

**SATISFACTION WITH CLINICAL CARE AND ASSOCIATED FACTORS AMONG PALLIATIVE
CARE PATIENTS AT BUKAVU PROVINCIAL GENERAL REFERENCE HOSPITAL,
DEMOCRATIC REPUBLIC OF CONGO**

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**A DISSERTATION SUBMITTED TO THE UGANDA CHRISTIAN UNIVERSITY TO THE
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DECLARATION

I **LWESSO GUILLAIN**, hereby declare that this dissertation titled “*Satisfaction with clinical care and associated factors among palliative care patients at Bukavu Provincial General Reference hospital, Democratic Republic of Congo*” is my original work, and it has not been submitted to any institution of higher learning for any academic award or publication, and all sources I have used or quoted have been indicated and acknowledged by means of references. I therefore present it for the award of the degree of Master of Public Health.

Signature.....

Date.....

LWESSO GUILLAIN

DEDICATION

This work is dedicated to my wife; Mrs. Bukiwa Nyassa Lydia, my brothers, my sisters and friends including my dear children, for the moral, spiritual and financial support that they gave me at all stages of my studies.


APPROVAL

This dissertation entitled “*Satisfaction with clinical care and associated factors among palliative care patients at Bukavu Provincial General Reference hospital , Democratic Republic of Congo*” by **Lwesso Guillain** has been prepared under my supervision and is submitted to the faculty of public health, nursing & midwifery in partial fulfilment of the requirements for the award of the degree of Master of Public Health of Uganda Christian University.



Dr. Gloria Kirungi

Research supervisor



Date

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Special thanks go to my supervisor Dr. Gloria Kirungi who guided me through this research process. Your support and care gave me a positive transformation in life and may the almighty God bless you abundantly.

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ACRONYMS

AOR	Adjusted Odds Ratio
APR	Adjusted Prevalence ratio
CI	Confidence Interval
COR	Crude odds ratio
CPR	Crude Prevalence ratio
CQI	Continuous Quality Improvement
DRC	Democratic Republic of Congo
MOH	Ministry of Health
PRR	Prevalence rate ratio
RBF	Results Based Financing
UHC	Universal Health Coverage
WHO	World Health Organization
HPGRB	Bukavu Provincial Referral General Hospital

OPERATIONAL DEFINITIONS

Patient satisfaction: This was defined as the extent to which a patient is satisfied with the palliative care services received. This was measured using 18 five-level Likert item questions weighted from 1 to 5 where a lower score represents less satisfaction and 5 represent the highest level of satisfaction. The the summated score of all questions were dichotomized using the meadian of the possible scores that range from 18 to 90. An individual that had a score above this median values (54) was regarded as being satisfied with palliative care ad one with equal or less than the median value was regarded as dissatisfied with palliative care services.

Palliative care Services: Palliative care in this study will refer to Symptom management, pain relief, home-based care, clinical based care, community mobilization and participation

ABSTRACT

Background: Patient satisfaction is a vital indicator of quality of healthcare. This study assessed the level of patient satisfaction with palliative care services and associated factors among adult HIV-positive patients receiving palliative care services at HPGRB .

Methods: A cross-sectional study enrolled 376 adult HIV-positive patients receiving palliative care at HPGRB using simple random sampling. A structured questionnaire assessed socio-demographics, health facility factors, and satisfaction using 18 Likert scale questions. Satisfaction was defined as a score above the median of possible scores. logistical regression was used to identified factors associated with satisfaction among patients receiving palliative care services. STATA v17.0 was used to analyze the data.

Results: The satisfaction level was 59.3% (95% CI: 54.3, 64.2). Being female (aPR 2.0, 95% CI: 1.7, 2.9), employed (aPR 3.5, 95% CI: 2.1, 5.9), and aged ≥ 50 years (aPR 6.3, 95% CI: 2.5, 13.9) were associated with higher satisfaction. Being non-Catholic (aPR 0.4, 95% CI: 0.2, 0.6) and waiting >3 hours (aPR 0.5, 95% CI: 0.4, 0.6) predicted lower satisfaction.

Conclusion: Satisfaction with palliative care at HPGRB is suboptimal. Targeted quality improvement initiatives focusing on waiting times, staff interactions, and expectations of non-Catholic patients could significantly improve satisfaction which would ultimately improve the quality of care.

CHAPTER ONE : INTRODUCTION

1.0 Introduction

This chapter includes the conceptual, contextual and theoretical perspectives of the dependent variable of the study are discussed in the background. This chapter also presents the statement of the problem, the purpose of the study, objectives of the study, research questions, scope of the study, significance of the study and the conceptual framework.

1.1 Background

Patient Satisfaction refers to the degree of congruence between expectation and accomplishment (Adejuyigbe, Ugowe, Anyabolu, & Babalola, 2022). Patient satisfaction as indicated by the World Health Organization (WHO) is a key element towards improving health care system and health care service delivery (Manzoor, Wei, Hussain, Asif, & Shah, 2019). Different scholars have used patient satisfaction indicator as a measure of quality of care and this resulted into development of appropriate intervention. Findings from patient satisfaction studies allow health care providers to identify service factors that need improvement, enables policy makers to understand patients' needs and, consequently, allows development of strategic plan for effective and better-quality services (Batbaatar, Dorjdagva, Luvsannyam, Savino, & Amenta, 2017). Globally, patient satisfaction according to a study conducted from German stood at 80% with a grouped median satisfaction at 5.04 (Schoenfelder, Klewer, & Kugler, 2011). Globally, patients are increasingly getting frustrated with the commercialization of medical services, proliferated bureaucratic

healthcare system and decaying patients-healthcare provider relationship (Ochan, Aaron, Aliyu, Mohiuddin, & Bamaiyi, 2018).

It is estimated that the magnitude of patient satisfaction varies significantly across sub-Saharan Africa. For instance, a study conducted in Ethiopia revealed that patient satisfaction was low at 48.4% (Wudu, 2021). Few numbers of patients appreciate the available healthcare services offered, while majority express their dissatisfaction with service delivery and in developing countries, it has been shown that the range of patients' satisfaction varies between 20% to 95% (Omona, 2021). Their complaints are on poor quality of healthcare services which among others are, due to limited patients-health care providers contact time, unethical practices, lack of physical comfort, unclean and unsafe environment (Omona, 2021).

Different scholars define patient satisfaction separately, for instance, it has also been defined as people's expectations for healthcare services on the basis of health, disease, quality-of-life, and other requirements (Wudu, 2021), others have further defined it as a subjective evaluation of the service received against the individual's expectations according to a study done from Nigeria (Bello & Olajubu, 2019), and it can as well be seen as the degree of congruency between a patient's expectations of ideal care and his /her perception of the real care she/he receives. Access to palliative care services in DR Congo is not a luxury to majority of patients with terminal illness such as cancer and HIV/AIDS. This is hampered by effect of poverty, the deterioration of the health system and the absence of a well-defined national policy on palliative care. Patients are for

the most part abandoned to the care of inexperienced family members. Because of no clear policy on management of patients with illness that require palliative component, the drive to improving care has been vested in the palliative association known as Palliafamilli association through her partners. The major issue that blocks palliative care in DR Congo is the lack of knowledge about palliative care both in the population and even in health professionals. Most patients are treated at home with strong family involvement in many aspects of care (Kananga, 2018).

The situation is quite different in public health facilities of North Indian state, where most inpatients were satisfied with care received from nurses and doctors, availability of medicines, and hospital environment. The domains of their dissatisfaction were cleanliness of rooms and bathrooms (Kaur et al., 2019).

In South-East Nigeria, patients' satisfaction with services at a tertiary hospital was found to be less than half (47.3%) with care received on admission, 51.8% with the cleanliness of the hospital environment and how power supply was maintained in the hospital 62.4% (Obi, 2018). The overall proportion of admitted patient satisfaction with nursing care in Public Hospitals of Eastern Amhara region, Northeastern Ethiopia was found to be sub-standard at 48.9% (Wudu, 2021). Similarly, most of the patients found to be dissatisfied with the nursing, pharmacy and laboratory services, while some others were still dissatisfied with the level of health education, communication and information they received about their illness (Anaba, Anaba, & Abuosi, 2020)

One way of assessing quality of health care is through patients' satisfaction with the services they receive (Mai, 2022), this was revealed in a study conducted from Northwest of Somalia. Inpatient services these include services like diagnostic and treatment services available to hospitalized patients and usually unavailable or only partially available in outpatient facilities. Examples are continuous supervision; medical treatment and nursing care; specialized treatment techniques, such as rehabilitation, occupational, movement, or recreation therapy; and social work services.

Various dimensions of patient satisfaction have been identified and viewed as being multidimensional which includes hospital structure, medical processes and outcome of health services (Kaur et al., 2019). Patient satisfaction also depends on many factors such as quality of clinical services, hospital infrastructure, physical comfort, emotional support and respect for patient preferences, social demographic, economic status of the patients and their expectations of care, attitudes towards the health care system, which all have direct influence on satisfaction levels (Asamrew, Endris, & Tadesse, 2020).

Patients' judgment of hospital service quality and their feedback are essential in quality-of-care monitoring and improvement as well as an established yardstick to measure success of the services being provided in the health facilities (Mithilesh Kumar, 2016, Nabbuye-Sekandi et al., 2011). It is well documented that if patients' level of satisfaction on quality of care does not meet their standard, they may decide to seek for treatment somewhere else (Khamis and Njau, 2014). Similarly, inpatient satisfaction with care is a standard indicator of the quality of care delivered

during hospitalization. A satisfied patient will recommend the hospital to friends and family and may express it four to five people while a dissatisfied one will complain 20 or more times. This is an important influence in determining whether a person seeks medical advice, complies with treatment and maintains a continuing relationship with practitioners (Tesfaye and Tegegne, 2019).

Good quality of care enhances clients' satisfaction and their use of services. To ensure patients are satisfied with quality of healthcare services delivered, patients services have to be delivered on time by friendly and respectful staff, are safe, produce positive result and that they can afford, provide them with adequate information about their condition and treatment, provide them with all the medicines they need, give privacy and confidentiality, are within their reach (distance) and given in a language they can understand, are comfortable, allow continuity of care and provide choice (Verulava, Jorbenadze, Karimi, Dangadze, & Barkalaia, 2018).

In low-income settings, much attention has been given to the importance of increasing the availability and accessibility of health services, but insufficient focus has been paid to assessing their quality (Warren et al., 2018). Although assessing patient satisfaction is regarded as an essential input for insuring quality of healthcare, it is often the most neglected. Thus, very little is known about patient satisfaction with inpatient services because there is no regular and comprehensive assessment of patients' satisfaction with inpatient services in the Hospital.

In a study conducted in Lubumbashi, the Democratic Republic of Congo, patient satisfaction was at 57% (Kes, Kyalubile, Kashala, Tshisand, & Mundongo, 2018). This study indicated that

engaging patients in routine care, effective communication and reduced waiting time were important factors associated with satisfaction with inpatient care. It is however not clear whether the level of patient satisfaction at Bukavu hospital is in optimal ranges to ensure effective service delivery.

Despite complaints among patients seeking palliative care at Bukavu Provincial General Reference Hospital (HPGRB) on waiting time to receive treatment, informal payments while seeking care, unprofessional service providers, and inconsistent stockout of drugs among others however no studies done on the level of patient's satisfaction among palliative patients as this is based on raw data from the facility. Hence, assessing patients' satisfaction with palliative care patients generate strategies for policy makers and health care providers to provide interventions at Bukavu hospital and other settings that share similar characteristics.

1.2 Problem Statement

Despite efforts by the Ministry of Health and stakeholders to improve care quality at Bukavu Provincial General Reference Hospital (HPGRB), general patient satisfaction is at 42%, far below WHO's 95% recommendation. The satisfaction status of palliative care patients at HPGRB is unknown. Hence, the problem of this study is low patient satisfaction with health care services, at Bukavu Provincial General Reference Hospital (HPGRB).

Reports from routine quality improvement indicate that patient satisfaction ranges between 40 to 60% from different departments and this is in line with a study conducted in DRC Congo which revealed that patient satisfaction stood at 42% (Kes et al., 2018). Bukavu is a regional referral hospital serving approx. 32,000 patients per year, amidst numerous challenges such as staff shortage, huge patient numbers, long waiting time, poor communication skills among staff, and negligence; gender discrimination, drug shortages; and absenteeism of health workers, poor attitude of health care workers among others. The highlighted gaps in service delivery are suggestive that patient's loyalty and compliance to ARVs for suppression of the virus and reduction of morbidity and mortality among the HIV patients could be affected.

Several factors influencing patient satisfaction encompass ethical practices, lengthy waiting time, weekend and night staff shortages, subpar cleanliness (e.g., toilets, bathrooms, wards), and recurrent drug shortages necessitating external purchases. To enhance satisfaction, the hospital implemented measures like a Continuous Quality Improvement (CQI) committee, suggestion

boxes for patient feedback, and Result Based Financing (RBF) in Bukavu, DRC. While these initiatives have partially improved patient satisfaction, it still falls short of WHO recommendations. Worse still, levels of patient satisfaction among palliative care patients remains unknown as there is no regular and comprehensive measurement and assessment of palliative care patients' satisfaction at this hospital. Therefore, this study assessed the level of satisfaction among palliative care patients and identified the associated factors in Provincial General Reference Hospital Bukavu (HPGRB) .

1.3 Study objective

1.3.1 General objective

The main objective of this study was to assess the level of patient satisfaction with clinical care and identify associated factors among HIV-positive patients receiving palliative care at Provincial General Reference Hospital Bukavu in DRC so as to improve access to and utilization of quality palliative care services.

1.3.2 Specific objectives

1. To determine the level of satisfaction of care among adult HIV positive patients receiving palliative care services at Bukavu Provincial General Reference Hospital in DRC
2. To identify the factors associated with satisfaction of care among adult HIV-positive patients receiving palliative care services at Bukavu Provincial General Reference Hospital in DRC

1.4 Research Questions

1. What is the level of satisfaction of care among adult HIV-positive patients receiving palliative care services?
2. What are the factors associated with satisfaction of care among adult HIV-positive patients receiving palliative care services?

1.5 Scope of the Study

1.5.1 Geographical scope

This study was conducted at the Bukavu Provincial General Reference Hospital (HPGRB) located in Bukavu city in the province of South Kivu. Located at the coordinates of Latitude: -2.4943364, Longitude: 28.8498628 on Avenue Michombero, Nkafu district, Kadutu commune, about 500 meters from the Place de l'Indépendance on the road leading to Kavumu Airport The hospital serves approximately 1,000,000- 2,000,000 million population. Between October and November 2010, the technical team from USAID developed a toolkit with a focus on HIV/AIDS patients on positive living, positive prevention and palliative care with a focus to improve the quality of care and patients` experience while accessing care (USAID, 2011). Bukavu hospital has a bed occupancy of 350 and serves as the main healthcare facility of Bukavu city and also serves as a reference centre for the province of South-Kivu for the holistic care of survivors of sexual violence as well as maternal care and family planning. Bukavu is a city in the eastern Democratic Republic of the Congo (DRC), lying at the extreme south-western edge of Lake Kivu, west of Cyangugu in

Rwanda, and separated from it by the outlet of the Ruzizi River. It also serves as the capital of the South Kivu province and the business hub. It is estimated that about 12,118 people living with HIV/AIDS receive palliative care services at this hospital and the number is expected to grow further based on the increasing prevalence of HIV in the region. Palliative care was integrated into the routine care of patients especially those with HIV/AIDS in this province and therefore understanding the level of satisfaction with this service is cardinal to ensure improved service delivery.

1.5.2 Content scope

This study focused on socio-demographic characteristics and patient-related factors of the patients receiving care at Bukavu Provincial General Reference hospital , Democratic Republic of Congo as indicated specifically in the questionnaire.

1.5.3 Time Scope

The primary data collection was done within a period of three months from January 2023 to March 2023.

Secondary data sources for use in this study involved a review of the scientific articles and reports with a focus on peer-reviewed journals and reports from the period of 2012 - 2023 as expected for data that is scientifically sound and relevant contextually in this study. Patients' files from Bukavu hospital will also be reviewed to support the information necessary for this study.

1.6 Justification

The Universal Health Coverage (UHC) monitoring framework defined by WHO and the World Bank Group in 2017 highlighted two major components that need to be assessed and these included effective health services coverage and financial protection coverage (Tichenor & Sridhar, 2017). Health services include prevention, promotion, treatment, rehabilitation and palliative care (Karara, Verbeke, & Nyssen, 2017). Therefore, it is cardinal for this study to assess the level of patient satisfaction and associated factors among patients seeking palliative care. Bukavu hospital is surrounded by a community with an estimated HIV prevalence of 1.2% according to (Kishabongo, Shabani, Bisangamo, Shindano, & Takaisi-Kikuni, 2020) and in the initial launch of the palliative care program, it was estimated that the palliative component would equally target this group. The rationale of this study was to assess the level of patient satisfaction, and the personal and institutional associated satisfaction among patients seeking palliative care services at Bukavu Provincial General Reference Hospital (HPGRB), DRC.

1.7 Significance

Policy makers: Findings will provide the government of DRC with basis statistics for policy making such that suitable policies and guidelines are set to ensure that patient satisfaction with palliative health services is achieved with government facilities offering palliative care services.

Public and Private NGO Hospitals: Findings from this study will enable public facilities as well as private NGO and other health care facilities with information on how structural and process

characteristics determines the satisfaction level of patients seeking palliative health care services. With such information, hospitals will be able to come up with strategies aimed at improving health care services for palliative patients for maximum satisfaction of patients.

Patients: Findings from this study will help Bukavu hospital to design interventions targeted at improving the experiences of patients with palliative care seeking care from this facility. This will ultimately improve patients' satisfaction and optimal service delivery.

To future researchers and academicians: The study will be of benefit to the academic world as it is expected to add to the existing body of knowledge and understanding of healthcare service quality in a DRC and how it can be implemented to enhance patient satisfaction. In addition, those in the academic world will be able to get reference material on the relationship between healthcare service quality and patient satisfaction. Furthermore, the study findings will add value to the pool of knowledge on the shelves of university libraries and will act as a ground for further research in the area of health.

1.8 Conceptual framework for the satisfaction of care among adult HIV positive patients receiving palliative care services.

Independent Variable

Health workers related factors

- Nursing care received
- Communication
- Waiting time
- Patient privacy

Health facility related factors

- Sanitary
- Provision of food to patients, water supply and power
- Availability of health workers
- Availability of medicines and other medical supplies.

Patient related factors

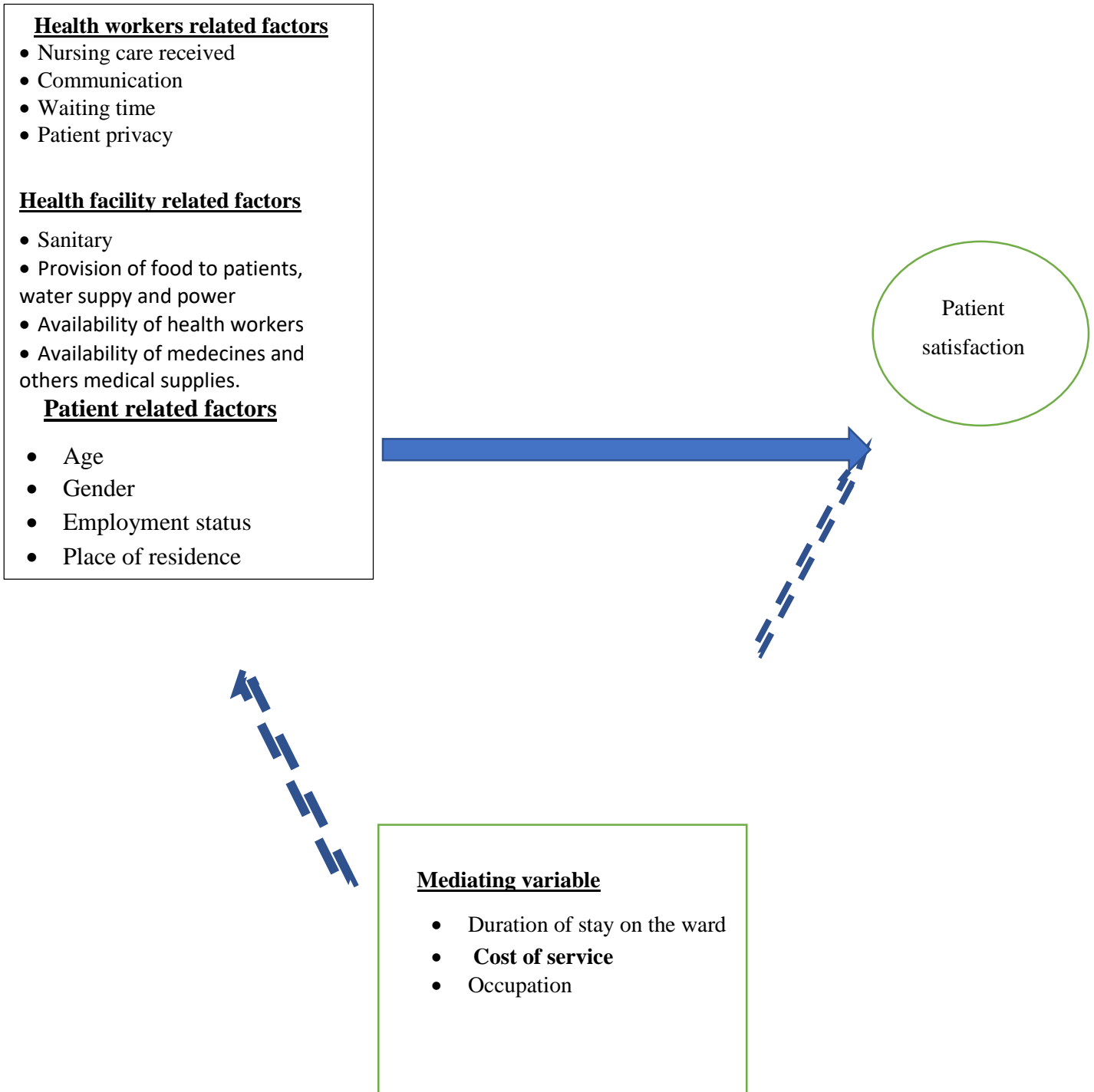
- Age
- Gender
- Employment status
- Place of residence

Dependent variable

Patient satisfaction

Mediating variable

- Duration of stay on the ward
- Cost of service
- Occupation



Narrative of conceptual Framework

This study will use the adapted Donabedian model to determine the level of patients' satisfaction with palliative care services in the study setting. This model addresses three core constructs and these include structure, process and outcome. Patient satisfaction will be measured using 18-questions (Marshall & Hays, 1994) that will be generated from the two dimensions of structure and process as demonstrated from the conceptual framework.

The structure construct addresses the manner in which palliative care is delivered to all palliative care patients.

Independent variables: These include Sanitary facilities Maintenance of power supply, Availability of health workers, and Availability of drugs. Health care delivery in particular palliative care is dependent on strong structures factors because they drive the process factors. For stance, the presence of adequate human resources trained in the delivery of qualitative care is very cardinal in the measure of patient satisfaction. This similarly applies to even presence of functioning equipment at the hospital for palliative patients to use. Under process factors, these are all interactions that occur between the patients and the service provide (Nurses, doctors and other health care workers) including nursing care, waiting time, staff attitude and

diagnoses of comorbidities. This tool demonstrates that the nursing care given to patients ultimately in an untidy environment consequently affects the level of satisfaction with palliative care services.

Dependent variable: As outcome it depends on independent variables moderating variable.

Moderating variable: The effect of mediating factors highlighted in the conceptual framework, directly and indirectly, affects the outcome and partly the process. For example, place of residence is often a predictor in the assessment of client satisfaction because, if a patient is coming from far places, they expect to receive services and return back to the facility on time. A delay (long waiting) at the facility will ultimately score satisfaction poorly, people who have a higher level of education may understand their rights as patients compared to patients who may have no formal education. Therefore, understanding the role of these modifiable factors is paramount in the assessment of patient satisfaction.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents the review of literature related to this study. The chapter reviews literature on the study variables; patient satisfaction (dependent variable), and the factors affecting satisfaction with care among palliative care patients (independent variables) according to the objectives of the study.

2.2 Overview of patient satisfaction

Patient satisfaction is one of the established yardsticks to measure success of the services being provided in the health facilities and is one of the most important indicators for quality of care

(Mithilesh Kumar, 2016, Tesfaye and Tegegne, 2019). Quality healthcare delivery and creation of patient satisfaction are the primary hospital's goals, and patient satisfaction has been described as the value and reaction of patients towards the care they received (Mulugeta et al., 2019). It can also be defined as a measure of the extent to which a patient is contented with the health care provided and their experience while using a health service (Omona et al., 2021).

A patient is the best judge since he or she accurately assesses and provides inputs which can help in the overall improvement of quality health care provision through the rectification of the system weaknesses by the concerned authorities. However, patients' perceptions about the healthcare system seem to have been largely ignored by healthcare managers most especially in developing countries (Mithilesh Kumar, 2016). Patient satisfaction depends upon many factors such as the quality of clinical services provided, availability of medicine, the behaviour of doctors and other health staff, cost of the services, hospital infrastructure, physical comfort, emotional support and respect for patient preferences (Mithilesh Kumar, 2016). Furthermore, 58% of key informant interviews indicated that long waiting times were the most common cause of dissatisfaction, while inadequate medicines were cited by 42%, with other challenges mentioned (but with a low frequency) were rude staff, poor sanitation, staff absence on weekend and night shifts, and some staff demanding money for treatment (Higenyi, 2013)

2.3 Measure of Patients' Satisfaction

There are various ways used to measure patient satisfaction including using electronic forms, phone calls, and face-to-face interviews with patients, with telephone follow-up of discharged patients, has been proposed in many articles as an accessible and low-cost method in which a lower time delay is reported compared to other methods (Makarem et al., 2016). The benefits of Electronic forms interviews include; excluding travelling for long distances, interviewing with people who are difficult to access, cost-effectiveness, saving information easily and quickly, removing the impact of the presence of the interviewer and the privacy of individuals, and their anonymity (e-mail) and many others. Electronic forms of the interview have limitations for example; reduced attention and concentration of participants, inability to use technology, insufficient Internet access, the problem of verifying the participant's identity and the lack of access to non-verbal reactions and how to obtain consent for participation in the study among others. Patient exists interviews are carried out using a structured study tool after discharge from wards/ interview schedules for a person seeking inpatient health care (Higenyi, 2013, Kaur et al., 2020, Marama et al., 2018). This has some advantages; exit interview allows the patients to provide constructive feedback about the health care services received which will help the health facility managers identify areas that can help improve the services being provided and improve on patient turn-up, and its cost-effective to facilitate quality exit interviews. However, patients may sugarcoat their responses for fear of being implicated by the health facility staff.

Face-to-face interviews are another approach used to measure patients' satisfaction by gathering information in relation to the patient experience with hospital care like as waiting time, ward environment, medical expenditure, overall satisfaction with hospital care, and their level of trust and confidence in care providers (Shan et al., 2016, Wudu, 2021). A face-to-face interview method provides advantages over other data collection methods such as; it captures verbal and non-verbal cues, including body language, which can indicate a level of discomfort with the questions being asked and provides accurate screening as the individual being interviewed is unable to provide false information during screening questions such as gender, age, or race. As with any data collection method, face-to-face interviews also provide some disadvantages over other data collection methods. These include; cost as a major disadvantage for face-to-face interviews since it requires personnel who will conduct interviews, and the quality of data received will often depend on the ability of the interviewer. Other than existing interviews for both outpatient and discharged patients, inpatient interviews can as well be conducted in the wards (Syed Shuja Qadri, 2012, Asamrew et al., 2020).

In DR Congo, many cancer patients in the terminal phase of their condition have minimal access to palliative care. There is a combined effect of poverty, the deterioration of the health system and the absence of a well-defined national policy on palliative care. Patients are for the most part abandoned to the care of inexperienced family members. The major issue that blocks palliative

care in RD Congo is the lack of knowledge about palliative care both in the population and even in health professionals.(© 2018 by American Society of Clinical Oncology)

However , with support of partners some hospitals have functional palliative care, this is the case of Bukavu Provincial general referral hospital that has 954 patients registered in HIV palliative care .

2.4 Level of Patient Satisfaction with Inpatient Services

Worldwide, there are varying levels of patient satisfaction between countries and within a country. In developed countries, patients are highly satisfied (90-95%) with the health care provided while in developing countries, it has been shown that the range of patients' satisfaction varies between 95% to < 20% (Omona et al., 2021, Marama et al., 2018).

The level of patient satisfaction especially with public health facilities is context-dependent and based on the dimensions of quality being assessed. Patient satisfaction was found to be higher in private health facilities at 66.7% compared to public health facilities at 40.1% (Tesfaye and Tegegne, 2019). Variables responsible for such levels were sex, patient's age, history of the previous admission, length of stay, waiting time before admission, and explanation given about the admission process. On contrary, results of an Institution-based cross-sectional study conducted among clients admitted to obstetrics and gynaecology wards of public hospitals in Mekelle town,

Ethiopia, showed that the observed satisfaction rate was high at 79.7% at 95% CI (75.8%, 83.6%) (Marama et al., 2018).

Results from a study conducted in Northwestern China on inpatient satisfaction with nursing care revealed a satisfaction level of 78.15% (Zhang et al., 2020). On contrary, the overall proportion of admitted patients' satisfaction with nursing care was 48.8% which was found to be substandard (Wudu, 2021). The situation was different in a public tertiary hospital in Trinidad and Tobago where the inpatient satisfaction levels ranged from 50% and 70% for management issues, treatment-related communication issues, environmental issues, and department of medical staff (Bahall and George, 2019). However, high levels of patient dissatisfaction with hospital care and were lack of trust as reported by about 24% of respondents (Shan et al., 2016). In addition, most of the patients were found to be dissatisfied with nursing, pharmacy and laboratory services, while some others were still dissatisfied with the level of health education, communication and information they received about their illness (Woldeyohanes, 2015). On contrary, the mean score of overall satisfaction with hospital services was 16.86 \pm 2.72 out of 20 with 58% of participants were highly satisfied with the services provided during their hospital stay and 83.7% intended to return to the same hospital in case of need (Makarem et al., 2016).

Findings from a study done in a tertiary Hospital in Southeast Nigeria showed that despite more than half of the surveyed patients being satisfied with some specific aspects of services given while on admission, those satisfied with overall experience were less than half (Obi, 2018).

This lowered level of patient satisfaction with inpatient services was also observed in a specialized hospital in Ethiopia where the overall net patient satisfaction level with hospital services was found to be 37.7% (Asamrew et al., 2020).

2.5 Factors associated with Patients' Satisfaction with Care

Satisfaction with care is a standard indicator of the quality of care delivered during hospitalization. A satisfied person will recommend the hospital to friends and family and may express that satisfaction to four to five people; while a dissatisfied one on the other hand will complain 20 or more (Tesfaye and Tegegne, 2019). The determination of health care service satisfaction of the admitted patient will provide information to their satisfaction in terms of the facilities in the hospital, availability and affordability of various health care services, and the manner of service delivery which include how well the necessary information is conveyed and the personnel who deliver the health care services (Tesfaye and Tegegne, 2019).

Domains of patient satisfaction with health care services have been viewed as multidimensional, which includes hospital structure/ environment, medical processes, and outcome of health care services, for which the majority of existing patient satisfaction studies have paid little attention (Mithilesh Kumar, 2016).

This, therefore, calls for a need to conduct patient satisfaction with inpatient services with factors aligned per the adapted Donabedian model which measures patient satisfaction with services in terms of structure and process that leads to the desired health outcome.

2.5.1. Health facility related factors

Sanitary factor

In a study conducted in North Indian State, results showed that poor cleanliness of rooms and bathrooms was the major reason for dissatisfaction with inpatient services (Kaur et al., 2020). Furthermore, in a study done in a specialized hospital in Ethiopia, results registered the highest very dissatisfaction proportion regarding the observed cleanness status of the toilets in the facility, with 42 (10.6%) study participants claiming that they were very dissatisfied with the cleanliness of toilets in the facility (Asamrew et al., 2020). The situation was found different in Southeast Nigeria where more than half (51.8%) were satisfied with the cleanliness of the hospital environment (Obi, 2018).

On contrary, in all inpatient healthcare services, the cleanliness of the ward scored the highest (76.7%) proportion of satisfaction (Woldeyohanes, 2015). Similarly, patients were more satisfied with the cleanliness in the ward 60% and the campus 56% as compared to toilets 20% (Mithilesh Kumar, 2016). This variation in the cleanliness of different structures requires further studies to be done in a rural setting to assess the perceptions of patients regarding those services.

Availability of medicines and other medical supplies

Much as it is expected by patients and their caretakers to have medicines provided by the hospital, 70% of the patients were dissatisfied as prescribed medicines were not available in the hospital and they had to bring them from outside which were unaffordable for 77% of the patients but had to buy it (Mithilesh Kumar, 2016). This was similar to a study that was conducted in public health facilities of a North Indian State where a lack of drugs and supplies was among the major reason for inpatient dissatisfaction (Kaur et al., 2020). Furthermore, results from a study conducted in Southeast Nigeria revealed that less than half of the inpatients were satisfied with the in-stock status of drugs 45.9% (Obi, 2018).

Availability of health care providers

Results from a study conducted in a tertiary care hospital in Ranchi, India indicated that 91% of the patients were satisfied with the availability of nursing staff in ward, while 80% were dissatisfied with inadequate paramedical staff in the ward (Mithilesh Kumar, 2016). Similarly, 34% of inpatients spent much of their time (7-12 hours) with their attendants rather than the assigned nurses (Wudu, 2021). Furthermore, the level of satisfaction regarding the availability of doctors was lower (46%) in the admitted patient (Syed Shuja Qadri, 2012). Nurses are the first-line individuals most likely to meet, spend the most time with, and rely on during hospitalization as opposed to other health care providers which might be different for a case of Congo's health care

system with inadequate staffing. Hence, the need to investigate patients about their perceptions of the availability of nurses and other health care cadres on the wards.

Provision of food to patients, water supply and maintenance of power

supply

Patients were most dissatisfied with food services in hospitals affiliated with the Tehran University of Medical Sciences (Makarem, 2016; Woldeyohanes, 2015). In addition, less than half of the respondents expressed satisfaction with the availability of good and affordable food in the hospital while more than half (62.4%) were satisfied with how the power supply was maintained in the hospital of Southeast Nigeria (Obi, 2018). This was different in a tertiary care Hospital in Ranchi-India where 52% of patients were more satisfied with the food in terms of its quality and timing, and 46% water supply (Mithilesh Kumar, 2016). This variation requires studies to be conducted in other facilities as most hospitals have limited funds to provide food for patients, hence leaving them dissatisfied.

2.5.2 Health workers related factors

Communication and education from providers

Results from a study done in North Indian State revealed that poor information about medicines was one of the major reasons cited for patients' dissatisfaction with inpatient services (Kaur et al.,

2020). The same study showed that the majority of the participants reported being satisfied with nurses who listened to them carefully and understandably explained things. Similarly, the majority 88.9% of patients were able to communicate with the nurses and physicians without any barriers at Jimma University Specialized hospital, Southwest Ethiopia (Woldeyohanes, 2015). In the same study, the dissatisfaction level was significantly higher for information service of the hospital, and illness education/communication.

Waiting time to receive services

A study conducted at Jimma University, a Specialized hospital indicated that patients were satisfied with the admission service, and waiting time, where the majority 52.6% got a physician within an hour after receiving their laboratory results and 52.9% received medical help at night at a time they needed it (Woldeyohanes, 2015). This was observed in a study done in a specialized hospital in Ethiopia where findings showed that almost half of the study participants were satisfied with the admission processes of the hospital 48.7% and the waiting time to get services 47% (Asamrew et al., 2020). This was different in North Indian State public health facilities where results showed that patients were dissatisfied with the long waiting time to receive services (Kaur et al., 2020).

Patient`s Privacy

Dissatisfaction level was found to be significantly higher for privacy with crowded rooms and confidentiality (Kaur, 2020; Woldeyohanes, 2015). On contrary, a cross-sectional study from

Northwestern China indicated that patients reported the highest satisfaction when nurses treated them as individuals (67.7%) and respected their privacy (60.8%) (Makarem et al., 2016, Zhang et al., 2020). Furthermore, results from a tertiary hospital in Southeast Nigeria indicated that 67.6% of patients were satisfied with the level of privacy given to them during their course of hospital stay (Obi, 2018). In addition, 42.5% and 55.0% of the patient were satisfied with measures taken to ensure confidentiality and privacy respectively (Asamrew et al., 2020). 94.1% were happy with the privacy observed at the facilities during physical examinations on the wards (Ochan et al., 2018). This implies if nursing care given to patients respects their privacy, and confidentiality and is taken as individuals, they are more likely to get satisfied with the services offered in a given hospital.

Nursing services

Nursing services are very critical in the management of inpatients as they make patients recommend the hospital to other patients or not. 86.1% of the patients reported having gotten the expected nursing care during their stay in the hospital and 81.96% recommended their families and friends visit the same hospital (Wudu, 2021). In addition, more than half (60.8%) of the patients were satisfied with the nursing care provided to them (Asamrew et al., 2020). This was observed in Southeast Nigeria as the majority of the participants reported being satisfied with the overall care received from nurses as they treated them with courtesy as well as participants got help as soon as wanted from nurses (Kaur et al., 2020). On contrary, inpatients had a significant

level of dissatisfaction with nursing services at Jimma University Specialized Hospital, Southwest Ethiopia (Woldeyohanes, 2015). The situation was not far different from patients admitted to a tertiary care hospital in rural Haryana where more (55%) of patients were dissatisfied with the behaviour of nurses than any other healthcare staff (Syed Shuja Qadri, 2012).

2.5.3 Patient-related factors affecting satisfaction with healthcare services.

Patients themselves have factors that affect their satisfaction of the services rendered in health facilities. This has been observed in a study that was conducted at Mpigi Health Center IV in which patients' satisfaction was at 58.0%, age of the respondents ($p=0.009$), gender ($p=0.048$), and employment status of respondents ($p=0.005$) were all found to be associated with patients' satisfaction (Omona et al., 2021). Furthermore, male study participants were found to be 0.71 times less likely to be satisfied compared to females, patients whose age was 18-30years and 31-40 years, were found to be 0.32 and 0.44 times less likely to have had satisfaction respectively, and study subjects who stayed above 8days as compared to those who stayed 27 days were found to be 4.99 times more likely to be satisfied (Tesfaye and Tegegne, 2019).

The level of overall adult patient satisfaction about inpatient nursing service in the hospital was very low 132(40.9%). Age category 35-44 years, respondents who had attended college and University, rural residents, patients admitted several times and patients admitted second time, and

duration of hospitalization more than 15days were factors associated with patient satisfaction (Mensa et al., 2017).

Patients with no formal education 60 (76.9%) and those from rural areas 75 (68.8%) were satisfied higher than their counterparts (Woldeyohanes, 2015). This implies that education level of a patient and where he/she resides plays an important role in determining the satisfaction of inpatient services provided by the health facility.

Results from hospitals of Eastern Amhara region, Northeastern Ethiopia indicated that having primary education (AOR=8.575; 95% CI: 1.770-14.532), and being a farmer by occupation (AOR=3.702; 95% CI: 1.047-13.087), were the important predictors for patient satisfaction with inpatient nursing care (Wudu, 2021).

2.5.4 Other healthcare services (Mediating variable)

In a study carried out in hospitals affiliated with the Tehran University of Medical Sciences results indicated that 58% of participants were highly satisfied with services provided in terms of physician and medical services, laboratory and radiology services (Makarem et al., 2016).

This study did not agree with findings from Jimma University Specialized hospital where patients' dissatisfaction was significantly higher with visiting hours, services to pharmacy and laboratory (Woldeyohanes, 2015). The study having been conducted in hospitals affiliated to university,

services tend to be better due to the students who normally provide care under great supervision which may not be the case in a rural public health facility.

In most health facilities, inpatients are not always administered their drugs on time. However, the case for tertiary care hospital in Ranchi, India was different as 85% of the inpatients were satisfied with the timing of dispensing medicines (Mithilesh Kumar, 2016).

Moreover, a research concluded that insured patients were more likely to be satisfied with the healthcare system when compared to uninsured patients (OR 2.79, 95% CI 2.07-3.77) (Maharlouei et al., 2017). At the same time, a study found that private health spending resulted to be negatively correlated with patient satisfaction with healthcare system as an increase of private health expenditures made patient satisfaction lower by 98.7% (Xesfingi & Vozikis, 2016). In addition, another study concluded that 37 utilization does not have any effect on patient satisfaction with healthcare system (Jackson et al., 2001).

2.6 Summary of literature gaps

2.6.1 Methodological gaps

The existing studies have been done among the general patients with no clear focus on palliative care patients. This study sought to determine the level of satisfaction care while this study focused on patients receiving palliative care at Bukavu provincial general referral hospital.

2.6.1.1 Knowledge gaps

There are intrinsic factors that affect patient satisfaction that are routinely overlooked focused on the external factors and health systems factors. This study will take into account the intrinsic factors that affect the patient outcomes and satisfaction.

2.6.1.2 Geographical Gaps

Also, there have been a few studies that have been done in Democratic Republic of Congo that focus on patient satisfaction.

2.7 Conclusion

The structural factors that affect patient satisfaction are related to health facility (Sanitary facilities, Availability of medicines and other medical supplies and health care providers), to health care providers (Nursing care, communication, waiting time and patients privacy) and patients factors (Age, sex, education, time to stay in the service and employment). While mediating factors are cost of service, time of staying in the service and occupation.

CHAPTER THREE: METHODOLOGY

3.0. Introduction

This chapter lays down the methodology that guided the study. It presents the research design, area and population of study, sample size and selection, data collection methods and instruments, procedure for data collection, data analysis, measurement variables and ethical considerations.

3.1 Study Design

A cross sectional study design that used quantitative methods of data collection to assess the level of patients' satisfaction with palliative care services and associated factors among adult HIV positive patients receiving services at the Bukavu Provincial General Reference Hospital , DRC

3.2 Study setting

This study was conducted at the Bukavu Provincial General Reference Hospital (HPGRB) located in Bukavu city in the province of South Kivu. The hospital serves approximately 1,000,000-2,000,000 million population. Between October and November 2010, the technical team from USAID developed a toolkit with a focus on HIV/AIDS patients on positive living, positive prevention and palliative care with a focus to improve the quality of care and patients' experience while accessing care (USAID, 2011). Bukavu hospital has a bed occupancy of 350 and serves as the main healthcare facility of Bukavu city and also serves as a reference centre for the province of South-Kivu for the holistic care of survivors of sexual violence as well as maternal care and family planning. Bukavu is a city in the eastern Democratic Republic of the Congo (DRC), lying at the extreme south-western edge of Lake Kivu, west of Cyangugu in Rwanda, and separated from it by the outlet of the Ruzizi River. It is estimated that about 12,118 people living with HIV/AIDS received palliative care services at this hospital in 2022 and the number is expected to grow further based on the high prevalence (around 1%) of HIV in the country. Palliative care was integrated into the routine care of patients especially those with HIV/AIDS in this province. The hospital is

located at the coordinates of Latitude: -2.4943364, Longitude: 28.8498628 on Avenue Michombero, Nkafu district, Kadutu commune, about 500 meters from the Place de l'Indépendance on the road leading to Kavumu Airport and Goma.



DR.Congo map , showing BUKAVU town where HPGRB is located (Google map available via license: [Creative Commons Attribution-NonCommercial 3.0 Unported](https://creativecommons.org/licenses/by-nc/3.0/)).

3.3 Study Population

Target population: 32,000 adult HIV-positive patients receiving of HIV care at Provincial General Reference Hospital Bukavu (HPGRB) in 2022.

Accessible population: 956 adult HIV positive patients aged 18 years and above actively receiving palliative care services at Provincial General Reference Hospital Bukavu (HPGRB) between January and March 2023.

Study population: 376 HIV positive patients aged 18 years and above actively receiving palliative care at Provincial General Reference Hospital Bukavu between January and March 2023 who fulfilled the eligibility criteria and formally consented to participate in the study.

3.4. Eligibility Criteria

3.4.1 Inclusion criteria

Patients who are;

- 18 years and above
- Received PC services at the hospital for at least three (3) months prior to data collection
- Provided written informed consent to participate in this study

3.4.2 Exclusion criteria

Twelve (12) patients who were critically sick and unable to participate in this study were excluded and internally referred to doctors for clinical care..

3.5 Sample size calculation

This study adopted the kish Leslie formula for calculating sample size for cross sectional studies (Israel, 1992).

$$n = \left[\frac{Z^2 PQ}{\delta^2} \right]$$

Where

Z is the value from the standard normal distribution reflecting the confidence level that was used (e.g., Z = 1.96 for 95%),

P is estimated prevalence of the problem under study,

Q is 100-p and δ^2 is the maximum error the investigator is willing to allow.

95% level of confidence

5% margin of error,

42% patient satisfaction in a study that was done from DRC Congo (Ndziessi, Bintsene-Mpika, & Bileckot, 2017).

Substituting into the formula above it gives;

$$(1.96)^2 \times (0.42) \times 1 - 0.42 / (0.05)^2 = 3.8416 \times 0.2436 / 0.0025 = 374.27$$

Considering a non-response rate of 5%, $374.27 / 0.95 = 393.96$ approximately 394 participants.

The total calculated sample size was 394 participants.

Response rate: A total of 394 questionnaires were given out to individuals to complete, of which only 376 were returned giving a response rate of 94.5%.

3.6. Sampling procedure

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3.6.1 Selection of Bukavu hospital

Bukavu city has six hospitals - two private for-profit, three private not-for-profit, and one government-aided hospital.

Table 3.1 . showing the hospitals and characterisitics in Bukavu city(From Provincial health division office)

No	Name of hospital	Type of hospital (PFP, PNFP, Government-aided)	Is it a teaching hospital (yes/no)	Number of HIV positive patients receiving care per hospital	Number of palliative care patients served in the last 12 months (January – December 2022)
1	Bukavu Provincial General Referral Hospital	PNFP	Yes	12118	956
2	Panzi hospital	PNFP	Yes	613	294
3	Chiriri hospital	PFP	No	179	104
4	Bagira hospital	Government-aided	No	208	190
5	Kadutu hospital	Government -aided	No	298	78
6	Bukavu Military hospital	Government-aided	No	96	43

HPGRB was purposively selected because: a) It is the main referral hospital for the South Kivu province, serving most of the patients b) It is a teaching hospital for medical students, with around 900 students c) It attends to the highest number of palliative care 987 patients last year compared to other facilities in the city and therefore, it would provide a good number of patients for this study.

b) selection of study participants

Participants were selected using simple random sampling method. The daily palliative care services attendance register was used to randomly select the participants. Every patient with an even registration number (2,4,6,8,10,...nth) was selected and assessed for eligibility.

Individuals found to be eligible to participate in the study were requested for formal consent to enroll in the study. This process was repeated daily for three months until when the required number of participants was attained.

Exit interviews were then conducted for all the selected and consented patients after receiving care at the hospital.

3.7 Study Variables

3.7.1 Dependent Variable

This was defined as the extent to which a patient is satisfied with the palliative care services received. This was measured using 18 five-level Likert item questions weighted from 1 to 5 where a lower score represents less satisfaction and 5 represent the highest level of satisfaction. The summated score of all questions were dichotomized using the median of the possible scores that range from 18 to 90. An individual that had a score above this median values (54) was regarded as being satisfied with palliative care and one with equal or less than the median value was regarded as dissatisfied with palliative care services.

3.7.2 Independent Variables

The independent variables included individual factors or patients related factors(age, sex, religion, employment status, area of residence, marital status, education level), health facility related

factors (sanitary, provision of food to health facility , water supply and power , availability of medicines , and availability of health workers and health worker related factors included only waiting time, privacy, nursing care and communication from the health workers.

3.7.3. Mediating variables

It includes duration of staying in the ward, cost of service and occupation of the patients that may also affect the patient satisfaction either directly or through factors of independent variable.

Right to satisfactory services for every patient receiving palliative care as a policy.

3.8 Data collection

Questionnaire: A structured questionnaire was used to collect data via a face-to-face interview.

The study questionnaire include sections highlighting health facility factors, patients factors and health workers factors demonstrated by Donabedian model and variables assessing patient satisfaction. The section to assess patient satisfaction has 18-questions on structure and process related factors using a 5-point Likert scale response ranging from 1 to 5. The English version of the questionnaire translated to French which is commonly used language by the community accessing care from this hospital.

3.8.1 Procedure of data collection

After obtaining a letter of approval from university, the researcher presented it to Bukavu hospital administration seek formal approval from the Hospital Administration. Approval letter from

hospital administration was presented to the in-charge of different departments. The researcher identified eligible participants. An oral presentation about the aim of the study, voluntary participation and confidentiality was given to the eligible participants before consent. The research assistant collected data from participants who consented to participate in the study. The research assistant issued questionnaires individually and filled the questionnaires in a private room attending to one patient at a time.

3.9 Data quality control

3.9.1 Reliability

The study questionnaire was pretested at Goma referral hospital palliative care clinic. This health facility in Goma region, DRC is at the same level as the Provincial General Reference Hospital, Bukavu and has relatively similar patients. A sample of 30 participants was used in the pre-test. The research assistants that helped in data collection were trained prior to the start of data collection for 2 days. There was no significant change in the tool however, what changed was the working of few questions in the questionnaire.

3.9.2 Validity

Validity refers to the degree to which an instrument measures what it's supposed to measure (Polit and Hungler, 1997). This study used face validity. Face validity is the extent to which a test is subjectively viewed as covering the concept it purports to measure. It refers to the transparency or relevance of a test as it appears to test participants. In other words, a test can be said to have

face validity if it "looks like" it is going to measure what it is supposed to measure.(*New Jersey: Wiley. pp. 637–638. [ISBN 978-0-470-17024-3](#)*)

For instance, if a test is prepared to measure whether patients receiving palliative care were satisfied or not with the service delivered , and it was shared with palliative care team, all agree that it looks like a good test of ability, this demonstrates face validity of the test. Face validity is often contrasted with content validity and construct validity.

3.10 Data management and Analysis

3.10.1 Data management

The hard copy questionnaires were sorted, coded and entered in Epidata software. The questionnaires and the consent forms were stored under lock and key cupboards and only accessible to the study team to avoid theft, loss and breach of confidentiality of the study participants. Back up source of data storage like laptop, flash disk and email will be used to store the soft copy of the dataset for further subsequent analysis. The data was the exported to STATA version 14.0 for analysis.

3.10.2 Data analysis

The descriptive statistics were summarized using the frequencies and percentages.

For objective 1: the proportion of participants with optimal level of satisfaction with palliative care services together with the logit 95% confidence interval (CI) was computed.

For objective 2: the factors associated with the optimal level of satisfaction were assessed using a modified Poisson regression model. At bivariate analysis, the crude prevalence ratio (cPR), 95% CI and the P values were computed. Independent variables with a P value of <0.2 were considered for the multivariate analysis. At multivariate analysis, interaction (Assessed using a -2 log likelihood) and confounding (using a cut off of 10 % change in crude and adjusted prevalence ratios) were assessed. Model building followed a backward elimination method. In the final model, statistical significance was set at a p values of 0.05, and the adjusted prevalence ratio (aPR) together with the 95% CI and the P values were computed.

3.11 Ethical considerations

Approvals: The ethical approval of this study was sought from the Uganda Christian University Faculty of Public Health, Nursing & Midwifery research and ethics committee (UCUREC-2023-442). An introductory letter from the school of public Health was used to seek administrative clearance from the hospital administration.

Consent: A written informed consent was obtained from the participants after explaining the purpose and procedures of the study.

Voluntary participation: Participants were informed that they are free to accept or refuse participation in the study without any consequences whatsoever and will also be informed that they have a right to withdraw from the study at any point in time.

Confidentiality: Participant identifiers instead of names were used on the questionnaires to avoid possible breach of confidentiality. The completed hard copy questionnaires were sorted, coded, and entered into Epidata software. The questionnaires and consent forms were stored under lock and key in cupboards accessible only to approved study team members. This ensured confidentiality and prevented unauthorized access or loss of study data. Soft copies of the dataset were stored on password-protected laptops, and a copy was also saved on the email account accessible to only the research team.

Language: The questionnaires were translated from English into French to facilitate administration as French is the commonly used local language.

Reerral of very sick participants: Very sick participants needing urgent medical care were referred to the health facility clinicians for appropriate management as per standard operating procedures.

Compensation/Benefit: Participants did not receive any direct compensation or benefits for taking part in the study. However, they would benefit indirectly from any improvements in palliative care services resulting from the study findings.

Risks: There were no foreseeable risks anticipated as a result of participating in this study. No biological samples were collected and no medical procedures performed.

3.12: LIMITATIONS

1. **Narrow geographical scope:** The study was conducted at only one health facility, which limits the generalizability of the findings. Satisfaction levels and associated factors could potentially differ across other hospitals and regions of DRC.
2. **Cross-sectional design:** The cross-sectional nature only provides a snapshot of satisfaction levels at one point in time. It limits inferences about causal relationships between the factors and satisfaction. A longitudinal study would better establish causality.

CHAPTER FOUR:STUDY RESULTS

4.0 RESULTS on satisfaction of patients seeking palliative care services and associated factors.

4.1 The Individual characteristics of study participants

About half of the participants were Males (193/376 (51.3%)), and slightly more than half were below the age of 50 years (202/376 (53.7%)). About two thirds were affiliated to the Catholic religion (233/376 (62.0%)), and 56.7% (213/376) were married. About two thirds stayed in an urban setting (231/376 (61.4%)), about the same had post-primary education and 57.4% (246/376) were employed (Table 4.1)

Table 4. 1: The individual characteristics of 376 adults HIV patients receiving palliative care services at HPGRB, DRC who participated in the study

Variable	Categories	Frequency (N =376)	Percentage (%)
Age (years)	<50 years	202	53.7
	50 & Above	174	46.3
Sex	Male	193	51.3
	Female	183	48.7
Religion	Catholic	233	62.0
	Others*	143	38.0
Marital status	Married	213	56.7
	Not married	163	43.3
Education level	Primary level or less	130	34.6
	Post-primary	246	65.4
Employment status	Unemployed	160	42.6

Residence	Employed	216	57.4
	Urban	231	61.4
	Rural	145	38.6

4.2 Level of satisfaction with palliative care services

The level of satisfaction of patients who were receiving palliative care services at HPGRB, DRC was 59.3% (95% CI: 52.9, 65.7), (Table 1).

Table 4.2: shows the level of satisfaction of patients receiving palliative care services8)

variable	Categories	Frequencies N=376	Percentages (%)	Confidence interval
Satisfaction with palliative care services	Satisfied	225	59.3	52.9, 65.7
	Not satisfied	154	40.7	32.9, 48.5

4.3 Factors associated with satisfaction with palliative care services

4.3.1 Bivariate analysis

At Bivariate analysis ann variables such as age, sex, religion, marital status. Education level, employment status, area of residence, waiting time and period on palliative care program had a P values <0.2 and were included in the multivariate analysis. This P-value was set as a cut off of variables to include in the multivariate phase and therefore, all variables that had a P-value less than 0.2 and were not linearly related each other were considered for multivariate analysis (Table 4.2).

Table 4.3: Bivariate analysis of factors associated with satisfaction with palliative care services among adult HIV patients at HPGRB, DRC

Variable	Categories	cPR (95% CI)	P value
Age (years)	50 years or below	Ref	
	Above 50 years	1.62 (1.37, 1.93)	<0.001*
Sex	Male	Ref	
	Female	2.46 (2.01, 3.01)	<0.001*
Religion	Catholics	Ref	
	Others [§]	0.73 (0.60, 0.89)	0.001*
Marital status	Married	Ref	
	Not married	1.25 (1.06, 1.47)	0.008*
Education level	Primary level or less	Ref	
	Post-Primary levels	0.91 (0.77, 1.08)	0.270
Employment status	Unemployed	Ref	
	Employed	1.25 (1.05, 1.49)	0.015*
Area of residence	Urban	Ref	
	Rural	0.82 (0.69, 0.99)	0.038*
Waiting time	< 3 hours	Ref	
	≥ 3 hours	0.47 (0.39, 0.58)	<0.001*
Period on Palliative care program	< 1 year	Ref	
	≥1 year	1.44 (1.23, 1.70)	<0.001*

[§]Other religions were Anglican, born again. *all values with significant p-value must include asterik

4.3.2 Multivariate analysis of factors associated with satisfaction with palliative care services

At multivariate analysis, Being a female, [aPR 2.0, 95% CI (1.7, 2.9)], employed [aPR 3.5, 95% CI (2.1, 5.9)], 50 years and above [aPR 6.3, 95% CI (2.5, 13.9)] and on the palliative care

program for more than 1 year, [aPR 21.4, 95% CI (7.4, 61.5)] were positively associated with Satisfaction. Being a non-catholic [aPR 0.4, 95% CI (0.2, 0.6)], and waiting for more than 3 hours to receive the palliative care service [aPR 0.5 95% CI (0.4, 0.6)] were negatively associated with satisfaction (Table 4. 3)

Residence and marital status confounded the relationship between age and level of satisfaction, while marital status confounded the relationship between employment status, religion and period on the palliative care program (Table 4. 3).

Table 4.4: Multivariate analysis of factors associated with satisfaction with palliative care services among adult HIV patients at HPGRB, DRC

Variable	Categories	aPR (95% CI)	P value
Age (years)	50 years or below	Ref	
	Above 50 years	6.26 (2.83, 13.85)	<0.001
Sex	Male	Ref	
	Female	2.00 (1.68, 2.39)	<0.001
Religion	Catholics	Ref	
	Others [§]	0.37 (0.22, 0.62)	<0.001
Marital status*	Married	Ref	
	Not married	2.12 (1.41, 3.18)	<0.001
Employment status	Unemployed	Ref	
	Employed	3.51 (2.09, 5.89)	<0.001
Area of residence*	Urban	Ref	
	Rural	0.84 (0.69, 1.02)	0.080
Waiting time	<3 hours	Ref	
	≥3 hours	0.45 (0.36, 0.56)	<0.001
Period on Palliative care program	<1 year	Ref	
	≥1 year	21.37 (7.43, 61.45)	
Age X Period on Palliative care program [#]		0.21 (0.12, 0.38)	<0.001

*Confounder [§]Other religions were Anglican, born again [#]Interaction term

4.4. Summary of key results

The level of satisfaction with palliative care services was suboptimal at 59.3% (95% CI: 54.3, 64.2). This is lower than the WHO recommended level of 95%.

Being female (aPR 2.0, 95% CI: 1.7, 2.9), employed (aPR 3.5, 95% CI: 2.1, 5.9), and aged 50 years and above (aPR 6.3, 95% CI: 2.5, 13.9) were positively associated with higher satisfaction levels. Affiliation to a non-Catholic religion (aPR 0.4, 95% CI: 0.2, 0.6) and waiting for 3 or more hours (aPR 0.5, 95% CI: 0.4, 0.6) were negatively associated with satisfaction.

CHAPTER FIVE: DISCUSSION OF RESULTS

5.0 Level of satisfaction of care among adult HIV positive patients receiving palliative care services at Bukavu provincial general reference hospital.

This study assessed the level of patient satisfaction and associated factors among 376 adult HIV-positive patients receiving palliative care at Bukavu Provincial General Reference Hospital (HPGRB) in the Democratic Republic of Congo. The study found that the level of satisfaction with palliative care services was 59.3%. This level of satisfaction is lower than the WHO recommended level of 95% for optimal patient satisfaction (Ghandourh, 2016).

The satisfaction level of 59.3% found in this study is suboptimal compared to WHO recommendations of 95%, however it does represent a slight improvement from 57% reported in Lubumbashi, DRC (Kes et al., 2018). This indicates gradual progress, likely due to quality improvement initiatives at the facility. However, the pace of improvement remains slow and significant gaps persist. Worldwide, there are varying levels of patient satisfaction between countries and within a country. In developed countries, patients are highly satisfied (90-95%) with the health care provided while in developing countries, it has been shown that the range of patients' satisfaction varies between 95% to < 20% (Omona et al., 2021, Marama et al., 2018).

The level of patient satisfaction especially with public health facilities is context-dependent and based on the dimensions of quality being assessed. Patient satisfaction was found to be higher in private health facilities at 66.7% compared to public health facilities at 40.1% (Tesfaye and Tegegne, 2019). Variables responsible for such levels were sex, patient's age, history of the previous admission, length of stay, waiting time before admission, and explanation given about the admission process. On contrary, results of an Institution-based cross-sectional study conducted among clients admitted to obstetrics and gynaecology wards of public hospitals in Mekelle town, Ethiopia, showed that the observed satisfaction rate was high at 79.7% at 95% CI (75.8%, 83.6%) (Marama et al., 2018).

Results from a study conducted in Northwestern China on inpatient satisfaction with nursing care revealed a satisfaction level of 78.15% (Zhang et al., 2020). On contrary, the overall proportion of admitted patients' satisfaction with nursing care was 48.8% which was found to be substandard (Wudu, 2021). The situation was different in a public tertiary hospital in Trinidad and Tobago where the inpatient satisfaction levels ranged from 50% and 70% for management issues, treatment-related communication issues, environmental issues, and department of medical staff (Bahall and George, 2019). However, high levels of patient dissatisfaction with hospital care and were lack of trust as reported by about 24% of respondents (Shan et al., 2016). In addition, most of the patients were found to be dissatisfied with nursing, pharmacy and laboratory services, while some others were still dissatisfied with the level of health education, communication and

information they received about their illness (Woldeyohanes, 2015). On contrary, the mean score of overall satisfaction with hospital services was 16.86+/-2.72 out of 20 with 58% of participants were highly satisfied with the services provided during their hospital stay and 83.7% intended to return to the same hospital in case of need (Makarem et al., 2016).

Findings from a study done in a tertiary Hospital in Southeast Nigeria showed that despite more than half of the surveyed patients being satisfied with some specific aspects of services given while on admission, those satisfied with overall experience were less than half (Obi, 2018).

This lowered level of patient satisfaction with inpatient services was also observed in a specialized hospital in Ethiopia where the overall net patient satisfaction level with hospital services was found to be 37.7% (Asamrew et al., 2020).

5.2. Factors associated with satisfaction of care among adult HIV-positive patients receiving palliative care services at Bukavu Provincial General Reference Hospital , DRC

Regarding factors associated with satisfaction, this study found that being female, employed, aged 50 years and above, and being on the palliative care program for over 1 year were positively associated with satisfaction.

Forestance, this study found that being female was associated with higher satisfaction levels (aPR 2.0, 95% CI: 1.7, 2.9). This aligns with previous studies that have reported higher satisfaction among females compared to males in healthcare settings (Marama, Bayu, Merga,

& Binu, 2018). The higher satisfaction among females could be attributed to their health-seeking behaviours. Literature shows that women tend to have better health-seeking behaviours, are more attentive to their health needs, and utilize health services more readily compared to men (Thompson et al., 2016). This predisposes them to having more positive interactions and experiences during care, hence higher satisfaction levels. Additionally, women are socialized to be more accepting and less demanding which could translate to higher satisfaction ratings (Hall & Dornan, 2012).

Being aged 50 years and above was associated with higher satisfaction levels (aPR 6.3, 95% CI: 2.5, 13.9) compared to those below 50 years. This concurs with previous studies that found older patients tend to report higher satisfaction (Mensa et al., 2017). A possible explanation is that older patients have lower expectations of care and are more patient, tolerant, and less demanding of services compared to younger patients (Hall & Dornan, 1990). They are also more appreciative of efforts by providers and do not scrutinize services as much. This contrasts with younger patients who expect higher standards, are less tolerant of inadequacies, and have lower thresholds for dissatisfaction.

Being non-Catholic was associated with lower satisfaction levels (aPR 0.4, 95% CI: 0.2, 0.6) compared to Catholics. This variable has received limited attention in previous satisfaction studies. However, religious beliefs, values and practices could shape expectations and

perceptions of health services leading to differences in satisfaction along religious lines (Benjamins, 2006). Non-Catholics in this setting potentially had different expectations and needs related to their specific religious beliefs that were likely not fully addressed, hence lower satisfaction scores. Further studies are needed to elucidate the specific aspects of care that lead to dissatisfaction among non-Catholic patients.

A study by Delgado-Guay et al.[8] involving 43 caregivers of patients with advanced cancer in an outpatient palliative care clinic reported that all the caregivers considered that spirituality and religiosity helped them to cope with their loved one's illness, and many of them reported that spirituality and religiosity had a positive impact on their loved one's physical and emotional symptoms. Interestingly, also it was reported the presence of spiritual pain in 58% of these caregivers. Caregivers with spiritual pain had higher levels of anxiety, depression, denial, more behavioral disengagement, more dysfunctional coping strategies, and worse quality of life than those who did not have spiritual pain.

No adherence with medical treatment is a critical threat to the health of those living with HIV disease. Unfortunately the search for explanatory factors for no adherence is still not fully developed, particularly in the area of religion and spirituality. Extant literature suggests that church attendance, religious practices and spiritual beliefs may improve health and generally benefit patients. However, religious beliefs may also play a negative role in treatment adherence due to the stigma attached to HIV disease, particularly in geographical areas and in population subgroups where religious practices are strong. In this exploratory study, HI positive individuals

(n = 306) in a southern state were surveyed as to their attitudes and beliefs surrounding HIV disease and adherence with medical treatment for the disease. The results indicate that multiple factors influence adherence with treatment and that certain religious practices are positively associated with adherence, but certain religious beliefs are negatively related to adherence. The findings of this study reinforce the importance of remembering and addressing a patient's religious beliefs as a part of medical care.

Faith communities play an important role in fostering belief systems of responsibility and compassion that are likely to help caregivers doing the emotionally difficult work of caring for others ..

Being employed was associated with higher satisfaction levels (aPR 3.5, 95% CI: 2.1, 5.9) compared to unemployed patients. Similar findings have been reported by previous studies (Woldeyohanes, 2015; Mensa et al., 2017). Employed patients likely have more financial resources, flexibility, and access to cope with healthcare demands. They can afford care at ancillary costs, take time off work to seek care, and obtain services promptly when needed. In contrast, unemployed patients face more barriers accessing and receiving timely care which could negatively impact their experiences and satisfaction (Carr-Hill, 2012).

Urban residence was associated with higher satisfaction, although this was not statistically significant in multivariate analysis. Previous studies have reported higher satisfaction among urban residents compared to rural residents (Woldeyohanes, 2015; Mensa et al., 2017). This

may be attributed to better access to health infrastructure, transportation, choices of providers, and exposure to quality services in urban areas versus limitations in rural settings. Rural patients likely have lower expectations that make them more tolerant of inadequacies. Further research is needed on rural-urban differences in satisfaction.

Long waiting times (≥ 3 hours) were associated with lower satisfaction levels (aPR 0.5, 95% CI: 0.4, 0.6) compared to waits under 3 hours. This finding is consistent with previous studies that found long waiting times to be a major determinant of dissatisfaction in healthcare (Higenyi et al., 2013). Excessive waits likely aggravate patients' pain, anxiety, and physical discomfort. They also signify disrespect for patients' time and unintentionally communicate that their needs are not urgent. Targeted efforts by hospitals to reduce waiting times through improved patient scheduling, more efficient processes, and adequate staffing could significantly improve patient satisfaction.

There was a significant interaction between age and duration in palliative care program in relation to satisfaction levels. Stratified analysis showed that compared to younger patients (< 50 years), older patients (≥ 50 years) who had been on the palliative care program for over 1 year had much higher satisfaction levels (21-fold) than their younger counterparts (7-fold). This suggests that older patients who have received palliative care for lengthy periods report exponentially higher satisfaction compared to other groups. This underscores the positive compounding effects of older age and longer enrolment in palliative care on satisfaction ratings.

The strengths of this study included the relatively large sample size and high response rate. However, the study was limited in scope geographically as it was conducted at only one health facility. Additionally, the cross-sectional design limits inferences about causality. Further studies should explore satisfaction levels and predictors in other facilities and regions.

Regard to cleanliness of waiting area, 60% of the respondents was satisfied with the cleanliness of waiting area. This finding is greater than the study conducted in India Super Specialty hospital had reported that 50% of the patients were satisfied with regard to the cleanliness of the hospital (5) and also similar study was conducted in India OPD of Tertiary Care Hospital in which 55.55% of patients were satisfied with cleanliness of waiting area (24) but this finding is lower than the study conducted at selected health facilities in six regions of Ethiopia in which 76.50 % (25). In the present study, nearly two third (64.3%) of the respondents did get all prescribed drugs from the hospital pharmacy.

Analyses of transitions from independent living to institutional care in the Kungsholmen study group between 1987 and 2000 showed that married/cohabiting people were less likely to move to institutional care than those living alone, but the effect of having a partner was the same for men and women (Hallberg & Lagergren 2009). The traditional notion of women as the main providers of spousal care has been challenged in a British populationbased study (Dahlberg et al. 2007) and in a US study, which found that men living at home were less likely to receive spousal care in the last year of life than women (Wachterman & Sommers 2006).

However, the opposite was found in a Canadian study in which home-dwelling men were most likely to report a spouse as primary caregiver, and women were most likely to report children or children-in-law as primary care givers.

Living with a spouse decreased the odds of receiving home help in the last 5 years of life by 62 %, and having children decreased the odds by 40 % after controlling for gender. Results showing that marital status influences end-of-life care similarly for men and women have been found in another Swedish study (Ernst Bravell et al. 2009), as well as in the Netherlands (Klinkenberg et al. 2005) and in the United States (Wachterman & Sommers 2006).

Also, it was shown that divorced or separated individuals were less likely to receive hospice services as were unmarried women. Finally, Wachterman and Sommers found that marital status had a significant effect on palliative care and service utilization especially when comparing men and women largely due to the disparities in the availability of informal caregiving. Even though there is an association between marital status and palliative care utilization, the marital relationship may not be as important as having an informal caregiver as a support and an advocat

Finally, Wachterman and Sommers found that marital status had a significant effect on palliative care and service utilization especially when comparing men and women largely due to the disparities in the availability of informal caregiving. Even though there is an association between marital status and palliative care utilization, the marital relationship may not be as important as having an informal caregiver as a support and an advocate. ...

The lack of a standardized national framework for palliative care contributes to variability in services across DRC (Rosa, 2018). Palliative care policies, infrastructure, staffing, and access to essential medicines are generally inadequate in the country (Kananga, 2018). These health system deficiencies trickle down to impact patient experiences and satisfaction at point of care. Specifically within the study setting, high patient volumes and limited staffing affect service delivery and quality of interactions between providers and patients, subsequently lowering satisfaction (Kishabongo et al., 2020). Drug stock-outs and lack of holistic palliative services also play a role (Kananga, 2018). Unmet expectations regarding pain management and psychosocial support negatively impact perceptions of care (Rosa, 2018).

Furthermore, misunderstandings regarding palliative care, communication barriers between providers and patients, and insufficient engagement of patients in their care process undermine satisfaction (Kes et al., 2018). Patients feel detached from decision-making and unable to voice their needs. Sociocultural factors also come into play. Inadequate family and community awareness of palliative care affects support and experiences of patients (Rosa, 2018). Local spiritual beliefs and values influence expectations which if unmet, can decrease satisfaction (Afolabi, Nkhoma, Maddocks, & Harding, 2021).

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1: CONCLUSION

This cross-sectional study found that the level of satisfaction with palliative care services at Provincial General Reference Hospital Bukavu was suboptimal at 59.3%,. Higher satisfaction was associated with being female, older age, employment, longer enrollment in palliative care, and Catholic religious affiliation. Dissatisfaction was associated with long waiting times and being non-Catholic.

The study results highlight important sociodemographic and health systems predictors of satisfaction that can inform targeted interventions. There is a need for concerted efforts to improve satisfaction through actions aimed at reducing waiting times, enhancing provider-patient engagement and communication, and addressing expectations of minority religious groups. Broader initiatives to advance national palliative care policies, infrastructure, training, and access to essential medicines and holistic services will also create an enabling environment for higher satisfaction.

6.2: RECOMMENDATIONS

Ministry of Health

1. Set national standards and targets for patient satisfaction levels with palliative care. This will guide health facilities and provide a benchmark for quality improvement.
2. Increase budget allocation for palliative care services to improve staffing, infrastructure, medicines and supplies. This will enable health facilities to make necessary improvements.
- 3.. Disseminate palliative care information and training opportunities to the community members including church leaders and other key influencers

Hospital Administrators

1. Hire more palliative care staff and increase service points to reduce waiting times. This will directly improve patients' experience.
2. Build capacity or educate the patient caretakers on basic palliative care approaches so as to continue with the care at home.
3. Implement staff training program focused on palliative care skills, communication and attitudes. This will improve interactions between staff and patients and ultimately improve long term client satisfaction.
4. Regularly monitor client satisfaction through focus group discussions, exit interviews and surveys

Palliative Care Staff

1. Adopt patient-centered care approaches like introducing yourself, explaining procedures, and answering questions. This will improve communication and perceptions of caring to patients on palliative care services.
2. Create a scheduling system for appointments to manage patient flow. This will reduce waiting times for patients, improve on work flows and efficiency. Thus, improved client satisfaction.

Researchers

1. Conduct multi-site studies on satisfaction with palliative care to inform the development of the national strategy. This will provide generalizable data with strong power and robust data.

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APPENDICES

Appendice 1: Workplan

ACTIVITY	December2022	January 2023	Feb-April 2023	May 2023	June-July	September 2023	Oct-Dec
Proposal development							
Submission to School of Public Health IRB							

Pre-testing of Data Collection Tools							
Data collection							
Data entry and analysis							
Write up the report					xx		
Submission of the final Dissertation to supervisor for review							
Submission of dissertation for examination						xx	
defense of the Dissertation						xx	
Manuscript writing and submission to peer reviewed journal						xx	

Appendice 2: Consent Form (ENGLISH VERSION)

Dear participant I am LWESSO GUILLAIN a master of Public Health from Uganda Christian University carrying out a research study on the topic; **Satisfaction with clinical care and associated factors among palliative care patients at Bukavu provincial general reference hospital, democratic republic of Congo.**

You have been chosen to participate in this because of your eligibility as far as this research is concerned since you are seeking palliative care at this hospital. You are free to ask any questions that you may have before agreeing to participate in this research. If you agree to participate, the following will happen to you; you will be asked to sign on this document to show that you have

voluntarily agreed to participate in this study. As you participate in this study, you will be asked a few questions about yourself. The interview will last for approximately ten to fifteen minutes.

Purpose: The information you give will be used for academic and health service delivery reform purposes.

Risks: We are dealing with slightly emotional research and may harm on you emotionally however; we should all work together because its end results are improving the quality of your health. No biological samples will be required and no medical procedures will be done on you. There may be some inconvenience in terms of time spent during the interview. However, participants will be given the opportunity to see their health workers immediately after the interview.

Benefits: It is important for you to know that you will not be paid to participate or participating in this study. Your participation in this study is your free will and nothing will happen to you if you do not agree to participate in this study. There will not be any additional cost incurred as a result of participating in this study.

Confidentiality: Your identity will not be revealed to any one as we shall only use codes to identify participants. Information obtained will only be accessible by the research team. Data will be kept under double lock and key and access will have restricted to only members of the research team.

Consent to participate: Your participation in this study is voluntary and even after enrolling into the study, you are free to withdraw from it without prior notice to researcher at any time when the study is still going on without being penalized. Withdraw from the study will not affect your treatment schedule and will not deter you from any health care packages.

Questions: If you have any questions related to the study, or your rights as a research participant, you can contact the researcher (Mr. Lwesso Guillain). +243-978401511

Statement of Consent.

I.....hereby voluntarily agree to participate in this study entitled; **Satisfaction with care and associated factors among palliative care patients at Bukavu provincial reference general hospital, democratic republic of Congo.** The study has been clearly explained to me and I understand what is going to be done, the risks, the benefits involved and my rights as a participant in this study. I understand that my decision to participate in this study will not affect me in any way. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I had opportunity to ask questions which were well answered. I therefore append my signature/thumbprint to show that I have agreed to participate and a copy of this document has been given to me.

Signature/ thumbprint of the participant.....date.....

Name signature of the interviewer..... Date.....

Appendice 3: Structured Questionnaire (English Version)

Title: Satisfaction with care and associated factors among palliative care patients at Bukavu Provincial general reference hospital, democratic republic of Congo

Introduction:

Dear participant, I am a student for Master of Public Health faculty of public health, nursing & midwifery Uganda Christian University. I am conducting research to assess “**Satisfaction with care and associated factors among palliative care patients at Bukavu Provincial general reference hospital , democratic republic of Congo**” Your participation in this study is of very great importance as the information you provide is very vital in improving service delivery. This research is absolutely for academic purposes and all responses obtained from you shall be treated with maximum confidentiality. I shall use codes instead of your personal names and you are entirely free to participate in this study and you may drop out of the study at any point in time without any penalty.

Instructions:

Questions will be read to you as you respond to one of the responses provided in the columns. You may seek clarification where you are not sure.

Date data collected.....

Time started..... Time ended.....

Questionnaire

General Information

1. Participant code:
2. Date of interview: [Month Day Year]
3. Name of Interviewer:

Thanks again for agreeing to participate. I will first begin by asking you some information about yourself.

Section A1: Socio-economic information			
Personal details: Now I would like to collect some personal information about your background.			
1.1	Your age in complete years	<input type="text"/> <input type="text"/>	
1.2	Sex	1=Male 2=Female 3- Prefer not to mention	
1.3	Religion	1= Anglican 2= Catholic 3= Moslem 4= Born again 5= Others	
1.4	Marital Status	1= Married 2= Single 3= Divorced 4=Separated 5=Windowed	
1.5	What is the highest level of education you have completed?	1=No formal education 2= Primary school 3= Lower secondary school 4= Higher secondary school 5= Tertiary and above	
1.6	Occupation	1= Unemployed 2= formal employment 3= informal employment	
1.10	Area of residence or where do you reside?	1=Urban 2=Rural	
Patient related factors associated with satisfaction with palliative care at Provincial General Reference Hospital Bukavu (HPGRB).			
2.1	How long do wait for to get services at this facility (hours)	<ul style="list-style-type: none"> • Less than 1 hour • 1 hour • 2 Hours • 3 hours • More than 3 Hours 	

2.2	For how long have you been admitted to this facility	<ul style="list-style-type: none"> • 1 day • 2 days • 3 Days • 4 Days • More than 4 days 	
	Length of stay on the palliative care program	<ul style="list-style-type: none"> • less than 1 year • 1-2 years • 3-4 years • More than 5 years 	
2.3	How do you rate the nursing care services at this facility	1=Very poor 2=Poor 3=Somewhat Good 4=Good 5= Very Good	
2.4	How do you rate the palliative care services at this facility	1=Very poor 2=Poor 3=Somewhat Good 4=Good 5= Very Good	
	Which service are you currently using in the hospital	1=Private Services 2=Public Services	
2.5	Have you ever used private services at this hospital?	1=No 2= Yes	
2.6	How do you rate the attitude of health care workers towards the patients at this hospital	1=Very poor 2=Poor 3=Somewhat Good 4=Good 5= Very Good	
2.7	How do you rate the sanitary facilities at this hospital (toilet, washing facilities)	1=Very poor 2=Poor 3=Somewhat Good 4=Good 5= Very Good	
2.8	Have you missed getting your drugs in the most recent visit to this hospital?	1=No 2= Yes	

2.9	Do you have to pay for some medical service while at this facility?	1=No 2= Yes	
2.10	Do you find it easy to communicate your medical challenges with health workers at this facility?	1=No 2= Yes	
2.11	Have you ever reached at this facility and fail to see any health worker? (day/evening/night/weekend)	1=No 2= Yes	

On the following pages are some things people say about medical care. Please read each one carefully, keeping in mind the medical care you are receiving now. (If you have not received care

Strongly

	<u>Agree</u>	<u>Agree</u>	<u>Uncertain</u>	<u>Strongly Disagree</u>	<u>Disagree</u>
1. Doctors are good about explaining the reason for medical tests	1	2	3	4	5
2. I think my doctor's office has everything needed to provide complete medical care	1	2	3	4	5
3. The medical care I have been receiving is just about perfect	1	2	3	4	5
4. Sometimes doctors make me wonder if their diagnosis is correct	1	2	3	4	5
5. I feel confident that I can get the medical care I need without being set back financially	1	2	3	4	5
6. When I go for medical care, they are careful to check everything when treating and examining me	1	2	3	4	5
7. I have to pay for more of my medical care than I can afford.....	1	2	3	4	5
8. I have easy access to the medical					

specialists I need..... 1 2 3 4 5
 recently, think about what you would expect if you needed care today.) We are interested in your feelings, good and bad, about the medical care you have received.

How strongly do you AGREE or DISAGREE with each of the following statements? (Circle One Number on Each Line)

	Strongly Agree	Agree	Uncertain	Strongly Disagree Disagree	
9. Where I get medical care, people have to wait too long for emergency treatment	1	2	3	4	5
10. Doctors act too business like and impersonal toward me	1	2	3	4	5
11. My doctors treat me in a very friendly and courteous manner	1	2	3	4	5
12. Those who provide my medical care sometimes hurry too much when they treat me	1	2	3	4	5
13. Doctors sometimes ignore what I tell them	1	2	3	4	5
14. I have some doubts about the ability of the doctors who treat me	1	2	3	4	5
15. Doctors usually spend plenty of time with me	1	2	3	4	5
16. I find it hard to get an appointment for medical care right away	1	2	3	4	5
17.					

I am dissatisfied with some things

about the medical care I receive .. . 1 2 3 4 5

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.

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..

1

8. I am able to get medical care

Whenever I need it 1 2 3 4 5

Instructions for Scoring the PSQ-18

The PSQ-18 yields separate scores for each of seven different subscales: General Satisfaction (Items 3 and 17); Technical Quality (Items 2, 4, 6, and 14); Interpersonal Manner (Items 10 and 11); Communication (Items 1 and 13); Financial Aspects (Items 5 and 7); Time Spent with Doctor (Items 12 and 15); Accessibility and Convenience (Items 8, 9, 16, and 18).

Some PSQ-18 items are worded so that agreement reflects satisfaction with medical care, whereas other items are worded so that agreement reflects dissatisfaction with medical care. All items should be scored so that high scores reflect satisfaction with medical care. After item scoring, items within the same subscale should be averaged together to create the 7 subscale scores.

Item Numbers	Original Response Value	Scored Value
	1 ----->	5
	2 ----->	4
	3 ----->	3
	4 ----->	2
1, 2, 3, 5, 6, 8, 11, 15, 18	5 ----->	1
	1 ----->	1
	2 ----->	2
	3 ----->	3
	4 ----->	4
4, 7, 9, 10, 12, 13, 14, 16, 17	5 ----->	5

Appendice 4 : Questionnaire de recherche (French Version)

Information générale

1. Code du participant :

2. Date de l'interview: [Mois jour Année]

3. Nom de l'Interviewer:

Merci pour votre participation pour cette recherche. Je veux commencer par demander votre information personnelle.

Section A1: information socio-économiques			
Details personnel:			
1.1	Ton age (en annee)	<input type="text"/>	<input type="text"/>
1.2	Saxe	1=Masculin 2=Feminin 3- Abstention	
1.3	Religion	1= Anglican 2= Catholique 3= Musulman 4= Protestant 5= Autres	

1.4	Etat Civil	1= Marie 2= Celibataire 3= Divorce 4=Separe 5=Veuve	
1.5	Quel est le plus haut niveau d'éducation que vous avez ?	1= Pas d'école normal 2= Niveau primaire 3= Ecole secondaire 4= Diploma d'état 5= Universitaire	
1.6	Occupation	1= Sans emploi 2= Employe 3= Pas d'emploi formel	
1.10	Quelle est votre residence?	1=Urbain 2=Rural	
Patient related factors associated with satisfaction with palliative care at Provincial General Reference Hospital Bukavu (HPGRB).			
2.1	Combien de temps attendez- vous pour obtenir un service dans cet hôpital (heure)	<ul style="list-style-type: none"> • Moins d'une heure • 1 heure • 2 heures • 3 heures • Plus de 3 heures 	
2.2	Depuis combien de temps êtes-vous admit dans cet établissement	<ul style="list-style-type: none"> • 1 jour • 2 jours • 3 jours • 4 jours • Plus de 4 jours 	
	Quelle est la duree la quelle vous etes dand le service de soins palliatifs	<ul style="list-style-type: none"> • Moins d'une annee • 1-2 annees • 3-4 annees • Plus de 5 ans 	

2.3	Comment évaluez-vous le service de soins infirmiers dans cet établissement.	1= Très mauvais 2= Mauvais 3= Un peu bien 4= Bien 5= Tres bien	
2.4	Comment évaluez-vous le service de soins palliatifs dans cet hôpital	1= Très mauvais 2= Mauvais 3= Très mauvais 4= Bien 5= Tres bien	
	Quel service utilisez-vous actuellement dans cet hôpital	1=Private Services 2=Public Services	
2.5	Avez-vous déjà utilise le service prive dans cet hôpital ?	1=No 2= Oui	
2.6	Comment évaluez-vous le comportement de personnel soignant envers les maladies dans cet hôpital	1= Très mauvais 2= Mauvais 3= Peu bien 4=Bien 5= Tres bien	
2.7	Comment évaluez-vous les services sanitaires de cet hôpital (toilette, douche,)	1= Très mauvais 2= Mauvais 3= Un peu bien 4= Bien 5= Tres bien	
2.8	Avez- vous manqué de prendre vos médicaments lors de la derniere visite a cet hospital ?	1=No 2= Oui	
2.9	Dois- tu payer pour certains services médicaux dans cet établissement ?	1=No 2= Oui	
2.10	Trouvez-vous facile de communiquer vos problèmes médicaux aux agents de santé de ces établissements?	1=No 2= Oui	
2.11	Etes-vous déjà arrive dans cet hôpital sans trouver le soignant? (Jour/ Soir/ nuit/weekend)	1=No 2= Oui	

Dans les pages suivantes, vous trouverez certaines questions concernant le sujet des soins médicaux. S'il vous plaît lisez attentivement, garder à l'esprit les soins médicaux que vous recevez maintenant. (Si vous n'aviez pas reçu de soin récemment réfléchissez à ce que vous attendez si vous aviez besoin des soins aujourd'hui.) , nous sommes beaucoup plus intéressés sur vos sentiments, bon ou mauvais, concernant le soin médicaux que vous recevez.

Dans quelle mesure êtes-vous d'ACCORD OU en DESACCORD avec chacun de déclarations suivantes ? (Encercler un chiffre sur chaque ligne)

	Fortement		Fortement		
	D'accord	D'accord	Pas accord	Pas accord	
9. La ou je reçois les soins médicaux les gens attendant long temps avant de recevoir le service d'urgence	1	2	3	4	5
10. Le médecin gère beaucoup des affaires personnelles avant de me recevoir	1	2	3	4	5
11. Mon médecin me traite de manière sympathique et courtoise	1	2	3	4	5
12. Ceux qui nous sert sont pressé a donner le service médical....	1	2	3	4	5
13. Le docteur de fois oublie ce que je lui dis	1	2	3	4	5
14. J'ai de fois des doutes concernant mon médecin traitant	1	2	3	4	5
15. Le docteur de fois prends asses de temps avec moi.	1	2	3	4	5
16. Je trouve difficile de fois de trouver le rendez-vous médical directement	1	2	3	4	5
17. Je ne suis pas satisfait avec les soins médicaux que je reçoive	1	2	3	4	5

.....	1	2	3	4	5
Je suis capable de trouver les soins médicaux partout où je me trouve et a					
1 8. n'importe quand					
.....	1	2	3	4	5

Instructions pour la notation de PSQ-18

Le PSQ-18 donne des scores distinct pour chacun des sept sous-échelles différent : La satisfaction générale (Items 3 and 17); Qualité technique (Items 2, 4, 6, and 14); Manière interpersonnelle (Items 10 and 11); La communication (Items 1 and 13); Aspect financier (Items 5 and 7); Temps passe avec le docteur (Items 12 and 15); l'accessibilité et la convenance (Items 8, 9, 16, and 18).

Certain éléments du PSQ-18 sont formulés de manière à ce que l'accord reflète la satisfaction à l'égard des soins médicaux. Tous les éléments doivent être de sorte que le score élevés reflète la satisfaction à l'égard des soins médicaux. Les éléments de la même sous-échelle doivent être en moyenne ensemble pour créer 7 scores de sous-échelle.

Nombre d'articles	La valeur de réponse d'origine	Valeur notée
	1 ----->	5
	2 ----->	4
	3 ----->	3
	4 ----->	2
1, 2, 3, 5, 6, 8, 11, 15, 18	5 ----->	1
	1 ----->	1
	2 ----->	2
	3 ----->	3
	4 ----->	4
4, 7, 9, 10, 12, 13, 14, 16, 17	5 ----->	5

Appendix 5: Uganda Christian University REC Approval letter



UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

23/01/2023

To: GUILLAIN LWESSO

UGANDA CHRISTIAN UNIVERSITY
+243977098354

Type: Initial Review

Re: UCUREC-2023-442: SATISFACTION WITH CARE AMONG PATIENTS RECEIVING PALLIATIVE CARE AT PROVINCIAL GENERAL REFERENCE HOSPITAL BUKAVU DEMOCRATIC REPUBLIC OF CONGO , Last, 2023-01-10

I am pleased to inform you that the Uganda Christian University REC, through expedited review held on **19/01/2023** approved the above referenced study. Approval of the research is for the period of **23/01/2023** to **23/01/2024**.

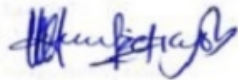
As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **23/01/2024** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Uganda Christian University REC:

No.	Document Title	Language	Version Number	Version Date
1	Data collection tools	English	Final	2023-01-10
2	Protocol	English	Last	2023-01-10

Yours Sincerely



Peter Waiswa
For: Uganda Christian University REC

Appendix 6 : Institutional ethics health committee from catholic university of
Bukavu



Bukavu, le 09/01/2023

N/Réf : UCB/CIES/NC/002/2023

Objet : Notre avis

Lwesso MUNUNGA Guillain
Etudiant en Master en Santé Publique
Uganda Christian University
+243 977098354
lwessoguy@gmail.com

Monsieur,

Le Comité Institutionnel d'Ethique de la Santé (C.I.E.S) de l'UCB a le plaisir de vous annoncer l'avis favorable à votre projet de recherche.

Votre protocole d'étude intitulé « *Satisfaction with care among patients receiving palliative care at provincial general referral hospital of Bukavu, Democratic Republic of Congo.* » a été approuvé sous le Numéro d'ordre **UCB/CIES/NC/002/2023**.

Pour rappel, la Commission se base sur les éléments suivants :

1. Pertinence ;
2. Respect de la personne humaine (consentement éclairé, nocivité, risque-bénéfice ou résultats du travail) ;
3. Méthodologie...

En vous remerciant pour cette collaboration, nous vous prions, d'agréer l'expression de nos sentiments de haute considération.



Le Comité Institutionnel d'Ethique de la Santé

Prof. Eloi BAGENDABANGA Macece

Eloi Bagendabanga Macece
Secrétaire

02, Avenue de la Mission, Bugabo (kadutu), Bukavu, DR Congo

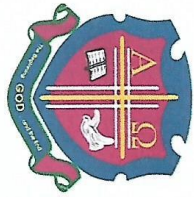
E-mail : chirimwamibr@hotmail.com / macece.bagendabanga@ucbukavu.ac.cd / kulama.bikungu@ucbukavu.ac.cd ;

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SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)

Date: ...25th March 2024.....

Name of Candidate: ...LWESSO MUNUNGA GUILAIN..... Reg. No:RJ19M21/361

Title of DissertationSATISFACTION WITH CLINICAL CARE AND ASSOCIATED FACTORS AMONG PALLIATIVE CARE PATIENTS A BUKAVU PROVINCIAL GENERAL REFERENCE HOSPITAL, DEMOCRATIC REPUBLIC OF CONGO .

SN	COMMENTS BY EXTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	The title could be improved by adding "clinical care"	The title has been improved	Page 1

Handwritten signature and date:
9, 2024

2	First sentence under 1.0 introduction should be replaced to improve the meaning under introduction correct the sentence which ends as----to ARVs for suppression of the virus and reduction of mobility among the 'HIV patients could be affected.' Attend to the highlighted error	Worked on	Page 16
3	The general objective should be made 'action oriented' at the end to address the question" and then what?	Done	Page 22

SN	COMMENTS BY VIVA VOCE PANNEL	ACTION TAKEN	INDICATOR
1	Independent variables; Where does government policy come in, is it a dependent or mediating variable?	In consultation with my supervisor, the supervisor advised that there is no data collected during the study on policies so this was not considered as a variable for the study. However, it is mentioned in the literature review.	Page 30
2	Please narrow your topic to HIV	The topic has been narrow to HIV	Page 1
3	Where are the recommendations coming from; what is feeding into the each recommendation as per your results. Ensure that your recommendations are	Recommendations are reviewed according to the results and aligned to the study objectives.	Page 69

(Signature)
 April 9, 2022

	informed by your research		
4	Need to look at the analysis and discuss it very well and do an assessment not to miss out any factors	Done	Page 69
5			

Lwesso Guillain.....

Signature



Supervisor's Name

Dr. Gloria Kivungi

Signature



9/12