

Assessment of level of hope of parents of children with cancer and associated factors among parents of children attending cancer treatment at Tikur Abessa Specialized Hospital, Addis Ababa, Ethiopia

by LIDIYA GIRMA

Submission date: 06-Jun-2024 11:34AM (UTC+0300)

Submission ID: 2396763779

File name: plagiarism_1_LIDIYA_GIRMA_THESIS,_2024_CD_p.docx (174.42K)

Word count: 8177

Character count: 45571



Abstract

Background: Childhood cancer (also called pediatric cancer) typically means different type of cancers that are found in children and teens, and sometimes young adults. Childhood cancers initiate from genetic alterations in individual cells, triggering their uncontrolled growth into masses or tumors. If left untreated, these tumors can infiltrate other bodily tissues, resulting in significant harm and potentially fatal consequences. When a child is diagnosed with cancer, the impact reverberates through the entire family, with parents bearing a significant emotional, economical and psychological burden and it makes the family to lose hope.

Objectives: To assess level of hope of parents of children with cancer and associated factor among children attending cancer treatment at Tikur Anbesa hospital, Addis Ababa, Ethiopia, 2024 G.C.

Methods: Health facility based cross-sectional study was conducted from February 19 to March 19, 2024 G.C at Tikur Anbesa hospital, Addis Ababa, Ethiopia. The data was gathered using structured pretested questionnaires and patient chart review by using Kobo collector. Then the data was exported to SPSS version 26 for analysis. Bivariate and multivariable linear regression analyses were conducted. A p-value of less than 0.05 was considered statistically significant.

Result: The overall score of hope level in parents of patients with cancer was 35.3 ± 4.68 . Among them, 10 cases (4.1%) had a low level of hope, 134 cases (55.4%) had a medium level of hope, and 98 cases (40.5%) had a high level of hope. Multiple linear regression analysis revealed that coping level and health status were independent factors influencing level of hope ($p < 0.05$).

Conclusion: As we navigate the complexities of pediatric cancer care, it is imperative for healthcare providers and support professionals to recognize the pivotal role of hope in parental well-being. By fostering hope and providing targeted support interventions, we can empower parents to navigate the challenges of childhood cancer with greater resilience and optimism. And by addressing the phenomenon of unrealistic hope, healthcare providers and support professionals can ensure that parents are supported with realistic expectations and provided with the necessary resources to navigate the challenges of childhood cancer with resilience and dignity.

Key words: Parents, Childhood cancer, Hope

1. INTRODUCTION

1.1. Background

Childhood cancer, often known as pediatric cancer, refers to various cancers that affect children, adolescents, and occasionally young adults (1). Childhood cancers start with genetic changes in single cells, much like adult cancers do. These changes then develop into a mass, or tumor, which spreads to other regions of the body and, if ignored, can be fatal. Childhood malignancies frequently differ from adult tumors in terms of their etiology, growth, and response to therapy (2).

The global cancer burden is mostly attributed to malignancies of childhood and adolescence (1). Annually, over 300,000 children and adolescents receive a cancer diagnosis globally(3). An estimated 29,000 children and adolescents under the age of 19 will be affected by cancer each year throughout Latin America and the Caribbean. Of these, roughly 10,000 will die from this disease (4).

Around 90% of pediatric cancer cases arise in low and middle-income countries. In these nations, over 80% of pediatric cancer diagnoses occur, yet less than 30% of patients survive due to limited access to diagnosis and treatment. In contrast, over 80% of pediatric cancer patients in high-income countries survive, highlighting the stark disparities in access to care and outcomes (5).

In Addis Ababa, Ethiopia, the average annual occurrence rate of cancer among children from 2012 to 2017 stood at 84.6 cases per million, with boys experiencing greater rates at 98.97 per million compared to girls at 69.7 per million. Over this period, there was a decline in the general cancer occurrence rate from 87.02 per million in 2012 to 51.07 per million in 2017(6).

The most prevalent types of childhood cancers globally encompass ² leukemia, brain cancers, lymphomas, and solid tumors like neuroblastoma and Wilms tumors (7). In Ethiopia, leukemia emerges as the most frequent childhood cancer, followed by lymphoma and renal tumors. (8).

The type of disease and its stage of progression will determine the kind of treatment a child with cancer receives. Treatments for common children malignancies include immunotherapy, chemotherapy, radiation therapy, surgery, and stem cell transplantation (9).

For families, children cancer is a significant and potentially life-altering disaster. Depending on the severity of the cancer and the health implications of treatment, children may require special care and resources. Therefore, it is reasonable to assume that this specific shock will have an impact on families' short and long-term financial well-being as well as their family dynamics and inadequate coping strategies (10).

Hope is a powerful tool for goal-setting and favorable outcomes, particularly in times of uncertainty, stress, or crisis (11). Hope is among the most valuable things in human life (12). It is a protective element necessary for life that may have a direct impact on health and happiness (11).

Parental hope is described as knowledge, conviction, or desire about the well-being of their child (13). It turns out that hope is the cornerstone that changes parents' life. Their children's cancer experience alters their outlook on disease and their own lives, allowing them to recover constructive coping mechanisms. Establishing hope, according to parents, lifted their spirits, encouraged acceptance, and made it possible for them to take care of their kids and themselves (14).

Hope is a particularly potent mechanism that helps parents of seriously ill children cope and build resilience. It influences the parents' decision making processes throughout the trajectory of their child's illness (15). A beneficial outcome of providing variables like parental comfort and care to family (16), among others, has been associated with an increase in hopefulness (17).

Parental hope plays a vital role in reducing psychological distress and maladjustment following a child's cancer diagnosis. Open communication between healthcare providers and parents is essential for nurturing and sustaining hope during this challenging time (18).

Supporting hope in pediatric oncology settings in low and middle-income countries can improve mood, promote acceptance, and enable parents to care for themselves and their children (14). Parents of children with cancer value hope and feel supported by healthcare professionals, who provide care, education, and a positive outlook (19).

1.2. Statement of The Problem

Usually, no known reason is identified when a child diagnosed with cancer. Parents find it extremely difficult, as they are left wondering why their child has cancer and whether there was anything they could have done to stop it. The whole family's life is turned upside down (20).

When a child got diagnosed with cancer, the impact reverberates through the entire family, with parents bearing a significant emotional, economical and psychological burden. Moreover, the family's financial resources and strengths are tested as they adapt to the demands of diagnosis and treatment schedules(21). Cancer and its treatment also result in the loss of economic resources and opportunities for employers and society (22).

Long-term, highly expensive, and comprehensive treatment can have a severe negative impact on family life. An average child loses seventy years of potential life when they pass away. Two thirds of those who do make it in the long term may experience serious adverse effects from their treatment, such as organ failure, neurocognitive impairments, decreased fertility, and secondary malignancies (20).

Parents have also expressed feelings of fear and a sense of loss of control (23), and the absence of hope due to the diagnosis of their child's cancer (24).

The psychological impact on parents cannot be underestimated. They frequently experience high levels of stress, anxiety, and depression. The uncertainty surrounding their child's prognosis, the constant worry about treatment outcomes, and the long-term effects of cancer and its treatments all contribute to their psychological distress. Sleep disturbances, difficulty concentrating, and a constant state of hypervigilance become common manifestations of their mental health struggles (25).

The loss of hope can profoundly affect the family's ability to cope, particularly impacting the parents' capacity to fulfill the demands of family life and to adjust to the additional needs of a child with cancer (26).

When parents lose hope, they may become less engaged in their child's treatment, leading to decreased adherence to medical recommendations and therapy. In Ethiopia, the high risk of treatment abandonment when there was no response to treatment or during relapse could be explained by the loss of hope (27). Research indicates that individuals with higher levels of

hope exhibit better adaptation, reduced stress, decreased levels of anxiety and depression, and tend to adopt a more proactive approach to problem-solving(6).

The provision of factors such as parental comfort has been associated with increased levels of hopefulness. (16) and care for the family caregivers (17). The capacity to influence hopefulness is significant, as hope is recognized as crucial for promoting family functioning and enhancing parents' ability to care for their child(11).

Pediatric oncology nurses play a critical role in identifying parents who may be at risk of developing mental health disorders. Early identification of parents at risk and providing them with counseling and support are vital for the well-being and adjustment of both the children and the parents. To facilitate timely and effective care, it's essential to not only identify the levels of hope among parents but also understand the factors that contribute to it. This holistic approach can significantly enhance the overall support provided to families facing pediatric cancer (28).

Despite increased attention to cancer, there remains a scarcity of studies focusing on the level of hope among parents. Therefore, there is a pressing need for further research into parental hope across families with children of all ages, spanning various stages of the cancer journey. Such studies are crucial for comprehending the depth of parental hope and its significance for both the child and the parents, along with associated factors. Therefore, the aim of this study is to assess the level of hope of parents of children with cancer and to find the contributing factors.

1.3. Significance of The Study

Despite the importance of assessing the level of hope in parents of children with cancer and understanding associated factors, there has been a notable absence of published studies in Ethiopia on this specific topic within pediatrics. Studying the level of hope and its related factors is crucial as it provides valuable insights into the psychological well-being of parents facing such challenges. Moreover, it enables early identification of those at risk, facilitates targeted interventions, and contributes significantly to the body of knowledge in pediatric nursing. Prioritizing the assessment of hope not only enhances support for parents but also improves the overall experience and outcomes for children with cancer and their families. Furthermore, this study serves as a baseline for future researchers and academic purposes, laying the groundwork for further exploration and advancement in this critical area.

2. LITERATURE REVIEW

2.1. Level of Hope

Hope serves as a vital wellspring of resilience and inner direction for parents. ² The level of hope among parents of children with cancer is a crucial aspect to explore in order to understand their psychological well-being better and provide effective support. Studies have investigated the levels of hope in the parents and have highlighted important findings.

A cross-sectional and descriptive correlational study conducted in Iran, specifically in Tehran, within the hematology/oncology ward of a large national children's university teaching hospital, focused on 240 mothers of children who got diagnosed with cancer. The study found that the mean score on the Herth Hope Index (HHI) among these mothers was 35.44.(29).

In a prospective, longitudinal, questionnaire-based cohort study conducted in the USA in 2018, involving parents and physicians of children diagnosed with cancer at two academic pediatric hospitals, it was found that 50% of parents reported feeling extremely hopeful overall at baseline. Interestingly, hopefulness remained relatively stable over time, with no significant changes observed. Moreover, the study revealed that regardless of prognosis, a majority of parents (51-58%) reported feeling extremely hopeful, with no statistically significant differences noted ($P = 0.66$) (30). In another study conducted in the USA, specifically at the Dana Farber Cancer Institute and Boston Children's Hospital in Boston, MA, it was found that nearly all parents, including those who acknowledged that their child's cancer was incurable or terminal, expressed hope for a cure. Specifically, 88% of parents held onto the hope that their child would be cured, reflecting the resilience and optimism prevalent among families facing childhood cancer diagnoses. (31).

In a cross-sectional survey conducted on parents of children diagnosed ⁵ with retinoblastoma and admitted to the Ninth People's Hospital affiliated with Shanghai Jiao Tong University School of Medicine and Qilu Children's Hospital of Shandong University, ¹ the hope level score of the ⁵ parents was found to be (35.36 ± 4.42) . This score suggests ⁵ that the hope level among parents of retinoblastoma patients was at a medium level(32).

2.2. ³ Factors Affecting Hope

The hope level of parents of children with cancer can be affected by a variety of factors. Sociodemographic factors which play a significant role in shaping ² the level of hope among parents of children with cancer. While relatively rare, certain studies have identified variations within specific populations. Female adolescents, for instance, displayed lower levels of hope compared to their male counterparts. (33). In another study, the results indicated that men tend to exhibit higher levels of hopefulness compared to women. Additionally, concerning age, there wasn't a consistent trend of gradual increase or decrease in hopefulness across the lifespan. Instead, the level of hopefulness fluctuated, showing ups and downs throughout different stages of life(34).

¹ In a cross-sectional survey utilizing convenient sampling at ¹ Shanghai Jiao Tong University School of Medicine and Qilu Children's Hospital of Shandong University, it was found that education level emerged as an independently influencing factor contributing to the variation in hope levels among participants. (32), ¹ the survey results showed that education level was a protective factor for hope level, which was consistent with the conclusions by Xiao et al (35) and Li et al (36). Individuals with higher levels of education are more inclined to acquire pertinent knowledge and social resources concerning diseases and health, thereby mentally preparing themselves and reducing the likelihood of experiencing ¹ negative emotions such as depression and anxiety. Higher educational attainment correlates with enhanced adaptability, reduced stress, diminished ¹ depression and anxiety, and increased capacity for active problem-solving (37).

³ In a cross-sectional and descriptive correlational study conducted in Tehran, Iran, among 240 mothers of children with cancer, findings indicated a positive correlation between the level of hope and spirituality(38). And also in a literature review carried out, following the methodology proposed by the Joanna Briggs between 2009 and 2019, shows that factors that promote hope, were focus on positives, faith/religion (39). A qualitative study done in Brazil, Belo Horizonte in the state of Minas Gerais shows factors that promote hope of parents were spirituality, positive guidance for the future (40). And in systematic review retrieved articles that has been published in English between January 2005 and October 2019 shows the integration of spirituality into the coping process has been found to have a profound impact on parental well-being and hope, offering a source of comfort, meaning, and strength (41).

Clinical characteristics of the child, including the stage and type of cancer, treatment outcomes, and prognosis, are important factors that significantly influence the level of hope among parents of children with cancer. A qualitative study done in Belo Horizonte, in the state of Minas Gerais shows that relationship with the child; Clinical improvement of the child has shown relation with hope level (40). A cross-sectional survey, along with a convenient sampling survey conducted at Shanghai Jiao Tong University, School of Medicine, and Qilu Children's Hospital of Shandong University in China, revealed that time since diagnosis and treatment type were identified as independent factors influencing the variance in parents' levels of hope(32).

Psychological distress experienced by parents of children with cancer can significantly impact their level of hope. Understanding the relationship between psychological distress and hope is crucial in developing interventions and support systems that can help parents maintain a positive outlook throughout their child's cancer journey. Study in a literature review , following the methodology proposed by the Joanna Briggs between 2009 and 2019, shows that factors that threaten parental hope are physical and emotional exhaustion, perceived negativity on the part of others, fear and uncertainty (39).

A cross-sectional survey and a convenient sampling survey conducted at Shanghai Jiao Tong University, School of Medicine, and Qilu Children's Hospital of Shandong University revealed a negative correlation between hope and parental psychological distress symptoms, as well as coping dysfunctions. Furthermore, the multiple linear regression analysis indicated that depression independently influenced the variance in hope levels(32).

Coping level of parents plays a crucial role in determining the level of hope they experience while navigating their child's cancer journey. Understanding the relationship between coping strategies and hope can provide valuable insights into the developing of interventions that enhance parental level of hope and well-being. In a systematic mixed-studies review retrieve articles that has been published in English between January 2005 and October 2019 findings revealed that hope level is negatively correlated with coping dysfunctions (42).

Social support also plays a vital role in shaping the hope level experienced by parents of children with cancer. The presence of a strong support network can provide emotional, informational, and practical assistance, which in turn influences parental coping strategies and fosters a sense of hope. In a cross-sectional and descriptive correlational study conducted in Iran, specifically in

Tehran, among 240 mothers of children with cancer, it was found that there existed a positive correlation between HHI total score and social support(43).

2.3. Conceptual Frame Work

The conceptual frame work hypothesized that parental socio-demographic characteristics, psychological factor, coping level, social support and child's illness conditions directly relate with the outcome variable which is parental hope level.

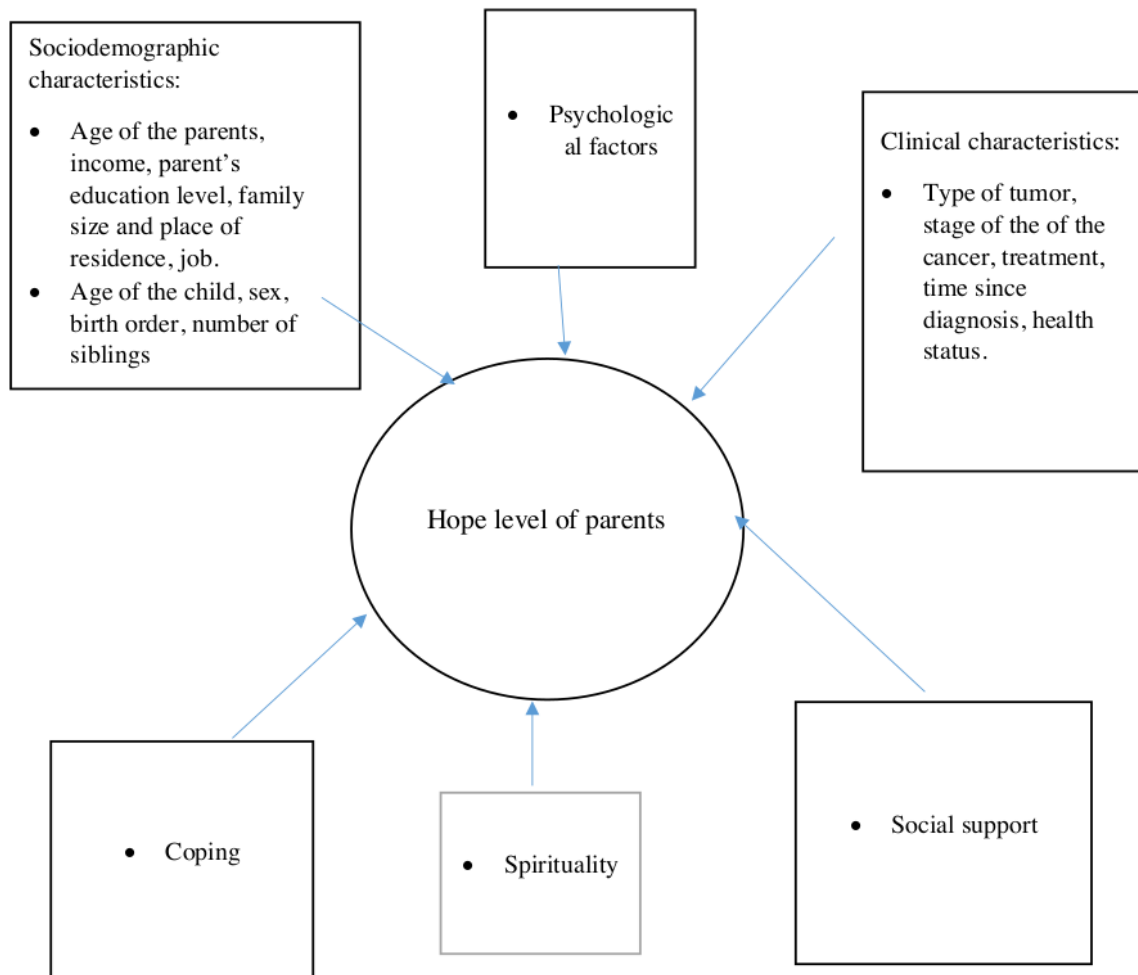


Figure 1: Conceptual frame work for Parental hope level of children with cancer at TASH, Addis Ababa, Ethiopia, 2024GC. (Source: This framework is constructed integrating ((18),(44),(39),(40)) literatures.)

3. OBJECTIVES

3.1. General Objective

- ❖ To assess level of hope³ of parents of children with cancer and associated factors² among parents of children attending cancer treatment at Tikur Anbesa specialized Hospital, Addis Ababa, Ethiopia, 2024.

3.2. Specific Objectives

- ❖ To assess level of hope³ of parents of children with cancer among parents of children attending cancer treatment at Tikur Anbesa specialized Hospital, Addis Ababa, Ethiopia, 2024.
- ❖ To identify factors associated with the level of hope³ of parents of children with cancer among parents of children² attending cancer treatment at Tikur Anbesa referral hospital, Addis Ababa, Ethiopia, 2024.

4. METHODOLOGY

4.1. Study Area and Period

The research was undertaken at the Oncology Unit of Tikur Anbesa Specialized Hospital (TASH) from February 19 to March 19, 2024.

TASH is a government-owned, large referral teaching hospital situated in the Lideta Sub City, administered by Addis Ababa University, College of Health Sciences. Notably, the hospital serves as the sole referral center for cancer in the country. With a total capacity of 800 beds, only 60 beds are dedicated to oncology patients, including 30 beds specifically allocated for pediatric cancer cases. The unit's registry indicates that the hospital attends to over 3,500 pediatric cancer patients annually. TASH provides a range of treatments, including chemotherapy, radiotherapy, and palliative care, positioning it as a prominent center for cancer care in the nation (45).

4.2. Study Design

The study utilized an institutional-based cross-sectional study design.

4.3. Population and Sampling

4.3.1. Source population

All parents of children receiving treatment for cancer at Tikur Anbesa Specialized Hospital were included in the study.

4.3.2. Study population

All parents of children with cancer attending treatment at TASH during the study period and meeting the inclusion criteria were eligible for participation.

4.3.3. Sample size determination

The sample size was calculated using the single population proportion formula. Considering a 95% confidence level, denoted by the standardized normal distribution curve value (1.96), and assuming a proportion of 50% due to the absence of prior similar studies on factors influencing the hope of parents of children with cancer, with a margin of error set at 5%.

n = required sample size

z= critical value at 95% CI

p= prevalence rate, p is taken as 50%

d=Margin of error to be 5%

$Z = 1.96$ $P = 0.5$ $d = 0.05$

$$N = \frac{(Z \alpha / 2)^2 p (1-p)}{d^2} = \frac{(1.96)^2 0.5(1-0.5)}{(0.05)^2} = 384$$

Since the flow of patients during the data collection period was less than 10,000, adjustments were made accordingly.

Formula was applied. $NF = \frac{n}{1 + n/n} = \frac{384}{1 + 384/525} = 222$ NF= desired sample size

n= the calculated sample size N= total population

After incorporating a 10% non-response rate, the final sample size was calculated 244.

4.4. Eligibility Criteria

4.4.1. Inclusion criteria

A parent who was giving care for a child with confirmed diagnosis who was waiting for treatment and who had started the cancer treatment.

4.4.2. Exclusion criteria

Parents of children who were critically ill during the data collection period

4.5. Study variables

4.5.1. Dependent variable

3
➤ Hope level of parents of children with cancer.

4.5.2. Independent variables

➤ Sociodemographic characteristics:

- Parents' Age, educational level, family structure, place of residence and occupation
- Child's age, sex, number of siblings, and birth number

- **Child clinical characteristics:** Type of cancer, stage of cancer, relapses , time since the diagnosis, number of treatment cycle, type of treatment (chemotherapy, hormonal therapy and immunotherapy Radiation.
- **Perceived psychological distress**
 - Social support
 - Coping level
 - Perceived spirituality level

4.6. Operational definition

Hope: Hope is the belief that the future will be better than the present, hope will be measured using the Herth Hope Index (HHI; Herth, 1992) (46).

Social support: The subjective perception of support provided to family caregivers by friends, family, and significant others will be assessed using the Oslo Social Support Scale (OSSS-3).

The OSSS-3 sum score can be categorized into three main levels of social support:

1. Scores ranging from 3 to 8 indicate poor social support.
2. Scores falling between 9 and 11 suggest moderate social support.
3. Scores ranging from 12 to 14 signify strong social support.(47).

Coping: coping is to deal with and attempt to overcome problems and difficulties (48).

Psychological distress: Psychological distress is characterized as the experience of unpleasant emotions or feelings when an individual feels overwhelmed, which can significantly impact their ability to engage in daily life activities. (49).

Spirituality perspective: The measurement of one's specific spiritual beliefs and engagement in spiritually related behaviors (50).

4.7. Data Collection Tools

A structured questionnaire, adapted from existing literature with modifications, was utilized for data collection. Face-to-face interviews were conducted with parents, supplemented by a review of the patient's medical records. The questionnaires were initially developed in English and then

translated into Amharic by language experts to ensure clarity for both enumerators and study participants. The Amharic version was translated back into English to ensure consistency.

Data collection took place in the outpatient and inpatient departments of pediatric oncology units at Tikur Anbesa Specialized Hospital. Four BSc nurses conducted the interviews, supervised by two MSc nurses specialized in oncology. The selection of data collectors and supervisors was based on their prior experience in data collection. They underwent one-day training on the research objectives, methodology, and data collection techniques. Continuous follow-up and supervision were provided by the principal investigator throughout the data collection period.

The survey consisted of three parts:

(a) A demographic questionnaire covering age, marital status, level of education, and clinical information such as the child's diagnosis and duration since diagnosis.

(b) The Herth Hope Index (HHI), which measures hope using a scale developed by Herth et al. (1992). The internal consistency ranged from 0.89 to 0.97, and the test-retest reliability coefficient was 0.91 across various adult patient populations. The scale comprises 12 items with four response categories ranging from "strongly disagree" to "strongly agree." A higher overall score indicates a higher level of hope.

(c) Assessment of parents' spirituality, psychosocial support, coping levels, and psychological distress.

Herth Hope Index: Hope was assessed using the Herth Hope Index (HHI), which was developed by Herth et al. in 1992. This scale, developed by Herth et al., demonstrates high internal consistency, ranging from 0.89 to 0.97, and a strong test-retest reliability coefficient of 0.91 across various adult patient populations. The HHI comprises 12 items, each rated on a scale of 1 to 4, with response categories ranging from "strongly disagree" to "strongly agree." A higher overall score on the HHI indicates a higher level of hope (46).

Oslo Social Support Scale (OSSS-3): This scale generates a sum score ranging from 3 to 14, where in higher scores indicate stronger levels of social support, while lower scores indicate poorer levels of social support.(47).

(CHIP Am): The Amharic version (CHIP Am) was used among parents of children with Cancer. Cronbach's alpha and composite reliability were calculated to assess the internal consistency reliability of the factors in the Amharic version CHIP-20. The results indicate good internal consistency, with a Cronbach's alpha value of .70(51).

PSS-10: The amharic version of the PSS-10 was used. Composite reliability coefficient and item-total correlation were computed to evaluate the internal consistency of the Amharic version of the PSS-10. The internal consistency of the PSS-10 and the negative factor fell within an acceptable range, whereas the positive factor was marginally acceptable, with coefficients of 0.77, 0.78, and 0.68, respectively. (49).

Spiritual Perspective Scale (SPS): The level of individuals' specific spiritual beliefs and engagement in spiritually related behaviors was assessed using the 10-item Spiritual Perspective Scale (SPS), developed by Reed in 1986 and 1987. The SPS yields a single score by capturing two dimensions: the frequency of spiritual behaviors (4 items) and spiritual beliefs (6 items). Participants rate each item on a 6-point Likert scale, ranging from 1 (not at all/strongly disagree) to 6 (about once a day/strongly agree). The scores are then averaged, resulting in a mean score ranging from 0 to 6, with higher scores indicating greater spirituality. Cronbach's alpha for the SPS was found to be 0.95 among hospitalized patients with incurable cancer and healthy adults, and ranged from 0.96 to 0.97 for family caregivers. These high alpha values demonstrate strong internal consistency reliability of the scale across different populations (50).

4.8. Data Quality Control

Data collectors and supervisors underwent a one-day training session on the research objectives, methodology, and data collection techniques. Throughout the data collection period, close supervision and monitoring were conducted by the supervisor and principal investigator to maintain data quality. At the end of each day, the collected data was carefully reviewed by the supervisor and principal investigator for completeness and logical consistency. Any discrepancies or issues identified were discussed, and corrective actions were undertaken for the subsequent day's data collection, involving all data collectors and the supervisor.

4.9. Pre-Test

A pre-test was conducted on 5% of the samples within the study area. Based on the findings of the pre-test, significant modifications were made to the survey instruments or procedures. Pre-tested subjects were then excluded from the actual data collection to ensure that the data collected accurately reflected the final version of the instruments and procedures.

4.10. Data Processing and Analysis

Data collection was facilitated using Kobo Collector, and subsequently, it was cleaned and edited as per the established protocols. The cleaned data was then transferred to the SPSS statistical software for analysis. Prior to analysis, the dataset was scrutinized for missing values and appropriate measures were taken. To prepare the data for analysis, continuous variables were transformed or consolidated into forms suitable for analysis, such as converting them into categorical variables. Descriptive statistics, including frequency and percentage, were employed to summarize the data, which were presented using tables. Bivariate and multivariate logistic regression analyses were conducted to ascertain the association between determinant factors and the hope level of parents of children with cancer. A P-value < 0.05 was considered statistically significant for all analyses, serving as the cutoff point for determining significance.

4.11. Ethical Consideration

Ethical clearance was obtained from Addis Ababa University College of Health Sciences, School of Nursing and Midwifery. Permission and cooperation were sought from the Department of Pediatric and Child Health of Tikur Anbessa Specialized Hospital (TASH). The aim of the study was clearly explained to all relevant individuals within the hospital and to the study participants themselves, and verbal informed consent was obtained. Participants were assured that their participation was voluntary and that they had the right to refuse or withdraw from the study at any time. They were informed that participation in the study carried no potential harm or additional benefits. To ensure confidentiality, the questionnaire did not include any identifying information such as the child's card number or the names of the child and caregiver. This measure was taken to protect the privacy of the participants.

4.12. Dissemination of the Result

Once the data collection and analysis are completed, the findings will be reported to ²Addis Ababa University, College of Health Sciences, School of Nursing. Additionally, a copy of the research report will be provided to the Pediatric and Child Health Department at Tikur Anbessa Specialized Hospital. Furthermore, the findings will be communicated to health planners and other relevant stakeholders to ensure that the results inform healthcare policies and practices. Consideration will also be given to publishing the research findings in peer-reviewed national or international journals, thereby contributing to the dissemination of knowledge and informing broader academic and clinical communities.

5. RESULT

5.1. The Sociodemographic Characteristics of The Parents

Out of the 244 parents approached for the interview, 242 provided complete responses, resulting in an impressive response rate of 99%. Regarding the place of residence, rural dwellers constituted the majority, accounting for 159 participants, which is equivalent to 65.5% of the total participants. Looking at the educational status of the fathers and mothers, a significant proportion had completed primary education (grades 1-8), with 33.5% of fathers and 29.3% of mothers falling into this category. Moreover, the majority of households had a family size of five members or more, with 163 households representing 67.4% of the total. The sociodemographic characteristics of the parents are presented on table 1.

Table 1: Sociodemographic characteristics of parents.

Variables		Frequency	Percentage
Parents age	<=29	64	26.4
	30-35	78	32.2
	>35	100	41.3
Mother's educational level	No formal education	41	16.9
	Primary level (1-8)	81	33.5
	Secondary (9-12)	68	28.1
	College and above	52	21.5
Fathers' educational level	No formal education	62	25.6
	Primary level (1-8)	71	29.3
	Secondary level	65	26.9
	College and above	44	18.2
Mother's occupation	Currently not employed	151	62.4
	Currently employed	91	37.6
Father's occupation	Currently not employed	9	3.7
	Currently employed	233	96.3
Type of family structure	Nuclear	15	6.2
	Joint	203	83.9
	single	24	9.9
Total family size	<=4	79	32.6
	>=5	163	67.4

5.2. Child Characteristics

Out of the 244 children included in the study, 146 (60.3%) were males, while 96 (39.7%) were females. The age range of the children spanned from 2 to 180 months, with a mean age of 70.55 months and a standard deviation of 44.179 months. In terms of pediatric cancer diagnoses, acute lymphoblastic leukemia emerged as the most common diagnosis, accounting for 110 cases (45.5%). Renal tumor (Wilms tumor) and soft tissue tumors/sarcoma followed with 41 cases (16.9%) and 31 cases (12.8%) respectively regarding the stage of cancer diagnosis, 27 cases (11.2%) were diagnosed at stage I, 29 cases (12.0%) at stage II, 19 cases (7.9%) at stage III, and 25 cases (10.3%) at stage IV. Characteristics children are presented in the table 2.

Table 2: Characteristics of children with cancer.

Variable						
AGE (months)	Mean	SD	Median	Q1	Q3	IQR
	70.55	44.17	60	36	108	60
				Frequency		Percentage
Gender	Male			146		60.3
	Female			96		39.7
Number of Children	1-2			139		57.4
	≥3			103		42.6
Type of Cancer	Solid			126		52.1
	Hemato/onco			110		45.5
	Unspecified malignant neoplasms			6		2.5
Type of solid cancer	CNS and spinal tumors (Brain tumor			14		5.8
	Soft tissue tumors/ sarcoma			31		12.8
	Retinoblastoma			25		10.3
	Renal tumor (Wilms tumor)			41		16.9
	Others *			19		7.8
Health status	Very good			107		44.2
	Good			112		46.3
	Poor			23		9.5
Stage of cancer	Early stage			35		14.5
	Advanced			118		48.8
	Not recorded			89		36.8
Type of treatment	Chemotherapy			233		96.3
	Others **			9		3.7
Relapse	Yes			93		38.4
	No			149		61.6

* Others indicate (Bone tumor, Germ cell tumors, Hepatic tumor, Malignant epithelial cell and Neuroblastoma). ** Others indicate (Radiotherapy, surgery, immunotherapy)

5.3. Perceived Psychological Distress Level

The overall mean score of perceived psychological distress level among parents of patients with cancer was 19.169 ± 10.5 . Among these, 85 cases (35.1%) had a low stress level (less than 13), 95 cases (39.3%) had a medium stress level (ranging from 0 to 13), and 62 cases (25.6%) had a high stress level (ranging from 27 to 40). Scores of each level are listed in table 3.

Table 3: Perceived distress level among parents of children with cancer.

Distress level	Frequency	Percentage
low stress	85	35.1
moderate stress	95	39.3
high stress	62	25.6

5.4. Social Support

The overall score of social support level in parents of patients with cancer was 53.02 ± 5.84 . Among these, 99 cases (40.9 %) had a low social support level, 77 cases (31.8%) had a medium social support level, and 66 cases (27.3 %) had a high social support level. Scores of each level are listed in Table 4.

Table 4: Social support level.

Social support level	Frequency	Percentage
Poor social support	99	40.9
Moderate social support	77	31.8
High social support	66	27.3

5.5. Descriptive Statistics of spirituality perceived level of parents of children with cancer.

The overall mean of the overall perceived spirituality in this study was 34.307 ($SD = 4.25$), with a range scale of 16–26. About 9 items had mean score above 5.00, including "How often do you engage in private prayer or meditation?" ($M = 5.67$ with a range scale of 1–6), "Forgiveness is an important part of my spirituality" ($M = 5.60$ with a range scale of 1–6), and "My spirituality is a significant part of my life." ($M = 5.48$ with a range scale of 1–6). The item with the lowest mean

scores, when compared to others was **"How often do you read spiritually-related material?"** (M = 4.53 with a range scale of 1–6). See table 5

Table 5: Spirituality perceived level of ²parents of children with cancer at TASH, Addis Ababa Ethiopia, Feb – March 2024.

Descriptive Statistics	M	SD	Subcategory
In talking with your family or friends, how often do you mention spiritual matters?	5.05	1.346	Behaviors
How often do you share with others the problems and joys of living according to your spiritual beliefs?	5.34	1.160	
How often do you read spiritually-related material?	4.53	1.802	
How often do you engage in private prayer or meditation?	5.67	.891	
Forgiveness is an important part of my spirituality.	5.60	.820	
I seek spiritual guidance in making decisions in my everyday life	5.31	1.070	
My spirituality is a significant part of my life.	5.48	.730	
I frequently feel very close to God or a "higher power" in prayer, during public worship or at important moments in my daily life.	5.36	.750	
⁶ My spiritual views have had an influence upon my life	5.32	.822	
My spirituality is especially important to me because it answers many questions about the meaning of life	5.36	.745	Beliefs

5.6. Descriptive Statistics of coping ²level of parents of children with cancer

The total mean of the overall coping level in this study was 67.15 ± 8.1 , with a range scale of 44–80. About 19 items had mean score above 3.00, including **"Investing myself in my child ren"** (M = 3.59 with a range scale of 2–4), **"Develop myself as a person"** (M = 3.56 with a range scale of 2–4), and **"Believing that my child will get better"** (M = 3.50 with a range scale of 3–4). The item with the lowest mean scores, when compared to others, was **"Doing things with my children"** (M = 2.98 with a range scale of 1–4). See table 6

Table 6: Coping ² level of parents of children with cancer.

Descriptive Statistics	Mean	SD
Doing things with my children	2.98	1.010
Having my child with the medical condition seen at the clinic/hospital regularly.	3.23	.831
Building a closer relationship with my spouse.	3.29	.845
Trying to maintain family stability	3.45	.569
Doing things with family relatives.	3.14	.875
Talking over personal feelings and concerns with spouse.	3.35	.634
Investing myself in my child (ren).	3.46	.591
Trusting my spouse (or former spouse) to help support my child and me.	3.38	.621
Believing that my child will get better	3.50	.501
Believing that things will always work out.	3.45	.531
Doing things together as a family (involving all members of the family).	3.33	.698
Investing myself in my child (ren).	3.59	.510
Becoming more self-reliant and dependent.	3.39	.650
Talking to someone (not a professional counselor/doctor) about how I feel.	3.02	.938
Investing time and energy in my job.	3.48	.540
Engaging in Relationships and Friendships, Which Help. Me to Feel Important and Appreciated.	3.37	.633
Develop myself as a person.	3.56	.505
Being sure prescribed medical treatments for the child(ren) are carried out	3.48	.533
Talking with other individual/parents in my situation.	3.28	.828
Talking with Doctor about my concerns about my child (ren) with the medical condition.	3.49	.613

¹ 5.7. Data of Hope Level

The overall level of hope in parents of children with cancer was 35.3 ± 4.68 . Scores for each level are detailed in Figure 2. Out of these, 10 cases (4.1%) exhibited a low level of hope, 134 cases (55.4%) demonstrated a medium level of hope, and 98 cases (40.5%) displayed a high level of hope.

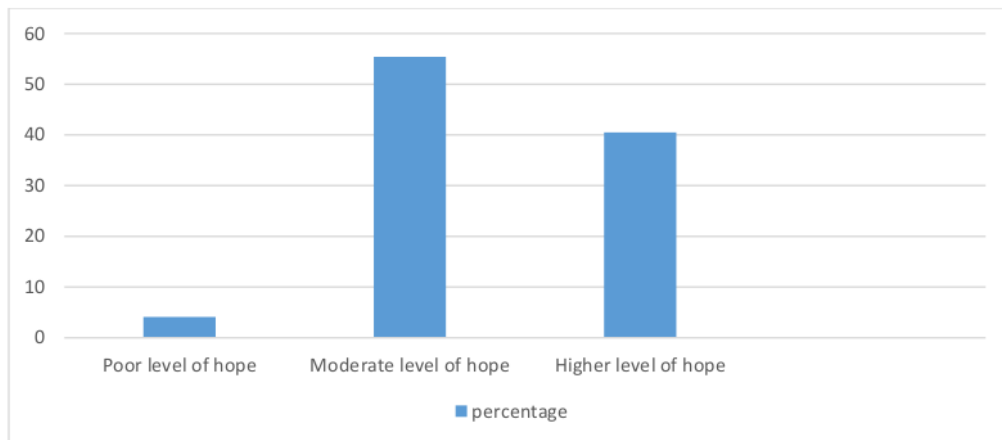


Figure 2: Hope level of parents of children with cancer scores of each level

The overall question has comprised 12 items that assess three primary dimensions: 1) Temporality and the future (items 1, 2, 6, and 11); 2) Preparation (items 4, 7, 10, and 12); and 3) Positive expectations and interconnection (items 3, 5, 8, and 9). Among these, the dimension with the highest score was interconnectedness, while the lowest dimension was the inner sense of temporality and future. See table 7 and 8

Table 7: Descriptive Statistics of hope level of parents of children with cancer

	Mean	SD
I have a positive outlook toward life	3.03	.783
I have short and/or long-range goals	2.70	1.083
I feel alone	2.34	.974
I can see possibilities in the midst of difficulties	3.18	.661
I have faith that gives me comfort	3.39	.545
I feel scared about my future	2.24	.944
I can recall happy/joyful times	3.00	.832
I have deep inner strength	3.30	.601
I am able to give and receive caring/love	3.15	.818
I have a sense of direction	2.63	1.175

Table 8: The hope score ranking in each dimension (N = 242)

Dimensions	Mean	Rank
Inner sense of temporality and future	11.15 ± 1.97	3
Inner positive readiness and expectancy	11.98 ± 2.32	2
Interconnectedness with self and others	12.19 ± 1.7	1
Total score	35.33± 5.97	

5.8. Factors associated with hope level.

A simple linear regression analysis was conducted between each independent variable and the hope level to determine variables for multiple linear regression. Coping ($P = 0.003$) and health status ($P = 0.001$) were found to be significant predictors of hope level. Maternal occupation ($P = 0.203$), child's age ($P = 0.25$), total family size ($P = 0.229$), parental age ($P = 0.186$), and psychological distress ($P = 0.257$) were also selected from parent-related variables. Additionally, stage of cancer ($P = 0.098$) and time since diagnosis ($P = 0.139$) were considered for multivariable analysis, meeting the criterion of $P\text{-value} \leq 0.25$ during binary analysis.

Accordingly, nine variables were included in the multiple-linear regression analysis. The outcome of the multiple regression analysis with the level of hope as the dependent variable are presented in Table 9. The multivariate linear regression analysis indicated that coping and the health status of children exhibited a significant positive relationship with the hope level ($\beta = 2.235$, $p < 0.005$), ($\beta = 1.1475$, $p < 0.005$), respectively. The model could explain 11.6% of the hope level of parents of children with cancer, and the remaining other factors can explain 89.4% ($R\text{ square} = 0.116$, $\text{unadjusted } R\text{ square} = 0.070$).

There is a positive linear association between coping, health status of the children and level of hope of parents. Keeping all other variables constant in the model, parents of children with very good health status were 2.89 more likely to have hope when compared with those whose children have poor health status, 2.89 (95% CI= (0.738, 5.042); $P = 0.009$). See table 9

Table 9: Multiple Linear Regression Analysis Predicting ³ hope level of ² parents of children with cancer, Addis Ababa, Ethiopia, March to April, 2024 (n=142).

Predictors	Crud Unstandardized β 95% CI of β	Adjusted Unstandardized β 95% CI of β
Age	0.008(-0.006,0.021)**	0.001(-0.014, 0.015)
Time Since Diagnosis	.001(.000,.003)**	0.001(-0.001, 0.003)
Parental age		
≤ 29	Ref	
30-35	1.275 (-0.277, 2.827)	0.911(-0.719, 2.541)
> 35	1.091(-.382, 2.564)**	0.422(1.198, 2.041)
Coping	2.235(.790, 3.679)*	1.713 (0.206, 3.220)*
Health status		
Poor	Ref	
Good	1.502(-0.529,3.533)	1.016(-1.080,3.112)
Very good	3.651(1.612,5.690) *	2.89(0.738,5.042) *
Mother's occupation		
Currently not employed	Ref	
Currently Employed	0.791(-.431, 2.013)**	0.399 (-0.858, 1.657)
Psychological distress		
High stress	Ref	
Moderate stress	-.743 (-2.271, 0.784) **	0.854 (-0.656, 2.364)
Low stress	.932 (-0.561, 2.425)	-0.114 (-1.666, 1.438)
Total family size		
≤ 4	Ref	
≥ 5	0.773 (-.490, 2.305)**	0.385 (-0.937, 1.707)
Stage of cancer		
Early stage	Ref	
Advanced stage	-.009(-1.777,1.760)**	0.445 (-1.485, 2.275)
Not recorded ²	-1.187(-3.021 ,0.646)	0.457 (-0.999, 1.912)

Notes: Constant=166.4, R=0.341, R Square =0.116, Adjusted R Square=0.070; **Significant at p value < 0.25 , * Significance value < 0.05 . Dependent variable: Information need. Max VIF 6.386 (no Multi-collinearity: VIF < 10).

6. DISCUSSION

The overall score of level of hope in parents of children with cancer was 35.3 ± 4.68 . Among them, 10 cases (4.1%) had a low level of hope, 134 cases (55.4%) had a medium level of hope, and 98 cases (40.5%) had a high level of hope. The results coincide with a cross-sectional and descriptive correlational investigation conducted in the hematology/oncology ward of a prominent national children's university teaching hospital in Tehran, Iran. The study encompassed 240 mothers of children with cancer, indicating that the average HHI score stood at 35.44(29) and In a cross-sectional survey on parents of children with retinoblastoma in China The study revealed that the hope level score among parents averaged at (35.36 ± 4.42) , indicating a medium level of hope(32).

Conversely, a study investigating the levels of hope of parents with childhood cancer patients, conducted in Boston and Philadelphia hospitals, discovered that 55% of parents exhibited high levels of hope(30). This inconsistency could stem from variations in survey timing and the composition of surveyed subjects it can also be from difference on our health settings and cure rate.

The highest scored dimension of the hope scale was the interconnectedness with self and others, probably because of community-centered living, extended family ties, and culture of helping of one another which increase their close relationship with their children and others (52–54). The inner sense of temporality and future were the lowest scored dimension, probably because of the unpredictable and difficult nature of the illness (55). The diagnosis of cancer in a child shatters the normal trajectory of life, leading parents to confront their worst fears and uncertainties about the future (51). The emotional toll of witnessing their child's suffering and grappling with the possibility of loss can make it challenging for parents to engage in long-term planning or envision a hopeful future (56,57). Additionally, the relentless focus on the present moment and the constant fear of what lies ahead can overshadow any sense of optimism or anticipation for the future, leaving parents feeling trapped in a state of perpetual crisis management (58).

Contrary to common assumptions, the notion that parents with a child diagnosed with cancer may lose hope oversimplifies the complex and multifaceted nature of hope, this finding aligns

with previous research indicating that hope levels remain elevated, even within pediatric palliative care settings, where parents are confronted with challenging prognoses (30).

³ The findings of the study reveal that coping emerges as a highly significant factor influencing the level of hope of parents of children with childhood cancer. This result underscores the pivotal role that coping mechanisms play in shaping parental hope amidst the challenges posed by their child's illness (56,59). The significance of coping suggests that parents who employ effective coping strategies may experience greater levels of hope, potentially serving as a source of resilience in navigating the emotional and practical complexities of their child's cancer journey and these results match those observed in earlier study which is done in a systematic mixed-studies review retrieve articles published in English between January 2005 and October 2019, which conclude that coping is significant factor which affects the hope level of parents (37).

In addition, the finding of this study shows positive significance association with a child's health status which significantly increase parental hope levels by validating treatment efficacy, signaling progress and achievement in the battle against cancer, reducing uncertainty and anxiety surrounding the illness, and empowering parents with a renewed sense of control over their child's health journey (60). Positive health outcomes affirm the effectiveness of medical interventions, providing reassurance and optimism to parents. Achieving milestones such as remission instills hope, while the reduction in anxiety enables parents to focus on the present and cherish moments with their child. Furthermore, positive health status empowers parents to advocate for their child's needs and actively participate in their care, fostering resilience and determination in the face of adversity (61). And also, a qualitative study done in Belo Horizonte, in the state of Minas Gerais shows that clinical improvement of the child has shown significant relation with hope level (36).

This study did not find significant associations between hope levels and other examined factors. It is possible that the lack of significance in these factors may indicate the multifaceted nature of parental hope, which may be influenced by a myriad of individual, interpersonal, and contextual variables beyond the scope of this study.

Despite the absence of significant findings in other factors, it is essential to consider potential implications and avenues for further exploration. For instance, factors such as social support, resilience, and spirituality (29) (32), though not found to be statistically significant in this study,

may still play important roles in shaping parental hope and warrant deeper investigation in future research.

Additionally, qualitative approaches or mixed-method designs could provide richer insights into the subjective experiences and perceptions of parents, offering a more comprehensive understanding of the factors contributing to their hope levels.

It's crucial to recognize the limitations of the study, which may have influenced the observed results. Factors such as sample size, measurement instruments, and methodology should be considered when interpreting the findings. Additionally, the study's focus on a specific population it may limit the generalizability of results to other contexts or populations.

7. STRENGTH AND LIMITATION OF THE STUDY

7.1. Strength of The Study

- Both patient interview and medical record data were used to assess variables.
- Standardized valid tool was used to assess the level of hope.

7.2. Limitation of The Study

- Having recall bias in the patients.
- In addition, this was a cross sectional study, relationship between variables can only be identified, rather than explained.

8. CONCLUSION AND RECOMMENDATION

8.1. Conclusion

In this study the overall score of level of hope in parents of patients with cancer was 35.3 ± 4.68 . Among them, 10 cases (4.1%) had a low level of hope, 134 cases (55.4%) had a medium level of hope, and 98 cases (40.5%) had a high level of hope and coping level and health status were independent affecting factor ($p < 0.05$).

As we navigate the complexities of pediatric cancer care, it is imperative for healthcare providers and support professionals to recognize the pivotal role of hope in parental well-being. By fostering hope and providing targeted support interventions, we can empower parents to navigate the challenges of childhood cancer with greater resilience and optimism. And by addressing the phenomenon of unrealistic hope, healthcare providers and support professionals can ensure that parents are supported with realistic expectations and provided with the necessary resources to navigate the challenges of childhood cancer with resilience and dignity(64).

8.2. Recommendation

Based on the findings of this study, the following issues shall be considered and promoted for improving the hope level of parents of children with cancer.

Recommendation for health professionals

It is essential for healthcare providers and support professionals to incorporate psychosocial interventions aimed at fostering hope and enhancing coping skills among parents of children with cancer and by giving parents an adequate and elaborated information which can help parents to know about their child situation and have realistic hope.

Recommendation for researchers

Looking ahead, future researchers should aim to build upon these findings by exploring additional factors, utilizing diverse methodological approaches, and considering longitudinal perspectives to capture the dynamic nature of parental hope over time. By advancing our understanding of the factors that shape parental hope in the face of childhood cancer, researchers and practitioners can better support and empower parents on their journey towards resilience and well-being.

Assessment of level of hope of parents of children with cancer and associated factors among parents of children attending cancer treatment at Tikur Abessa Specialized Hospital, Addis Ababa, Ethiopia

ORIGINALITY REPORT

12%

SIMILARITY INDEX

%

INTERNET SOURCES

12%

PUBLICATIONS

%

STUDENT PAPERS

PRIMARY SOURCES

1

Changjuan Zeng, Wenting Cao, Ting Zhao, Li Li, Lili Hou. "Hope level and associated factors among parents of retinoblastoma patients during COVID-19 pandemic: a cross-sectional study", BMC Psychiatry, 2021

Publication

4%

2

Esubalew Mezgebu, Emebet Berhan, Leul Deribe. "

Predictors of Resilience Among Parents of Children with Cancer: Cross-Sectional Study

", Cancer Management and Research, 2020

Publication

2%

3

Hazal Ozdemir Koyu, Gökce Algül, Naime ALTAY, Ebru KILICARSLAN TORUNER. "Hope Experiences in Parents of Children With Cancer and Affecting Factors", Research Square Platform LLC, 2022

Publication

2%

4

David B. Nicholas, Anu Chahauver, David Brownstone, Ross Hetherington, Ted McNeill, Eric Bouffet. "Evaluation of an Online Peer Support Network for Fathers of a Child With a Brain Tumor", Social Work in Health Care, 2012

Publication

1 %

5

Changjuan Zeng, Wenting Cao, Ting Zhao, Li Li, Lili Hou. "Hope, Depression, Anxiety and Associated Factors Among Parents of Retinoblastoma Patients During the Pneumonia Epidemic in COVID-19: A Cross-Sectional Study", Research Square, 2021

Publication

1 %

6

In Seo La, Meg Johantgen, Carla L. Storr, John G. Cagle, Shijun Zhu, Alyson Ross. "Spirituality among family caregivers of cancer patients: The Spiritual Perspective Scale", Research in Nursing & Health, 2020

Publication

1 %

7

Salomé, Geraldo Magela, Sergio Aguinaldo de Almeida, and Lydia Masako Ferreira. "Association of Sociodemographic Factors with Hope for Cure, Religiosity, and Spirituality in Patients with Venous Ulcers :", Advances in Skin & Wound Care, 2015.

Publication

1 %

8

Guillaume Gronier, Djamel Aïssaoui, Françoise Schwander, Tanya Cara-Nova. "Psychometric properties of the French version of the Herth Hope Index assessment (HHI-F)", European Review of Applied Psychology, 2023

Publication

1 %

Exclude quotes On

Exclude matches < 1 %

Exclude bibliography On