

Leukemia among caretakers of children below 15 years attending Uganda Cancer Institute. A Cross-Sectional Study.

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Abstract

Background

Childhood leukemia is a significant health concern globally, representing a considerable proportion of cancer diagnoses in children under 15 years of age. The study aims to assess the knowledge and attitudes towards leukemia among caretakers of children below 15 years attending the Uganda Cancer Institute.

Methodology:

A cross-sectional descriptive design to assess the knowledge and attitudes of caretakers of children with leukemia attending the Uganda Cancer Institute in Kampala. A sample size of approximately 119 mothers was determined using convenience sampling. Data were analyzed using statistical software SPSS. Descriptive statistics were used to summarize sociodemographic characteristics, knowledge levels, and attitudes of caretakers.

Results

A total of 119 children were involved in the study over the period, and their caretakers were tested for their level of knowledge regarding leukemia. The data analyzed showed that 54(45.38%) caretakers had low knowledge about leukemia, followed by 35(28.57%) caretakers having moderate knowledge and 31(26.05%) having high knowledge about leukemia in their children. The majority of caretakers (37.9%) have a negative attitude towards childhood leukemia. This includes fear, stigma, or misconception about the disease. A considerable number (31.9%) had a neutral attitude, indicating uncertainty or lack of clear understanding. Only 30.3% of the caretakers demonstrated a positive attitude, suggesting that fewer caretakers are open to early diagnosis, treatment, and support for affected children.

Conclusion

The study highlights a concerning lack of knowledge among caretakers regarding childhood leukemia, with the majority exhibiting low levels of understanding about the disease. This gap in awareness is critical, as it may hinder timely diagnosis and treatment for affected children. The attitudes of caretakers towards childhood leukemia reveal a predominance of negativity.

Recommendations

There should be implementation of comprehensive educational initiatives aimed at caretakers to improve their understanding of childhood leukemia.

Keywords: Leukemia, Children below 15 years, Uganda Cancer Institute, Knowledge and Attitude

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Background

Childhood leukemia is a significant health concern globally, representing a considerable proportion of cancer diagnoses in children under 15 years of age. In Uganda, the incidence of childhood leukemia is increasing, with the Uganda Cancer Institute being a primary referral center for pediatric oncology (Uganda Cancer Institute, 2020). The diagnosis of leukemia not only affects the child but also has profound implications for the family, especially caretakers who often assume the primary caregiving role. Understanding the knowledge and attitudes of caretakers regarding their child's illness is crucial for improving health outcomes and providing adequate support (Afolabi *et al.*, 2019). Caretakers are typically the main decision-makers in

healthcare for their children. Their knowledge about leukemia, its symptoms, treatment options, and potential outcomes can significantly influence their child's treatment adherence and overall well-being (Raghavan *et al.*, 2020). However, there is a concerning lack of research focusing specifically on the knowledge and attitudes of caretakers in Uganda regarding childhood leukemia. This gap in the literature highlights the need for comprehensive studies to explore these dimensions and inform healthcare practices. Caretakers of children suffering from Leukemia are expected to have adequate knowledge and a positive attitude towards the disease so that they can seek immediate care and follow the medication prescription; failure to understand the condition leads to fear and stigma surrounding cancer,

which may delay seeking appropriate medical care and adherence to treatment regimens (Kumar *et al.*, 2021). Despite advancements in cancer treatment creating awareness, it's not clear whether caretakers having children with leukemia at Uganda Cancer Institute have adequate knowledge and attitude towards the disease; therefore, this study aims to determine the knowledge and attitude of caretakers having children with leukemia below 15 years of age. Furthermore, caretakers' attitudes towards their child's illness can impact their emotional well-being and coping mechanisms (Sullivan *et al.*, 2018). There is a pressing need to assess these factors to enhance support systems for families affected by childhood leukemia. The study aims to assess the knowledge and attitude towards leukemia among caretakers of children below 15 years attending Uganda Cancer Institute.

Methodology

Research design

This study employed a cross-sectional descriptive design to assess the knowledge and attitudes of caretakers of children with leukemia attending the Uganda Cancer Institute in Kampala. This design was appropriate as it allowed collection of data at a single point in time, providing a snapshot of the mothers' knowledge and attitudes, which can be correlated with sociodemographic factors.

Study setting

The research was conducted at the Uganda Cancer Institute (UCI) in Kampala, which serves as a primary referral center for pediatric oncology in Uganda. The UCI provides comprehensive cancer care, including diagnosis, treatment, and support services for children diagnosed with leukemia and their families.

Study population

The target population for this study was caregivers of children under 15 years of age who have been diagnosed with leukemia and are currently receiving treatment at the Uganda Cancer Institute.

Sample size determination

The study sample size was determined according to the following formula for cross-sectional studies Sekalan *et al.*, 2012.

$$N = \frac{Z^2 P(1-p)}{D^2}$$

Where N=desired sample size

Z=Number of standard deviations usually set at 1.96, which corresponds to a 95% level of confidence.

P=Target population estimated to have a particular characteristic. In the absence of a known

D= degree of accuracy level, which is 0.09(9%)

(1-p) is the proportion of the population without a

characteristic. Using the above formula: $N = 1.96^2 \times 0.5(1-0.5)$

$$= 119.0$$

Therefore, the sample size is 119.

Inclusion criteria included:

Caretakers with children diagnosed with leukemia.

Exclusion criteria included:

Caretakers whose children have been diagnosed with leukemia for less than three months.

Sample Size and Sampling Technique

The sample size of approximately 119 mothers was determined using convenience sampling. This method was chosen due to its practicality in a clinical setting where participants are readily available. The sample size was calculated to ensure sufficient power to detect significant differences in knowledge and attitudes based on sociodemographic factors.

Data collection tools

Data were collected using a structured questionnaire developed specifically for this study. The questionnaire consisted of three main sections:

Sociodemographic Information: This section gathered data on the caretaker's age, education level, socioeconomic status, marital status, and cultural background.

Knowledge Assessment: This section included multiple-choice questions designed to evaluate caretakers' knowledge about leukemia, its symptoms, treatment options, and potential outcomes.

Attitude Assessment: This section utilized a Likert scale to assess caretakers' attitudes towards their child's illness, treatment adherence, and interactions with healthcare providers. Statements will cover areas such as feelings about treatment, perceived support from healthcare providers, and beliefs about cancer.

Data collection procedure

Data collection took place at the Uganda Cancer Institute during scheduled outpatient visits. Trained research assistants administered the questionnaires to caretakers who consented to participate in the study. Informed consent was obtained from all participants before data collection, ensuring that they understood the purpose of the study and their rights as participants.

Data analysis

Data were analyzed using statistical software (e.g., SPSS). Descriptive statistics were used to summarize sociodemographic characteristics, knowledge levels, and attitudes of caretakers. Inferential statistics, including chi-square tests and t-tests, will be used to explore relationships between sociodemographic factors and knowledge/attitude

scores.

Ethical considerations

Ethical approval for the study was obtained from the

Institutional Review Board of the Uganda Cancer Institute. Participation was voluntary, and confidentiality was maintained throughout the research process. Participants had the right to withdraw from the study at any time without any repercussions.

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Results

Social demographic characteristics of the study participants.

Table 1: Social demographic characteristics of the mother.

Variable	Frequency (n=119)	Percentage (%)
Residence		
Urban area	32	26.9
Rural area	87	73.1
Marital status		
Married/cohabiting	26	21.8
Single	18	15.1
Divorced	50	42.0
Widowed	25	21.0
Education level		
Primary	23	19.3
Secondary	51	42.9
Tertiary	17	14.3
None	28	23.5
Occupation		
Civil servant	17	14.3
Peasant	53	44.5
Self employed	49	41.2

Most children were female (50.5%), with ages ranging from 1-15 years. When grouped by age, the majority were between 5-9 years (44.5%), with a mean age of 6.5 years, while the smallest were between 0-4 years, with a percentage of 11.8%. The demographic characteristics of the enrolled children are shown in the table below. The majority of the caretakers were in rural areas (73.1%), with the majority

of the caretakers divorced (42.0%), followed by married/cohabiting (21.8%), then widowed (21.0%), and the least single (15.1%). More than half of the enrolled parents (42.9%) had secondary level education, (19.3%) had primary level education, (14.3%) had tertiary level education, and (23.5%) had no educational background. The majority of the parents were peasant workers (44.5%).

Table 2: Social demographic characteristics of the children.

Variable	Frequency (n=119)	Percentage (%)
Gender		
Male	59	49.6
Female	60	50.4
Child's age group		
0 - 4 years	14	11.8
5-9 years	53	44.5
10- 15 years	52	43.7

Level of knowledge of mother regarding leukemia in children.**Table 3: Level of knowledge of caretakers regarding leukemia in children.**

Level of knowledge of mother regarding leukemia in children	Frequency (n=119)	Percentage (%)
Low knowledge	54	45.38%
Moderate knowledge	34	28.57%
High knowledge	31	26.05%
Total	119	100

A total of 119 children were involved in the study over the period, and their mothers were tested for their level of knowledge regarding leukemia. The data analyzed showed that 54(45.38%) mothers had low knowledge about leukemia, followed by 35(28.57%) caretakers having

moderate knowledge and 31(26.05%) having high knowledge about leukemia in their children. This shows that the majority of mothers fall under low knowledge, which suggests a significant gap in awareness about childhood leukemia.

Attitudes of caretakers towards Childhood Leukemia.**Table 4: Attitudes of caretakers towards Childhood Leukemia**

Attitude	Frequency (n-119)	Percentage (%)
Negative attitude	45	37.8%
Neutral attitude	38	31.9%
Positive attitude	36	30.3%
Total	119	100

The findings show that the majority of caretakers (37.9%) have a negative attitude towards childhood leukemia. This includes fear, stigma, or misconceptions about the disease. A considerable number (31.9%) had a neutral attitude, indicating uncertainty or lack of clear understanding. Only 30.3% of the caretakers demonstrated a positive attitude, suggesting that fewer caretakers are open to early diagnosis, treatment, and support for affected children.

Discussion

A total of 119 children were involved in the study over the period, and their caretakers were tested for their level of knowledge regarding leukemia. The data analyzed showed that 54(45.38%) caretakers had low knowledge about leukemia, followed by 35(28.57%) caretakers having moderate knowledge, and 31(26.05%) having high knowledge about leukemia in their children.

This shows that the majority of caretakers fall under low knowledge, which suggests a significant gap in awareness about childhood leukemia.

The study findings were similar to the study conducted by (Bloch *et al.*, 2014) in Kenya at Kenyatta National Hospital, which found out an occurrence of leukemia disease was 50(48.3%). The deviation or variation in the knowledge rates might have been due to differences in the sample size used, geographical location, among others, or population differences.

The findings show that the majority of caretakers (37.9%)

have a negative attitude towards childhood leukemia. This includes fear, stigma, or misconceptions about the disease. A considerable number (31.9%) had a neutral attitude, indicating uncertainty or lack of clear understanding. Only 30.3% of the caretakers demonstrated a positive attitude, suggesting that fewer caretakers are open to early diagnosis, treatment, and support for affected children. This study finding was close to a study carried out in Lira, Uganda (Okello *et al.*, 2020), where only 33.0% had a positive attitude towards leukemia in children.

Conclusion

The study highlights a concerning lack of knowledge among caretakers regarding childhood leukemia, with a significant majority (45.38%) exhibiting low levels of understanding about the disease. This gap in awareness is critical, as it may hinder timely diagnosis and treatment for affected children. Furthermore, the attitudes of mothers towards childhood leukemia reveal a predominance of negativity, with 37.9% expressing fear and misconceptions about the disease. Only 30.3% of caretakers demonstrated a positive attitude, indicating a reluctance to engage in early diagnosis and support for children with leukemia.

Limitations

The use of convenience sampling limited the generalizability of findings to all caretakers of children with leukemia in

Uganda.

Self-reported data introduced bias; caretakers might provide socially desirable responses rather than their true beliefs or knowledge.

The cross-sectional design did not allow for causal inferences regarding the relationships between knowledge, attitudes, and sociodemographic factors.

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Recommendations.

Educational Programs: Implement comprehensive educational initiatives aimed at caretakers to improve their understanding of childhood leukemia. Workshops and informational sessions can help dispel myths and provide accurate information about the disease.

Support Groups: Establish support groups for caretakers of children with leukemia. These groups can offer emotional support, share experiences, and provide resources that can help alleviate fear and stigma.

Regular Screening and Awareness Campaigns: Conduct regular awareness campaigns in communities to promote early diagnosis and treatment. This can include partnerships with healthcare providers to facilitate screenings and informational outreach.

Involvement of Healthcare Professionals: Encourage healthcare professionals to engage with caretakers during medical visits, providing them with clear and empathetic communication about childhood leukemia and its management.

Research on Attitudes: Further research should be conducted to understand the underlying reasons for negative attitudes towards childhood leukemia among caretakers, which can inform targeted interventions to improve perceptions and knowledge.

List of acronyms

UCI: Uganda Cancer Institute

SPSS: Statistical Package for the Social Sciences

Source of funding

The study was not funded.

Conflict of interest

The author did not declare any conflict of interest.

Data availability

Data available upon request

Author contribution

Hellen Asizu collected data and drafted the manuscript of the study

Anthony Ssekitoaleko supervised the study

Francisco Semuwemba supervised the study

Hasifa Nansereko supervised the study

Jane Frank Nalubega supervised the study

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