned relatively well in the face of cancer. Other studies have also found many children with cancer do have some psychological impairment but functions well in psychosocial areas with a subset needing clinical psychological intervention to cope (25,34). Onyango in a study of psychological sequalae in adult cancer patients also found that most psychological problems went without being detected by the treating physicians (40).

Total Behaviour Problem Score (TBPS)

The total behaviour problem score included all items on the behaviour checklist and profile. It objectively measures and describes behaviour and is superior to specific scales in the comprehensive assessment of the psychological status of patients as provided for in the manual. In this study it was found that 53 patients out of the total of 63 (84%) were in the pathological level of TBPS meaning they were psychologically maladjusted on the basis of behaviour problem index. Those in the pathological level showed behavioural pathology as measured by the TBPS obtained with the guide of the manual for the CBCL.

The study showed that the behavioural problem score was significantly higher for children who had psychiatric disorders than for children who had not. It was found that 84% of the subjects had scores in the pathological level. The results also concurred with similar findings carried out in other settings (21-24) with the current study showing higher rate of PM.

In terms of age and gender, the study established that males aged less than 6 years showed a higher psychological morbidity (57%) compared to females (47.3%). In the age category of 6-12 years males showed a higher psychological morbidity (80.6%) whereas females in the same range showed a lower level (59.1%) as seen in figure 4.5. Other studies (21 – 24) have also found variations in symptomatology of behaviour in different developmental stages based on age and sex (41). In the current study this could be due to severity of cancer and the effects of treatment or time intervention. However, to evaluate this relationship, one would need a different type of study from the current one. Older children showed higher levels of the psychopathologies and this occurs with studies done elsewhere (41).

Behavioural Profile Types of the Patients

A factor analysis of the child behaviour was carried out to aid in identifying the behaviour profiles of the subjects through the manual developed for purpose of scoring the CBCL. The behaviour profile was used to show the scale having the largest factor loadings. The profile types provided a broader view of children's behaviour problem patterns than the categories of the DSM system.

It was found in this study that most parents reported the symptoms to have started with the presence of the neoplastic condition of the patient. The findings also indicated that 53 patients (84%) were in the pathological level of the behaviour profile as compared to only 10 (16%) patients whose behaviour profile was in the normal level, where pathological level and normal levels indicated behavioural pathology and absence of the same respectively.

The following behaviour profile types were found in the patients as measured by the behaviour profile scales: depressed profile in the pathological level (36.5%), depressed

profile in the normal level (63.5%), social withdrawal in the pathological level (84.1%) and the same profile in the normal level (15.9%), somatic complaints, schizoid obsessive and hyperactive profiles accounted for 25.4%, 1.6% and 3.2% respectively of the subjects in the pathological level. The profiles of sex problems delinquent, aggressive and cruel were all about 98% in the normal level. These findings show that majority of the profiles in the pathological level were picked in the scales of the social withdrawal, depression and somatic complaints. These were in the pattern found in other studies (41) but with a higher PM in the current study.

The findings showed that there were similar prevalence rates of depressed cases in the profile in both males and females (6.3%) aged below 6 years. Those aged between 6 and 12 years showed higher depressed cases in the pathological level for both sexes (1.23%). For the profile scale of social withdrawal, it was found that majority of the males (34.9%) aged 6 and above years were in the pathological level as compared to their female counterparts who showed lower scales (15.9%) in the same range. It was also found that for profile scales of Schizoid Obsessive, Hyperactive, sex problems, delinquent, aggressive and cruel, majority of the subjects were in the normal range in all the age categories and in both sexes (98%). This reflects a similar trend in the western world. (41).

Marital status of parents of study cases.

From the study it was found that 78% of the parents of patients were married, 3.2% separated, 7.9% single parents and 1.6% living away from each other due to work while 6.3% were widowed. The findings thus showed that in terms of marital status majority of the parents were married while very few were separated or living away from each other. The study therefore showed that majority (78%) of the patients came

from relatively stable families with no past history of divorce (78%) and absence of mental illness (98.4%) and low level of substance use as measured by a majority (74.6%) no response to substance use in the questionnaire. In the current study marital status was found not to be significantly (p=1.0) related to PM. In other studies single parenthood was found to be a risk factor for psychological morbidity (21). This difference in findings could be due to the fact that majority of the parents in the current study were living together with a very small minority of 5 being single (8%).

Family History of Mental Illness And Psychoactive Substance Use.

It was found that minority of the parents had past history of mental illness as indicated by yes responses of 3%.

The study findings also showed a low positive response rate on the question of substance use by parents. There was a positive response from 23.8% of the patients' parents who said that they used non– prescription psychoactive substance. In the current study the family history of mental illness and substance use (alcohol) by 24% parents did not show a statistically significant association (p=0.95) with PM of the study cases. This may reflect that low level f substance use by parents and very low level of mental illness may have had no impact on the family and hence the child as reported in other studies (27).

Type of Treatment modalities found in the study cases

It was found that chemotherapy was the main type of treatment (78.8%) of the patients. Other kinds of treatment were surgery (6.6%), radiotherapy (3.3%) and combined treatment (16%). The effect of chemotherapy causing alopecia and surgery causing visible scars or loss of limb showed strong association with increased psychiatric morbidity (p=0.01). Other studies have found scars and alopecia left after

treatment to particularly raise levels of social anxiety due to the changes in physical appearance (19,30)

Neoplastic conditions found in the study cases.

The findings showed that majority of the patients had acute lymphoblastic leukaemia and non-Hodkin's Lymphoma (29.8%) and 21%) respectively. Burkitt's lymphoma was found to account for 15.8% of the studied cases. The rest of the neoplastic conditions included retinoblastoma, acute lymphoblastoma, Wilm's tumour, Osteogenic Sarcoma, Embryonal sarcoma, benign cystic teratoma and Rhabdomyoscarcoma which accounted for less than 10%. Burkitt's Lymphoma and Rhabdomyosarcoma showed increased level of PM (P=0.01). Other studies have found cancer of skin to particularly raise level of social anxiety due to the changes in physical appearance (18-26).

Age

In the present study it was found that age distribution was as follows: 18% of the patients were aged less than 6 years but more than 3 years while 76% were aged between 6-11 years with only 6% being 12-16 years. In the study all the target groups were represented with the category of 6-11 years being the majority of the subjects. Therefore the age category requirements of the checklist and profile were met in this study as determined by use of the scoring manual. Age was found to be significantly related to psychopathology in that older cases showed higher levels of morbidity. Studies done elsewhere have found similar results (6,20).

Sex

The findings also showed that 61.9% of the subjects were male while 38.1% were female. The age category of 6-12 years had the highest percentage of male subjects

(50.8%). This showed both sexes were fairly well distributed and represented in the study. Sex was found to be significantly related to level of PM and Pendley (20) found similar results in a study of 20 children with cancer but William (6) found age to only affect the kind of psychopathology manifested. In the current study however variations of pm were found in both sexes.

Order of birth, Number of Siblings and Hospitalization

Order of birth, number of siblings and period of staying in hospital was found not affecting level of morbidity as seen in table 4.8. Other studies have found period of hospitalization to increase level of PM (12-13).

Level of Formal Education and Income of Parents

The level of education of parents, occupation and income were used as parameters of SES. The study established that 37% of the parents had primary education, 48% had secondary education and college and university levels accounted for 6% and 3% respectively. Therefore, majority (48%) of the parents had secondary education, meaning that majority (57%) of the parents had secondary and post-secondary education. Income and parents' level of education were not found to be significantly associated with PM but Kazak and Van (19) found low SES as exacerbating factor for PM. This was similarly found in the current study, where majority of study cases were from low SES parents and the prevalence of PM was very high (84%).

Catchment Area of the Study Cases

When the kind of residence of the patients was assessed using the socio-demographic questionnaire it was found that majority (58.3%) of patients lived in rural areas while the rest (47.7%) lived in urban areas. The findings indicate that most of the patients were rural residents. The results did not show any significant difference in the level of

psychological morbidity between rural and urban dwellers among the study cases. This similarity could have been due to their similarity of low SES(19). Other studies have found that combination of rural environment coupled with low SES are positively correlated with increase in morbidity (19).

Religion

Religion was also a factor that was subjected to the socio-demographic questionnaire in the study which established that majority (92.2%) of the subjects were Christians, 6.3% were Muslims while 2% followed Traditional African Belief. In the present study except SES the socio-demographic parameters were not found to be risk factors for behavioural pathology in the patients as measured by total behaviour problem score and behaviour profile scales. It is the presence of neoplasia, which showed a strong positive correlation with the psychological morbidity. However, Sarah (34) found that psychological problems of these children may be exacerbated if their parents had no religious affiliation. In this study all parents (100%) practised religion and this may explain the difference.

Limitations

This was a cross-sectional survey of an individual unit within a large national referral hospital offering a wide range of specialised treatment. The research was undertaken within 12 month time scale and limited population. It involved only Paediatric oncology population. The period of the study could have been relatively short considering the rate of admissions per year and children with cancer attending other hospitals in the country.

The focus of the study was limited to Psychological aspects of the subjects and their socio-demographic correlates. The data was obtained from the parents of patients out of their own experience and knowledge of patients. The study only covers the range of ages 4-16 years of the oncology population. This left out the adolescence development stage as the child behaviour checklist and profile were not suitable for adolescence psycho-oncology study.

This cross-sectional study was limited to descriptive and inferential statistics. Since it was limited to descriptive and inferential statistics in its analysis, it did not therefore evaluate the subjects in their post-treatment period nor does it appraise the time effect on the psychological status of the patients. This would be better done in a longitudinal study which was outside the scope of the present study.

Due to some respondents being illiterate the researcher spent a lot of time explaining each question in the checklist and this was tedious and time-consuming since there were more than 113 items to respond to.

Since the checklist was written in English language it was not easy to come up with the Kiswahili version for some of the respondent (parents) who were not conversant in English. It was difficult to translate some items appropriately to Kiswahili. Also some respondents who were literate misunderstood some questions and the whole exercise had to be done all over again by the researcher directly explaining the questions to the respondent.

The checklist was also very long with many questions which could take some respondents a whole week to respond to the questions and complete them. In addition, the unexpected death of a study case out of the study made it necessary picking another one. This ended up delaying the process.

Conclusions

Although the present study found pm to be higher than those found in other studies, it was not established whether neoplasia alone was the aetiology of the psychological morbidity. The behavioural pathology was found in both stable and unstable families. It was found that other than SES the socio-demographic variables were not significantly related to the morbidity. However malignancy was found to have a very strong relationship with psychiatric morbidity and pathological behaviour profile. Also the findings did not establish a significant relationship between substance use and the morbidity. The findings showed that 53 out of 63 subjects were having psychological disorders as screened by use of child behaviour checklist and behaviour profile as scored by the manual which meant that majority (84%) of subjects were psychologically maladjusted.

This study has established that behavioural problems and adjustment disorders are highly prevalent and clinically significant in the children with cancer in a Kenyan psycho-oncology setting and higher than it is in the American and European settings. This is where in the current study the prevalence rate of psychological morbidity was found to be 84% which was higher than with 59% and 62% in the western world.

Though it is difficult to clinically prevent the psychological morbidity and behavioural problems arising out of childhood neoplasm, these can be objectively diagnosed and evaluated by use of appropriate instruments for proper clinical intervention. It would be clinically not advisable to call for wholesome psychiatric consultation for patients in the psycho-oncology setting but some children who are in the non-clinical mental health referral or treatment may be candidates for potential need for help. These

findings also indicated children whose behaviour warranted professional help or the parents' need or desire for help regarding their children's psychological problems.

This study thus contributes to not only clinical services but also in training of professionals in the psychiatric, psycho-oncology, medical field and research. The study also contributes to understanding of the psycho-pathology of children with cancer as it adds valuable knowledge regarding this section of clinical population in the local Kenyan situation.

Recommendations

From the findings of the study the following recommendations are made:-

(1) For clinical services health institutions managing paediatric cancer patients should have a policy of having psycho-oncology staff in their establishment. Also clinicians need to routinely evaluate the symptoms manifestation of oncology psychopathology for diagnosis and intervention.

(2) In terms of future research much needs to be done to improve the design and methodology so as to include the epidemiological, aetiological, outcome, experimental intervention and operations aspects of the study. This would reasonably improve scientific knowledge and clinical services in psycho-oncology field.

(3) Parents in the families of cancer children should be sensitized in recognizing behavioural symptoms of children's oncology psychopathology in order to seek treatment of their children.

(4) Social skills training and coping strategies should be taught to the parents of children with cancer to facilitate adaptation and improve adjustment to the effects of cancer and its treatment. This includes identification of the

exacerbating and ameliorating factors of the psychosocial maladjustment to cancer and managing them early to avert serious levels of psychiatric morbidity of these children with cancer.

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APPENDIX A

Sociodemographic Questionnaire

1. Patient's Serial Number .....
2. Age .....
3. Sex .....
4. Order of birth .....
5. Caregiver (tick where applicable)
   a) Parents.....
   b) Relative describe) .....
6. Years of formal education of patient.....
7. Residence : rural/urban details)
8. Number of siblings .....
9. Marital status of parents (tick Where applicable)
   a) Married/divorced/separated....
   b) Separated/.....
11. Income of parents.....
12. Level of education of parents
    (i) Religion
    a Christian.....
    b. Muslim.....
    c. Budhist.....
    d. Traditional African belief
    e. Any other.....
    (iii) Past History of Mental illness in the family. If Yes (Give the relative as parent or sibling..... No.....
13. Alcohol/drug (name it) used by:
    (a) Parent(s) .....
    (b) Sibling(s).....
14. Occupation of each parent
    (a) Mother.....
    (b) Father.....

c) Cohabitation

d) Widowed

10. Family type

a) Single parent.....

b) Monogamous.....

c) Polygamous.....

15. Total period of stay at hospital since current admission .....

16. Type of cancer.....

Diagnosis(detailed) .....

17. Principal systems involved by the neoplastic conditions

a) Cardiovascular system.....

b) Respiratory systems.....

c) Gastro-intestinal tract.....

d) Central nervous system.....

e) Haematological .....

f) Ear, nose and throat.....

g) Integument.....

h) Musculo-skeletal.....

i) Other (specify)

j) Location of neoplasm.

(a) Primary.....

(b) Secondary.....

18. Current treatment.

a) Chemotherapy (types of drugs given) .....

b) Radiotherapy.....

c) Surgical.....

d) Combined treatment (specify)

.....

19. Complications.....

APPENDIX B

Child Behaviour Check List (Ages 4 to 16 Years)

Child's Name _____

This is a list of items that describe children and youth. For each item that describes your child now or within the past 6 months, please write 2 if the item is very true or often true of your child. Write 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, write 0.

Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) 1= somewhat or Sometimes True 2 = Very True or Often True.

NB: The Questions follow in the next page.

1. Acts too young for his/her age……..
2. Allergy (describe)
3. Argues a lot……
4. Asthma……..
5. Behaves like opposite sex……..
6. Bowel movements outside toilet…..
7. Bragging, boasting……..
8. Can't concentrate, cant pay attention for long…
9. Can't get his/her mind off cetain thoughts; obsession (describe)____
10. Can't sit still, restless, or hyperactive…..
11. Clings to adults or too dependent…..
12. Complains of loneliness…..
13. Confused or seems to be in a fog…..
14. Cries a lot……..
15. Cruel to animals……..
16. Cruelty, bullying or meanness to others…
17. Daydreams or gets lost in his/her thoughts….
18. Deliberately harms self or attempt suicide
19. Demands a lot of attention…….
20. Destroys his/her own things…
21. Destroys things belonging to his/her family or others…..
22. Disobedient at home……..
23. Disobedient at school……..
24. Doesn't eat well……..
25. Doesn't get along with other kids
26. Doesn't seem to feel guilty after misbehaving
27. Easily jealous……
28. Eats or drinks things that are not food- don't include sweets
29. Fears certain animals, situations or places other than school (describe)
30. Fears going to school……..
31. Fears he/she might think or do something bad…….
32. Feels he/she has to be perfect……..

33. Feels or complains that no one loves him/her.....

34. Feels others are out to get him/her

35. Feels worthless or inferior.....

36. Gets hurt a lot, accident-prone....

37. Gets in many fights.....

38. Gets teased a lot.....

39. Hangs around with others who gets in trouble .....

40. Hears sounds or voices that aren't there (describe)____

41. Impulsive or acts without thinking

42. Would rather be alone than with others....

43. Lying or cheating.....

44. Bites fingernails.....

45. Nervous, high-strung, or tense.....

46. Nervous movement or twitching describe_____

47. Nightmares.....

48. Not liked by other kids.....

49. Constipated doesn't move bowels....

50. Too fearful or anxious

51. Feels dizzy.....

52. Feels too guilty.....

53. Overreacting.....

54. Overtired.....

55. Overweight.....

56. Physical problems without known medical cause:

a) Aches or pains.....

b) Headaches

c) Nausea, feels sick....

d) Problems with eyes (describe)____

e) Rashes or other skin problems

f) Stomachaches or cramps.....

g) Vomiting, throwing up.....

h) Other (describe)_____

57. Physically attacks people.....

58. Picks nose, skin, or other parts of the body (describe)

59. Plays with own sex parts in public....

60. Plays with own sex parts too much....

61. Poor school work.

62. Poorly coordinated or clumsy....

63. Prefers being with older kids……

64. Prefers being with younger kids…

65. Refuses to talk……

66. Repeat certain acts over and over, compulsions (describe)….

67. Runs away from home…….

68. Screams a lot……..

69. Secretive, keeps things to self…

70. Sees things that aren't there (describe)___

71. Self conscious or easily embarrassed

72. Sets fires……..

73. Sexual problems

74. Showing off or clowning……..

75. Shy or timid……..

76. Sleeps less than most kids……

77. Sleeps more than most kids during day and/or night (describe)_____

78. Smears or plays with bowel movements

79. Speech problem (describe)_____

80. Stares blankly ……..

81. Steals at home……..

82. Steals outside home……..

83. Stores up things he/she doesn't need (describe)____

84. Strange in behaviour (describe)_____

85. Strange in ideas (describe)_____

86. Stubborn, sullen, or irritable……

87. Sudden changes in mood or feelings…..

88. Sulks a lot……

89. Suspicious……..

90. Swearing or obscene language……..

91. Talks about killing self……..

92. Talks or walks in sleep (describe)_____

93. Talks too much……

94. Teases a lot……

95. Temper tantrums or hot temper……..

96. Thinks about sex too much ……..

97. Threatens people……..

98. Thumb-sucking……..

99. Too concerned with neatness or cleanliness……..

100. Trouble sleeping

(describe)_____

101. Truancy skips school.....

102. Under active, slow moving, or

lacks energy.....

103. Unhappy, sad, or depressed.....

104. Unusually loud.....

105. Uses alcohol or drugs

(describe)_____

106. Vandalism.....

107. Wets self during the

day.....

108. Wets the bed.....

109. Whining.....

110. Wishes to be opposite

sex.....

111. Withdrawn, doesn't get involved

with

others.....

112. Worries.....

113. Please write in any problems your

child has that were not listed above:

(a)_____

(b)_____

(c)_____

APPENDIX C

Orodha Ya Mambo Yanaonekana kwa Watoto na Vijana –Umuri Miaka 4 – 16

Jina la Mtoto…………………………………………………………………..

Mambo haya yanaonekana sana kwa watoto na vijana. Majibu yako yatasaidia daktari kujua jinsi ya kusaidia wewe na mtoto wako.

Kwa jambo ambalo linaeleza tabia ya mwanao kuanzia sasa ama miezi sita iliyopita tafadhali andika nambari mbili (2) kama jambo hilo nila kweli kabisa kuhusu mwanao.

Kama jambo hilo huna hakika nalo kabisda ama huwa linatokea mara chache andika moja (1); kama jambo hilo hujapata kuliona likifanywa na mwanao andika sufuri (0). Tafadhali jibu maswali yote kwa uwezo wako hata kama mambo utakayoulizwa hujapata kuyaona yakifanywa na mwanao.

0 = si kweli kabisa 1 = kuna kweli kiasi fulani 2 = kweli kabisa.

1. Hutenda kama mtoto mdogo hata kama umri wake in mkubwa ……………
2. Husumbuliwa na mwili alapo vitu Fulani au kugusa vitu Fulani (allergy) (eleza)……………
3. Hushindana sana kwa maneno………..
4. Pumu (Asthma):……………………..
5. Huiga matendo ya jinsia tofauti………………..
6. Huenda haja zake nje ya choo………………..
7. Hujisifu/Hujigamba/Hujivuna……………..
8. Hana makini ya mambo kwa muda mrefu……………

9. Hulishughulikia jambo Fulani kwa muda mrefu kuliko inavyo faa (eleza)....

10. Hatulii/Hurandaranda.....

11. Hufuatafuata wakubwa zake/Hajitegemei.....

12. Hulalamika akosapo kuona wengine/upweke.....

13. Huchanganyikiwa.....

14. Hulia sana.....

15. Hutesa wanyama.....

16. Hutesa/Husumbua wengine.....

17. Hupoteza uzingatifu/makini.....

18. Hujiumiza makusudi au hujaribu kujiua.....

19. Hutaka apendelewe sana.....

20. Huharibu vitu vyake mwenyewe.....

21. Huharibu vitu vya watu wa familia yake au vya wengine.....

22. Hatii nyumbani.....

23. Hatii shuleni.....

24. Hali vyema.....

25. Hana uhusiano mzuri na watoto wengine.....

26. Hajisikii makosa yake hata baada ya kuyatenda/kuyafanya.....

27. Ana wivu.....

28. Hula na hunyua vitu hata kama haviliwi wala kunywewa (si peremende au pipi) (eleza).....

29. Huogopa baadhi ya wanyama, hali zingine au mahali kwingine ila shule (eleza).....

30. Huogopa kwenda shuleni.....

31. Huogopa aweza kufikiria au kutenda/kufanya jambo mbaya.....

32. Hujifikiria yeye hafai kuwa na makosa ama kasoro yoyote.....

33. Huchulia au hulalamika kwamba hakuna ampendaye.....

34. Huchukulias wengine wanamtega/humwonea.....

35. Hujihisi, hujifikiria yeye hana maana au yeye ni bure/duni, hawezi chochote.....

36. Hujeruhiwa jeruhiwa.....

37. Hupigana sana na wengine.....

38. Wengine humchokoza sana.....

39. Hupendelea kwandamana na watoto wachokozi na watundu/ambao huwa mashakani ama ambao hujikuta kwa shida.....

40. Husikia sauti sizizosikika na wengine (eleza).....

41. Hutenda bila kufikiria.....

42. Hupenda kujitenga sana au kuwa peke yake.....

43. Hudanyanya/Husema uongo.....

44. Huuma huuma kucha/hutafuna kucha.....

45. Ana wasiwasi.....

46. Kuyumbayumba/kuhamahama (eleza).....

47. Ndoto mbaya.....

48. Hapendwi na watoto wengine.....

49. Husumbuka anapokunia/kinyezi kutotoka kwa urahisi.....

50. Huogopa sana au mwenye wasiwasi.....

51. Huona kizunguzungu.....

52. Hujichukulia mwenye makosa sana.....

53. Hula zaidi ya kiasi.....

54. Huchoka sana.....

55. Mnene zaidi ya kiasi.....

56. Shinda za kimwili zisizo na tiba.

    a) Uchungu na kuumwa.....

    b) Huumwa na kichwa.....

    c) Hujisikia kama kutapika.....

    d) Shida za macho (eleza).....

    e) Kuparara au magonjwa ya ngozi.....

    f) Huumwa na tumbo au hukazwa na matumbo.....

    g) Kutapika.....

    h) Mengine (eleza).....

57. Hushambulia watu.....

58. Hujikunakuna pua, hukuna ngozi ya mwili au sehemu zingine za mwili (eleza)

59. Hugusa/Hucheza na sehemu zake za siri hadharani au mbele ya watu.....

60. Hucheza na sehemu zake za siri sana.....

61. Kazi mbaya ya shuleni.....

62. Hukosa mpango wa kazi yake.....

63. Hupendelea kukaa na watoto walio wakubwa kuliko yeye.....

64. Hupendelea kukaa na watoto wadogo kuliko yeye.....

65. Hukataa kusema/kuongea.....

66. Hurudia mambo Fulani mara kadha (eleza).....

67. Hutoroka nyumbani.....

68. Hulia sana kwa hofu.....

69. Hujificha sana mambo yake.....

70. Huona mambo yasioonekana au vitu visioonekana na watu wengine (eleza)

71. Huaibika.....

72. Ana tabia ya kuwasha moto.....

73. Shida za jinsia/ngono (eleza).....

74. Hujionyesha .....

75. Huona haya.....

76. Hulala kidogo akilinganishwa na watoto wengine.....

77. Hulala zaidi ya watoto wengine wakati wa mchana au usiku (eleza)

78. Hucheza au hujichafua kwa kinyezi (mavi).....

79. Ana shida ya kuongea (eleza).....

80. Kutazama bila kufikiria.....

81. Huiba nyumbani.....

82. Huiba nje ya nyumbani.....

83. Huweka vitu asivyo vihitaji (eleza).....

84. Tabia zisizoeleweka (eleza).....

85. Mawazo/mafikira yasiyoeleweka (eleza).....

86. Si mtiifu hukasirika.....

87. Hali zake hubadilikabadilika/hufurahi na hukasirika haraka...

88. Hukasirika sana.....

89. Hushuku/hufikiria watu wengine visivyo.....

90. Huapa au hutumia lugha chafu.....

91. Hutishia kujiua.....

92. Hutembea au hunena akiwa amelala (eleza).....

93. *Huongea sana*.....

94. Hukasirika makusudi.....

95. Huwa na hasira nyingi sana.....

96. Hufikiria sana mambo ya ngono.....

97. Hutisha watu.....

98. Hunyonya kidole cha gumba/kidole kikubwa.....

99. Hushughulika sana na usafi.....

100. Hupata shida kabla ya kupata usingizi (eleza).....

101. Hutoroka shuleni.....

102. Hana nguvu au uwezo wa kutenda kwa haraka/mnyonge....

103. Haonyeshi furaha na pia huhuzunika.....

104. Huongea na sauti ya juu kuliko kawaida.....

105. Hutumia pombe au dawa za kulevya (eleza).....

106. Huharibu vitu.....

107. Hujikojolea mchana.....

108. Hukojoa kitandani.....

109. Hulalamika.....

110. Hupendelea kuwa wa jinsia tofauti na yake.....

111. Hujitenga na wengine.....

112. Huwa na hofu.....

Tafadhali andika shinda zingine ambazo unaziona na mtoto wako lakini hazijatajwa hapa. a) ..... b) ..... c).....

APPENDIX D

Scoring System of the Child Behaviour Checklist

1. Compute the total behaviour problem sore by summing up the Os, Is and 2s entered for the child by the parent.
2. Where more than one problem has been entered for item 113, the one having the highest score should be counted.
3. Where a parent has entered a problem for item 56th or 113th that is not covered by another item in the CBCL, include the score for 56th or 113th.
4. Cross-check the total behaviour problem score through subtracting the number of items scored as present from the sum of 1s and 2s entered by the parent in the CBCL.
5. Check the total behaviour score of each study case against the cut-off points to determine which cases show psychological morbidity and which case do not manifest symptomatology as provided in the table below.

This represents the cut off points of total behaviour problem scores marking the limit of normal and pathological levels. Scores greater than the ones indicated are in the pathological level and vice versa, the level index being from 0 to 240, according to the manual (41).

Cutoff Points for Behavioural Assessment Scores.

Age groups	Females Scores	Males Scores
4 – 5	42	42
6 – 11	37	40
12 – 16	37	38

APPENDIX E

List of Studies Done Using Child Behaviour Checklist.

1. Achenback, T. M, & Eldelbrock, C. S. 1981; 46 - 188.
2. Benjamin, P. Y., Levinshon, M., and Hauson, E. Intellectual and emotional sequelae of Reyes Syndrome. 1992; 10: - 587.
3. Cohen-Sandler, R., Berman, A.L., and King, R. A., A. follow-up study of hospitalized suicidal children.1992; **21**: 398 - 403.
4. Feinstein, C. B., Egan, J., and Couners, C. K. A survey of depressive symptomatology in a child.1980; 1:1
5. Frame, C., and Matson, J. L. Behavioural treatment of depression in a prepubertal child. 1992; **13**; 239 – 243.
4. Hermann, B. P. Neuropsychological functioning and psychopathology in children with epilepsy. 1982; **23**:545 – 554.
5. Mash, E.J. and Johnston, C. Parental perceptions of child behaviour problems. Journal of Consulting and Clinical Psychology. 1983; **51**: 86 – 99.
6. Mash, E. J., John, C., and Kovitz, K. A. A. comparison of the mother – child interactions of physically abused and non-abused children during play and task situations. Journal of Clinical Child Psychology.
7. McArdle, J., and Brown, C., H. Prevalence of behaviour problems in 6 to 12 year old girls and boys in a rural community. American Academy of Child Psychiatry. Washington D.C. 1992; 1:2.

9. Michael, R. L., Salszman, L. F., and Dainer, K. K. Normalizing effects of methylphenidate on hyperactive children's vigilance performance and evoked potentials. Journal of Psychophysiology.1991; **18**: 665 – 677.

10. Mitchell, M. K. The effects of Hodgkin's disease on the socializing skills of adolescents. 1992.

11. Sawyer, M. G., Minde, K., and Zuker, R. The burned child – scarred for life? A study of the psychosocial impact of a burn injury at different developmental stages. 1982; **9**:205 – 213.

APPENDIX F

Informed Consent Explanation:

Psychological Aspects of the Paediatric Cancer Patients in Kenyatta National Hospital

There are various psychological aspects associated with paediatric cancer. This study seeks to establish the main psychological disorders and other related aspects of paediatric cancer in- patients in Kenyatta National Hospital. The results of the study will be used for purposes of providing diagnostic and therapeutic services for the paediatric oncology population.

You are required to provide information that is true to the best of your knowledge by responding to the questions asked. There are no invasive procedures involved and no potential or actual harm can befall you/your child through participation. Participation is fully voluntary and your anonymity is guaranteed, as the information obtained will be treated confidentially. After the interview, you will benefit from diagnostic and psychotherapeutic services for you including your child and also referral to other appropriate treatment if need be. You are free to withdraw at will at any stage without any adverse consequences to you.

In case of any questions relating to your participation in the study, please contact the investigator,

Ibari G. Kirimi

Faculty of Medicine

University of Nairobi

Kenyatta National Hospital

P.O. Box 19676

Nairobi.

Telephone: 2726300, Ext: 43562

APPENDIX G

Consent Form

I hereby consent to participate in the study entitled "Psychological Aspects of the Paediatric Cancer Patients in Kenyatta National Hospital", the nature and purpose of which I fully understand as explained to me.

Participant signature: _____

(If under 18 years, Parent/Guardian signature: _____

Date: _____

Investigator's Name: _____

Location: _____

Serial No.: _____

APPENDIX H

Flow Chart