

Association between Socioeconomic and Psychological Experiences of Parents with Children on Leukemia Treatment in Kenyatta National Hospital, Kenya

Roselyne Anyango Okumu¹, Margret Muiva², Miriam Wagoro³, Fatmah Abdallah⁴, Erick Oweya⁵

¹Cancer Treatment Centre, Kenyatta National Hospital, Departments of ²Nursing Education and Oncology and ³Mental Health, School of Nursing Sciences, University of Nairobi, ⁴Department of Hematology and Blood Transfusion, School of Medicine, University of Nairobi, Nairobi, Kenya, ⁵Department of Extramural, University of Nairobi, Kikuyu Campus, Nairobi, Kenya



Corresponding author: Roselyne Anyango Okumu, MScN Oncology

Cancer Treatment Centre, Kenyatta National Hospital, Nairobi, Kenya

Tel: +254(0)722 322092

E-mail: rozyokumu@yahoo.com

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ABSTRACT

Objective: The survival rate for children with leukemia has increased dramatically since the late 1990s; treatment effects of the disease can be extremely stressful for families. Research on psychological and socioeconomic effects of leukemia treatment had been conducted in Western countries, but little is known within Africa including Kenya.

Methods: This was a cross-sectional study with a sample of 62 out of 72 parents of children undergoing leukemia treatment at Kenyatta National Hospital. Data were collected between May and August 2015 using structured questionnaires while qualitative data were collected using focus group discussions. This manuscript is based on quantitative data which were entered into EpiData version 3.1 and analyzed using SPSS

version 20. Psychological distress index was created by counting the number of psychological experiences reported by respondents. Kendall's tau-b was used to test the association between the psychological distress index and socioeconomic characteristics; $P \leq 0.05$ was considered statistically significant.

Results: The respondents experienced anxiety, shock, and fatigue. Spending a higher proportion of family's income was associated with higher psychological distress index ($P = 0.009$). The economic challenge led to significantly heightened tension in the family ($P = 0.021$). **Conclusions:** Financial challenge is a major cause of psychological distress thus needs for financial support through collaboration with government institutions, for example, NHIF, development agencies, and nongovernment

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organization who can contribute toward the treatment cost. Need to decentralize effective leukemia treatment centers. Psychological support and counseling should be done to alleviate tension. The nurse needs to be empathetic when caring for the child and family as well as to apply the ethical

principles of justice and beneficence so that the child gets the best care despite the financial challenge.

Key words: Child, parent, psychological distress index, socioeconomic, treatment

Introduction

Leukemia is a type of cancer of the blood or bone marrow characterized by an increase of abnormal white blood cells.^[1] Some signs and symptoms of leukemia include fever, chills, fatigue, frequent infection, anorexia, petechia, swollen tender lymph nodes, bleeding gums, bone/joint pain, and cranial nerve palsies.^[2] Leukemia treatment leads to prolonged hospitalizations and interrupted schooling. Parents grieve and they must cope with anxieties, fears, and frustration brought about by interactions with the sick child. Parents also need to integrate the child's needs into established family routines and to manage the strain in social, economic, and psychological aspects of family life.^[3]

Statement of the problem

Worldwide, the diagnosis of childhood leukemia has an important psychological impact on the child and its family, who are faced with a life-threatening illness. In 2014, the American Cancer Society estimated that almost 16,000 children would be diagnosed with cancer/leukemia in the USA.^[4] Fortunately, as a result of improved therapies, survival among pediatric cancer patients is high, with more than 80% living beyond 5 years from diagnosis.^[5] Understandably, the psychological, sociologic, and financial effects of the disease can be extremely stressful for families.^[6]

Although almost 70% of pediatric cancer patients survive 10 years, the cancer experience can be distressing for parents and children.^[7] This affects parents' psychological and physical health. Psychological, economic, and social problems created or exacerbated by leukemia treatment on the child's parents leads to increased demands and threaten patients' return to health.^[8] Few studies have been conducted to document these issues, particularly from the perspective of the parents who care for a child with cancer. In Kenya, there is no study that has been conducted to find out the relationship between socioeconomic and psychological experiences of parents whose children are undergoing leukemia treatment.

Problem justification

The experience of pediatric cancer patient is different from that of adults with cancer because the whole family particularly the parents, and in some cases, the grandparents are usually completely involved in the child's illness.^[6] It has been reported that parents can develop posttraumatic stress disorder from dealing with a child's illness. Siblings may be ignored by parents who are preoccupied with the

sick child and who may be absent from home.^[7] In addition to the disruptions of family dynamics, financial hardship associated with caring for a child with leukemia as a source of psychological distress to the parents.^[8]

Most research on psychological experiences of parents whose children are undergoing leukemia treatment has been conducted in Western countries; thus little information is available on the parental experiences in non-Western countries.^[3] In Africa, especially in Kenya, little is known about the influence of socioeconomic on psychological experiences by the parents when their children are undergoing leukemia treatment.

Purpose of the study

The purpose of this study was to explore the association between the socioeconomic and psychological experiences of parents whose children were undergoing leukemia treatment at Kenyatta National Hospital (KNH).

Methods

This was a descriptive cross-sectional study. The research had both quantitative and qualitative data (collected through focus group discussions). However, this manuscript is mainly informed by the quantitative aspect. Structured questionnaires were administered to collect both open- and closed-ended responses.

Research setting and population

The study was carried out in KNH (the largest teaching and referral hospital in Kenya) which provides specialized services to cancer patients. The study population consisted of consenting parents and guardians of children (below 15 years) undergoing leukemia treatment at KNH.

Participant recruitment process

Parents and guardians of children (aged 15 years or below) undergoing leukemia treatment in hemato-oncology clinic, pediatric oncology ward, and other general pediatric wards with oncology units were considered eligible for the study. The researcher approached the potential respondents individually, explained the aims of the study and offered them an opportunity to participate in the study. Consenting respondents were recruited.

Sample size determination and formula

From the health records, KNH treats an average of 72 pediatric leukemia cases at any time of the year (either as

outpatients or inpatient). The treatment of one child takes an average of 6 months. A sample size of 62 respondents was determined using Yamane Taro (1967:886) formula. Due to lack of a sampling frame, it became impossible to obtain a random sample, as such the first 62 willing parents and guardians were offered the chance to participate in the study. This represents 93.9% response rate, four having declined to participate but they were replaced.

Research instrument

The respondents were interviewed by the researcher and responses recorded in a structured questionnaire which had both open- and closed-ended questions. The questionnaire was translated from English into Kiswahili for ease of understanding, using translation and back-translation method. It was pretested in one of the hemato-oncology wards in KNH to ascertain its reliability and validity, these informed minor adjustments before the actual data collection. Completing a questionnaire took between 30 and 40 min.

Some ideas were borrowed from the National Comprehensive Cancer Network (USA) problem list, but there was a need to have others added from the pilot study findings. This necessitated the need to create a different measure of psychological distress index.

Data collection procedure

Both qualitative and quantitative data were collected; however, this manuscript is based on quantitative data which were collected on the demographic characteristics of the respondents as well as their psychological and socioeconomic experiences. Each questionnaire was then verified for completeness at the end of the interview. The actual data collection was between May and August 2015 in all pediatric oncology units at KNH.

Ethical considerations

Permission to carry out this study was granted by the joint Ethics and Research Committee of the KNH and University of Nairobi College of Health Science (KNH/UON-ERC). Clearance to conduct the study was obtained from KNH Research Department. Permission was granted from KNH administration as well as the specific ward managers.

The purpose of the research, risks, and benefits was explained both verbally and in writing to participants who, in turn, gave written informed consents. Those who did not opt to join the study were assured of no negative consequences. Confidentiality and privacy were ensured using password-restricted access to computer documents; materials in hard copy were kept under lock and key, anonymity was guaranteed using respondents' codes.

Data management and analysis

At the end of each session, the researcher reviewed each questionnaire to ensure completeness and clarity. An EpiData version 3.1 (270108) database was used for data entry to enforce validation checks while verification was accomplished using double entry, comparison, and correction. The epi data was manufactured by the "Epi data Association, Odense, Denmark." Data analysis was done using Statistical Package for Social Sciences (SPSS) Statistics version 20, manufactured by International Business Machine Corp, Newyork, USA.

Respondents mentioned the distressing psychological experiences they went through due to the children's leukemia treatment, for example, anxiety, shock (trauma), and fatigue. A binary variable was used to capture the psychological experiences with 1 representing the presence of a specific psychological experience and 0 otherwise. A psychological distress index was created by counting the number of psychological experiences reported. Reliability of the psychological experiences was tested using Cronbach's alpha; with a value of 0.7, thus the tool was considered adequately reliable.

Due to nonnormality of the psychological distress index, Kendal tau-b was used to measure the association between the psychological distress index and various demographic and socioeconomic characteristics of respondents. Lower $P \leq 0.05$ was used to indicate statistically significant associations. Quantitative data were presented in tables, graphs, and charts.

Results

The study results were documented starting from psychological experiences then demographic characteristics. This was followed by association between psychological distress index and economic as well as social characteristics.

Psychological experiences

This was reported in terms of shock, anxiety, fatigue, and anger as shown in Figure 1.

Association between psychological distress index and demographic characteristics of respondents

There were no significant correlations found between psychological distress index and the personal characteristics, for example, age, gender, level of education, place of residence, and education [Table 1].

Association between psychological distress index and economic characteristics

Socioeconomic characteristics included family's monthly income, the percentage of income used on the child's

treatment, mode of payment of hospital bills, health insurance, and availability of people who contribute to the sick child's well-being either financially or otherwise. There was a significant association between percentage of income spent and psychological distress index [Table 2].

Modality of payment of hospital bill

Majority of the respondents had the National Hospital Insurance Fund (NHIF) as shown in Figure 2.

Association between psychological distress index and social characteristics

The social characteristics considered in the study included relationship of the breadwinner to the sick child, whether the child had other relatives who contributed to their well-being and the effect of child's treatment on the family unit. There was a significant association between heightened tension as well as strained finances with psychological distress index [Table 3].

Discussion

The majority of the respondents were living outside Nairobi County, in line with the International Atomic Energy Agency that in Kenya; patients with cancer have to travel from across the country as far as 600 kilometers to access treatment which is available mainly in the capital city^[9] in Nairobi. The long distance traveled may be a barrier to patients and families receiving good quality of life. The distance may lead to inability to get to medical appointments or to buy drugs, groceries, and to participate in peer support. This finding is supported by the American Cancer Society and Cancer Care report that they received more than 100,000 requests annually for transportation, so patients can get to medical appointments, pickup medications, or receive other health services.^[8]

There was no significant association between other demographic characteristics and respondents' psychological distress index. This is further explained that factors more than demographics may affect the outcome of psychological distress index.^[10]

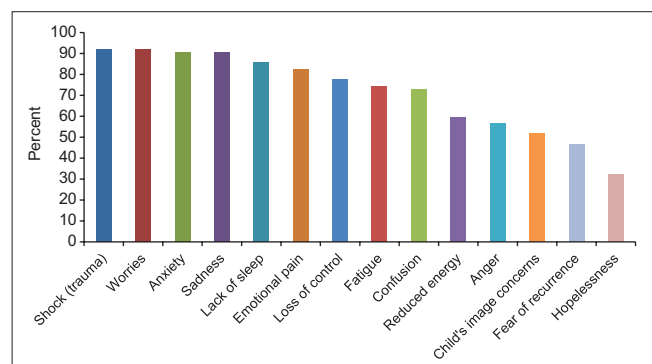


Figure 1: Main psychological experiences

Leukemia diagnosis and treatment caused distressing psychological effects on the parents and guardians. The respondents were traumatized, anxious, and fatigued. This is similar to previous findings that parents of children with cancer report feelings of anxiety and depression.^[11] The majority of the respondents had emotional pain. This is supported by the findings of the Children's Cancer and Leukemia Group^[12] that parents become worried and stressed as they come to terms with the diagnosis and what it means for the child to go through treatment. Strained family finances and heightened tension in the family were significantly associated with psychological distress index as supported by^[13] that impact of treatment of childhood cancer on parents includes negative impact of financial costs and changes or tension in marital relationships.

Limitations

Use of nonvalidated measure in the study through the creation of psychological distress index tool as well as recall bias because the researcher was not able to observe

Table 1: Association between psychological distress index and demographic characteristics of respondents (n=62)

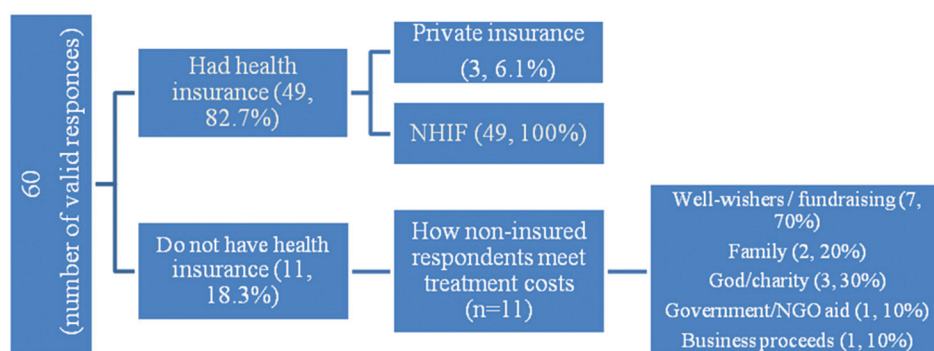
Characteristics	Frequency	Percentage	Kendall's correlation coefficient	P
Age (years)			0.141	0.177
20-29	22	35.5		
30-39	29	46.8		
40-49	8	12.9		
50-59	2	3.2		
Over 60	1	1.6		
Gender			0.122	0.271
Male	7	11.3		
Female	55	88.7		
Marital status			-0.006	0.956
Single	13	21.0		
Married	45	72.6		
Separated	1	1.6		
Widowed	3	4.8		
Residence			0.059	0.536
Nairobi	14	22.6		
Outside Nairobi	48	77.4		
Highest level of formal education			-0.012	0.909
None	3	4.8		
Primary	31	50.0		
Secondary	20	32.3		
College	5	8.1		
University	3	4.8		
Type of employment			0.164	0.126
Regular/permanent employment	8	12.9		
Casual employment	15	24.2		
Unemployed	39	62.9		

Table 2: Association between psychological distress index and economic characteristics

Economic characteristics	Income in dollars (USD)	n	Frequency	Percentage	Kendall's correlation coefficient	P
Family's monthly income	0-50	49	23	46.9	-1.51	0.195
	51-100	49	14	28.6		
	101-200	49	6	12.2		
	201-500	49	5	10.2		
	501-1000	49	1	2.04		
Percentage of monthly income spent on child's treatment (answered by parents only) (%)	<1/2	48	5	10.4	0.289	0.009
	50-99	48	22	45.8		
	100	48	17	35.4		
Have health insurance	Yes	60	49	81.7	-0.119	0.292
	No	60	11	18.3		
Insurance meets all the illness cost of treatment	Yes	49	3	6.1	0.011	0.933
	No	49	46	93.9		
Have experienced inability to buy medication or pay hospital bills	Yes	59	52	88.1	-0.107	0.349
	No	59	7	11.9		

Table 3: Association between psychological distress index and social characteristics (n=62)

Characteristics	Respondents/responses	Frequency	Percentage	Kendall's correlation coefficient	P
Main bread winner in the sick child's household	Father	35	56.5	0.050	0.634
	Mother	17	27.4		
	Grandparent	3	4.8		
	Other	1	1.6		
	Both parents equally	6	9.7		
Child has people who contributing to their wellbeing	Yes	39	62.9	-0.059	0.596
	No	23	37.1		
Effects of leukemia treatment on the family unit					
Strained finances	Yes	59	95.2	-0.223	0.045
	No	3	4.8		
It has restricted social interaction	Yes	51	82.3	-0.099	0.371
	No	11	17.7		
It has heightened tension in the family	Yes	25	40.3	-0.256	0.021
	No	37	59.7		
Brought emotional conflict	Yes	51	82.3	0.066	0.175
	No	11	17.7		
Brought the family closer	Yes	36	58.1	0.033	0.767
	No	26	42.9		

**Figure 2: Modality of payment of hospital bill**

directly some aspects of socioeconomic and psychological experiences parents could have been going through.

Conclusion

Leukemia diagnosis and treatment posed psychological distress which manifested in the form of shock, anxiety, worries, anger, sadness, and fatigue. The respondents experienced financial hardship as well as challenge of traveling long distance to receive a very critical treatment that their children required. There were increased levels of tension in the family as a result of leukemia diagnosis and treatment.

Recommendations

The Kenyan Government needs to develop programs for parents who care for children with catastrophic illnesses so that parents do not have to struggle financially to provide treatment for the child with leukemia. This can be done through ensuring that parents have NHIF and that it pays for all the treatment cost. The development agencies as well as nongovernmental bodies should collaborate with the government and public hospitals to ensure adequate financial support for treatment of leukemia and other cancer; this can be done through donations in the form of kind or cash. Of importance is also decentralization of effective leukemia treatment to other parts of the country to reduce the distance traveled by patients and families.

There is a need to provide psychological support to parents with children on leukemia treatment through assessment of psychological distress level and counseling as well as offering appropriate psychological support. The nurse should encourage parents to get periods of rest to avoid fatigue. In case, the manifestation of psychological distress is extreme, then there may be need to consider anxiolytics as well as to refer to a psychologist. To alleviate tension and anxiety, the nurse needs to share adequate information concerning the diagnosis and treatment with the family, thereby helping the family to see prospects of treatment and enhance their sense of control of the situation.

The nurse should do a comprehensive assessment of the child regarding the illness and socioeconomic status of the family. Comprehensive cancer care should ensure the provision of appropriate psychosocial care. The nurse should facilitate effective communication between patients, their families, and care providers, identifying psychosocial health needs, designing and implementing a plan that links the patient/family with needed health-care services, coordinates biomedical and psychosocial health-care services. He/she needs to participate in identifying the

most appropriate treatment for the child considering the cost implications as well as the efficacy. The nurse needs to administer the treatment in a professional manner as well as to give health education to the child and the family on treatment process, and how to manage side effects. The nurse needs to support patients and families in managing their illness and health and to systematically monitor, evaluate, and readjust plans. Throughout the treatment process, there is a need for the nurse to remain ethical, apply the principle of beneficence and justice as well as being empathetic to the child and the family. These would allay the anxiety as well as help the child receive the best care despite the financial challenges because having a child on leukemia treatment is very difficult emotionally and financially.

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Conflicts of interest

There are no conflicts of interest.

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