ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCE

SCHOOL OF ALLIED HEALTH SCIENCES

DEPARTMENT OF NURSING AND MIDWIFERY

ASSESSMENT OF HEALTH CARE NEEDS AND ASSOCIATED FACTORS AMONG FAMILIES WITH CANCER SURVIVOR CHILDREN AT TIKUR ANBESSA SPECIALIZED HOSPITAL, IN ADDIS ABABA, ETHIOPIA 2024: (CROSS SECTIONAL STUDY)

BY SEYFEDIN BARKEDA (BSC IN PUBLIC HEALTH)

A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE PROGRAM OF ADDISS ABEBA UNIVERSITY COLLAGE OF HEALTH SCIENCE, SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE MASTER DEGREE IN PEDIATRICS AND CHILD HEALTH NURSING

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APROVAL SHEET

We the undersigned certify that this thesis has been submitted for examination with our approval as supervisors.

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STATEMENT OF DECLARATION

By my signature below, I declare and affirm that this thesis is my own original work. I have followed all ethical principles of scholarship in the preparation, data collection, data analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis. This thesis is submitted in partial fulfillment of the requirement for a graduate degree of masters from the Addis Ababa University at College of Health Sciences, School of Allied Health Sciences, department of Nursing and Midwifery. The thesis is deposited in the Addis Ababa University, Digital Library and is made available to local, national and international scientific community. I solemnly declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate. Brief quotations from this thesis may be used without special permission provided that accurate and complete acknowledgement of the source is made. Requests for permission for extended quotations from, or reproduction of, this thesis in whole or in part may be granted by the Head of the Department or all advisors of the thesis when in his or her judgment the proposed use of the material is in the interest of scholarship and publication. In all other instances, however, permission must be obtained from the author of the thesis.

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Contents

ACRONYMS AND LIST OF ABBREVATIONS

AAU	Addis Ababa University
AAUHCS	Addis Ababa University Collage of Health Science
CBHI-	Community based health insurance
CCS-	Childhood cancer survivors
CNAT-C	Comprehensive needs assessment tool of caregivers
EHSP	Essential health service package
ETB-	Ethiopian birr
HRQoL	Health-related quality of life
HSCT	Hematopoietic Stem cell transplant
LMICs	Low and middle income countries
LICs	Low-income countries
NHIF	National health insurance fund
NCD	Non communicable disease
OPD	Out-patient department
PTSD	Post traumatic stress disorder
PTSS	Post traumatic stress syndrome
QoL	Quality of life
SPSS	Statistical package for social science
SCNS-P&C	Supportive care needs survey of partner and caregivers
TASH	Tikur Anbessa Specialized Hospital
UHC	Universal health coverage
WHO	World health organization

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ABSRACT

Background: Childhood cancer is a global health concern, affecting early childhood and adolescence. It's the second most prevalent cause of death in both industrialized and developing countries, with 90% in Africa, especially Ethiopia, due to a lack of early diagnostic facilities and control initiatives. Family caregivers face stress after recovery of their child illness; they have diverse needs, including psychosocial, emotional, spiritual, cognitive, healthcare service, health information, and financial needs, which should be addressed to provide comprehensive cancer care. **Objective:** Assessment of the healthcare needs of family caregivers who are caring for their children with cancer at Tikur Anbessa Specialized Hospital in Addis Ababa. **Methods**: A cross-sectional study surveyed 239 caregivers using SCNS-P&C for healthcare needs and medical records for clinical and socio-demographic data. Logistic regression including bivariate and multivariate analysis considering 95% confidence interval (CI) was utilized to examine association between dependent and independent variables. P-value <.05 was considered statistically significant. **Result:** Total Unmet needs of family caregivers' were 49.8%. On average, most participants reported unmet information and practical needs (61.9%), followed by health care and service needs (60.9%) and work and social life needs (60%). The top most unmet needs were getting emotional support (83.2%) and finding out financial support (78.3%). Discussing concerns with physicians (75.3%), accessing support services for caregivers (75.3%) were other frequently reported health care needs. Seven variables showed a statistically significant association with family caregivers' health care needs, including: female family caregivers, young adult and unemployed caregivers, family caregivers having children with relapsed cancer, having more than 3 children, and having a male child with cancer (AOR=4.729; 95% CI: 2.149-10.405), (AOR=5.850; 95% CI: 1.750-19.562), (AOR=4.019; 95% CI: 1.704-9.483), (AOR=4.789; 95% CI: 1.645-13.939), (AOR=4.726; 95% CI: 1.628- 13.720) and (AOR=2.575; 95% CI: 1.152-5.755) respectively. Also, single parents (divorced and widowed) have more health care needs than married parents. **Conclusion and Recommendations:** In the study, unmet family caregivers needs was high. Emotional, psychosocial, and financial support to manage living expenses and child cancer treatment are predictors for unmet family caregivers needs. Therefore, the findings suggested nurse-led interventions to improve parents' quality of life, such as involving support groups, psychosocial support from health care providers, governmental and nongovernmental organizations collaboration. Further qualitative studies are recommended to explore deeply their further needs.

Keywords: Childhood cancer, family caregivers, health care need

CHAPTER ONE: INTRODUCTION

1.1 Background of the study

Cancer is a condition in which aberrant cells proliferate and develop out of control, encroaching on neighboring tissues and traveling to other areas of the body via blood vessels and lymphatic systems, impairing the normal cells' ability to function (1). Childhood cancer is a global, life-threatening, non-communicable condition that is on the rise (2,3). Cancer is a major cause of death for children in both developed and developing nations, exacerbating infectious diseases and malnutrition-related mortality (4). Unlike adult cancer, childhood cancer is highly curable, even in resource-constrained settings, if diagnosed early and treated effectively. A rise in childhood cancer diagnoses has made cancer the second most common cause of death for children between the ages of five and fourteen. It affects 400,000 new cases annually, with 90% of this burden in LMICs (5). Despite the rising cancer burden, there are insufficient diagnostic facilities and control programs in most African countries (6). Over 90% of childhood cancer deaths occur in low-resource settings because many children in low- and middle-income countries do not receive or complete care (7).

Each year, there are more than a total of 150,000 cancer cases, or approximately 6,000 new cases of pediatric cancer, according to hospital records that were published in 2015 in Ethiopia(8). The mortality rates for most pediatric cancer cases are near 100% in developing countries. The most common childhood malignancies encountered include lymphomas, leukemia, soft tissue sarcomas, osteosarcoma, and neuroblastoma (9).

The crisis due to illness and hospitalization of Children causes tension and anxiety for their families, as they are the primary support and care provider for sick children (10). The period following their child’s diagnosis and the initiation of treatment may be stressful and disturbing leading them to depression. The childhood cancer burdens the caregivers by causing physical, mental, emotional, and behavioral changes or developing psychological stress. This high demand can lead to burnout, reduced quality of life, and strain on caregivers. Previous study results showed that it is generally known that parents of children with cancer experience a tremendous psychological burden, with depressive symptoms frequently resulting from mild-to-severe stress. The main causes include their child's cancer diagnosis and treatment, chemotherapy side effects or medication reactions, lack of social support or financial struggles, ignorance of the illness, seeing potential death

in another sick child and insufficient knowledge about how to take care of their child while undergoing treatment.

Cancer treatment typically includes chemotherapy, radiotherapy, and surgery. The treatment course needs frequent visits from health care institutions to ensure rehabilitation (11). At this time, family members play a crucial role in managing a sick child with cancer. Often, cancer disease management is complex in terms of cost and time. Therefore, early discharge (transferring from healthcare to community care) and self-management are considered as means of solution. The sick child care responsibility falls over the shoulders of the mother, particularly in African culture. The woman will be in a position to handle medical emergencies, patient transfers, provide social and psychological support, and act as a legal assistant (3).

Family caregivers need support in understanding, managing symptoms, providing personal care, and discussing the disease. Sudden life changes disrupt family and psychosomatic balance, leading to increased physical and mental illnesses and eventually reducing social interactions (12). Childhood cancer causes stress for the parents, which leads them to seek supportive care to manage stressors (13). Supportive care includes physical, emotional, psychological, and spiritual domains. Giving family-centered care and support will increase survival rates for childhood cancers and family caregivers' psychological wellbeing. This study aims to assess the family caregivers' health care needs and the associated factors. Africa faces limited investment in cancer control programs due to health demands and limited knowledge about child burden and families. Despite the growing global attention to fighting this reality, childhood cancer control was given low and medium priority in Ethiopia's recently revised essential health services package (EHSP), probably due to inadequate advocacy work on the burden and the high chance of a cure for childhood cancer (14).

1.2. Statement of the problem

A family caregiver provides comprehensive care without age segregation, involving family caregivers in emotional, physical, and instrumental support to address difficulties in patients (15). Pediatric cancer affects patients and family caregivers, affecting their quality of life and family functioning (16). Parents of children with life-threatening diseases face numerous unmet healthcare needs, including informational, financial, emotional, physical, psychological, educational, and spiritual needs, requiring continuous supportive care in order to meet the basic needs of children (17).

Cancer diagnosis can cause shock, suffering, and changes in daily routines (18), disrupting psychosomatic balance and family functioning, leading to fitness decline, increased somatic ailments, and limited social and professional connections (12). Chemotherapy can cause pain, anxiety, depression, stress, and burnout in caregivers (19–21). Studies showed that mothers experience higher stress levels than fathers (22). High medical expenses can lead to a family's income decrease due to resigning from work or limiting work hours to care for a sick child (23). Financial needs include those related to care and treatment (24) and other logistical problems (18).

Cancer in children significantly impacts their lives and family caregivers' psychological wellbeing, often leading to anxiety, fear, and depression (3), prompting parents to seek supportive care (13). Assessing families' needs, especially during disease onset, is crucial for predicting psychosocial risks and responding promptly (25).

Parents of cancer patients require clear, understandable information about their child's condition for effective healthcare participation and childcare decisions (26,27), including long-term effects, psychological consequences, parental performance, behavioral problems, education, sleep disorders, eating, communication and emotional needs (28). Family Caregivers' of Children with cancer face emotional needs like uncertainty about treatment, cure, and future (29–31).

Providing care to a cancer-diagnosed child requires a full-time task since patients require assistance to watch out for chemotherapy side effects and emergency comorbidities. These responsibilities can last for years until the patient is cured or passes away. Parents of cancer survivors report prolonged stress, even after their children's recovery. Caregivers face physical, mental, financial, and social responsibilities, and it also affects inter-personal relationships (32). This can lead to a decline in social networks and an increased burden on mothers (33). Family Caregivers usually find less time for socializing with friends and family due to their full-time careers, especially

in resource-limited environments. These parents find it difficult to care for themselves, their home, and most importantly, their ill children (8).

Support is crucial in extreme crises, as caregivers may lack the necessary resources to cope with diagnosis and disease management in low-resource settings due to the scarcity of healthcare personnel. There are surprisingly few cancer specialists in Ethiopia, according to the Federal Ministry of Health (34). These factors make parents or other family members primarily responsible for the care of the child with cancer. This could cause parents to be stressed because of how their child's cancer diagnosis would influence their ability to give him or her necessary treatment.

Clinics lack support mechanisms, burdening caregivers, with only patients receiving distress tests and treatment plans, potentially affecting patient health (35) and potentially affecting cancer treatment for children (36). Since doctors are primarily concerned about their patients care, family caregivers are sometimes overlooked and thus missed. Parents frequently experience feelings of guilt when their kid receives a cancer diagnosis, which can have a long-term emotional and financial impact on the child and their family. As a result, parents of cancer survivors may be more vulnerable to physical and mental health problems. An increasing body of literature supports that different degrees of parental distress persist even after treatment completed (37).

Parents of children with cancer face significant emotional distress due to uncertainty about diagnosis, treatment, and future life, requiring psychological support, empathy, and mutual understanding (38). Healthcare needs assessments help prioritize service needs, allocate resources, and develop cost-effective solutions for family caregivers, addressing challenges such as patient prioritization only, screening time, and reluctance to discuss their concerns publicly (39).

Ethiopia reports 80% of cancer cases are diagnosed at advanced stages; of those diagnosed cancer cases, children account for 20%. With 12,192 children dying annually from all forms of cancer and 8,800 children dying each year (34), Tikur Anbessa Specialized Hospital (TASH), Ethiopia's only pediatric oncology unit, provides comprehensive treatment for 500–600 children annually, but research on the family caregivers' health care needs shows that none or few are available (40). This study aims to determine the level of healthcare needs of family caregivers of cancer survivor children and associated factors at Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia.

1.3. Significance of the study

The late presentation of children with advanced cancer stages in LMICs is a result of low cancer awareness and treatment delays, which increase the treatment burden on medical professionals and place more responsibility on family caregivers (26). It is necessary to acknowledge the magnitude of the caregiver burden, special needs, and challenges experienced by family health caregivers of children with cancer who are responsible for delivering cancer care.

The study's results may provide guidance on how caregivers are impacted and how to effectively implement government programs and policies to meet the health care needs of these family caregivers. The Federal Ministry of Health (FMOH), public health policy makers, and health care planners will use the study's findings to prioritize service needs in order to improve the quality of cancer care and the well-being of family caregivers. Understanding family caregivers' healthcare needs is crucial for creating support networks and for developing public health policies.

Additionally, it enables medical professionals providing pediatric oncology care to cancer patients to attend to the family caregivers' top priority needs. It helps nurses teach family caregivers' coping methods for their stress and give the best care they can for their sick children. It advances our understanding of the treatment of pediatric cancer and lays the groundwork for the development of best practices and guidelines.

Generally, the findings can help allocate resources and implement programs, contributing to a global understanding of pediatric oncology care and developing best practices for similar healthcare settings. Researchers can also use them as a baseline source of data for future research on family caregivers' healthcare needs.

CHAPTER TWO: LITERATURE REVIEW

The literature search focused on the work and financial needs, psychological and emotional needs, informational and communication needs, health care and service needs domain, and factors affecting family caregivers' health care needs.

2.1. Family caregivers health care needs

Family caregivers offer ongoing support to sick children in terms of physical and emotional care. These care supports require general preparation, as such information, medical, emotional, and financial support for family caregivers can improve their psychological well-being and lower morbidity and mortality. However, assessing their needs is challenging due to prioritizing patients, a lack of screening time, and reluctance to discuss their concerns publicly. The informal nature of assessments also makes their needs less visible.

A Polish study reveals 70% of family caregivers' of cancer survivor children require medical information, 55% psychological support, and 30% financial assistance. Age, education, and gender do not differ. The length of illness and the type of needs varied. Elderly children need emotional support more. Comorbidities increase assistance (10).

An investigation in West Java, Indonesia, found that the majority of participants (71.8%) reported unmet information and practical needs, followed by work and social life needs (61.7%). Unmet needs of caregivers include financial support and travel insurance (81.4%), discussing concerns with physicians, accessing the best medical care, and information on treatment side effects (78.2%) (41).

A survey found that 83% of parents have over ten unmet needs, with information being the most significant. 49% of parents reported anxiety symptoms. Higher education levels and fewer children were associated with higher psychological requirements (42).

2.2. Work and Social needs

Medical expenses are mostly made up of costs spent using healthcare for hospitalization, diagnosis, treatment/chemotherapy, professional fees, and patient food. Nonmedical expenses include all family-borne out-of-pocket costs during the course of treatment (transport, food, hotel, communication, etc.). Lifesaving cancer therapy is costly, and the financial costs of hidden non-medical expenses and loss of income due to reduction or termination of parental employment that are rarely reported and may result in financial burden for families can cause family disruption. Financial

difficulties continue to be a significant source of stress for families whose children have cancer, but they are still not well understood. The financial load can have long-term implications for the financial security, quality of life, and future well-being of the entire family, including the affected child's siblings, in addition to the stress of the diagnosis and treatment.

Warner et al. (2021) highlight the financial strain on families in developing countries due to pediatric cancer treatment, highlighting the severe financial challenges faced by cancer patients (43). Financial toxicity during cancer treatment, particularly in resource-limited countries, is a significant issue, with nonmedical expenses accounting for over 45% of total expenditure, particularly in rural areas (44). Families traveling outside their region to access health services should receive medical travel subsidies and reimbursement for meals, accommodation, and gas expenses (43) and having health-insurance could have the potential of improving treatment outcomes and survival (45).

The occurrence of financial needs and highly valued support for financial needs related to care and treatment have been demonstrated in numerous studies (24). In contrast, Qingying et al. showed that as long as the family was assured that the child would receive treatment, financial needs were less of a priority than were other logistical problems (18).

Landowska’s 2022 study in Poland found that only 30% were in the financial needs domain, but in West Java, Indonesia, a study revealed that cancer patients often face unmet needs such as financial support and travel insurance (81.4%). High treatment costs disrupt caregivers' social lives and financial sources in Ghana, while financial difficulties in India lead to stress and debt, negatively impacting families' financial stability but not leading to withdrawal from care. US parents of cancer children report job disruptions, with 42% resigning, the wealthiest families losing only 5%, and 50% of the lowest households losing over 40% (60).

2.3. Psychological and Emotional needs

Family caregivers of CCS are reported to have an increased risk of anxiety, depression, posttraumatic stress disorder (46), and impaired health-related quality of life(HRQoL) compared to the general population. They have higher psychological and emotional needs. The experience of parenting a child with cancer may be more traumatic than the actual disease. It has been noted that burnout symptoms like headaches, sleeplessness, and exhaustion are common in caretakers. Cancer in children significantly impacts caregivers' psychological wellbeing, leading to anxiety, fear, and depression, resulting in deteriorated mental well-being and increased worry during therapy (3). The

most important emotional need was the feeling of uncertainty about the child's cancer, cure, diagnosis, treatment, symptom management, and the future (47).

Caregivers face psychosocial burden, burnout symptoms, and negative effects from child behavioral and physical changes due to cancer treatment, with 75% reporting overwhelming burden (3).

Research primarily focuses on adult caregivers of cancer patients, neglecting the psychosocial make-up of young caregivers due to their higher psychological challenges (48). Bruce's research indicates that parents are more likely to develop PTSD and PTSS. Studies on cancer parents reveal increased stress, anxiety, and depression among caregivers (23). Unsar et al.'s 2021 study found that caregivers' burden is influenced by age and daily or hourly care, with younger, female caregivers spending longer daily.

In KwaZulu Natal, South Africa, parents faced new responsibilities (67), causing unease among mothers. Despite her recovery, the family struggled to restore stability (49). Wiener et al's study in the USA revealed that siblings experience loneliness due to their parents' hospitalization, disrupting daily life routines and leading to psychological problems.

A Moroccan study shows caregivers face reduced socialization and neglect their families (49), potentially hindering quality care (50). Wang et al. link patient QoL to caregiver unfulfilled demands (51). Research shows a negative correlation between primary caregivers' health outcomes and pediatric cancer care (52), emphasizing the importance of informal caregivers' collaboration and compliance in successful management (53).

2.4. Information and communication needs

Families need clear and concise information about a child's health, which is crucial for informed healthcare participation and childcare decisions, especially for African cancer patients (54). Parents of cancer patients often complain of incomplete information provided by the medical team about the condition and treatment of their children (27,55), but Mitchell et al.'s study found that parents were satisfied with the medical information provided by doctors and nurses during the diagnosis and treatment process (49).

A Polish study highlights the need for parents to have accurate health information for informed healthcare decisions (56). The survey found 70% needed medical information, which was the highest among parents' unmet needs. Parents of older children need emotional support and should provide necessary medical information during diagnosis and treatment. A Korean study reveals caregivers of childhood cancer survivors have the highest unmet needs for information about the

illness, therapies, patient care, and financial support, suggesting comprehensive cancer care (57). Higher household incomes and older caregivers of cancer patients have lower unmet information needs (78), while younger caregivers have more, possibly due to increased infertility and post-treatment effects.

Research in West Java, Indonesia, shows that 71.8% of participants feel their practical and information needs are not met, including discussing concerns with doctors, receiving the best medical care, and receiving emotional support.

2.5. Health Care and Service Needs

The health care and service needs include caregivers getting emotional support for themselves from family and the community and addressing problems with sex life from health professionals. The main causes of parents' dissatisfaction with their needs are structural shortcomings such as inadequate structure, lack of systematized comfort care services, absence of family involvement, and legal, security, and financial concerns (58), despite the emphasis placed by policymakers on the significance of community-based service delivery. In another perspective, meeting the needs of mothers whose children have cancer can be achieved by offering comfort care and considering it from a variety of perspectives.

Some parents in the community expressed dissatisfaction at being neglected or alone after learning that their child had cancer. The sense of being unsupported was widespread among divorcees, widows, widowers, and single parents. They reasoned that having a spouse assist in caring for the cancerous child would lessen the load.

Community services could help by organizing the family's belongings, helping them get ready for the funeral, and easing their existential and emotional suffering while they mourn. In order to meet the requirements of the patient at home (59) and the family, community nurses can provide direct support (60). For families receiving palliative and end-of-life care, outside assistance and community involvement may also be options (61).

It is taboo to discuss sexuality, and many feel embarrassed about it (62). Medical practitioners understand that having sex is a personal matter (63). To provide holistic care, the palliative care approach still necessitates a thorough evaluation of any possible problems affecting the patient and their family (45). There is still a lack of confidence among medical personnel to talk to patients and their families about sexuality concerns. Before bringing up this topic, health providers

should be aware of social norms about sex (64), but also recognize that one's capacity for sexual expression lasts all the way to death (65).

The health system struggles to provide adequate counseling services due to a shortage of specialized medical personnel, negative attitudes among healthcare personnel, and communication barriers resulting from linguistic barriers (66).

A survey in West Java, Indonesia, found that family caregivers face challenges in meeting patients' needs, with balancing social interaction with discomfort, financial struggles, and emotional struggles being the most common unmet needs. This issue is also prevalent in developing Asian countries (67).

The study in Iran revealed variations in hospital support services and health service accessibility across different trials, possibly due to varying healthcare systems in different countries (29). Caregivers get enough support from their families and friends; they may not need further support from the health care professional.

2.6. Factors Affecting Health Care Needs

2.6.1. Socio-demographic factors of the caregivers

Various factors and variables can influence parents' needs and dissatisfaction. Identifying and addressing these needs is crucial. Recognizing women's unique characteristics also helps caregivers focus on their needs. Such characteristics include age, gender, religion, marital status, educational status, occupation, monthly income, types of relationships with a patient, family size, and place of residence.

The study on Zimbabwean caregivers revealed that the majority were female, married, unemployed, and educated, with 79.2% of caregivers being female.

The study found that caregivers with higher household income had a lower likelihood of unmet information demands since they had easier time learning about health-related topics, such as preventive services. That suggests it's crucial to educate parents of children with cancer living in lower socioeconomic classes. Second, there was a higher likelihood of unmet information needs among caregivers of older CCS than those with young adults, possibly due to the need for data on infertility and post-treatment consequences (50). In the result of multiple logistic regression analysis, which was done to find independent relationships between specific CCS and caregiver characteristics and the demands of the caregivers in each CNAT-C area, mother caregivers were significantly more likely than male caregivers to have higher requirements in terms of psychological and health issues: 3.79 (2.52–5.69), family and social support: 3.17 (2.09–4.81), and religious/spiritual support: 1.69 (1.14–2.55). Caregivers with higher levels of education showed a greater need for religious or spiritual support 1.71(0.85–3.46), 0.048 at $P < 0.01$. Caregivers were less likely to have greater requirements for information, religious or spiritual support, or practical support as their monthly household income increased. Information demands were more likely to be more significant for caregivers with older CCS (68). Caregivers of children with HSCT have higher unmet practical help requirements, as they may experience stress, an increased risk of transplant problems, and late consequences (69), requiring more practical care than other cancer treatments for cancer patients. The study found that family caregivers of childhood cancer patients often suffer from anxiety, depression, psychological distress, and impaired health-related quality of life, with mother-caregivers having a higher unmet need (46).

A study in Iran found that female caregivers have a higher care burden than male caregivers due to Iranian culture's emphasis on motherhood. An Iranian study revealed that married mothers

experienced a lower care burden than single mothers (70,71). Some research has found no connection between the burden of care and employment status (56). However, a 2019 study in Mexico found that gender doesn't affect care requirements (13). Single caregivers have a lighter care burden, unlike married mothers. Studies in Canada and the Netherlands show single moms have a significant care burden. However, compared to married caregivers, single caregivers appear to be more vulnerable to financial difficulties and parenting stress (57,72), which adds to their heavy care load. Higher-educated caregivers have a lower care load (73). but some research shows no connection between education and care burden (56). Higher-educated individuals may have better stress management and problem-solving abilities (56,74), while low-educated caregivers may come from lower socioeconomic backgrounds with limited resources (75). Wealthy families may have better treatment or community support services (76). Employed caregivers experience a lower care burden than jobless ones (73,75).

A study in Turkey found that highly educated primary caregivers have fewer unmet needs in maintaining their strength and confronting family issues. They seek information online and establish social support networks to maintain their strength. Poverty significantly predicts unmet cancer care needs in the Omani community, with parents of cancer patients often facing more financial difficulties than those with other chronic illnesses. Awareness of available financial aid options can help alleviate the psychosocial toll (77). Caregivers in countries that have no free cancer treatment face significant stress due to the time and financial burden of caring for a sick child.

2.6.2. Socio-demographic factors of the child

The age, sex, and birth order of the child, number of children are included in the socio-demographic characteristics of the child.

A study in Poland found that 70% of parents of children suffering from cancer have moderate or high needs in medical information, 55% need help in psychological or emotional fields, and 30% in financial domains. The duration of the illness significantly influenced the type and intensity of the needs. A strong positive linear relationship was found between psychological needs and the number of children, with 73% of respondents reporting moderate or high needs. Common items included emotional support from relatives, health information, and assistance in everyday functioning (78). The study reveals that 50% of Zimbabwean children with Wilm's tumors receive chemotherapy, with the majority being male. Caregivers' durations range from six months to one year (79).

A study in Zambia interviewed 15 parents of children with cancer, ranging in age from 20 to over 58. There were both male and female childhood cancer cases, with ages ranging from 2 to 14 years old. Out of the 15 cases, 14 knew their condition, while one was still seeking a diagnosis. Four of the 15 children had kidney, leukemia, retinoblastoma, lymphoma, liver, and lung cancer. Fourteen parents reported their children receiving treatment, while one child had low blood and platelet counts (80). Research shows that a child's age doesn't predict the stress associated with providing care, with younger, unwell children requiring more (56). However, no correlation was found between caregivers' care burden and the sex of the ill child (81), but male unwell children reported a higher burden (82). Nonetheless, raising a child, whether boys or girls, with cancer exposes caregivers to a high burden of care.

2.6.3 Clinical Characteristics of the Child

Clinical characteristics of children: type of cancer, stage or disease complexity, relapse or recurrence, type and length of treatment, aggressive diagnostic procedures. The study found that the length of illness and a child's requirements varied significantly. Parents of children with less than three years of illness reported more informational and emotional needs, while those with longer illnesses reported more physical and financial requirements (83).

The study analyzed 494 cancer patients and their caregivers, with the majority of them being mothers. The majority were diagnosed with solid tumors, with the remaining 45.0% being hematologic malignancies. The mean age was 13.8 years, and all patients received chemotherapy. Between the various levels of CCS characteristics, there was no discernible difference in the distribution of scores in each CNAT-C domain according to the various levels of each CCS characteristic. On the other hand, compared to caregivers of children with hematologic malignancies, parents of children with solid tumors need greater practical support. Furthermore, the need for practical support was highest among caregivers of children who had received chemotherapy plus surgery plus radiation therapy, followed by those who had received HSCT plus other therapies, and the lowest among caregivers of children who had only received chemotherapy (50).

The study found that the length of illness and the child's needs varied, with parents of sicker children reporting more emotional and informational needs than somatic and financial demands. Parents of children who were sick for more than three years were more likely to report emotional and informational needs. At $p = 0.01$, the differences were statistically significant. The number of children and psychological demands were strongly associated (10).

2.6.4. Psychological factor

Parents of children with cancer face greater psychological distress, affecting their caregiving and healthcare needs. Cancer diagnosis and treatment cause numerous psychological problems. Care burden is one of the most common psychological problems (84). Caregivers of children with cancer face a care burden due to treatment challenges, financial issues, a lack of disease information, feelings of inadequacy, future concerns, and disorganized family life (74,85).

Research shows that parents of children with cancer face higher psychological challenges, requiring more emotional and psychological support than general population parents (86). A study by Qingying and colleagues found that Chinese parents of cancer-stricken children require the most emotional support, including informational and emotional support, with fear, worries, and sadness being the most significant emotional needs (emotional needs M = 4.12, SD = 0.94; psychosocial needs M = 3.94, SD = 0.87). This includes the sensation of ambiguity regarding the child's cancer (30,31,87). Parents of children with life-threatening illnesses (49) require emotional support, including empathy, mutual understanding, and psychological support, from both informal and important healthcare providers (38). During crises, support is crucial. Therapy interventions should focus on the parent's local environment and coping mechanisms to enhance functioning and aid in adaptation. Long-term emotional crises may not always be linked to a child's disease (88), and parents may experience positive changes due to managing illness demands (89).

2.6.5. Social Support

Support is crucial for caregivers to make informed decisions about their child's treatment, reduce loneliness, and improve mental well-being. It helps manage health needs, reduce stress, and prevent burnout. Support organizations, counseling services, and training workshops can help low-income caregivers' access resources for their child-rearing needs. Supportive care is essential for parents dealing with childhood cancer, providing necessary services to meet physical, informational, psychosocial, emotional, practical, and spiritual needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases. The social support system that surrounds parents of cancer patients has a significant impact on how hopeful they feel. A good support system can offer practical, emotional, and informational help, which in turn affects parental coping mechanisms and encourages optimism.

2.6.6. Family Coping and Resilience

The 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 developing interventions that enhance parental hope and well-being. Sources for coping are the support of one's family, the community, and medical professionals and their individual ways of handling and adjusting to stress. Family resilience refers to how families adapt to difficult life circumstances, serving as a protective barrier against traumatic events. Parents of cancer-stricken children often employ avoidance and denial coping mechanisms due to emotional suffering.

A Zambian study found that many caregivers were unaware of children's cancer symptoms and signs, leading to late visits and missed appointments (80). Findings from systematic mixed-studies evaluation of publications published in English between January 2005 and October 2019 indicate a negative correlation between parental psychological suffering and hope.

2.6.7. Patient-Clinician Communication

The health system faces challenges like a shortage of specialized medical personnel, inadequate counseling, and negative attitudes from healthcare professionals, leading to communication gaps between patients and caregivers (80). Parents of cancer patients often complain about incomplete medical information provided by the medical team, despite the importance of clear and understandable information for their children's healthcare (27,55).

Caregivers of children with cancer often face a care burden due to lack of information, feelings of inadequacy, future worries, and disorganized family life. Ensuring written information is easily understandable and available in languages other than English is crucial (90)**.** Young cancer patients emphasize healthcare professionals' empathy, trust, and active listening during information exchanges, (91), while patients express dissatisfaction with test result explanations and lack of upfront discussion about treatment impact. Patients reported distress due to a lack of continuity of care and suboptimal care coordination (36,92).

Cancer patients often lack information about treatments, symptoms, self-management advice, and healthcare system navigation (93–95), leading to psychological distress and unmet needs (96,97) They desire ongoing healthcare contact (68,105), particularly in remote areas (98)**.** Advanced cancer patients require information and access to palliative care services to facilitate end-of-life discussions within their multidisciplinary team (99–101). Qingying et al.'s studies revealed that parents' unmet

needs, particularly regarding their child's treatment, side effects, and coping strategies, were the most significant (18). Borjalil et al.'s study identified four main themes for parents' health information needs: medical, physical health, healthcare, and family lifestyle information (102). Adamsi et al. identified the primary information needs of cancer patient families, including treatment, diagnosis, coping strategies, self-care, types of cancer, hospital care, and rehabilitation (103). Inman suggests that parents of children with cancer should receive comprehensive health information about long-term effects, physical and psychological consequences, parental performance, behavioral issues, education, sleep disorders, and communication (28). Mitchell et al. emphasize the importance of parents of children with cancer receiving appropriate medical information from doctors and nurses during diagnosis and treatment (49).

Communication on Spiritual Needs:

A lot of cancer patients had "death anxiety," or a distressing fear of the unknown and end of life, which has been linked to poor mental health outcomes (104). Patients often struggle to communicate their existential concerns with healthcare providers due to lack of confidence, time, or skill in discussing spiritual issues (101). Cancer patients experienced loss of religion (36), while others found strength in nature and used prayer and faith as coping strategies (105). Parents identified spiritual needs for their child's illness, seeking support from monks and religious practices, regardless of beliefs, and seeking meaning for their experience and explanations (87,106).

Communication on Cognitive needs:

Brain cancer-affected young people often lack timely support, affecting their self-care, social skills, and educational attainment (107). Educational providers are not tailored to meet their unique learning, teaching, and assessment needs.

2.6.8. Spirituality

Parents of children with cancer have varying degrees of hope, and one major factor influencing this is spirituality. It has been discovered that including spirituality in the coping process significantly improves parental hope and well-being by providing a source of solace, purpose, and strength. Spirituality, religion, and effective provider-parent communication may strengthen parents' hope (35). A study in Ethiopia found that sociocultural factors, like religious beliefs, can affect family caregiving for cancer patients (83). A study conducted in Iran found a positive connection between spirituality and the hope score (36). Focusing on the positives and having faith or religion are

elements that support hope; on the other hand, physical and emotional tiredness, the perception of negativity from others, fear, and uncertainty are factors that undermine parental hope (33).

2.7. Conceptual Frame Work

The following conceptual framework is designed to show the link between the outcome variable and the factors associated to it.

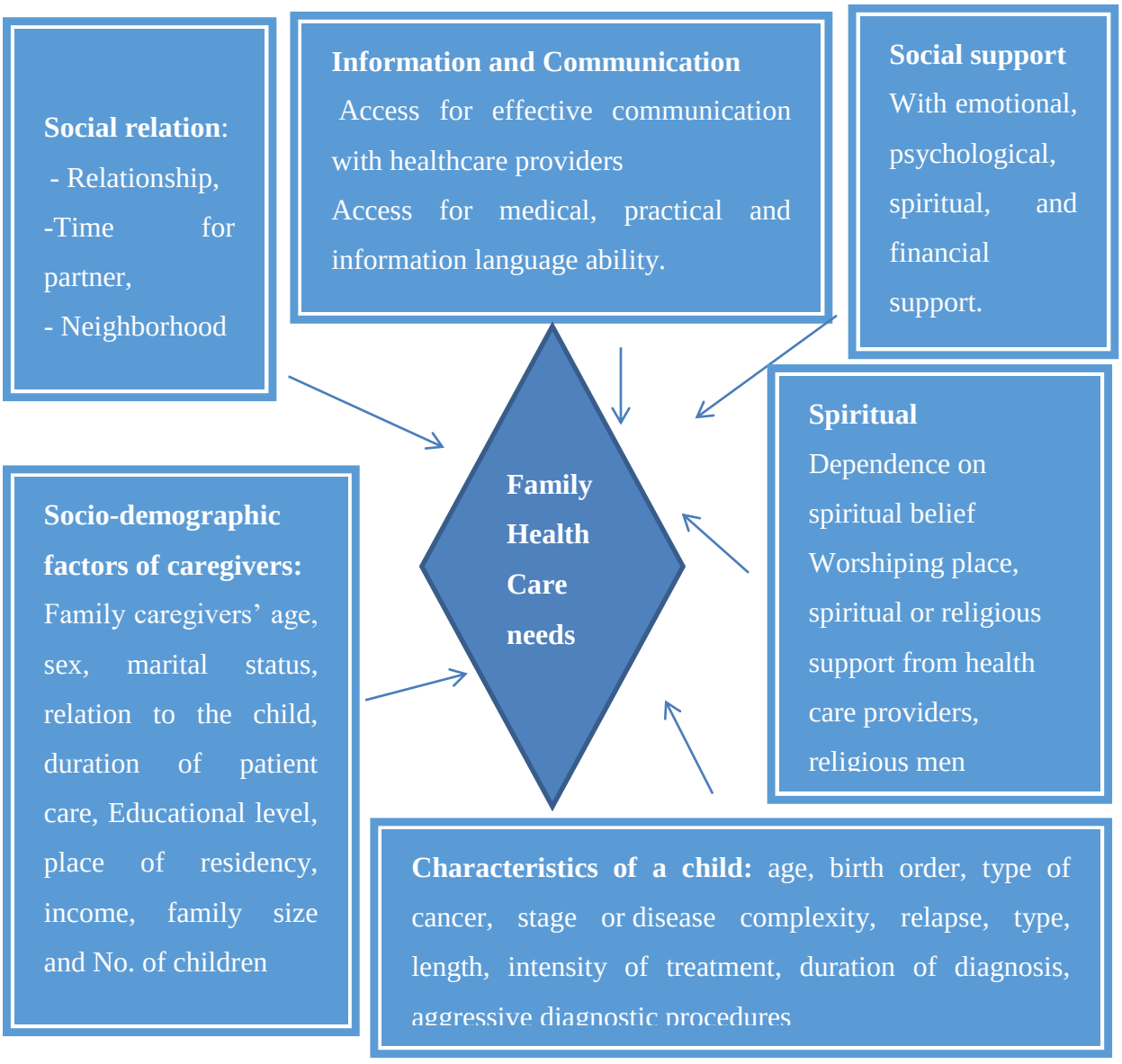

Figure 1: conceptual frame work: To assess risk factors impacting the caregiving experience of family caregivers of children diagnosed with cancer at Tikur Anbessa Specialized Hospital in Addis Ababa, adapted after analyzing various kinds of literature, it shows the relationship between the dependent and independent variables (108,109).

Research Questions

What is the level of health care needs of family caregivers' of children diagnosed with cancer?

What are the factors associated with health care needs of family caregivers' of children diagnosed with cancer?

CHAPTER THREE: OBJECTIVES

3.1 General objective

Assessment of family caregiver's health care needs when caring for their children with cancer in Tikur Anbessa Specialized hospital, Addis Ababa

3.2 Specific objectives

1. To determine the level of health care needs among family caregivers' of children diagnosed with cancer at Tikur Anbessa specialized hospital.
2. To identify the factors significantly associated with healthcare needs of family caregivers' of children diagnosed with cancer at Tikur Anbessa Specialized Hospital.

CHAPTER FOUR: METHODS AND MATERIALS

4.1. Study area and period

Tikur Anbessa Specialized Hospital is the largest and oldest referral hospital in Ethiopia, established in 1961, giving services to all communities. TASH is a referral and teaching hospital. Located in the Arada sub-city of Addis Ababa, Ethiopia. According to current documents, it has been the only site where cancer cases are treated within the country. The unit was providing services for the community with a workforce of four oncologists, three palliative care specialists, and six pharmacists, of whom three were working in adult age groups, two were in pediatrics, and one of them, who hold a master degree, serves as manager. There were also 26 nurses working actively in the unit. This oncology unit was providing services to these workforces on both an inpatient and an outpatient basis. The hospital currently has 800 beds, of which only 30 are for pediatric cancer patients. Data from the unit's registry indicate that it provides inpatient and outpatient services for around 500–600 children with cancer annually. The pediatric oncology ward is staffed with hematopathologists, residents, and nurses. The study took place in this hospital at Amestegna Day care under this hospital because it is the nation's only referral center, and the oncology department provides a wide range of diagnostic and treatment options, such as radiotherapy, chemotherapy, surgery, and palliative care. The study will be at Amestegna Day Care center under the TASH. The study was conducted from February 19 to March19.

4.2. Study design

An institution-based, cross-sectional study design was employed to measure the magnitude of the problem. A mixed method is difficult because time and resource limitations make it difficult to do.

4.2.1. Source population:

All family caregivers who were responsible for caring for all children diagnosed with cancer in Tikur Anbessa Specialized Hospital, Addis Ababa.

4.2.2. Study Population

The family caregivers who were available during the study period to assess their health care needs while caring for their children diagnosed cancer and have had started any cancer treatment at Tikur Anbessa Specialized Hospital.

4.2.3. Sample size determination

An extrapolation from the Tikur Anbessa Specialized Hospital (TASH) suggests that around 6,000 new cases of childhood cancer are diagnosed annually (110). On average, 500 per month. The sample size (n) required for the study will be calculated using the formula to estimate a single population proportion. The standard normal curve value for a 95% confidence level (1.96), taking 50% of the proportion because there was no previous similar study on factors influencing the family health care needs of parents of children with cancer, and taking the margin of error to be 5%.

$n = Z^2 (p) (q)/d^2$

Where

n= the desired sample size (if the target population is greater than 10,000) Z = is the standard normal deviation at 95% confidence interval (Z = 1.96 for 95%)

z= critical value at 95% CI

n = P = the proportion in the target population estimated the family health care needs. Prevalence rate, p is taken as 50%, since there hasn't been any research done on the topic, the minimal sample size was calculated using 50%.

d is the precision level, which is set at 0.05 or +/-5%.

Z = 1.96 P = 0.5 d = 0.05

Q is equal to 1-P, e is the admissible error (0.05)

Considering that 50% of caregiver is burdened with being caregivers. Replacement n = 1.96 × 1.96 x 0.5 x 0.5 / 0.05 x 0.05

n=384

Since the target population was less than 10,000, the following formula was used to calculate the final sample size nf = n/ (1 + n / N)

Where nf = the desired sample size when the population is less than 10,000, n = the desired population when the sample size is greater than 10,000

N = the estimate of the population nf = 384 / 1 + 384 / 500

nf= 217 caregivers.

After adding 10% non-response rate the final sample size will be 239

4.3. Eligibility criteria

4.3.1. Inclusion Criteria

Family caregivers' whose children were diagnosed with cancer and have had started any cancer treatment because it is enough to show us some level of burden impacted to the family caregivers.

The family caregivers who are willingly accepted to take part in the study and gave their consent.

4.3.2. Exclusion Criteria

Parents whose kids hadn't begun any cancer treatment.

4.4. Sampling technique

TASH, the biggest teaching and referral hospital in Ethiopia, was chosen on purpose. The qualified volunteers were chosen by simple random sampling technique.

4.5. Study variables

4.5.1. Independent Variables

Socio-demographic Characteristics of the child: Age, sex, place of residence, number of children and birth order.

Child clinical Characteristics: Type of cancer, stage, time since diagnosis, relapse/ recurrence, type and length of treatment, no of treatment cycle, length of caring hours, disease prognosis and traditional treatment (herbal, holy water or praying ceremony).

Socio-demographic Characteristics of the caregivers: Age of the parents, type of marriage, relation with the patient, income, parent's education level, family size, place of resident, and job type/ governmental or private / fulltime or par time.

Psychological factors refer anxiety, stress, depression and fear of death of child.

Social relation: relationship, time for partner, neighborhood

Communication refers to language ability and understanding of caregivers.

Sociocultural factors: refers to the family caregivers' engagement in traditional healing practice or spiritual activities (praying, worshiping, and holy water) in addition to seeking medication.

Coping mechanisms: family resilience and coping mechanism refers to the family caregivers' adaption to stressful situation.

4.5.2 Dependent variable

The family caregivers' health care needs: refers to the total score of the need questions. The score ranges from low to high; range 20 and 96, respectively; the highest score indicates greater need.

Based on the score, the need was categorized into low or high level needs.

High level need refers to score above the mean of the need questions.

Low level need refers to bellow the mean score of the need question (110).

4.6. Operational definitions

Family caregivers or primary caregiver: A blood related family who engaged in health care provision for a sick child with cancer disease.

Caregivers' health care needs: A health care needs of the caregiver parents for cancer survivor children. The needs include psychosocial, emotional, spiritual, cognitive, medical, and financial needs.

Psychological and emotional needs: psychological and emotional needs expressed by the cancer survivor's children, family caregivers'.

Information/communication needs: the information and communication needs expressed by the cancer survivor children family caregivers' related to existed diagnosis.

Spiritual needs: cancer survivor children's Parents spiritual needs in relation to the child illness.

Supportive care: The person-centered comprehensive support provided for the caregivers' of cancer survivor children.

Childhood cancer: children under the age of 15 diagnosed with any type of cancer admitted or attending at oncology clinic OPD, attending their treatment care in Black Lion Specialized hospital.

Childhood cancer survivors: a child with cancer from the time of diagnosis through the balance of his or her life.

4.7. Data Collection tools

Data was collected using a structured questionnaire, adapted and modified from previous studies (67). It was a standardized instrument; its validity was assessed, and the Cronbach's alpha coefficient was 0.94. The instrument has three parts. Section-I consists of socio-demography of the caregiver parents; section-II comprises the socio-demography and the clinical characteristic of the cancer survivor. Section-III comprises caregivers' health care needs questionnaire. The questionnaire consists 45 items measured with 5-point Likert scale (1—not applicable, 2-satisfied 3—low need, 4—moderate need, 5—high need).

4.8. Data Collection Procedure

Data was collected using structured questionnaire interview, in which the questionnaire is adopted from previously done studies and modified in the form that it will answer our objectives. The participants were selected by simple random/ lottery method.

To facilitate user-friendliness, the questionnaire was translated into Amharic and then back into English for data entry. Interviewer administered structured questionnaire was used to collect data on caregiver needs using cob-collect tool and a thorough review of medical records to get clinical and socio-demographic data of the child.

4.9. Data quality assurance

The questionnaire was translated into Amharic and then back translated to English for checking its consistency.

Pretesting before the actual data collection in 5% similar population in TASH oncology ward, which was not included in the study. To prevent interviewer bias and ensure data quality, all data collectors and supervisors was received a one day training focusing on how the interview will be conducted. To insure participant' privacy, data collection was held in a small room found beside the respective institution. Completed questionnaires were checked in daily base by the researcher and research assistants, to ensure the completeness of the filled questionnaire.

4.10. Data processing and analysis

Descriptive and statically analysis was run to analyze the data. Descriptive analysis of the continuous variables was presented in the form of means, standard deviations, and medians, for the categorical variable percentages and frequency were calculated. Logistic regression model was used to determine the associated factors. Bivariate analysis was used identify the significantly associated predictor variables with the dependent variable. The significantly associated variables at p-value less than or equal to 0.2 were taken to multivariate analysis; level of significance was determined by P-value <.05 and 95% confidence interval (CI). Their results were presented in text and table with description of odds ratio, p value and 95% CI.

4.11. Ethical Consideration

The study was conducted after ethical clearance was issued from Addis Ababa University College of Health Science, School of nursing and midwifery, and department of nursing research review board. Supporting letter was also written by the nursing department of TASH. Confidentiality of the information was assured and privacy of the information also maintained. Additionally, informed consent was developed in Amharic and we asked for the interviewees their consent to take part in the study. They were enrolled in the study after they decided to do so. They have given the right and the freedom to withdraw them from the study and are not obliged to answer all of the questions.

4.12. Dissemination and Utilization of Results

The study's findings were presented to the Addis Ababa University College of Health Science, department of Nursing and Midwifery, and the oncology department. To the Federal Minister of Health for intervention programs, planning, and implementation, and for published in reputable journals.

CHARTER FIVE: RESULTS

5.1 Socio-demographic characteristics

The study was conducted from March 1 to April 30, 2024 and recruited 239 respondents. The overall response rate was excellent (100%). The majority of the respondents were in the age categories of 30–40, 20–29 and 41–50 years: 50.2% (n =120), 25.1% (n=60) and 17.6 %((n = 42), respectively. Only 7.1 % (n=17) were in the age range 51–60. The respondents were almost similar; females were 51% (n = 122) and males were 49% (n = 117). Most 91.6% (n = 219) of the respondents were married, and only 1.7% (n = 4) were divorced. Most of the 74.1% (n = 177) of the respondents were residing outside Addis Ababa, and the rest were from Addis Ababa city. More than 58% (n = 139) of them were urban dwellers, and the rest were rural dwellers. Most of the caregivers, 35.6% (n = 85) and 27.1% (n = 65), attained education up to the primary level and never attended formal education, respectively, while the rest 37.1% (n=89) attained education at the high school and university levels. The findings are presented in Table 1 below.

Demographic Characteristics of Respondents (n=239)

Most respondents were in the age range 30-40 years 50.2% (n=120), females 51% (n=122), most were married 91.1% (n=117), 74.1% (n = 177) of the respondents were residing outside Addis Ababa. Urban dwellers were 58% (n = 139) and most of them 35.6% (n = 85) attained primary level education. See table1 below.

Table 1: Demographic Characteristics of Family caregivers' of children diagnosed with cancer at Tikur Anbessa Hospital from February 19 to March19 (n=239)

S/NO	Variables	Category	Frequency (n)	Percent (%)
1	Age(years)	20–29	60	25.1%
		30–40	120	50.2%
		41–50	42	17.6%
		51–60	17	7.1%
2	Gender	1. Male	117	49.0%
		2. Female	122	51.0%
3	Marital status	Single	11	4.6%
		Married	219	91.6%
		Divorced	4	1.7%
		Widowed	5	2.1%
4	Residence	Urban	139	58.2%
		Rural	100	41.8
5	Region	Addis Ababa	62	2.9%
		Other areas	177	74.1%
6	Level of Education	Never attended formal education	65	27.2%
		Primary education (1-8)	85	35.6%
		High school (9-12)	41	17.2%
		Collage or higher	48	20.1%
7	Employment status	Self –employed	113	47.3%
		Government-employed	38	15.9%
		Unemployed.	88	36.8%
9	Community based government insurance	Getting insurance	228	95.4%
		Not getting insurance	11	11%
10	Monthly income	0-1650 per month in ETB	102	42.7%

		1651-5250 per month in ETB	80	33.4%
		5251-10899 per month in ETB	42	17.9%
		Above 10899 per month in ETB	14	5.9%
11	Household Family size	1-3	46	19.2%
		4-6	127	53.1%
		7-9	60	25.1
		More	6	2.5%
12	History of Alternative Treatment	Using alternative treatment	127	53.1%
		Not using	112	46.9%

Table 2: Demographic and clinical Characteristics of Children Diagnosed with cancer at Tikur Anbessa Hospital from February 19 to March 19 (n=239)

S/NO	Variables	Category	Frequency (n)	Percent (%)
1	Age(years)	Up to 5 years	103	43.1%
		5-10 years	97	40.6%
		11-15 years	39	16.3%
2	Gender	1. Male	151	63.2%
		2. Female	88	36.8%
3	Number of child	One	44	18%
		Two	68	28.5%
		Three	43	18%
		Greater	84	35%
4	Childs birth order	First	79	33.1%
		Second	64	26.8%
		Third	40	16.7%
		Greater	56	23.4%
5	Time since diagnosis	3-12 m	110	46%
		1-2 y	85	35.6%
		3-4 y	30	12.6%
		>4 y	14	5.9%
6	Type of cancer	Solid cancer	130	54.4%
		Hematologic	109	45.6%
7	Relapse	Yes	41	17.2%
		No	198	82.8%

5.2. Overview of reported supportive care needs

Most participants reported unmet supportive care needs in all SCNS-P&C domains (Table 3). The greatest unmet need was getting emotional support for parents (83.2%) and finding out about financial support and travel insurance for a person with cancer (78.3%) (Table 3). Additional unmet needs included discussing concerns with physicians (77.8%), getting support from family (75.3%), obtaining the best medical care (74.3%), and accessing information about the cancer's prognosis or likely outcome (72.3%). The top met needs were obtaining adequate pain control (37%), exploring spiritual belief (39.3%), problems with sex life, dealing with others not acknowledging the impact of caring for a person with cancer, and accessing information about the potential fertility problems in a person with cancer (40.2%). Other top-met needs were finding more accessible hospital parking, coping with the person's recovery not turning out the way you expected (41%), and accessing information about the benefits and side effects of treatments (42%).

5.3. Health Care and Service Needs Domain

Unmet needs in this domain were reported by participants as 40.1% to 75.3%, or on average, 60.9% of participants. Addressing problems with sex life was the least reported unmet need (40.2% of participants), while getting more support from family was the greatest unmet need (75.3% of participants).

5.4. Psychological and Emotional Needs Domain

Unmet psycho-emotional needs were reported by 39.3%–83.2% of our sample, or on average, 59.3% of participants. Getting emotional support for them was reported as the top unmet need of participants (83.2%). Exploring spiritual belief (39.3%), coping with the person's cancer's recovery not turning out the way you expected (41%), and working through your feelings about death and dying (46.1%) were the top needs met by participants.

5.5. Work and social/security needs

The reporting of unmet needs in this domain varied from 40.2% to 78.3% (average 60% of participants). Financial support and travel insurance were chosen as unmet needs by 78.3% of participants, whereas dealing with others not acknowledging the impact of caregiving on their lives and finding more accessible hospital parking were reported as unmet needs by only 40.2% and 41% of participants, respectively.

5.6. Information and Practical Needs Domain

Information and practical needs were reported as unmet by 37% to 77.8% of participants, or on average by 61.9% of participants. Obtaining adequate pain control for a person with cancer was the least reported unmet need (37%). Having opportunities to discuss your concerns with the doctor (77.8%) was the top unmet need.

Table 3: Breakdown of Supportive Care Needs of Family Caregivers per Individual SCNS-P&C Item (n =239)

	Item	Frequency(n)	No-Low need		Moderate-high need	
	Domain Information/communication and practical needs /(2-10, 11-14, 16-19,45)		**N**	**%**	**N**	**%**
2	Accessing information about the person with cancer's prognosis, or likely outcome	239	66	27.6	173	72.3
3	Accessing information about support services for careers of people with cancer.	239	71	29.7	168	70.3
4	Accessing information about alternative therapies?	239	74	31	165	69
5	Accessing information on what the person with cancer's physical needs is likely to be.	239	81	27.6	158	66.1
6	Accessing information about the benefits and side effects of treatments?	239	137	57.3	102	42.7
7	Obtaining the best medical care for the person with cancer?	239	61	25.5	178	74.3
8	Accessing local health care services when needed?	239	88	36.7	151	63.2
9	Being involved in the person with cancer's care, together with the medical team?	239	92	41.4	140	58.6
10	Having opportunities to discuss your concerns with the doctors?	239	53	22.7	186	77.8
11	11. Feeling confident that all the doctors are talking to each other to coordinate the person with cancer care?	239	71	29.7	168	70.3
12	Ensuring there is an ongoing case manager to coordinate services for the person with cancer	239	113	47.3	126	52.7
13	Making sure complaints regarding the person with cancer's care are properly addressed?	239	67	28	172	72
14	Reducing stress in the person with cancer's life?	239	83	34.7	156	65

16	Obtaining adequate pain control for the person with cancer?	239	149	62.3	90	37
17	Addressing fears about the person with cancer's physical or mental deterioration?	239	99	41.4	140	58.6
18	Accessing information about the potential fertility problems in a person with cancer?	239	143	59.8	96	40.2
19	Caring for the person with cancer on a practical level, such as bathing, changing dressings, or giving medications?	239	95	39.7	144	60.3
45	Having opportunities to participate in decision-making about the person with cancer's treatment?	239	87	36.4	152	63.6
	Health care service (26, 27, 28, 30, 33)					
26	Communicating with the person you are caring for?	239	94	39	145	61
27	Communicating with the family?	239	48	20.1	156	65.3
28	Getting more support from your family?	239	59	24.6	180	75.3
30	Handling the topic of cancer in social situations or at work?	239	86	36	153	64.0
33	Understanding the experience of the person with cancer?	239	96	40.1	143	59.9
36	Addressing problems with your sex life?	239	143	59.8	96	40.2
	Work and social/security needs (20-25, 29, 40)					
20	Finding more accessible hospital parking?	239	141	59.1	98	41
21	Adapting to changes to the person with cancer's working life, or usual activities?	239	93	38.9	146	61.3
22	The impact that caring for the person with cancer has had on your working life or usual activities?	239	105	43.9	134	56.1
23	Finding out about financial support and government benefits for you and/or the person with cancer?	239	52	21.7	187	78.3
24	Obtaining life and/or travel insurance for the person with cancer	239	52	21.7	187	78.3
25	Accessing legal services?	239	97	40.6	142	59.5
29	Talking to other people who have cared for someone with cancer?	239	29	35.9	153	64
40	Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	239	143	59.8	96	40.2

	Psychological and emotional needs (1, 15, 31, 32, 33, 34, 35, 37, 38, 39, 41, 42, 43, 44)					
1	Accessing information relevant to your needs as a career/partner.	239	72	30.2	167	69.8
15	Looking after your own health, including eating and sleeping properly?	239	88	36.8	151	63.2
31	Managing concerns about cancer coming back?	239	93	38.9	146	61.1
32	The impact that cancer has had on your relationship with the person with cancer?	239	89	37.2	150	62.8
33	Understanding the experience of the person with cancer?	239	90	37.2	149	62.3
34	Balancing the needs of the person with cancer and your own needs?	239	102	42..6	137	57.3
35	Adjusting to changes in the person with cancer's body?	239	69	28.9	170	71.1
36	Addressing problems with your sex life?	239	89	37.3	150	62.7
37	Getting emotional support for your-self?	239	40	16.8	199	83.2
38	Getting emotional support for your loved ones?	239	109	45.6	130	54.4
39	Working through your feelings about death and dying?	239	129	53.9	110	46.1
41	Coping with the person with cancer's recovery not turning out the way you expected?	239	141	59	98	41
42	Making decisions about your life in the context of uncertainty?	239	115	48.1	124	51.9
43	Exploring your spiritual beliefs?	239	143	60.7	94	39.3
44	Finding meaning in the person with cancer's illness.	239	86	36	153	64

Table 4: Top Met and Unmet needs in the sample (n=239)

Item No	Variables	Frequency(n)	No-Low need		Moderate-high need	
			N	%	N	%
37	Getting emotional support for your-self?	239	40	16.8	199	83.2
23	Finding out about financial support and government benefits for you and/or the person with cancer?	239	52	21.7	187	78.3
24	Obtaining life and/or travel insurance for the person with cancer	239	52	21.7	187	78.3
10	Having opportunities to discuss your concerns with the doctors?	239	53	22.7	186	77.8
28	Getting more support from your family?	239	59	24.6	180	75.3
7	Obtaining the best medical care for the person	239	61	25.5	178	74.3
2	Accessing information about the person with cancer's prognosis, or likely outcome	239	66	27.6	173	72.3
16	Obtaining adequate pain control for the person with cancer?	239	149	62.3	90	37
43	Exploring your spiritual beliefs?	239	143	60.7	94	39.3
36	Addressing problems with your sex life?	239	143	59.8	96	40.2
18	Accessing information about the potential fertility problems in a person with cancer?	239	143	59.8	96	40.2
40	Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	239	143	59.8	96	40.2
20	Finding more accessible hospital parking?	239	141	59.1	98	41
41	Coping with the person with cancer's recovery not turning out the way you expected?	239	141	59	98	41
6	Accessing information about the benefits and side effects of treatments?	239	137	57.3	102	42.3
42	Making decisions about your life in the context of uncertainty?	239	115	48.1	124	51.9

5.7. Factors associated with family health care need

Relapse of childhood cancer, employment status, age and sex of the family caregivers, and the sex of the child, number of children, and marital status are factors associated with or having significant effects on the health care needs of the family caregivers. Female caregivers have more health care needs than male caregivers 4.729(2.149, 10.405) at a p-value < 0.05. Parents with children with relapsed cancer showed 4.789 times more health care needs than those who had no relapse, and family caregivers who have three or more children in the home also have more health care needs than those with single or two children. Young adult family caregivers need more health care than older family caregivers. Family caregivers who are unemployed need more health care than those who have a permanent job, are government-employed, or are self-employed. See table 5 below.

Significant variable only (Backward variable selection)

Table 5: Results of Bivariate and Multivariate Analysis of Factors Associated with family caregiver's health care needs among family caregiver's in Black lion Hospital , Addis Ababa , 2024 (n=239).

Variables	Categories	COR(95% CI)	AOR(95% CI)	p-value
Child 's Gender	Girls		1	
	Boys	1.504(.885,2.55)	2.575 (1.152, 5.755)*	.021
No. of children	Greater		1	.005
	One	.174(.079,.383)	.212 (.073, .614)**	.004
	Two	.215(.108,.429)	.278 (.108, .715) **	.008
	Three	.661(.302,1.44)	.970 (.323, 2.909)	.956
Family caregivers' age	20–29		1	.016
	30–40	.545(.287,1.036)	.334 (.131, .849)*	.021
	41–50	.364(.168,.788)	.259 (.079, .848) *	.026
	51–60	.200(.088,.455)	.171 (.051, .572) **	.004
Family caregivers' Gender	Male		1	
	Female	4.144(2.403,7.146)	4.729(2.149,10.405)***	.000
Marital status	Single		1	.000
	Married	.178(.090,.354)	.165 (.063, .432)***	.000
	Divorced	2.973(1.066,8.2940	4.449(1.089,18.178)*	.038
	Widowed	1.712(.589,4.975)	2.293 (.593, 8.873)	.229
Employment Status	Self-employed		1	.004
	Governmental	1.000(.399,2.509)	1.458 (.397, 5.348)	.570
	Unemployed	3.522(1.971,6.2920	4.019(1.704,9.483)**	.001
Relapse	Yes	3.750(1.739,8.088)	4.789(1.645,13.939)**	.004
	No		1	

* Significant association at p-value < 0.05, p-value < 0.01** and p-value < 0.001***, 1 - Reference

CHAPTER SIX: DISCUSSION, CONCLUSION AND RECOMMENDATION

6.1. Unmet Needs of Family Caregivers

We aimed to comprehensively map the supportive care needs of family caregivers in the resource-challenged Ethiopian context. Total Unmet needs of family caregivers' on the Supportive Care Needs Survey of Family Caregivers were 49.8%. On average, most participants reported unmet information and practical needs (61.9%), followed by health care and service needs (60.9%) and work and social life needs (60%). The greatest unmet need was getting emotional support for the family caregivers (83.2%). Since the health professional or nurse ratio to clients in the oncology department is not proportional and staff have high workloads to give enough emotional support to families of cancer-suffering children throughout the course of palliative care, parent caregivers may develop anxiety and depression when they hear about their child's cancer diagnoses, but long-term emotional crises may not always be linked to a child's disease (88), and parents may experience positive changes due to managing illness demands (89). The most important emotional need was the feeling of uncertainty about the child's cancer, cure, diagnosis, treatment, symptom management, and the future (47). Caregivers face psychosocial burden, burnout symptoms, and negative effects from child behavioral and physical changes due to cancer treatment, with 75% reporting overwhelming burden (3).

The second top unmet need in the survey was finding out about financial support and travel insurance for a person with cancer (78.3%), and then discussing concerns with physicians (75.3%), accessing support services for caregivers and partners (75.3%), obtaining the best medical care (74.3%), and accessing information about the cancer's prognosis or likely outcome (72.3%).

Research shows that parents of children with cancer face higher psychological challenges, requiring more emotional and psychological support than general population parents (86). A study by Qingying and colleagues found that Chinese parents of cancer-stricken children require the most emotional support, including informational and emotional support, with fear, worries, and sadness being the most significant emotional needs (emotional needs M = 4.12, SD = 0.94; psychosocial needs M = 3.94, SD = 0.87). This includes the sensation of ambiguity regarding the child's cancer (30,31,87). Parents of children with life-threatening illnesses (49) require emotional support, including empathy, mutual understanding, and psychological support, from both informal and important healthcare providers (38). During crises, support is crucial. Therapy interventions should focus on the parent's local environment and coping mechanisms to enhance functioning and aid in

adaptation. In addition as a Morocco study showed caregivers face reduced socialization and neglect their families (49), potentially hindering quality care (50). Wang et al. link patient QoL to caregiver unfulfilled demands (51). Research shows a negative correlation between primary caregivers' health outcomes and pediatric cancer care (52), emphasizing the importance of informal caregivers' collaboration and compliance in successful management (53).

Finding out about financial support and travel insurance for a person with cancer (78.3%) was the second top unmet needs in the report. Uncertainty around finances was a logical concern in our sample; 95.4% of Ethiopia's health insurance users struggle financially, particularly around balancing living costs and cancer-related costs, because most of them have extended families and most families are unemployed. In terms of low income, the study showed most of the caregivers was in the range of 601–1650 ETB (26.8%) and 1650–3200 (25.5%). Most of them travel from remote areas outside of Addis Ababa, the capital city of Ethiopia, where the only compressive oncology care is given. They travel a long distance to get the service, and they struggle to fund travel costs for their sick kids and house rent or the house needed for temporary settlement. Before the government covered health insurance, low-income families rarely took sick family members to hospitals; most resided in remote areas where communities were isolated, with limited facilities and difficult transportation. 74.1% of the participants reported as they were outside Addis Ababa, where the oncology cares available (table 1 above). However, even now, free treatment at the hospital does not always cover all expenses, like prescribed medications and laboratory workups. Since chemo-therapy drugs were not regularly available at the hospital, the drugs were also very expensive, and some were hard to find even in private drug stores.

A recent report also stated that Ethiopian palliative care is only available in one city, Addis Ababa, the capital city of Ethiopia, leaving the rest of the country without access to specialist care. Treatment centers for cancer are still limited in Ethiopia, which practically leaves family caregivers with little choice in finding the best medical care for patients.

Warner et al. (2021) highlight the financial strain on families in developing countries due to pediatric cancer treatment, highlighting the severe financial challenges faced by cancer patients (43). Financial toxicity during cancer treatment, particularly in resource-limited countries, is a significant issue, with nonmedical expenses accounting for over 45% of total expenditure, particularly in rural areas (44). Families traveling outside their region to access health services should receive medical travel subsidies and reimbursement for meals, accommodation, and gas expenses (43) and having

health-insurance could have the potential of improving treatment outcomes and survival (45). The occurrence of financial needs and highly valued support for financial needs related to care and treatment have been demonstrated in numerous studies (24). Poverty significantly predicts unmet cancer care needs in the Omani community, with parents of cancer patients often facing more financial difficulties than those with other chronic illnesses. Awareness of available financial aid options can help alleviate the psychosocial toll (77). Caregivers in countries that have no free cancer treatment face significant stress due to the time and financial burden of caring for a sick child.

In contrast, Qingying et al. showed that as long as the family was assured that the child would receive treatment, financial needs were less of a priority than were other logistical problems (18). Landowska's 2022 study in Poland found that only 30% were in the financial needs domain, but in West Java, Indonesia, a study revealed that cancer patients often face unmet needs such as financial support and travel insurance (81.4%). High treatment costs disrupt caregivers' social lives and financial sources in Ghana, while financial difficulties in India lead to stress and debt, negatively impacting families' financial stability but not leading to withdrawal from care. US parents of cancer children report job disruptions, with 42% resigning, the wealthiest families losing only 5%, and 50% of the lowest households losing over 40% (60).

Another most reported important unmet need was discussing concerns with physicians (75.3%), accessing support services for caregivers and partners (75.3%) and accessing information about the cancer's prognosis or likely outcome (72.3%). Families need clear and concise information about a child's health, which is crucial for informed healthcare participation and childcare decisions, especially for African cancer patients and their caregivers (54). Our participants reported a general paucity of knowledge, particularly about the information required for prognosis, among clients who were primarily from rural locations, had limited internet access, had low levels of education, and faced language problems. A previous study conducted in our nation revealed that parents of children diagnosed with cancer reported either receiving insufficient information from medical personnel or no information at all. Moreover, they asserted that the details supplied by medical experts were restricted to general descriptions of the child's illness and its treatments. Though commonly sought, information on the causes of the child's specific medication regimen, drug side effects, the long-term effects of the disease, and what to expect from the child's illness was greatly requested but infrequently supplied.

Parents of cancer patients often complain of incomplete information provided by the medical team about the condition and treatment of their children (27,55). The survey found 70% needed medical information, which was the highest among parents' unmet needs. Parents of older children need emotional support and should provide necessary medical information during diagnosis and treatment. A Korean study reveals caregivers of childhood cancer survivors have the highest unmet needs for information about the illness, therapies, patient care, and financial support, suggesting comprehensive cancer care (57). Higher household incomes and older caregivers of cancer patients have lower unmet information needs (78).

The most challenging task for family caregivers seems to be balancing the needs for social activities with managing patients' discomfort as well as emotional and financial swings. These challenges also exist in other developing countries. Family caregivers need extra support and guidance during care transitions. Palliative care providers and family caregivers have complementary roles in developing strong relationships with patients and their families. In contrast, the government of industrialized nations like the UK equips health care support workers with the necessary skill set to offer patients with at-home care (111). In a country like Ethiopia with few resources, nurses may take the lead in developing palliative care services. Our participants reported feeling that there was a general lack of information. Typically, there are minutes or hours of waiting to be transferred from the site of diagnosis to a clinic. However, the consultation with the doctor can take a few minutes. It could be quite challenging for patients and their families to talk about the patient's health in this incredibly short amount of time (112). The lack of information may be addressed, for example, by depending more on direct relationships with nurses. In order for the healthcare system to work well, nurses have a strategic role in how the system functions and delivers the best quality care (113).

6.2. Children's and Family Caregivers' Characteristics significantly associated with family caregivers' health care needs

In the result of multiple logistic regression analysis, which was done to find independent relationships between family caregivers healthcare needs and caregiver characteristics. Mother-caregivers have a higher unmet need than fathers. Similar study found that family caregivers of childhood cancer patients often suffer from anxiety, depression, psychological distress, and impaired health-related quality of life, with mother-caregivers having a higher unmet need (46). In another study in Iran found that female caregivers have a higher care burden than male caregivers due to Iranian culture's emphasis on motherhood. Our study showed married family caregivers experienced

a lower care burden than single one .165 (.063, .432) .000 at P < 0.001. Similar study revealed that married mothers experienced a lower care burden than single mothers (70,71). Studies in Canada and the Netherlands show single moms have a significant care burden. However, compared to married caregivers, single caregivers appear to be more vulnerable to financial difficulties and parenting stress (57,72), which adds to their heavy care load. However, a 2019 study in Mexico found that gender doesn't affect care requirements (13). In addition our study showed that younger family caregivers had showed more healthcare needs than older family caregivers.

Family having male child with cancer and child with history of relapse showed more burden than female child 2.575 (1.152, 5.755) .02 at p < 0.05 and 4.789(1.645, 13.939) .004 at p< 0.01 respectively. Research shows that a child's age doesn't predict the stress associated with providing care, with younger, unwell children requiring more (56). However, no correlation was found between caregivers' care burden and the sex of the ill child (81), but male unwell children reported a higher burden (82). Nonetheless, raising a child, whether boys or girls, with cancer exposes caregivers to a high burden of care.

6.3. Met Needs of Family Caregivers

The top met needs were obtaining adequate pain control (37%), exploring spiritual belief (39.3%), problems with sex life, dealing with others not acknowledging the impact of caring for a person with cancer, and accessing information about the potential fertility problems in a person with cancer (40.2%). Other top-met needs were finding more accessible hospital parking, coping with the person’s recovery not turning out the way you expected (41%), and accessing information about the benefits and side effects of treatments (42%). (See table 4 above.)

Although assuming a caregiving role might lead family caregivers to sacrifice their own needs, 150 of the sample overall did not report a significant impact on their sexual life. This may be due to the fact that health care professionals recognize that sexual activity is a private issue. 149 people in the sample reported having adequate pain control when needed. There is enough pain control available in the health facility for them and their kids when needed, and they also have enough information about the side effects of the treatment, especially chemotherapy.

Another met need in my study was exploring spiritual belief; 145 of the sample overall did not report a significant need for exploring their spiritual belief. This study showed that most of 239 samples were using either or both praying ceremonies and holy water at the same time for their medical treatment. A previous study in Ethiopia found that parents of children with cancer often use coping

mechanisms such as prayer, religious beliefs, crying, accepting their condition, discussing it with health providers, and denial.

6.4. Limitation and Strength

The response rate was 100%, which was outstanding overall. Participants reflect all Ethiopians by coming from a variety of demographic and geographic backgrounds with multicultural backgrounds and heterogeneity. Since the Black Lion Hospital is the sole referral facility for all-inclusive cancer care, our sample was drawn from all districts. Pretests were conducted in comparable populations but were excluded from the study to verify the SCNS-P&C questionnaires prior to data collection. Nonresponse bias is thought to be minimal.

Although a quantitative study was conducted, a qualitative investigation is recommended to obtain deeper insights into the healthcare needs of family caregivers. I used an interviewer to make sure that each participant had a varied educational background, which would have influenced their responses and prevented them from being totally honest because they might have felt that their service is not provided in the way that they would have liked.

6.5. Conclusions

1. Parents of children with cancer experience a high level of needs, especially psychological, emotional support from health professionals and families, financial support is the second most unmet need and information. These data suggest that the existing healthcare system does not meet the needs of parents of sick children.
2. Most of their sick children were diagnosed between the ages of 3 to 12 months, since they showed a high level of emotional support need, and a low level of income, and most of the caregivers were coming from outside Addis Ababa, making their transportation challenging to come to Black Lion Hospital for follow-up care.
3. By using the finding of this study, health care providers need to formulate and apply how to address the health care needs of family caregivers.

6.6. Recommendations

1. To reproduce and generalize the research findings to a larger Ethiopian environment, more investigation is needed. It is crucial to uncover the experiences of unfulfilled needs among family caregivers if a qualitative study on the family health care needs and associated factors will clearly to identify the emotions that they could not express on paper. Length of illness, type and duration of cancer treatment and type of cancer needs further study.

2. Nurse-led therapies that are both comprehensive and flexible should to be used. When it comes to creating palliative care services, oncology nurses will play a critical role in connecting issues with their essential roles in providing patients and families with support for everyday needs, spiritual requirements, and symptom management (114). This oncology nurses could made outpatient clinic for consultation, train family to provide basic care and self-care at home, and monitor progress and emerging needs via remote or home visits.

3. Policymakers must take into account providing full funding for the treatment of childhood cancer through universal health care.

4. Consider cancer treatment facilities to be decentralized outside Addis Ababa.

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ANNEXES

ANNEX 1: Information Sheet

Here, I am, the undersigned, at Addis Ababa University College of health science, department of nursing and midwifery, currently undertaking research on a topic entitled assessment of family caregiver's health care needs when caring for their children with cancer in Tikur Anbessa Specialized hospital, Addis Ababa, Ethiopia. For this study, you will be selected as a participant, and before getting your permission or assent to your participation, you need to know all necessary information related to the study. Thus, this information will be detailed as follows:

Objective: To assess family caregiver's health care needs when caring for their children with cancer in Tikur Anbessa Addis Ababa, Ethiopia, in 2024.

Significance of the study: The research findings will be helpful in the evaluation of the family health care needs of children with cancer in a community and used to influence public policy decisions, including the development of strategic health care plans, emphasizing psychosocial support, influence the allocation of resources and the implementation of programs that address the specific needs of this vulnerable population

Participants included: All family caregiver's caring for their children with cancer admitted in Tikur Anbessa Specialized hospital, Addis Ababa in the study.

Confidentiality: All information you give will be kept confidential and won't be accessible to any third party. Your name won't be registered on the question sheet, so you will not be identified.

Risks and Benefits of the Study: The study will be carried out using an interviewer administered questionnaire. The procedure doesn't cause any physical or psychological trauma. Furthermore, you will not be forced to respond to the information you do not know. There is no payment for your participation in the study but participating in the study and giving your information to questions asked will have great input in efforts to improve quality of life of children with cancer and their family caregivers in Tikur Anbessa Specialized hospital, Addis Ababa.

Assent: Your participation in the study will be totally based on your willingness. You have the right not to participate from the beginning or to stop at any time after starting to participate. You will not be forced to respond to a question you do not know, and you can ask any question you like.

Name of principal investigator (PI): Seyfedin Barkeda

Date:_____ Signature_____ Address of PI: Mobile: +251927436060

E-mail: seyfedinbarkeda8@gmail.com

Data Collector Name: _____Date _____ Signature _____

Supervisor Name: _____Date _____ Signature

ANNEX 2: English Consent confirmation form

I have read the consent explanation and understood its content. I have been given the opportunity to discuss all my concerns with the researcher. I have had my questions answered in language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I understand that all efforts will be made to keep information regarding my personal identity confidential. I understand that by signing this consent form, I have not given up any of the legal rights thatI have as a participant in a research study.

I agree to participate in this research study: Yes/ No

I agree to fill in the questionnaire Yes/No

Participant signature/ Thumb stamp ---------- Date----------

Participants' printed name……Date……..

Researcher's statement

I the undersigned have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has freely given his/ her consent.

Researchers Name…….Signature……Date ……..

Role in the study……

Witness Name……Signature……Date: ……

Witness contact: Tel Number: ---------- P. O Box ---------- Email ----------

ANNEX 3: ENGLISH QUESTIONNAIRE

Directions for completing the questionnaire

Before filling in this questionnaire, we are requesting you to read, understand and sign the attached consent for.

Please do not write your name in any of the pages of the questionnaire.

Please read carefully the instructions at the beginning of each section of the questionnaire before answering the questions in that section.

Please answer all the questions in each section if possible.

Section -I Socio-demographic questionnaires

S.N	Socio-demographic factors of child	Response	Remark
1	Gender	1. Male 2. Female	
2	Age	1. Up to 5 years 2. 5–10 years 3. 11-15 years	
3	No of children	1. One 2. Two 3. Three 4. Greater	
4	Childs birth order	1. First 2. Second 3. Third 4. Greater	
	Socio-demographic factors of family caregiver		
5	Caregiver's age	1. 20–29 2. 30–40 3. 41–50 4. 51–60	
6	Caregiver's sex	1.Male 2. Female	
7	Caregiver's relation to the children	1. Father 2. Mother 3. Uncle/Aunt 4. Grandparent 5. Other	
8	Place of residence	1. Rural 2. Urban	
9	Family monthly income	……ETB	

10	Caregiver's occupation	1. Self –employed 2. Government- employed 3. Unemployed.	
11	Caregiver's education	1. Never attended formal education 2. Primary education(1-8) 3. High school (9-12) 4. Collage or higher	
12	Caregiver's marital status	1. Single 2. Married 3. Divorced 4. Widowed	
13	Total family size	…….	

Section-II Clinical Characteristics of the children

S.N	**General Clinical Characteristics**	**Response**	
14	Time since diagnosis	1. 3–12 m 2. 1–2 y 3. 3–4 y 4. > 4y	
15	Recurrent, if the answer is yes skip the next question	1. Yes 2. No	
16	No of relapses	1. once 2. twice 3. above	
S.N	**Cancer specific Characteristics**	**Response**	
17	Type of cancer	1. Solid cancer 2. Hematologic/ leukemia	
18	Solid tumor staging	1. Stage 0	Tis, N0, M0
		2. Stage 1	T1-T2, N0, M0
		3. Stage 2	T2-T4, N0, M0
		4. Stage 3	T1-T4, N1-N3, M0
		5. Stage 4	T1-T4, N1-N4, M1
		1. Stage I	- Enlargement of lymph nodes, - no metastasis to organs
		2. Stage II	- Enlargement of Liver, Spleen and LN

	Hematologic tumor staging	3. Stage III	- Anemia in addition to Enlargement of the above organs, - More than 2 organs affected
		4. Stage V	Decreased Plt number,(bleeding tendency), Lung started to be affected including to the other organs affected in early stages The anemia is acute
19	Type of treatment	1. Chemotherapy 2. Radiotherapy 3. Hormonal therapy 4. Immunotherapy	
20	Treatment cycle	_____	
21	In your view what would be the outcome of your child treatment?	1.Very good 2.Good 3. Fair 4. Poor	
22	History of Alternative treatment, if answer is no skip the next question	1.YES 2. NO	
23	Name of Alternative treatment	1. Holy water 2.Traditional healer	

ANNEX 4. Supportive care needs survey of caregivers (SCNS - P&C) questionnaire

Instructions

Caring for or living with someone with cancer may raise issues for you that are distinct from the needs of the person with cancer. We are interested in finding out more about your needs as a support person, or carer for someone with cancer. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of caring for or living with a person with cancer. Please always ensure that you answer the questions in regard to YOUR OWN EXPERIENCE AS A CARER of a child with cancer, not in regard to what the child with cancer may be experiencing.

Put a circle around the number which best describes whether you have needed help with this in the last month. If you feel the question is not relevant to your situation please make sure to circle option 1 'Not applicable'.

There are 5 possible answers to choose from: to indicate your level of needs on a 5-point Likert scale (1—not applicable, 2- satisfied, and 3— low need, 4— moderate need and 5— high need).

In the last month, what was your level of need for help with:	No need		Some need		
	Not Applicable	Satisfied	Low need	Moderate Need	High need
1. Accessing information relevant to your needs as a carer	1	2	3	4	5
2. Accessing information about the person with cancer's prognosis, or likely outcome.	1	2	3	4	5
3. Accessing information about support services for careers of people with cancer.	1	2	3	4	5
4. Accessing information about alternative therapies?	1	2	3	4	5
5. Accessing information on what the person with cancer's physical needs is likely to be.	1	2	3	4	5
6. Accessing information about the benefits		2	3	4	5

and side effects of treatments?	1				
7. Obtaining the best medical care for the person with cancer?	1	2	3	4	5
8. Accessing local health care services when needed?	1	2	3	4	5
9. Being involved in the person with cancer's care, together with the medical team?	1	2	3	4	5
10. Having opportunities to discuss your concerns with the doctors?	1	2	3	4	5
11. Feeling confident that all the doctors are talking to each other to coordinate the person with cancer care?	1	2	3	4	5
12. Ensuring there is an ongoing case manager to coordinate services for the person with cancer?	1	2	3	4	5
13. Making sure complaints regarding the person with cancer's care are properly addressed?	1	2	3	4	5
14. Reducing stress in the person with cancer's life	1	2	3	4	5
15. Looking after your own health, including eating and sleeping properly?	1	2	3	4	5
16. Obtaining adequate pain control for the person with cancer?	1	2	3	4	5
17. Addressing fears about the person with cancer's physical or mental deterioration?	1	2	3	4	5
18. Accessing information about the potential fertility problems in a person with cancer?	1	2	3	4	5

19. Caring for the person with cancer on a practical level, such as bathing, changing dressings, or giving medications?	1	2	3	4	5
20. Finding more accessible hospital parking?	1	2	3	4	5
21. Adapting to changes to the person with cancer's working life, or usual activities?	1	2	3	4	5
22. The impact that caring for the person with cancer has had on your working life, or usual activities	1	2	3	4	5
23. Finding out about financial support and government benefits for you and/or the person with cancer?	1	2	3	4	5
24. Obtaining life and/or travel insurance for the person with cancer?	1	2	3	4	5
25. Accessing legal services?	1	2	3	4	5
26. Communicating with the person you are caring for?	1	2	3	4	5
27. Communicating with the family?	1	2	3	4	5
28. Getting more support from your family?	1	2	3	4	5
29. Talking to other people who have cared for someone with cancer?	1	2	3	4	5
30. Handling the topic of cancer in social situations or at work?	1	2	3	4	5
31. Managing concerns about cancer coming back?	1	2	3	4	5
32. The impact that cancer has had on your relationship with the person with cancer?	1	2	3	4	5
33. Understanding the experience of the person with cancer?	1	2	3	4	5
34. Balancing the needs of the person with	1	2	3	4	5

cancer and your own needs?					
35. Adjusting to changes in the person with cancer's body?	1	2	3	4	5
36. Addressing problems with your sex life?	1	2	3	4	5
37. Getting emotional support for you?	1	2	3	4	5
38. Getting emotional support for your loved ones?	1	2	3	4	5
39. Working through your feelings about death and dying?	1	2	3	4	5
40. Dealing with others not acknowledging the impact on your life of caring for a person with cancer?	1	2	3	4	5
41. Coping with the person with cancer's recovery not turning out the way you expected?	1	2	3	4	5
42. Making decisions about your life in the context of uncertainty?	1	2	3	4	5
43. Exploring your spiritual beliefs?	1	2	3	4	5
44. Finding meaning in the person with cancer's illness.	1	2	3	4	5
45. Having opportunities to participate in decision making about the person with cancer's treatment	1	2	3	4	5

የአማርኛ ቅጂ መጠይቆች

አባሪ 1፡ ስለጥናቱ መረጃ / information

እነሆ እኔ በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ የነርሲንግ እና አዋላጅ ትምህርት ክፍል በአሁኑ ወቅት በአዲስ አበባ ኢትዮጵያ፤በምናከናውነው የጥናት አና ምርምር፤ በጥቁር አንበሳ ሆስፒታል የካንሰረ ታማሚ ሕፃናት እናቶች ወይም ተንከባካቢ-ቤተሰቦች ፤ ተማሚ ልጆቻቸውን ለመንከባከብ የሚያስፈልጋቸውን የጤና እንክብካቤ ፍላጎቶች በሚል ርዕስ ምርምር እያካሄድኩ ነው። ለዚህ ጥናት እንደ ተሳታፊ ሆነው ተመርጠዋል፤ እናም እርስዎ ወደ ቃለ መጠየቁ ከመግባቶ በፊት ወይም ለተሳትፎ ፈቃድዎን ከመስጠቶ በፊት ከጥናቱ ጋር የተዛመዱ ሁሉንም አስፈላጊ መረጃዎች ማወቅ ያስፈልግዎታል። ስለሆነም ይህ መረጃ እንደሚከተለው በዝርዝር ይከናወናል።

የጥናቱ ዋና ዓላማ:- በጥቁር አንቢሳ ሆስፒታል በ 2024 ህጻናት የካነሰር ታማሚዎችን የሚንከባከቡ ቤተሰብ ተንከባካቢዎች የጤና እንክብካቤ ፍላጎታቸውን መገምገም ይሆናል።

የጥናቱ አስፈላጊነት/ ጥቅም፡- የጥናቱ ግኝቶች በማህበረሰብ ውስጥ ካንሰር ያለባቸውን ልጆች ተነከበካቢ ቤተሰብ ጤና አጠባበቅ ፍላጎቶች ለመገምገም እና የህዝበ ፖሊሲ ውሳኔዎችን ለማሻሻል ይረዳል:: የስትራቴጂካዊ የጤና እንክብካቤ እቅዶችን ማዘጋጀትን ጨምሮ፤ የስነ-ልቦና ድጋፍን በማጉላት፤ የዚህን የተጋላጭ ህዝብ ልዩ ፍላጎቶች የሚያሟሉ የግብአት ድልደላ እና የፕሮግራሞች ትግበራ ናቸው።

የሚካተቱት ተሳታፊዎች፡- ሁሉም በካንሰር የታመሙ እና በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል፣ በመታከም ላይ ያሉ ልጆቻቸውን የሚንከባከቡትን የቤተሰብ ተንከባካቢ/ ወላጆች በጥናቱ ተካተዋል።

ምስጢራዊነት/ ምስጥር መጠበቅ፡- በዚሁ ጥናት ላይ የሚሰጡን መረጃ በሙሉ ሚስጢራዊነቱ ተጠብቆ ይቀመጣል በተጨማሪም ከጥናቱ ወይም ከአጥኚው ውጪ ለማንኛውም ሶስተኛ ወገን ተደራሽ አይሆንም። :: ስምዎ በጥያቄ ወረቀቱ ላይ አይመዘገብም፣ የሚሰጡን መረጃ በፍይል ከእርዎ ስም ውጪ በኮድ ተደርጎ ይቀመጣል።

ስለጥናቱ ጥቅም እና ጉደት መረጃ፡- ጥናቱ የሚካሄደው በቃለ መጠይቅ አድራጊ የሚነበብ መጠይቅ በመጠቀም ነው። አሰራሩ ምንም አይነት አካላዊ እና ስነልቦናዊ ጉዳት አያስከትልም። በተጨማሪም ስለማያውቁት መረጃ ምላሽ ለመስጠት አይገደዱም። በጥናቱ ላይ ለመሳተፍ ምንም አይነት ክፍያ ባይኖርም በጥናቱ መሳተፍ እና ለተጠየቁት ጥያቄዎች መረጃዎትን መስጠት በጥቁር አንበሳ

ስፔሻላይዝድ ሆስፒታል በካንሰር የተጠቁ ህፃናትን እና ተንከባካቢዎቻቸውን ጤናቸውን ለማሻሻል ለሚደረገው ጥረት ትልቅ አስተዋፅኦ ይኖረዋል።

የተሳታፊዎች መብት፤ በዚህ ጥናት መሳተፍ አለመሳተፍ በተሳታፊዎች ምርጫ ይወሰናል። በጥናቱ ለመሳተፍ ፈቃደኛ አለመሆን ምንም አይነት ቅጣት ወይም የህክምና አገልግሎት ማጣትን አያስከትልም። እንዲሁም ከጥናቱ ባለቤት ጋር ያለውን ግንኙነትም አያሻክርም። የሚሰጡትን መረጃም ካልተስማማዎት በማንኛውም ጊዜ ማቋረጥ ይችላሉ። ስለዚህ መረጃ ለመስጠት ፍቃደኛ ከሆኑ አዎ በማለት ሊገልጹልን ይችላሉ።

የዋናው ጥነት አድረጊ ስም (PI): አቶ ሰይፈዲን ባርቀዳ

ቀን:_____ ፊርማ_____ የዋናው ጥነት አድረጊ አድራሻ፡

ሞባይል፡ +251927436060

ኢሜል፡ seyfedinbarkeda8@gmail.com

የመረጃ ሰብሳቢ ስም፡- _____ ቀን _____ ፊርማ _____

የተቆጣጣሪ ስም፡- _____ቀን _____ ፊርማ—----------

አባሪ 2፡ ፈቃድ ማረጋገጫ ቅጽ/ consent form

የፍቃድ ማብራሪያውን አንብቤ ይዘቱን ተረድቻለሁ። ሁሉንም ስጋቶቼን ከተመራማሪው ጋር እንድወያይ እድል ተሰጥቶኛል። ለጥያቄዎቼ በምረዳው ቋንቋ መልስ አግኝቻለሁ። ጉዳቱ እና ጥቅሞቹ ተብራርተውልኛል። በዚህ ጥናት ውስጥ ያለኝ ተሳትፎ በፈቃደኝነት እንደሆነ እና በማንኛውም ጊዜ ለማቋረጥ መምረጥ እንደምችል ተረድቻለሁ። የእኔን የግል ማንነት በሚስጥር ለመጠበቅ ሁሉም ጥረቶች እንደሚደረጉ ተረድቻለሁ። ይህን የስምምነት ቅጽ በመፈረም በምርምር ጥናት ውስጥ እንደ ተሳታፊ ያለኝን ማንኛውንም ህጋዊ መብቶች እንዳልተወው ተረድቻለሁ።

በዚህ የምርምር ጥናት ለመሳተፍ ተስማምቻለሁ፡ አዎ/ አይ

መጠይቁን ለመመላት ተስማምቻለሁ አዎ/ አይ

የተሳታፊ ስም እና ፊርማ/ የአውራ ጣት አሻራ ---------- ቀን ----------

የተመራማሪው መግለጫ

እኔ ከዚህ በታች የፈረምኩኝ የዚህን ጥናት ተዛማጅነት ዝርዝሮች ከላይ ለተጠቀሰው ተሳታፊ ሙሉ በሙሉ አብራርቻለሁ እናም ተሳታፊው ተረድቶ በነፃነት ፈቃዱን እንደሰጠ አምናለሁ።

የተመራማሪዎች ስም፡ ----------ፊርማ---------- ቀን----------

በጥናቱ ውስጥ ያላቸው ሚና----------

የምሥክር ስም----------ፊርማ---------- ቀን----------

የምስክሮች አድራሻ፡- ስልክ ቁጥር፡---------- ፖ.ሳ.ቁ.---------- ኢሜል ----------

አባሪ 3፡ የአማረኛ ቅጂ መጠይቅዎች

መጠይቁን ለመሙላት አቅጣጫዎች፡- ይህንን መጠይቅ ከመሙላትዎ በፊት፣ የተያያዘውን ስምምነት እንዲያነቡ፣ እንዲረዱ እና እንዲፈርሙ እንጠይቃለን።

እባክዎን ስምዎን በማንኛውም የመጠይቁ ገጽ ላይ አይጻፉ።

እባኮትን በክፍል ውስጥ ያሉትን ጥያቄዎች ከመመለስዎ በፊት በእያንዳንዱ የመጠይቁ ክፍል መጀመሪያ ላይ ያሉትን መመሪያዎች በጥንቃቄ ያንብቡ።

እባክዎን ከተቻለ በእያንዳንዱ ክፍል ያሉትን ሁሉንም ጥያቄዎች ይመልሱ።

ክፍል -I የሶሺዮ-ዴሞግራፊ/ የስነ ሕዝብ አወቃቀር መጠይቆች

ተ.ቁ.	**የልጆች ስነ ሕዝባዊ መጠይቆች**	**ምላሽ**
1	ጾታ	1. ወንድ 2. ሴት
2	እድሜ	1. እሰከ 5 ዓመት 2. 5—10 ዓመት 3. 11-15 ዓመት
3	የልጆች ብዛት	1. አንድ 2. ሁለት 3. ሶስት 4. ከዛ በላይ
4	ስንተኛ ልጅ ነው	1. አንደኛ 2. ሁለተኛ 3. ሶስተኛ 4. ከዛ በላይ
	የወላጅ ስነ ሕዝባዊ መጠይቆች	
5	የወላጅ/ተንከባካቢ እድሜ	1. 20—29 ዓመት 2. 30—40 » 3. 41—50 » 4. 51—60 »
6	ጾታ	1.ወንድ 2. ሴት
7	ከልጁ ጋር ያለው ዝምድና	1. አባት 2. እናት 3. አጎት/ አክስት 4. አያት 5. ሌላ
8	መኖሪያ አድራሻ	1. ከተማ

		2. ገጠር
9	የወላጅ ወራሃዊ ገቢ	……ብር
10	የወላጅ የገቢ አይነት/ ስራ	1.የግል ተዳዳሪ 2. የመንግስት 3. ስራ አጥ
11	የወላጅ የትምህርት ደረጃ	1. መደበኛ ትምህርት በጭራሽ አልተከታተልም። 2. የመጀመሪያ ደረጃ ትምህርት (1-8) 3. ሁለተኛ ደረጃ ትምህርት (9-12) 4. ኮላጅ ወይም ከዚያ በላይ
12	የትደር ሁኔታ	1.ያለገባ 2. ያገባ 3.በፊቺ የተለያዩ 4. በሞት የተለየ/ የለየች
13	ጠቅላላ የቤተሰብ ብዛት	--------

ክፍል -II የልጆች ክሊኒካዊ ባህሪያት መጠይቅ

ተ.ቁ.	ጠቅላላ ክሊኒካዊ ባህሪያት	
14	የልጁ ህመም ከታወቀ ስንት ጊዜ ሆነ?	1. 3—12 ወር 2. 1—2 ዓመት 3. 3—4 ዓመት 4. ከ 4 ዓመት በላይ
15	የለጁ ህመም ተደጋጋሚ ነው?	1. አዎ 2. አይ
16	ካንሰር/ ህመሙ ስንቴ አገረሸበት ወይም ተከሰተ?	1 አንዴ 2. ሁለቴ 3. ከዛ በላይ
ተ.ቁ.	የካንሰር ልዩ ባህሪያት	ምላሽ
17	የካንሰር ዓይነት	1. ዕጢ / ጠንካራ ነቀርሳ 2. የደም ካነሰር
18	የካንሰሩ የዕድገት ደረጃ	

	የጠንካራ ዕጢ የዕድገት ደረጃ	
	1. ደረጃ ዜሮ	Tis, N0, M0
	2. ደረጃ አንድ	T1-T2, N0, M0
	3. » ሁለት	T2-T4, N0, M0
	4. » ሶስት	T1-T4, N1-N3, M0
	5. » አራት	T1-T4, N1-N4, M1
	የደም ካንሰር የዕድገት ደረጃ	
	1. ደረጃ አንድ	- የሊምፍ ኖድ ዕድገት ደረጃ መጨመር ፣ - ወደ ሰውነት አከለት ምንም መሰራጨት የለም።
	2. ደረጀ ሁለት	- የጉበት, ጣፊያ እና ሊምፍኖድ ማደግ
	3. ደረጃ ሶስት	- ከላይ ከተጠቀሱት የአካል ክፍሎች መጨመር በተጨማሪ የደም ማነስ; - ከ 2 በላይ የአካል ክፍሎች መጎዳት
	4. ደረጃ አራት	- የ Plt ቁጥር መቀነስ,(በቀላሉ የደም መፍሰስ ወይም መድማት) - በመጀመሪያዎቹ ደረጃዎች የተጎዱትነ የአካል ክፍሎችን ጨምሮ ሳንባ መታመም መጀመረ - የደም ማነስ አጣዳፊ መሆን
19	የሕክምና ዓይነት	1. ኪሞቴራፒ 2. ራዲዮቴራፒ 3. የሆርሞን ሕክምና 4. የበሽታ መከላከያ ህክምና/ ሆርሞናልቴራፒ
20	የሕክምና ዑደት/ ህክምነውን ስንት ጊዜ ወሰደ ?	…….
21	በእርስዎ እይታ የልጅዎ ሕክምና ውጤት ምን ይሆናል ብለው ያስባሉ?	1. በጣም ጥሩ 2. ጥሩ 3. ፍትሃዊ 4. ምነም ለወጥ የለም
22	የአማራጭ/ባህላዊ ሕክምና ተጠቅመዋል? ፤መልሱ ምንም ከሆነ የሚቀጥለውን ጥያቄ ይዝለሉ	1. አዎ 2. አይ
23	የአማራጭ ሕክምና ስም	1. የተቀደሰ ውሃ 2. ባህላዊ መድሀኒት

አባሪ 4. የተነከባከቢ ወለጆች የድጋፍ እንክብካቤ ፍላጎቶች ዳሰሳዊ መጠይቅ

ካንሰር ያለበት ሰውን መንከባከብ ወይም አብሮ መኖር የካንሰር ታማሚው የተለዩ ፍላጎቶች ወይም ጉዳዮችን ሊያነሳልዎ ይችላል። እንደ ድጋፍ ሰጪ ወይም ካንሰር ተማሚውን እንደመንከባካዎ ስለ ፍላጎቶችዎ የበለጠ ለማወቅ ፍላጎት አለን። በሚቀጥሉት ገፆች ላይ ላለው እያንዳንዱ ነገር፣ ካንሰር ያለበትን ሰው በመንከባከብ ወይም አብሮ በመኖርዎ ምክንያት በዚህ ጉዳይ ላይ ባለፈው ወር ውስጥ እርዳታ ያስፈልገዎት እንደሆነ ያመልክቱ።ተማሚ ልጆን ተንከባካቢ እንደመሆንዎ እባኮትን በመንከባከብ ዙሪያ ካሎት ተሞክሮው አንጻር ሁሉንም ጥያቄዎችን መመለስዎን ያረጋግጡ ።

ባለፈው ወር በዚህ ጉዳይ ላይ እርዳታ ያስፈልግዎት እንደሆነ በደንብ የሚገልጸውን ቁጥሩን ክብብ ያድርጉ። ጥያቄው ከእርስዎ ሁኔታ ጋር የማይገናኝ መስሎ ከተሰማዎት እባክዎን አማራጭ 1 ‹አይተገበርም› የሚለውን ክብብ ያድርጉ። ለመምረጥ 4 ሊሆኑ የሚችሉ መልሶች አሉ፡-

ባለፈው ወር በዚህ ጉዳይ ላይ እርዳታ ያስፈልግዎት እንደሆነ :-	አይተገበርም	በቂ ነው	ጥቀት ፍላጎት	መካከኛ ፍላጎት	ከፍተኛ ፍላጎት
1. እንደ ቅረብ ብተሰብ/ ተነከባካቢ ከፍላጎትዎ ጋር የሚዛመዱ መረጃዎችን ያገኛሉ					
2. ስለካንሰር ተካሚው የወደፊት የመዳን ተሰፋ/ ለወጥ መረጃ ማግኘት ወይም ውጤቱን ማግኘት					
3. ስለአስታማሚ የሚሰጠውን የድጋፍ አገልግሎት እና እንክብካቤ መረጃ ማግኘት					
4. ስለ አማራጭ ሕክምናዎች መረጃ ማግኘት					
5. ስለካነሰር ታማሚው አካለዊ ድጋፈፍ ፍላጎቶች መረጃ ማግኘት					

6. ስለ ካንሰር መድሃኒት ጥቅሞቹ እና የጎንዮሽ ጉዳቶች መረጃ ማግኘት					
7. የካንሰር ተማሚው ፍቱን መድሀኒት እና ምርጥ የሕክምና እንክብካቤ ማግኘት					
8. እነደ አስፈላጊነቱ የአካባቢ/ የሰፈር የጤና እንክብካቤ አገልግሎቶችን ማግኘት መቻል					
9. በካንሰር ታከሚው ሀክምና እና እንክብካቤ አገልግሎት ላይ ከህክምና ቡድን ጋር አብሮ መሳተፍ					
10. ስለራስዎ ማንኛውንም የሚያሳስቦትን ጉደይ ከሀኪሙ ጋር ለመወያየት እድሎችን ማግኘት					
11. ሁሉም ዶክተሮች በራስ መተማመን ስሜት በመግባባት ታካሚውን ለካንሰር ህክምና መቀበል እና መርዳት					
12. ቀጣይነት ያለው የተለያዩ አገልግሎቶችን ማግኘት እነዲችሉ የሚረዱ አሰተባባሪ አካላትን ማግኘት መቻል					
13. የካንሰር ታማሚው ማንኛውም የህክምና ችግሮች እና ጥያቄ በተገቢው ሁኔታ መፍታት መቻል					
14. በካንሰር ታማሚው ህይወት ላይ የገጠመውን ጭንቀት መቀነስ መቻል					

15.ስለራስዎ የጤና ሁኔታ ክትትል ይደረግሎታል፤ በአግባቡ መብላት እና መተኛት የመሳሰሉትን ።					
16. ታመሚው በቂ የህመም ማስታገሻ ማግኘት					
17. ካንሰር ታመሚው በተከሰቱ አካላዊ ለውጦች እና አእምሮአዊ ጉዳቶችሳቢያ የተከሰቱ ፍራትና ጭንቀት ማስወገድ መቻል					
18. በካንሰር በተያዘው ሰው ላይ ሊከሰቱ ስለሚችሉ የመራባት ችግሮች መረጃን ማግኘት					
19. ካንሰር ታማሚውን የመንከባከብ ትግበራ ለምሳሌ ከመታጠብ ጋር፡ ልብሶችን መለወጥ፡ ወይም መድሃኒቶችን መስጠት					
20. በቂ የሆነ የሆስፒታል የመኪና ማቆሚያ ማግኘት					
21. የተለመዱ የስራ ህይወትን ወይም ተግባራትን እና ህመምተኛውን መንከባከብ በአነድ ለይ ማስኬድ መቻል					
22. የካንሰር ህመምተኛውን መንከባከብ በስራ ህይወትዎ ወይም በተለመዱ እንቅስቃሴዎች ላይ ያሳደረው ተጽእኖ					
23.እርስዎ ወይም ታከሚው የገንዘብ ድጋፍ					

እና የመንግስት ጥቅማጥቅሞችን ማግኘት መቻል					
24. የካንሰር ታማሚው የህይወት እና /ወይም የጉዞ ዋስትና ማግኘት መቻል					
25. የህግ አገልግሎቶችን ማግኘት					
26. እርስዎ ከታመሚው ጋር መግባባት/ መነጋገር መቻል					
27. ከቤተሰብ ጋር መግባባት/ መነጋገር					
28. የቤተሰብ ድጋፍ ማግኘት መቻል					
29.ከሌሎች የካነሰር ተማሚ ቤተሰቦች እና ለተማሚ እንክብካቤ አድርገው ከሚየውቁ ሌሎች ሰዎች ጋር መወያየት መቻል።					
30. ስለካንሰር ርዕስ በማህበራዊ/ በስራ ቦታ ማውራት መቻል					
31. ስለ ካንሰር ተመልሶ የመምጣት ስጋቶችን መቆጣጠር					
32. ካንሰር በእርስዎ እና በካንሰር ታማሚዊ ባለው ግንኙነት ላይያሳደረው ተጽእኖ					
33. የካንሰር ታመሚውን ስሜቶች መረዳት መቻል					
34. የካንሰር ተማሚውን እና የእራስዎን					

ፍላጎቶች ማመጣጠን መቻል					
35. በታመሚው የካንሰር አካል ላይ ለውጦችን ማስተካከል					
36. ከወሲብ ህይወትዎ ጋር ያሉ ችግሮችን መፍታት					
37. ስለራስዎ ስሜታዊ ድጋፍ ማግኘት					
38.ስለታማሚው ስሜታዊ ድጋፍ ማግኘት የሚሉት					
39. ስለ ሞት እና መሞት ያለዎት ስሜት ላይ መስራት/ ድገፍ መግኘት					
40. ካንሰር ያለበትን ሰው መንከባከብ በህይወቶ ላይ የሚያሳድረውን ተጽእኖ እውቀና ከማየሰጥ ጋር መገናኘት/መወያየት					
41. የካንሰር ተማሚው በሚፈለጉት መልኩ የሚጠበቀውን ለውጥ ባያመጣ እነዬት ይቋቋሙታል					
42. የህይወትዎ ውሳኔዎችን ማድረግ እርግጠኛ ባልሆኑዋቸው ጉደዮች					
43. መንፈሳዊ እምነቶችዎን ማሰስ/ መወያየት					
44. የካንሰር በሽታ ባለው ሰው ውስጥ ትርጉም ማግኘት					

45. **የታማሚው የካነሰር ህክምና ውሳኔ ለይ የመሳተፍ እድሎች መኖራቸው**					

Addis Ababa University, College of Health Sciences, School of Nursing and Midwifery
አዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ፥ ነርሲንግና ሚድዋይፈሪ ት/ት ቤት
Institutional Review Board

Form AAUMF 03-008

Institutional Review Decision

Meeting No: 04/2016EC
Review Date: March 01/2024
Protocol number: SNM/32/2024

Protocol Title: Assessment of health care needs and associated factors among families of cancer survivor children at Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia, 2024: Cross sectional study.		
Principal Investigator:	Seyfedin Barkeda	
Institute:	AAU-CHS-School of Nursing & Midwifery	
Elements Reviewed (AAUMF 01-008)	☐ Attached	☒ **Not attached**
Review of Revised Application ☐ Yes ☒ **No**	Date of Previous review:	
Decision of the meeting:	☐ Approved ☒ **Approved with Recommendation** ☐ Resubmission ☐ Disapproved	

I: Elements approved-
1. Protocol version No: 1
2. Protocol version date:
3. Informed consent version No: 1
4. Informed consent version date:

II: Obligations of the PI-
1. Should comply with the standard international and national scientific and ethical guidelines.
2. All amendments and changes made in protocol and consent form needs IRB approval.
3. End of the study, including manuscript and thesis works should be reported to the IRB

III: To NERC ☐
Institutional Review Board (IRB) approval period from: March 02/2024, to July 20, 2024
Follow up report is expected in: 3 Months___ 6 Months **X** 9 Months__ One year____

Chairperson, IRB
Dr. Dr. Daniel Mengistu (Associate Professor)

Signature:
Date: 15/03/2024

Seal:

ጥቁር አንበሳ
TIKUR ANBESSA

COLLEGE OF HEALTH SCIENCES

Ref.no/ቁጥር: CHS/NSG/127/2016/24

Date/ቀን: 2/26/2024

To: _____

From: Dr. Girum Sebsibe

Chair, Department of Nursing

Subject: Support Letter

The Pediatric and Child Health Nursing Master's students in their 2nd year have finished their thesis prposals and are getting ready to gather data in the field.

This is therefore, I respectfully request that your good office assist them in obtaining the data required to complete their thesis work.

Encl: A copy of ethical clearance letter

With Regards,

Tel: +251-11-5511211, Zambia St. P.O.Box: 9086 Addis Abeba, Ethiopia