بسم الله الرحمن الرحيم

كلية نبتة
NAPATA COLLEGE

Faculty of Medicine

Assessment patient’s satisfaction of palliative care service in adult cancer in Khartoum state 2022

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By

Abdullah Malik Abdul Majid
Mohammed Mustafa Babekir
Mohammed Omer Sir Al-khatim
Hadeel Edriss Ahmed
Yousif Moawia Ahmed

Supervisor

Dr Moneer Ali Abdallah

MBBS, MPH, PDHM ,DMRE,MME,MD

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بسم الله الرحمن الرحيم

وقل رب زدني علما

صدق الله العظيم

DEDICATION

This thesis is dedicated to our parentsfor their love, endless support and encouragement, our brothers, sisters andfriends who encourage us to continue develop myselfand searchfor the best in every opportunity.

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The realization of this work was only possible due to the several people's collaboration, to which desire to express my gratefulness.

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Abstract

Background and Aims: Patient satisfaction is an important quality indicator of health care service. The concept ofhome-based palliative care has been recently introduced in many countries, but the patients' satisfaction with this care remained unexplored. This study aimed to assess the satisfaction of the cancer patients receiving this care.

Methods: This cross-sectional study was conducted among 51 surviving cancer patients above 18 years of age registered under the home-based care service of the Department of Palliative Medicine, at Radiation and isotope centre of Khartoum (RICK) - Sudan. Data were collected by face-to-face interviews using a structured questionnaire based on the FAMCARE P16 questionnaire from November to December 2022. Descriptive analysis was done for the sociodemographic and satisfaction-related indicators.

Result: The majority of the patients (88.2%) were satisfied with the service provided by the home care team. Most (76.5%) of the patients were women, and the mean age was 56.25 ± 14.8

years. The median duration of getting home-based care was 4 months. Main satisfaction indicators were—assessment of physical symptoms (70.6%), providing information about pain management (70.6%), the inclusion of the family in decision making (76.5%), coordination of care between the members of the home care team (84.3%) and availability of doctors, nurses and palliative care assistants (74.5%).

Conclusion: Despite the limitations, the overall satisfaction level of the patients regarding homebased palliative care services in Sudan is very high

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Abbreviations	**Meaning**
AIDS	acquired immune deficiency syndrome
CPC	Center of Palliative Care
GDP	gross domestic product
NCDs	non-communicable diseases
RICK	Radiation and isotope centre of Khartoum
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION, RATIONALE & OBJECTIVES

Chapter 1

Introduction

1.1 Introduction

Palliative care is a holistic approach that focuses on improving the quality of life of patients with life-limiting illness and their families by assessment and prevention of physical, psychosocial, and spiritual sufferings [1]. In the last few decades, there is an enormous growth in the field of palliative care, and it has been integrated into the mainstream healthcare system in many countries [2] Still, about 40 million people worldwide are in the need of palliative care, 34% of them are diagnosed with cancer of different stages, but only about 14% of them are currently receiving this care [3].

Although survival in patients with cancer has increased markedly in the past few decades, more than a third ofpatients with cancer still die within 5 years ofthe diagnosis [4]. This is often preceded by a period of months, sometimes years, in which patients receive palliative care. When cure or life prolongation is the main goal, care for patients with cancer is mostly provided by hospital professionals. At the end of life, when the main goal of care is improvement in the quality of life rather than cure or life prolongation, most patients prefer to remain at home [5]. The diagnosis of cancer itself and its treatment-related side effects give rise to various physical, psychosocial, and spiritual sufferings [6, 7]. It has been evidenced that palliative care helps this patient and their families to deal with these problems [1]. Among different palliative care delivery system models, the cost-effectiveness and higher patient satisfaction reported in home-based palliative care services increased the popularity of this service around the world [8]. Although in many countries, palliative care is an essential part of the health care system, in many lower-middle and lower income countries, the concept of palliative care is still new. There are some isolated initiatives of providing home-based palliative care have been taken. Approximately 0.6 million patients need palliative care worldwide, but less than 4000 people have received this care until now [9]. Along with institutional care, a few private and autonomous institutes are providing home-based palliative care in a small scale. But most of these services are confined within the capital city. Due to a lack of proper record keeping and collaboration, the extent of these services remained unexplored. The Department of Palliative Medicine has taken a pioneering role, and has been delivering home-based palliative care [10].

Patient satisfaction is one of the main indicators in assessing the quality of the service provided by the home-care team. However, there is no such study done to assess the satisfaction level of cancer patients receiving this service. This study assessed the satisfaction with care in the cancer patients receiving home-based palliative care in Khartoum –Sudan

1.2 Problem statement

Satisfaction of patients and caregivers is an important indicator of quality of care and may be particularly relevant for patients whose disease is not curable. Satisfaction with palliative care is related to other constructs such as quality of life and quality of death, but is a distinct concept that includes accessibility, coordination and personalization of care, symptom management, communication and education, emotional support, and support of decision making. Patient satisfaction is an important quality indicator of health care service. The concept of home-based palliative care has been recently introduced in Sudan, but the patients' satisfaction with this care remained unexplored.

1.3 Justification

Cancer diagnosis could be a very unpleasant and painful experience. Cancer has an effect on economic, social and familial status of patients which also influences their psychological and sexual performance. Generally, cancer has a negative impact on the quality of patients’ life which makes them in need of receiving palliative care. Palliative care is provided for life-threatening illnesses while helping patients cope with chronic illness over the year. The diagnosis of cancer itself and its treatment-related side effects give rise to various physical, psychosocial, and spiritual sufferings. It has been evidenced that palliative care helps this patient and their families to deal with these problems. This study aimed to assess the satisfaction of the cancer patients receiving this care

1.4 Objectives

1.4.1 General Objective ○ To Assess patient’s satisfaction of palliative care service in adult cancer in Khartoum state

1.4.2 Specific Objectives

○ To determine Sociodemographic characteristics of the patients and primary caregivers

○ To evaluate Indicators of patient satisfaction

○ To assess patient’s satisfaction of palliative care service in adult cancer

CHAPTER TWO

LITERATURE REVIEW

Chapter 2

Literature Review

2.1 Palliative care

Palliative care (derived from the Latin root palliate, or 'to cloak') is an interdisciplinary medical caregiving approach aimed at optimizing quality of life and mitigating suffering among people with serious, complex, and often terminal illnesses [11]. Within the published literature, many definitions of palliative care exist. The World Health Organization (WHO) describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." [12] In the past, palliative care was a disease specific approach, but today the WHO takes a more broad approach, that the principles of palliative care should be applied as early as possible to any chronic and ultimately fatal illness [13].

Palliative care is appropriate for individuals with serious illnesses across the age spectrum and can be provided as the main goal of care or in tandem with curative treatment. It is provided by an interdisciplinary team which can include physicians, nurses, occupational and physical therapists, psychologists, social workers, chaplains, and dietitians. Palliative care can be provided in a variety of contexts, including hospitals, outpatient, skilled-nursing, and home settings. Although an important part of end-of-life care, palliative care is not limited to individuals near the end of life [11]. Evidence supports the efficacy of a palliative care approach in improvement of a person's quality of life [14]. Palliative care's main focus is to improve the quality of life for those with chronic illnesses. It is commonly the case that palliative care is provided at the end of life, but it can be helpful for a person of any stage of illness that is critical or any age [15].

2.2 Palliative care in oncology

Palliative care in oncology is necessary when the incurability becomes a reality before the inefficiency of curative treatment and disease progression [16]. At this stage, the assessment of quality of life becomes critical, since the search for it in all its nuances, and even to the detriment of the prolongation of life, becomes very important. Care in the context of palliative assistance differs from curative care because it reaffirms life and faces death as a reality to be experienced with relatives. In such a situation, care has the premise of improving the quality of life of patients and their families before an advanced illness by the prevention and relief of suffering and the appreciation of culture, spirituality, and beliefs and values that permeate the "terminally" [17]. The quality of life has been defined by the World Health Organization (WHO) "as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. In health, quality of life is related to the impact of diseases and treatments that influence it. However, assessing quality of life – a subjective and abstract construction – is admittedly a complex task. The definition adopted by the WHO is complex and demonstrates the positive and negative aspects of life. This is a multidimensional concept that deals with the relationship between environment and physiopsychological aspects of the individual, level of independence, social relationships and personal beliefs [18]. Nevertheless, three aspects are common to all definitions: subjectivity, dimensionality and bipolarity. Assuming that both the cancer as its treatment may adversely influence the perception of quality of life, the latter is still considered a critical measure in oncology [19]. The diagnosis of cancer brings major changes in the way of living, with emotional and physical changes caused by the discomfort, pain, disfigurement, dependency and loss of selfesteem. In addition, cancer carries the stigma and the condition of finiteness before a disease considered for many people without the possibility of cure. Furthermore, it is known that over 50% of cancer patients present five common symptoms that may interfere with the perception of quality of life: fatigue, weakness, pain, weight loss and anorexia [20].

2.3 The need for palliative care in developing countries

The need for palliative care in developing countries is significant towing to the high disease burden. By 2008 an estimated 22 million people in the region were living with HIV/acquired immune deficiency syndrome (AIDS), i.e., 67% of the global disease burden, with 1Æ9 million new infections reported in that year alone [21]. There were over 700 000 new cancer cases and nearly 600 000 cancer-related deaths in Africa in 2007, [22] and it is expected that cancer rates will grow by 400% over the next 50 years [23]. Early diagnosis is fundamental in the management of cancer as it allows for timely treatment while disease burden is still in its earliest stages hence preventing unnecessary complications. Consequently, prognosis may improve, and a cure can be attained with minimal side or late effects, particularly for childhood hematological malignancies, such as

Burkitt Lymphoma and acute leukemia. Unfortunately, early diagnosis is rarely heard of in developing countries where patients usually present late with advanced cancer. In a combined prospective and retrospective study of 194 children diagnosed with cancer at a single center in South Africa between 2000 and 2009, investigators found that there was considerable delay in diagnosing childhood cancer due mostly to physician delays, among other factors [24]. Lack of resources and basic infrastructure mean that most Africans have no access to cancer screening, early diagnosis, treatment or palliative care – the fundamentals for a cancer control program. Cancer treatment modalities, such as radiotherapy and effective chemotherapy are available to <20% of the population in Africa, and consequently a cancer diagnosis is almost a sentence to a painful and distressing death. There are major challenges in the management of common cancers, such as lymphomas, in sub-Saharan Africa and, as noted by researchers in Botswana, such challenges include:

1. Lack of epidemiological data due to absence of reliable and accurate cancer registries. 2 The high prevalence of HIV infection that has led to a high incidence of opportunistic infections during and after chemotherapy treatment, and reduced hematological tolerance to conventional doses. 3 Difficulties in making an early diagnosis because symptoms and signs might coincide with those of HIV or opportunistic infections. 4 Lack of adequately equipped public hospitals leading to a poorly resourced service of limited value [25]

The WHO has made cancer in developing countries a priority and has produced important guidelines to assist such countries to establish national cancer control programs that are relevant to their settings [26]. As an example, Sudan has instituted a comprehensive national cancer control programme, which is focused on prevention, early detection, improved treatment and palliative care. Apart from cancer and HIV infection, Africa is filled with other life-threatening illnesses, among which is Sickle Cell Disease. The greatest burden of sickle cell anaemia occurs in subSaharan Africa, where 75% of the 300 000 global births of affected children live, and where 50– 80% ofthese patients will die before adulthood. Even with the growing awareness ofthe magnitude of the growing cancer problem in the developing world, there are substantial challenges [27] including insufficient political priority and funding amongst donor agencies and governments that have many competing priorities; fragmented and underfinanced health care systems that have not been setup for chronic disease management; a lack of cancer awareness, knowledge and capacity amongst health workers; and lack of diagnostic and treatment capacity, among others. The burden of symptoms amongst cancer patients is enormous with very few patients being able to access quality palliative care services. Indeed, in a study carried out in two African countries to determine the symptom prevalence and burden amongst advanced cancer patients [28], the authors noted that pain and psychological problems were four of the five most common symptoms, found in more than 3 out of 4 patients. The prevalence of symptoms is multidimensional, hence the need for holistic approaches to patient assessment and management. Following the WHO estimation of need as 1% of a country's total population, approximately 9Æ67 million people are in need of palliative care across Africa. However, notwithstanding this great need, current provision of palliative care in Africa is inconsistent and access to culturally appropriate, holistic palliative care is at best limited, and at worst non-existent (Harding & Higginson, 2005). a survey of hospice and palliative care services in Africa found not only that 45% (21/47) of African countries had no identified hospice or palliative care activity, but that only 9% (n = 4) could be classified as having services approaching some measure of integration with mainstream service providers [29].

2.4 Palliative care for cancer patients in Sudan

The fight against cancer is complex and the increasing burden of the disease makes it one of the most serious health threats to the population in low and middle income countries. Sudan is one of these countries and has been facing an increasing number of cancer patients during recent decades. Sudan was the largest country in Africa until July 2011 when the South Sudan people voted and separated into an independent country. Sudan now is the third largest country in Africa (after Algeria and the Democratic Republic of the Congo). It is situated in northern Africa at a crossroads between the Horn of Africa and the Middle East. Its 853 km long coastline in the east borders the Red Sea and it has land borders with Egypt, Eritrea, Ethiopia, South Sudan, the Central African Republic, Chad, and Libya.The total population was estimated in 2012 to be 37,195,000, and the total expenditure on health as a percentage of gross domestic product (GDP) was estimated to be 7.3% [30, 31]. The epidemiological profile of Sudan is largely dominated by communicable diseases such as malaria and tuberculosis. In addition to the burden of communicable diseases, Sudan is also experiencing a rapidly increasing burden of non-communicable diseases (NCDs). Of these, diabetes mellitus, cardiovascular diseases, and cancer have been among the top ten causes of hospital admissions and deaths in Sudan since 1998, according to the Federal Ministry of Health.

The probability of dying, between ages 30 and 70 years from the four main NCDs which include cancers, diabetes, cardiovascular, and chronic respiratory disease, is 17%. NCDs are estimated to account for 34% of total deaths with cancer causing 5% of the mortality [32]. In spite of the fact that cancer has become among the top ten killer diseases in Sudan, there is no established programme for comprehensive cancer control. The majority of cancer patients are diagnosed with an advanced type of cancer where curative treatment has little if any effect. The need for palliative care (PC) is urgent.

2.5 Previous studies

Many studies 21 relevant qualitative studies, only one of which focused specificallyon satisfaction. This study evaluated perceptions of physicians'skills in end-of-lifecare using focus groups from a variety of populations and perspectives [33]. Another study evaluated quality of end-of-life care through secondary analyses of qualitative studies evaluating advance directives and control at the end of life in several populations [34]. Two studies evaluated nurses, including interviews with nurses and bereaved hospice families about the nurse–family spiritual relationship [35] and with patients about palliative care nurses [36]. Two focused on the experience of quality of life, quality of dying, or a good death, including interviews with caregivers of patients with cancer who had died [37] and with patients with terminal cancer [38]. Several focused on needs, a concept closely related to satisfaction, including after-death interviews with caregivers about informational needs, [39] interviews with current caregivers of terminally ill patients about their experiences and needs [40] and focus groups with patients with advanced cancer about help they were receiving and their needs [41]. Although different studies defined the domains somewhat differently, there was general agreement on major areas of importance, and most themes were identified in more than one study. In addition, these studies all found that the domains of satisfaction were important in the related concepts that they focused on, such as quality of life or patient needs. The review identified only one study on the related concept of dissatisfaction [42]. This after-death interview study of caregivers ofpatients with breast cancer found that discussing dissatisfaction was difficult because of grief, regrets, and thoughts of whether death could have been avoided. Differentiating caregivers' from patients' sources of dissatisfaction was challenging. Key concerns were similar to those in the satisfaction studies, including inadequacy of providers'skills, knowledge, manner, communication, and empathy. Other concerns included difficulties with navigating the healthcare system and inadequate service array or availability. Several studies evaluated satisfactionin specific settings or from different providers. Although the overall themes were the same, different concerns were more prominent in specific situations. A focus group study evaluating intensive care [43] and an interview study of family members of patients who had died in the hospital [44] found that lack of physician availability or continuity and insufficient information and discussion of options were important concerns.

CHAPTER THREE

MATERIALS & METHODS

Chapter 3

Methods

3.1 Study design

This study was Cross sectional study.

3.2 Study duration

Study was done from during period from November to December 2022.

3.3 Study population

All surviving cancer patients currently registered under the Department of Palliative Medicine, at Radiation and isotope centre of Khartoum (RICK) - Sudan

3.4 Study area

The study was done in the Department of Palliative Medicine, at Radiation and isotope centre of Khartoum (RICK) - Sudan

3.5 Sampling techniques and Sample size

The current study was included According to the Center of Palliative Care (CPC) database in December 2022, the number of registered cancer patients receiving home-based palliative care. During data collection was included all patients eligible for the study.

Inclusion criteria All l the surviving cancer patients who registered under this service up to 2022, above 18 years of age, willing to participate, and got at least three visits from the home care team was included.Those caregivers (paid or family members) who take care of the patients at least 5 days per week was included.

Exclusion criteria Those who were delirious, disoriented, or unable to communicate was excluded from the study. Occasional caregivers was excluded from the study.

3.6 Data collection

Interview structured questionnaire consisted of two part: part one (sociodemographic information, diagnosis and treatment history, caregiver related information. And part two: patient’s satisfaction of palliative care service in adult cancer

3.7 Instruments

The questionnaire had two major parts. The first part contained the sociodemographic, disease, treatment, and primary caregiver-related information collected from the hospital record. The second part of the questionnaire contain questions from the FAMCARE P-16 questionnaire developed by Loetal.[33] which was used to assess the satisfaction level of the study subjects. This instrument had four indicators—care of physical symptoms (items 1, 2, 5, 7, 8), providing information (items 2, 4, 6, 9, 10), family support (items 14, 15, 16), access to care (items 11, 12, 13). The corrected version will test among 10 cancer patients (10% of the total sample size) admitted to both the palliative medicine and oncology department of Radiation and isotope centre ofKhartoum (RICK) for linguistic and content validation. Necessary wording or sentence structure changes will be made based on the patients' responses.

3.8 Data analysis

All data was analyzed by SPSS version 22.0 after editing and logical checking. Categorical variables such as sex, education, marital and occupational status, knowledge and belief about the disease prognosis, treatment, and side effects, the relationship of the primary caregiver with the patient was reported as frequency and percentage. Continuous variables such as age, monthly family income, duration of getting home-based palliative care will present in mean, SD, and median as appropriate. Number of satisfied patients with each component will present in frequency and percentage. The level of satisfaction will present in three categories based on mean and SD. The value below lower limit of mean−1 SD will categorize as not satisfied, the range between upper and lower limit of mean±1SD will categorize as satisfied and the value above mean+1SD was categorized as very satisfied. Correlation matrix was done to see the correlation among the
satisfaction indicators. $p<0.05$ will consider as significant

3.9 Ethical Considerations

Objectives and goals was explained at the beginning of the questionnaire to all participating mothers, and their enrollment was after they consented to participate in the study. Research ethics includes the approval sheet, anonymity, confidentiality, and ethical eligibility. Ethical feasibility in this study comes from the Ethics Committee of faculty of medicine, NAPATA College -Then the permission was taken from director manger of RICK

CHAPTER FOUR

RESULTS

Chapter 4.

Results

The majority (76.5%) of the patients were women, and the mean age was 56.25±14.8 years. More than half (58.8%) of the patients were married and lived with their partners. Common sites of the primary cancer were breast (39.2%), genitourinary system (23.5%), and gastrointestinal tract (17.6%). More than half (55.8%) of the patients had metastasis at the time of referral to palliative care, and 80% of them were currently only on palliative management. The median duration of receiving home-based palliative care of the patients was four months (ranging from 6 days to 1 year) (Table 4.1).

Almost 97% of the patients had family members as their primary caregivers, mostly their children (53.2%) or spouses (29.8%) (Figure 4.1), and 57.6% of the primary caregivers were women (Figure 4.2).

The majority of the patients were very satisfied with the assessment of physical symptoms (70.6%), providing information about pain management (70.6%), the inclusion of the family in decision making (76.5%), coordination of care between the members the home care team (84.3%) and availability of doctors, nurses and PCAs in the time of need (74.5%) (Table 2).

The majority of the patients (88.2%) were satisfied with the service provided by the home care team (Figure 4.3).

Table 4.1 Sociodemographic characteristics of the patients

Variables		**n (%)**
Sociodemographic characteristics of the patients (n=51)		
Gender	Men	12 (23.5)
	Women	39 (76.5)
Age, years	<45	13 (25.5)

Mean±SD 56.25±14.8	45-65	26 (51.0)
	>65	12 (23.5)
Marital status	Single (unmarried/divorced/ widow	21 (41.2
	Married	30 (58.8)
Educational status	Illiterate	6 (11.8)
	Primary	16 (31.4)
	secondary	18 (35.3)
	Graduate or above	11 (21.6)
Primary sites of cancer	Gastrointestinal system	9 (17.6)
	Genitourinary system	12 (23.5)
	Breast	20 (39.2)
	Others	10 (5.6)
Staging of cancer at referral	Up to stage III	12 (23.1)
	Stage IV	25 (48.1)
	Unknown	15 (28.8)
Duration of getting home-based palliative care (months)	<1	18 (35.3)
	1-6	15 (29.4
	>6	18 (35.3)

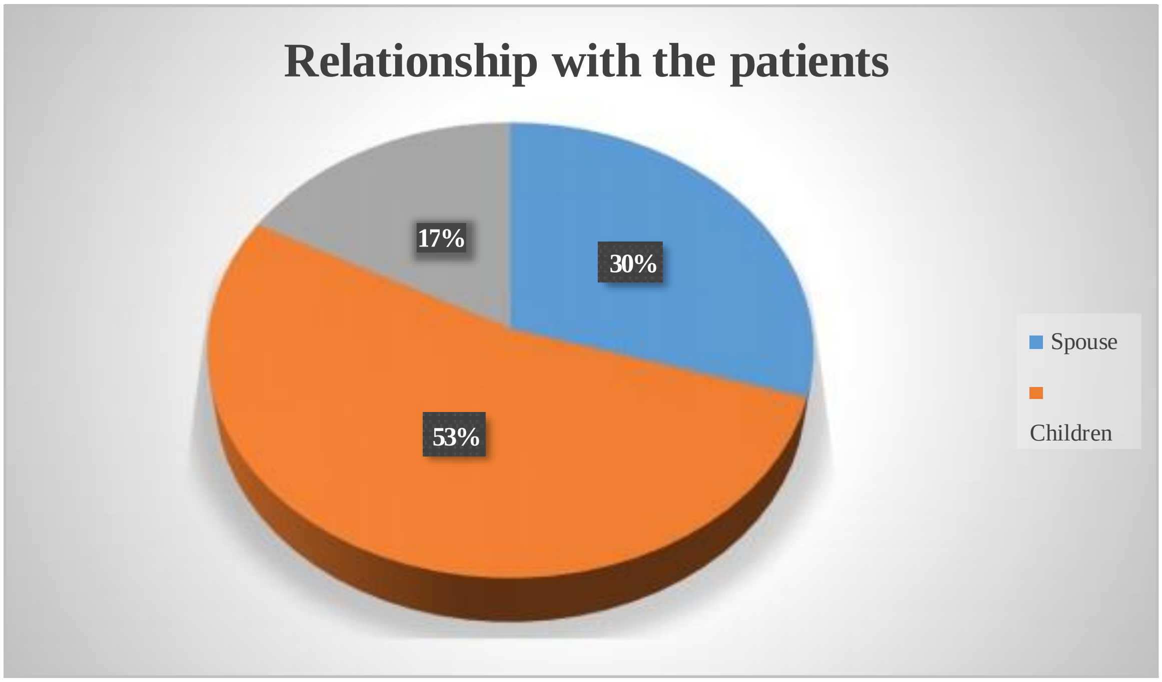

Figure 4.1: Relationship of primary caregivers with the patients

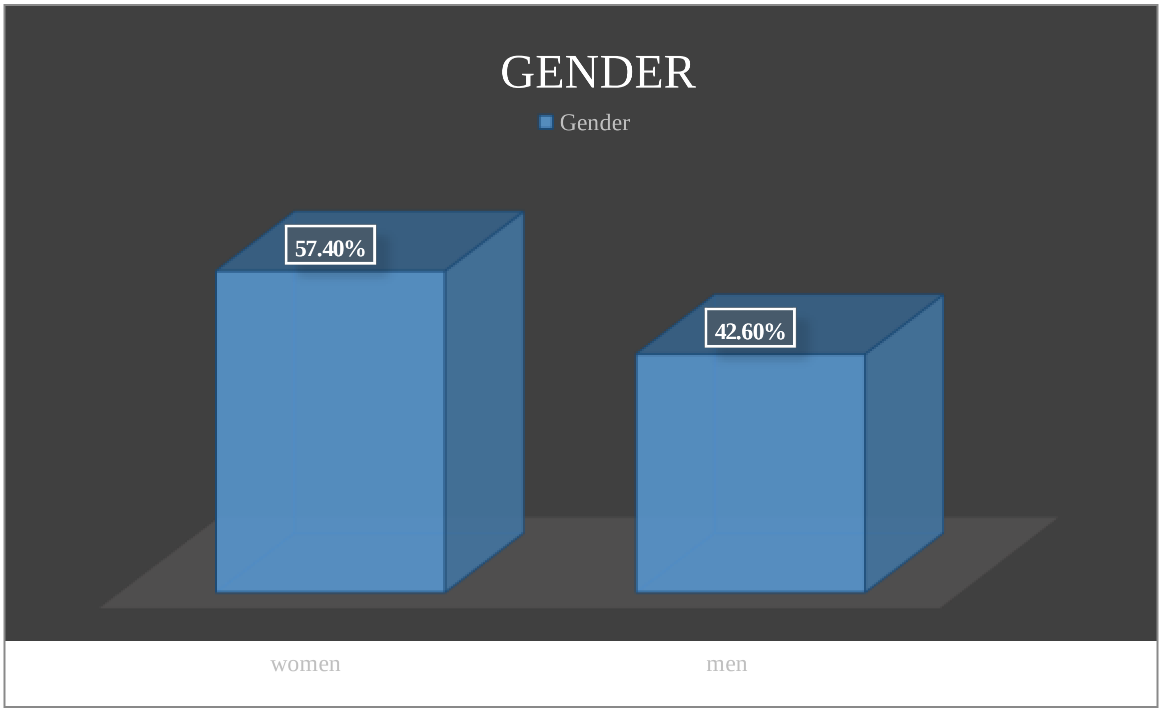

Figure 4.2: Gender of primary caregivers Table 4.2 Indicators of patient satisfaction (n = 51)

Variables		**No of respondents, n (%)**			
		Very dissatisfied	Undetermined	Satisfied	Very satisfied
Care of physical symptoms	Doctor's attention to symptom description	0	0	10 (19.6)	41 (80.4)
	Assessing the symptoms	0	0	15 (29.4)	36 (70.6)
	Treatment of symptoms	2 (3.9)	0	28 (54.9)	21 (41.2)
	Tests performed:	0	5 (9.8)	30 (58.8)	16 (31.4)
	Follow up	0	1 (2)	31 (60.8)	19 (37.3)
Providing information	Pain management	1 (2)	2 (3.9)	12 (23.5)	36 (70.6)
	Treatment side effects	1 (2)	3 (5.9)	29 (56.9)	18 (35.3)
	About tests and reports	0	9 (17.6)	28 (54.9)	14 (27.5)
	About prognosis	1 (2)	4 (7.8)	20 (39.2)	26 (51.1)
	Answering the question asked	0	0	13 (25.5)	38 (74.5)
Support to the family	Inclusion of family in decision making	0	1 (2)	11 (21.6)	39 (76.5)
	Coordination of care	0	1 (2)	7 (13.7)	43 (84.3)
	Availability of doctors to the family	0	1 (2.0)	21(41.2)	29 (56.9)
Access to the care	Referral to specialist	0	43 (84.3)	3 (5.9)	5 (9.8)
	Availability of doctors	0	0	13 (25.5)	38 (74.5)
	Availability of nurses and PCA	1 (2.0)	2 (3.9)	10 (19.6)	38 (74.5)

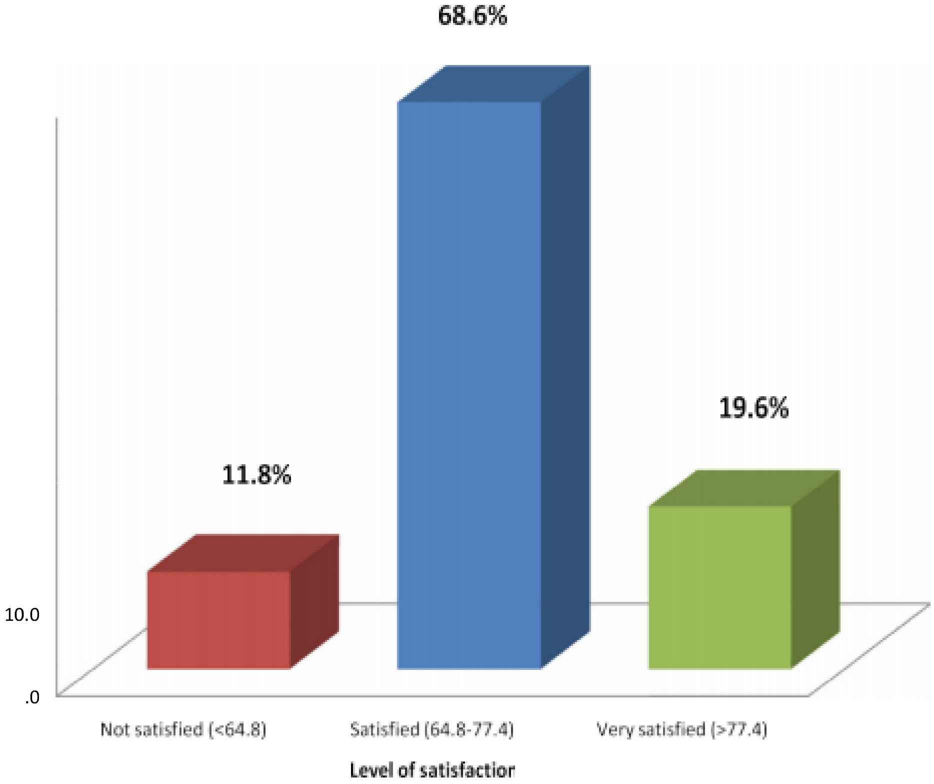

Figure 4.2: Level of satisfaction (categorization done based on mean ± 1SD (71.1± 6.3)

CHAPTER FIVE

DISCUSSION, CONCLUSION & RECOMMENDATIONS

Chapter 5

Discussion,

5.1 Discussion

This is the first study in Sudan assessing the satisfaction with the care of the patients' receiving such palliative care. Measuring patients' satisfaction is important for evaluating the outcome of the care provided by the home care team. It gives valuable information about the patient's experience with the service, measures their compliance with the treatment, identifies the under-lying weaknesses, and evaluates the performance of the home care team [45, 46].

In our study, the majority (88.2%) of the patients are satisfied with the service provided by the home care team. This finding is almost close to the satisfaction level (93%–96%) of the countries like the United States with well-developed home-based palliative care delivery systems [47]. This satisfaction level is also similar to the satisfaction level of the patients from India receiving such care, where isolated home-based palliative service is present. In both scenarios, the satisfaction level of the patients with the care provided by the home care team is very high [48].

The majority (80.4%) of the patients in this study are very satisfied with the attention given by the home care team members during the assessment of their sufferings. It indicates better communication between the home care team and the patients, where more than half (61%) of the patients attending government hospitals of Sudan show dissatisfaction about the health care providers' lack of attention to their symptom description [49]. In this study, patients receiving homebased palliative care are also very satisfied with the information provided by the home care team about their disease and treatment. Satisfaction regarding the care of physical symptoms and satisfaction regarding the provision of information are also found to be highly correlated, which means giving proper information about the disease and treatment improves the patients' satisfaction regarding physical symptom care. This finding is on par with the performance of the home care team of Kerala, India, which is considered as a model for the developing home-based palliative care service like ours [48].

The majority of the patients in our study are very satisfied with the inclusion of family members in decision making (76.5%) and availability of the doctors and nurses in need (75.5%),in contrast to earlier studies where the main dissatisfaction arises from the long waiting time for the doctors and nurses in hospitals [49]. Also the inclusion of family members in decision making are mostly ignored in most hospital setting in Bangladesh, so the family members do not feel connected with the health care team [50]. High satisfaction level with home-based palliative care indicates that it can be a solution to provide necessary care to the patients in need and improve their satisfaction level.

5.2 Conclusion

Patient satisfaction is one ofthe important quality indicators ofhealthcare service. Despite the limitations, overall satisfaction on the care provided by the home care team is high

5.3 Recommendations

The current study can be interpreted as a first step in the research on cancer characteristics. However, the results of this study should be treated with caution due to the small sample size and the lack of details regarding the participants' characteristics.

Future research could further examine the differences in speech characteristics between different Cancer patients and healthy controls. It could also contribute to a deeper understanding of the acoustic measurements suitable for e-health measurements.

Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for indi- viduals with advanced serious illness who are nearing the end of life.

CHAPTER SIX

REFERENCES & APPENDIX

Chapter 6

Reference

6.1 References

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6.2 Appendix

NAPTA College

Faculty of medicine

Questionnaire

Assessment patient's satisfaction of palliative care service in adult cancer in Khartoum state 2022

Part 1: Sociodemographic characteristics of the patients and primary caregiver

A) Sociodemographic characteristics of the patients

Age: …………… Years

Gender: Male Female

Marital status: single (unmarried/divorced/ widow) Married

Educational status: Illiterate Primary Up to higher secondary Graduate or above

Primary sites of cancer: Gastrointestinal system Genitourinary system Breast Others

Staging of cancer at referral: Up to stage III Stage IV Unknown

Duration of getting home-based palliative care (months): <1 1–6 >6

B) Characteristics of primary caregivers

Age: …………… Years

Gender: Man Women

Relationship with the patients: Spouse ☐ Children ☐ Others

Part 2: assessment of patient's satisfaction of palliative care service in adult cancer

A) Care of physical symptoms

Doctor's attention to symptom description:

Satisfied ☐ Undetermined ☐ Very dissatisfied ☐ Very satisfied ☐

Assessing the symptoms:

Satisfied Undetermined Very dissatisfied Very satisfied ☐

Treatment of the symptoms:

Satisfied Undetermined Very dissatisfied Very satisfied

Tests performed:

Satisfied ☐ Undetermined ☐ Very dissatisfied ☐ Very satisfied

Followup:

Satisfied Undetermined Very dissatisfied Very satisfied

B) <u>Providing information</u>

Pain management

Satisfied Undetermined Very dissatisfied Very satisfied

Treatment side effects

Satisfied ☐ Undetermined ☐ Very dissatisfied ☐ Very satisfied

About tests and reports

Satisfied ☐ Undetermined ☐ Very dissatisfied ☐ Very satisfied

About prognosis

Satisfied Undetermined Very dissatisfied Very satisfied

Answering the question asked

Satisfied Undetermined Very dissatisfied Very satisfied

C) <u>Support to the family</u>

Inclusion of family in decision making

Satisfied ☐ Undetermined ☐ Very dissatisfied ☐ Very satisfied

Coordination of care

Satisfied Undetermined Very dissatisfied Very satisfied

Availability of doctors to the family

Satisfied Undetermined Very dissatisfied Very satisfied

Very

satisfied

Very
satisfied

D) <u>Access to the care</u>

Referral to specialist

Satisfied	Undetermined	Very dissatisfied	Very satisfied

Availability of doctors

Satisfied	Undetermined	Very dissatisfied	Very satisfied

Availability of nurses and palliative care assistant

Satisfied Undetermined Very dissatisfied Very satisfied