UNIVERSITY of RWANDA

COLLEGE OF MEDICINE & HEALTH SCIENCES

SCHOOL OF MEDICINE & PHARMACY

PALLIATIVE CARE NEEDS ASSESSMENT IN ADULT PATIENTS ADMITTED AT BUTARE UNIVERSITY TEACHING HOSPITAL

(A Descriptive cross-sectional study)

Saad Ngoga, MD

College of medicine and health sciences

School of medicine and pharmacy

Master of medicine in internal medicine

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(A Descriptive cross-sectional study)

Dissertation submitted to the college of Medicine and Health Sciences in partial fulfillment of the requirement for the award of Degree of Master of Medicine in INTERNAL MEDICINE in the college of Medicine and Health Sciences from University of Rwanda

BY

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DECLARATION

We, Dr Jean Pierre Sibomana and Professor Jean Paul Rwabihama, have supervised the dissertation entitled "**Palliative care needs assessment in adult patients admitted at Butare University Teaching Hospital Internal medicine**" done by Dr Saad Ngoga.

The work is original and has never been presented or submitted anywhere for a degree or examination.

Dr. Saad Ngoga

Date: 30.07.2020

Signature: 

Dr. Jean Pierre Sibomana, MD, MMed (Internal Medicine)

Date: 30/07/2020

Signature: 

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To the all capable all knowing, the Almighty GOD, for he is all sustainer, my inner strength, my permanent advisor and teacher, without him me and this work would be no more.

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To the Internal medicine department team and patients for giving me the platform of this great work.

DEDICATION

I, Solely Dedicate this work to my Late Mum UWIMANA, and my big brother DIDA for she was and remains to be my motivation in life, your combined unconditional love and support has made me the person I am today.

ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome 1

APCA: African Palliative care Association 2

BUTH: Butare University Teaching Hospital 4

COPD: chronic obstructive pulmonary diease 12

HIV: Human Immunodeficiency Virus 1

IPOS: Integrated palliative outcome scale 6

IRB: Institutional review board 10

iSOCO: Integrated social and community medicine 3

MUSA: Mutuelle de Sante (Mutual health Insurance) 11

NCDs: NonCommunicableDiseases 1

PC: Palliative Care 3

PLWHA: People Living With HIV/AIDS 3

POS: Palliative outcome scale 6

POS-S: Palliative Outcome Scale for Symptoms 6

PPS: Palliative performance scale 6

WHO: World Health Organisation 1

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ABSTRACT

Background: Growing burden of life limiting illnesses including cancer and non communicable diseases, poor socioeconomic living standards, inadequate knowledge and awareness to palliative care, patients' late presentation and lack of essential medicines for symptom control; reflects a huge need for palliative care among inpatients at Butare university teaching hospital. The aim of this study was to assess palliative care needs in adult patients admitted at Butare university teaching hospital internal medicine.
Methods: Using IPOS + PPS (Integrated palliative outcome scale and palliative performance scale) questionnaire, a cross sectional survey of patients charts and interviews were conducted between July 2019 and September 2019 at Butare university teaching hospital. Descriptive data analysis using SPSS v16 was done to determine the point prevalence of inpatients with life limiting condition and characteristics of their palliative care needs.
Results: 247 patients' notes were surveyed and 52% (130) patients had a life limiting illness, among those with life limiting illness 90% (118) and 48% of total inpatients fulfilled criteria for interview. Mean age was 50 years, females 53%, males 47% and major diagnosis categories were cancer 26%, cardiovascular 23% endocrine 14%, HIV/AIDS 10%, renal failure, chronic respiratory diseases, neurological and others 8.5%, 8.5%, 6.8%, 1.7% respectively. The most prevalent palliative care need was need for social support 81%, and 93% needed spiritual support. Main physical needs were need for fatigue 69%, pain 68% relief among others. All patients in this survey had a palliative care need.
Conclusion: This study highlighted a growing burden of life limiting illnesses especially non-cancer non-communicable conditions and a universal need for palliative care among inpatients at Butare university teaching hospital. There is high burden of physical, psychological, social and spiritual needs, reflecting poor palliative care services at BUTH. Strengthening existing palliative care trained personnel and encouraging communication between patients and health care providers would great improve palliative care climate in hospitalized patients with life limiting conditions at BUTH.

Key words: life limiting illnesses, palliative care needs assessment, Butare university teaching hospital.

CHAPTER I: INTRODUCTION.

I.1. Background:

Palliative care needs in the developed countries have been thoroughly studied (1–3), in developing countries however, needs for palliative care are still under investigation and because of their complexities and dynamicity the already done studies are insufficient to clearly identify the exact needs among patients (4). With growing burden of cancer, non-communicable diseases and poor socioeconomic living standards in south western Rwanda (5,6), these needs continue to increase and change hence the continuous need for palliative care .

Palliative care needs are entirely reflected in the ongoing burden of cancer and other non communicable diseases and incurable chronic viral infections like HIV/AIDS that has been growing and has affected a significant proportion of world's population. Cancer alone is responsible for about 9.6 million deaths making it the second leading cause of death in the entire world, 70% of these deaths occur in low and middle income countries (7).

World health organization global status report indicated that 38 million deaths were caused by Non communicable diseases every year (8). By the year 2025 its estimated that non communicable diseases mortality will increase dramatically to over 70% of all deaths globally, and 85% of these will occur in low resource countries most of which are found in Africa (9). With this heavy charge from NCDs and Cancer (6), palliative care should be an integral tool in management and relieving the suffering of patients.

World health organization (WHO) defines palliative care as " an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychological, social and spiritual"(10). Africa and in Rwanda particularly, social needs are far common and most pressing. In Uganda lack of food, shelter and school fees (11) were the prominent social needs among those with life limiting diseases.

According to APCA atlas 19% of African countries don't have any sort of palliative care model and opioid use for the rest of African countries was very low and 58% did not have a palliative care representative in their respective ministries of health (12). Although Rwanda is among the African countries with better palliative care services Rwanda only has 4.6 services of palliative care per million populations (12) a very low coverage compared to western countries (13).

Palliative care need in European countries is far less compared to the need among African countries especially in sub-Sahara region; studies from Belgium and New zealand showed that the need for palliative care with in hospital settings were 4.8% and 9.2% respectively (1,3) which is so much lower compared to 99% need of palliation in some sub Saharan countries (14). Morphine availability in high income countries is so much higher than in low income countries, for instance in the USA and Canada availability of morphine is 55000 and 68000 Mg per patient per year while in Haiti only 5Mg of morphine is available for one patient per year (15). Existing poor socioeconomic living standards and weak healthcare systems fuel suffering of patients with life limiting illnesses in low income countries (5) where most common needs appear to be social such as lack of food, shelter and school fees (11).

In Rwanda, the need for palliative care can be perceived through the epidemiology of chronic diseases and cancer. In 2018 HIV prevalence in Rwanda was estimated at 2.5% and around 2600 deaths were attributed to aids related illness (16), Morbidity and Mortality of life limiting conditions where 13% of deaths were from Cancer, 14% Cardiovascular diseases, 3% Chronic respiratory diseases, 2% Diabetes mellitus (6). In the same line palliative care needs have been growing proportionally to morbidity and mortality of life limiting conditions.

Palliative care in Rwanda has been growing since 2010 and in 2011, Rwanda has adopted palliative care in its health care policy with allocated budget towards palliative care as part of NCDs program, this is the first country to do so in entire Africa (17). Due to strong and political will to wards health for all in Rwanda, this has been possible and easy to pass and implement (17). This has been long awaited for and it has given a great platform for local healthcare providers and foreign partners to advance palliative care in Rwanda.

Palliative care is partially integrated into the education system in Rwanda, where under integrated social and community medicine (iSOCO), palliative care courses and training are being offered in undergraduate medical education and post graduate programs especially in Internal medicine residency and nursing school (18). This training is still optional and inconsistent it's not fully implemented because of the lack of official approval from academic council of the University of Rwanda to become permanent and compulsory courses of the curriculum (19). Currently there's ongoing university of Rwanda committee developing palliative care curriculum for full integration in ongoing medical training at the University of Rwanda in both nursing and medical schools.

With private and nonprofit partnerships ministry of health has facilitated dissemination of palliative care both in community and in-hospital settings (17). There are 4 palliative care services (hospices or other PC services), 6 home based PC services (12) most of these services are community based and 1 hospice center, there is only few fully functional hospital based palliative care unit (20) out of 48 referral and district hospitals (21) and this projects enormous need to PC in Rwanda.

Despite a remarkable progress of palliative care in Africa in the last decade (22), where some countries have grown from total lack of care for a chronically or end of life patients to integration of palliative care programs in national health care policies (17), palliative care have remained a scarce necessity in all over Africa and Rwanda in particular (23).

Palliative care needs in Rwanda has been studied on in only a few studies, one on needs for all with life limiting illness including non cancer patients and another specific to PLWHA both show a very high need of palliative care in Rwanda particularly in tertiary hospital settings (17,24). In these studies, 99% or all participants had unmet palliative care need with most common symptoms found to be nausea and vomiting 34%, pain 32%, psychosocial, financial needs 77%, and nutritional support.

Patients with chronic, incurable or terminal illnesses may have burden of symptoms which include Physical, psychological, social and spiritual that need to be addressed (25,26). Studies on assessment of palliative care needs have been undertaken elsewhere and it was found that pain has a significant prevalence in patients with life limiting illnesses both in west and in developing countries (27,28). In part this is due to inadequate pain management and negative attitudes towards opioid use that is still present in both health care providers and patients (29).

Need for constipation relief is prevalent in patients with cancer who are on opioid like analgesics (26) and has a negative impact on these patients quality of life in different dimensions (30). Religion and spirituality needs are as well high among chronically ill patients, and they are results of total absence of spiritual support among terminally ill patients in teaching hospitals (31,32). Spiritual issues are mainly biphasic, higher at the time of diagnosis and at the end stage (33). Religious and spiritual support would be of a great importance towards sick patients and their families to help in confronting their illnesses (34,35).

Psychological needs like depression and anxiety were as well surveyed and abundant among patients with incurable illnesses and have negative influence on quality of life (36). Early recognition and meeting these needs can dramatically improve quality of living by boosting their physical and mental coping to disease (37)

I.2 Justification of the study and problem statement.

Despite recent efforts by ministry of health and partners in advancing palliative care in Rwanda (17,38), increasing prevalence of life limiting illnesses (6,16), patients late presentations (39), in-adequate trained personnel (40), and overwhelmed health care providers (41), palliative care needs have enormously outgrown palliative delivery within tertiary health care facilities including BUTH in Rwanda.

Butare university teaching hospital (BUTH) is in the poorest region of the country in the southern province (one of five provinces) of Rwanda (42) where 67% of her population are under the poverty line (5), thus palliative care needs in this area maybe particularly high and complex due to lack of self and family support.

There is no known data regarding palliative care needs in admitted patients at BUTH, Identifying these needs in hospitalized patients with life limiting illnesses at Butare university teaching hospital is cornerstone to improving the overall quality of their life..

I.3 Research question.

What are the physical, psychological, social and spiritual palliative care needs and characteristics of patients with life limiting conditions admitted at Butare university teaching hospital in internal medicine from July 2019 to September 2019?

I.4 Aim of the study.

The main aim of this study is to assess the magnitude palliative care needs and characteristics of patients with life limiting illnesses in adult patients admitted at Butare university teaching hospital in internal medicine to inform policy and healthcare providers.

I.5 Objectives of the study

- Determine the point prevalence of patients admitted with life limiting conditions at BUTH.
- Determine socio-demographic characteristics, causative diseases and palliative performance level of patients with life limiting conditions at BUTH.
- Assess the needs of palliative care in patients with life limiting conditions at BUTH.

CHAPTER II: METHODOLOGY

Palliative care needs in the context of this study were defined as patient's bothering symptoms present at the time of data collection or in the last three to 7 days. These included physical symptoms, social, psychosocial and spiritual needs (50).

II.1 Study design.

This study design was a descriptive, cross sectional study patients' palliative care needs among those with life limiting illnesses following a point prevalence survey of patients' charts.

II.2 Study setting.

Butare university teaching hospital (BUTH) is one of the oldest hospitals in Rwanda founded in 1928 and became a teaching hospital in 1966. It located in the poorest region of the country in the southern province (one of five provinces) of Rwanda (42) where 67% of her population are under the poverty line (5), it receives referred patients from both southern province and a large part of western province district hospitals. These patients are usually referred in their end stages of illnesses for further investigations and specialized care, these patients are poor (5)and most of them can't afford additional medicines out of their insurance. Although we didn't investigate the total capacity of the hospital, the turnover is seemingly high.

Internal Medicine department of BUTH, cares for all internal medicine specialties which include oncology and all non-communicable diseases. All specialties are managed in same wards comprised of 4 general ward blocs, private and semi private rooms; the estimated total bed capacity is 62.

Health care providers include consultants who are assigned to specific ward blocks and private rooms. Residents and nurses are the daily treating team, and spend the most time with patients; they rotate from one block to another on a scheduled period of time and have a generalized idea of most of admitted patients in internal medicine department.

Residents as specializing medical doctors in internal medicine are responsible for admitting all referred patients and carry out full assessments including social circumstances and they are always in contact with their consultants as their supervisors, they are supposed to report any difficulties in clinical and social management of patients. There is a palliative care committee at BUTH composed of a team whose responsibilities were to manage palliative care needs in inpatients among others. Unfortunately in recent years their work has faded mainly due to appointment of members to others responsibilities and transfer to other centers.

II.3 Population of the study.

All Patients 18 years and older because 18 is the legal age to give an informed consent, confirmed diagnosis of terminal illness or incurable disease or cancer by primary treating doctor or through patients notes who were admitted in Internal medicine department at BUTH.

II.4 Inclusion criteria

Need of palliative care was presence of any unmet reported need whether physical, psychological, social and spiritual (50).

Life limiting conditions were conditions without expected cure and from which the sufferer is expected to die at any given point in time (58).

All patients with life limiting condition and in need of palliative care admitted at BUTH Internal medicine with legal ability to consent for study participation were enrolled.

II.5 Exclusion criteria

Critically ill patients who were unable to support a long interview and Patients with stroke who sustained aphasia were excluded.

Patients less than 18 years old the legal age in Rwanda were also excluded.

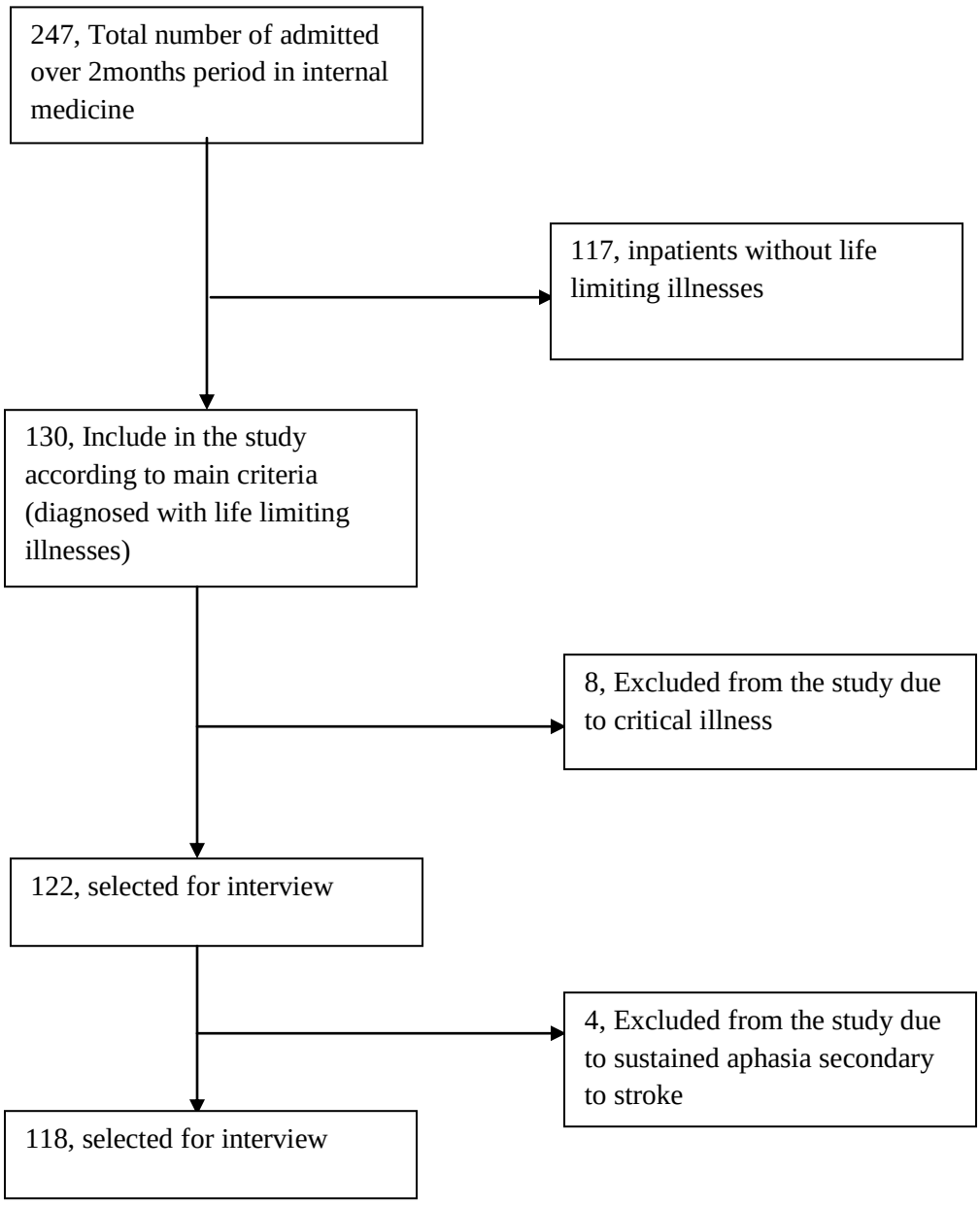

Figure 1: Selection flowchart for study participants

II.6 Sampling and sample size

The sample size was all the patients with life limiting illnesses (chronic organ failure, degenerative diseases, endocrine disorders and cancer) who were admitted at BUTH Internal medicine at the time of data collection.

II.7 Data Collection and Measurements.

Through an established validated questionnaire, the integrated palliative outcome scale (IPOS) questionnaire that integrates items from African palliative care association palliative outcome scale (APCA/POS), palliative outcome scale (POS) and the palliative outcome scale symptoms (POS-S), which were developed and validated to be used in different settings and cultures (43–45); the IPOS questionnaire was also validated and used in different studies and proved appropriate in different cultural settings (46), and the Palliative performance scale (PPS) from the Victoria Hospice center (47) and validated for use (48) were used to collect data, entered in SPSS v.16 to measure performance status, volume and describe characteristics of adult patients in need of palliative care admitted at BUTH.

Data collection was conducted from July 2019 to September 2019. Using integrated palliative outcome scale (IPOS) (46) and Palliative performance scale (PPS)(47) questionnaire. The questionnaire comprised of 4 main categories; 1) demographic characteristics, 2) 1 table addressing multidimensional physical needs 3) 1 table addressing multidimensional psychosocial and spiritual needs, 3) close ended and multiple choice questions addressing more needs especially social and cultural needs, 4) palliative performance table, grading from 100% full performance; normal activity and work with no activity of disease down to 0% death through other stages of reduced performance and significant disease activity.

Research team was introduced to the treatment team to present permission for data collection from the local ethical committee. Patients were approached for consent to participate and to use his or her chart.

A pilot survey was carried out on first 20 patients to test the translated questionnaire and continued data collection after confirming its feasibility, Patients' charts were retrieved from nursing station of every ward block to identify those with life limiting condition. Trained nurse and the principal investigator recorded data from patients through one on one interview process using IPOS and PPS combining questionnaire which took approximately 20 minutes each.

Data collected were the defining illness (which was directly recorded from patient charts), socio-demographic data, physical and psychological symptoms burden, spiritual/beliefs, social/financial and patients' knowledge of his or her disease and patient's PPS level (these were all recorded through interview).

II.8 Data Analysis.

Data were entered and analyzed in excel and SPSS v16 soft ware. Descriptive statistics were used to summarize findings, to identify appropriate prevalence of life limiting illnesses frequencies, percentages of palliative care needs among the study population.

II.9 Ethical Considerations.

After acquiring approval from the university and hospital Institutional review board (IRB) on protection of rights of human subjects, an informed written consent was obtained from each patient that participated in the study after the study and its objectives were explained fully and understood.

Patients with unmet needs were advocated where applicable. Data and results of the study were well protected on strong password protected computer as far as patients confidentiality is concerned. The conclusion and results from the study will be shared with treating team and published for both clinical and academic purposes respectively.

II.10 Duration of the Study.

We started data collection in July-2019 and finalized data analysis and other paper works in march-2020. As soon as university research board has reviewed and approved this work we shall immediately submit for publication.

CHAPTER III: STUDY RESULTS AND ANALYSIS.

247 patients were admitted during the data collection period and the prevalence of patients of life limiting illnesses were 52% (130 patients).

III.1: Socio-demographic characteristics and volume of the study population.

Table 1: Baseline Characteristics.

		Frequency	Percent
Age group	<35	22	18.6
	36-65	77	65.3
	>65	19	16.1
Gender	Men	55	46.6
	Women	63	53.4
Marital status	Single	15	12.7
	In legal marriage	61	51.7
	In illegal marriage	16	13.6
	Divorced	1	0.8
	Separated	3	2.5
	Widow	22	18.6
Occupation	Farmer	73	61.9
	Monthly paying job	10	8.5
	Private paying job	6	5.1
	No occupation	29	24.6
Health insurance	MUSA	100	84.7
	Premium	16	13.5
	None	2	1.7
Patients diagnosis	Cancer	32	27.1
	Cardiovascular	27	22.9
	Endocrine	17	14.4
	HIV/AIDS	14	11.9
	Respiratory	10	8.5
	Neurological	8	6.8
	Renal	8	6.8
	Chronic liver disease	1	0.8
	Hematological	1	0.8

Female participants were slightly higher with 53% whereas male participants were 47%, majority of our study participants 65% were aged 36-65 years, with a mean age of 50.14 years only 16% were above 65 years, and 64% were married, 18% their partners had died. Many participants 38% had a range of at least 4-6 children and 98% of all study participants had health insurance, 84% uses MUSA (mutuelle de santé) community mutual health insurance.

Through patients medical charts review, participants' diagnosis of life limiting illness was made. For the purpose of analysis diagnoses were categorized in Cancer, Cardiovascular diseases, Endocrine diseases, HIV/AIDS, Chronic obstructive respiratory diseases, Neurological and Renal diseases.

Majority of participants had Cancer 27% followed by cardiovascular diseases 23% Endocrine (diabetes) 14% and HIV/AIDS 12%. Other important categories of disease included chronic obstructive pulmonary diseases (COPD) 8% and Neurological diseases (spinal cord and degenerative neurological diseases) 7%.

III.2 General Patients' palliative characteristics of study population.

Specific palliative care needs (characteristics) were assessed after we divided them into four major categories as stipulated in palliative care definition (10). These needs were categorized in dimensions, from either slight to overwhelming or from occasionally to always. Significant presence of need was considered if patient scored within the last 3 most negative categories according to IPOS questionnaire.

III.2.1 Physical needs (symptoms) in order of severity.

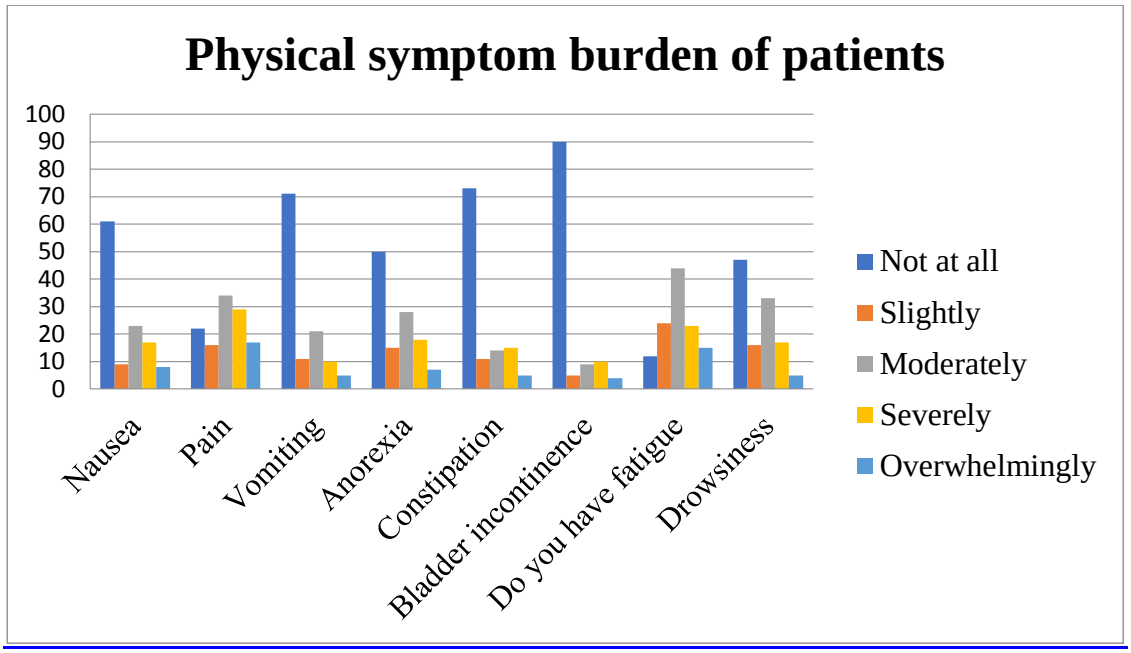

Figure 2: Physical symptoms burden of patients

Pain, and fatigue were among the most popular complaints during interviews and as shown table 2, scores in three most negative dimensions (moderate to overwhelmingly) was around 68% with pain, and majority of participants had fatigue with 69%, constipation was found in only 29% and 45% of study population were anorexic.

Table 2: Cumulative score on palliative performance scale

PPS Score (%)	Frequency	Percent
40	8	6.8
50	26	22.0
60	32	27.1
70	17	14.4
80	11	9.3
90	10	8.5
100	14	11.9
Total	118	100.0

Patients who were in the hospital with PPS score of 50% or lower (patients with extensive disease who required considerable assistance and unable to do any work) were 34 (28%).

III.2.2 Spiritual/Religious and Disease knowledge of the study population

Table 3: Spiritual/Religious and disease knowledge of the study population

		Frequency(n=118)	(%)
Awareness of disease		81	68.6
Knowledge of natural progress of the disease		52	44.1
Belief that the disease is curable		58	49.2
Being a member of any religious or spiritual group		116	98.3
Willing that own religious or spiritual group be involved to help cope with the illness nature		110	93.2
Feeling abandoned or punished by God or not supported by church/faith with this disease.		31	26.3
Willingness to share disease and its natural progress to the care taker.		98	83
Getting panic to die from this illness	**Never**	50	42.4
	Rarely	13	11.0
	Sometimes	37	31.4
	Almost daily	18	15.3

Though 98% of participants belonged to a religious group, 46% reported to panic about dying from their disease at least sometimes to almost daily and 93.2% wished to have religious group help them coping with the disease. 68.8% reported to know their disease and only 44.1% knew their disease natural progress.

Table 4: Psychosocial characteristics

		Frequency	(%)
Rating of anxiety	Not at all	25	21.2
	Occasionally	11	9.3
	Sometimes	26	22.0
	Most of the time	33	28.0
	Always	23	19.5
Family anxiety	Not at all	24	20.3
	Occasionally	11	9.3
	Sometimes	27	22.9
	Most of the time	33	28.0
	Always	23	19.5
Depression	Not at all	33	28.0
	Occasionally	20	16.9
	Sometimes	28	23.7
	Most of the time	22	18.6
	Always	15	12.7
Having a care taker	Yes	106	89.8
Need of more support than a family, friends or insurance can provide	Yes	96	81
Frequency of family member visit in the hospital	Not yet any visit	32	27
	Not enough	26	22
	Satisfactory	60	51
Ability to share feeling with family member or friends as wished	Never	50	42.4
	Rarely	13	11.0
	Sometime	37	31.4
	Almost daily	18	15.3

III.2.3 Psychosocial needs among the study population

Depression, anxiety and social support are reported on the table above. Only 21.2% and 20.3% of patients reported no self or family anxiety respectively. only 28% did not report presence of depression while 18.6 and 12.7% reported depression most of the times and always which makes more than 30% of patients with significant depression. 51% were satisfied with family member visits and 27% had no visitors at all during the past course of admission.

CHAPTER IV: DISCUSSION.

IV.1 Magnitude/ volume of palliative care patients at BUTH

In this study, results revealed both a high prevalence of life limiting illnesses and need for palliative care at BUTH, 52% (130) of admitted patients a percentage higher than previous studies in the country (14) and the region (50) although in most studies HIV/AIDS patients were the dominating subjects (24,50). Disease burden was found high and the larger percentage of our study participants were those with non communicable diseases 60% other than Cancer or HIV/AIDS, although Cancer and HIV/AIDS were also in significant proportions 27% and 13% respectively making this study results a reflection from different pathologies. All participants in this study, showed a palliative care need, which is the same case in some studies in the region (50,52), although these studies reflected mostly cancer and HIV/AIDS patients due to a limited number of people with NCDs in their sample population, the striking findings being a very great need in spiritual support and disease information where spiritual need was 93% and 51% did not whether their disease was incurable and 31% did not even know their diagnosis, just like in other prior studies (24,50) pain is still prevalent 68% both in Cancer and non cancer patients. These results show an urgent need of palliative care reforms in all dimensions and pathologies at Butare University Teaching Hospital.

To our knowledge, no previous palliative care needs study have been conducted at Butare university teaching hospital. This is a need assessment study done to identify magnitude and characteristics of needs in all four palliative categories to inform practice and policy.

IV.2 Baseline demographic characteristics

Mean age of our study population was 50.14 years, this is a relatively young age but slightly older than other populations in other sub-Saharan studies done in Uganda and Malawi (50,53) where average age was 38 years.

The reason to why participants in these studies especially in the sub-Saharan region is young was not studied but it could be attributed to relatively low life expectance secondary to poor living standards and premature exposure to ailments when compared to the western countries (54), another reason could be an increasing surge of NCDs and HIV related cancers (9,16) and hematological malignancies due to rapid urbanization and industrialization[28], but the exact association is another area of research. There wasn't much or significant gender differences among our study population 47% male versus 53% female which is in line of other above mentioned studies. This highlights a need for early screening of NCDs and certain cancers like cervical and breast cancers and increase awareness for early health care consultation.

Most of participants were subsistence farmers 62% and a significant percentage classified in the poorest category (category 1) of social class (ubudehe) 21% and 36% in category two implying poor living standards which would indicate an increased need of palliative care especially on the financial aspect. 84% of patients had community based insurance and only 13% had premium insurance.

Being the poorest region in the country, patients that are admitted here at BUTH are indeed very poor (5) and this makes them even more vulnerable to the impacts of chronic illnesses hence an increased need for palliative socioeconomic support.

In this study we found a very high prevalence of non cancer diseases; cardiovascular 23% including (stroke, hypertension, rheumatic heart diseases, and cardiomyopathies) and , Endocrine (mainly diabetes) 14% and HIV/AIDS were 12% among others. This has corresponded to previous qualitative study done by Mukasahaha et al.(14) where cardiovascular diseases were predominant with 29%, and HIV/AIDS 13%. This means that the need for palliative care in other conditions other than cancer is growing. Similarly, Cancer was also found as a major diagnosis 27% (which included leukemia, gastric cancers, breast cancers and others) in this study, leading to palliative outcome similar to one study done in Rwanda 29% (52) and slightly higher than that from Uganda 18% (50). The burden of these diseases remains high and growing, thus need for palliation is as well growing very steadily and without palliative care these patients would suffer treatable symptoms.

IV.3 The burden of Palliative needs at BUTH

IV.3.1 Physical needs

The burden of palliative care needs was high in our study with most unmet palliative needs being fatigue 69% and pain 68%. Need for constipation relief was also high 29% and 30% experienced vomiting. These findings were similar to those from recent studies (50) in most symptoms, for the pain however, our findings were higher when compared to 32% and 47% (50,52) pain burden were much higher in one study done booth in Uganda and south Africa (27) in 2001. Lack of consistent availability of basic medications for pain and other symptoms could be a major contributor where morphine syrups are few months out of hospital stock, and most patients rely on the hospital supply because they can't afford to buy for themselves. This demonstrates prevalence of a high symptom burden and calls for advocacy to improve symptom management especially pain, among healthcare providers.

The poorest palliative performance status in our study was measured in only 28% of study population suggesting presence of extensive disease evidence, and a high need in assistance all basic activities although majority had PPS score above 60% which is relatively not bad this PPS score is equivalent to a reduced ambulation with some evidence of disease but still able to self care (47). This finding warrants strengthening of physical rehabilitation among chronically ill patients in hospital settings.

IV.3.2 Psychological needs

Among other investigated needs were psychological needs which included depression, anxiety and family worries, it was found that depression and anxiety were both prevalent 53% and 69% respectively, 56% of study population did not know the natural course of their condition and 32% did not even know their diagnosis. In this study this is a much higher burden when compared to one study done in china (37) but when compared to African studies, the burden of sadness and anxiety were comparably same high especially in HIV/AIDS patients (56).

Although there is limited data on psychosocial support among chronically ill patients without primary mental disorder, These results were expected there is no readily available psychological support to chronically ill patients these services are offered mainly to patients with primary psychological disorders, there is also no routine counseling sessions during diagnosis announcement especially in non communicable diseases, there is also poor communication between patients and health care providers which may result in more anxiety and depression. According to these results Psychological support is highly needed to help sufferers cope with their illnesses at BUTH strengthening the already existing team would benefit greatly in alleviating psychologically associated burden of life limiting illnesses.

IV.3.3 Socio-economical needs

This study confirmed an insufficient social and financial support among patients with life limiting illness at Butare university teaching hospital most of these patients support depended on family and friends who were already poor. 81% of participants needed additional support, 47% could not afford desired meals and 42% could not afford further hospital bills and 79% have been impoverished and practically affected by their illness. Similar studies in the region revealed same social and financial problem (11), although there is an existing social fund in the hospital, they are very limited due to overwhelming number of needy patients including the acutely ill ones and most of chronically ill patients cannot afford any medications that are not available in the hospital pharmacy. 79% patients reported that their practical problems resulted from illness were not addressed, which reflects the attention given only to acute and pathological effects of disease and lack of adequate knowledge and training in palliative care. Social and financial support is definitely in need to improve the general well being of patients at BUTH.

IV.3.4 Religious and spiritual needs

Spiritual aspects of palliative care are paramount and can be used to increase hope and acceptance among patients with life limiting illness (35), they also impact positively their overall quality of life (34).

In our study, 98% had a religious affiliation, similar to the same study above that was done in the USA (34) with 96% of religious affiliation, 93% wished to involve their spiritual groups or leaders in helping them cope with their illnesses. only 15% were worried about dying and they thought main reason for worry was not about their illness but more of leaving family in worst conditions, this indicates that spiritual needs were also associated with anxiety and personal considerations towards others and not only satisfaction in life as confirmed in certain studies (31). This study demonstrates a great need for spiritual support among patients with life limiting illnesses.

Among the identified areas of research this study highlighted; are health care providers knowledge towards palliative care, Impact of religious beliefs on quality of life among chronically ill patients, palliative care needs in critically ill patients or in end of life.
These study results are intended to inform policy and clinicians to relook the implementation of already existing palliative care measure at Butare university teaching hospital.

IV.4. Study limitation

This study was not able to assess the needs of critically ill or end of life care due to inability to participate in interview; however, these encounters were only 12 patients among 130 selected patients. As per scales used in this study were originally in English language, we do not confirm perfection in translation we made to Kinyarwanda language, but we had peer review to minimize mistakes of translation and to our knowledge there was no misunderstandings between researchers and participants. As this was a single center study applicability of results in other centers might not be accurate.

CHAPTER V. CONCLUSION AND RECOMMENDATIONS

V.1. Conclusion

This study highlighted a significant prevalence of patients with life limiting conditions with an enormous need of palliative care, majority of study population were 50 years old and women slightly dominated. Overall social economic status of patients with life limiting conditions at BUTH was poor belonging in lowest ubudehe class 1 and 2 relying of government support for health care. There is also a great burden of disease and symptoms among patients admitted at BUTH with low performance status in one-third of study participants. Non-communicable diseases predominated followed by cancer and HIV/AIDS. Majority of patients with life limiting illnesses admitted at BUTH were experiencing unmet needs and therefore the need for palliation was very high in all dimensions of palliative care be it physical, social, psychological or spiritual.

This study intended to inform both clinicians and policy making individuals and organs through highlighting the magnitude palliative care needs at Butare university teaching hospital done in response to an observed increase in need of palliative care in this setting. Strengthening the existing platform for palliative care through training and retraining of health care providers on several aspects of palliative care, follow up on implementation and maintaining palliative care as routine at BUTH would dramatically improve quality of life in patients with life limiting illnesses at BUTH Internal medicine.

REFERENCES.

1. Desmedt MS, De La Kethulle YL, Deveugele MI, Keirse EA, Paulus DJ, Menten JJ, et al. Palliative inpatients in general hospitals: A one day observational study in Belgium. BMC Palliat Care [Internet]. 2011 Dec 2 [cited 2020 Jun 21];10(1):2. Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/1472-684X-10-2

2. Hughes MT, Smith TJ. The Growth of Palliative Care in the United States. Annu Rev Public Health [Internet]. 2014 Mar 18 [cited 2020 Jun 26];35(1):459–75. Available from: https://pubmed.ncbi.nlm.nih.gov/24641562/

3. Gott M, Frey R, Raphael D, O'Callaghan A, Robinson J, Boyd M. Palliative care need and management in the acute hospital setting: A census of one New Zealand Hospital [Internet]. Vol. 12, BMC Palliative Care. BioMed Central Ltd.; 2013 [cited 2020 Jun 21]. p. 15. Available from: /pmc/articles/PMC3636052/?report=abstract

4. Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. Vol. 365, Lancet. Elsevier; 2005. p. 1971–7.

5. The World Bank. RWANDA Poverty Assessment. 2015;(April):188.

6. Damasceno A. Noncommunicable Diseases. Heart of Africa: Clinical Profile of an Evolving Burden of Heart Disease in Africa. World health organization; 2016. 155–157 p.

7. Ferlay, J., Soerjomataram I et al. cancer incidence and mortality worldwide: IARC cancer base no. 11 [Internet]. GLOBOCAN 2012 v10 Int Agency Res Cancer, Lyon. 2014;

8. World Health Organization. Global Status Report On Noncommunicable Diseases 2014. report [Internet]. 2014;xi. Available from: https://apps.who.int/iris/bitstream/handle/10665/148114/9789241564854_eng.pdf;jsessionid=7FFCACF66E29BC97FF96565D3AD2A014?sequence=1

9. World Health Organization. non communicable diseases; progressmonitor [Internet]. geneva; 2015. Available from: www.who.

10. National Cancer Control Programme. POLICIES AND MANAGERIAL GUIDELINES [Internet]. geneva; 2002. 1–203 p. Available from: http://www.hdnet.org

11. Kikule E. A good death in Uganda: Survey of needs for palliative care for terminally ill people in urban areas [Internet]. Vol. 327, British Medical Journal. 2003 [cited 2020 Jun 20]. p. 192–4. Available from: https://europepmc.org/articles/PMC166119

12. Rhee JY, Luyirika E, Namisango E, Powell RA, Garralda E, Pons JJ, et al. APCA Atlas of Palliative Care in Africa. 2017. 48 p.

13. Centeno C, Lynch T, Garralda E, Carrasco JM, Guillen-Grima F, Clark D. Coverage and development of specialist palliative care services across the World Health Organization European Region (2005-2012): Results from a European Association for Palliative Care Task Force survey of 53 Countries. Palliat Med [Internet]. 2016 Apr 1 [cited 2020 Jul 1];30(4):351–62. Available from: https://europepmc.org/articles/PMC4800456

14. Mukasahaha D, Uwinkindi F, Grant L, Downing J, Turyahikayo J, Leng M, et al. Assessment of Palliative Care Needs in Hospital Settings in Rwanda. Vol. 4, Journal of Global Oncology. 2018. p. 111s-111s.

15. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. Vol. 391, The Lancet. Lancet Publishing Group; 2018. p. 1391–454.

16. CDC(Center for disease control and prevention). CDC global HIV$ AIDS country profile. In Center for disease control and prevention; 2018. Available from: https://www.cdc.gov/globalhivtb/where-we-work/rwanda/rwanda.html

17. Krakauer EL, Muhimpundu MA, Mukasahaha D, Tayari JC, Ntizimira C, Uhagaze B, et al. Palliative Care in Rwanda: Aiming for Universal Access. J Pain Symptom Manage. 2018;55(2):S77–80.

18. Flinkenflögel M, Cubaka VK, Schriver M, Kyamanywa P, Muhumuza I, Kallestrup P, et al. The desired Rwandan health care provider: Development and delivery of undergraduate social and community medicine training. Educ Prim Care. 2015;26(5):343–8.

19. Rosa WE, Male MA, Uwimana P, Ntizimira CR, Sego R, Nankundwa E, et al. The Advancement of Palliative Care in Rwanda: Transnational Partnerships and Educational Innovation. J Hosp Palliat Nurs. 2018 Jun 1;20(3):304–12.

20. Dr.osee Sebatunzi. Lessons learnt from 5 years of palliative care at the Kibagabaga Palliative Care Centre in Rwanda [Internet]. ehospice. 2013 [cited 2020 Jun 26]. Available from: https://ehospice.com/inter_childrens_posts/lessons-learnt-from-5-years-of-palliative-care-at-the-kibagabaga-palliative-care-centre-in-rwanda/

21. RMDC. List of hospitals [Internet]. www.rmdc.rw. 2012 [cited 2020 Jul 1]. Available from: http://www.rmdc.rw/spip.php?article11

22. Kamonyo ES. The Palliative Care Journey in Kenya and Uganda. J Pain Symptom Manage. 2018 Feb 1;55(2):S46–54.

23. Grant L, Downing J, Namukwaya E, Leng M, Murray S. Palliative care in Africa since 2005: good progress, but much further to go. BMJ Support Palliat Care. 2011;1(2).

24. Uwimana J, Struthers P. Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda. Vol. 4, Sahara J. 2007. p. 575–85.

25. Peltzer K, Phaswana-Mafuya N. The symptom experience of people living with HIV and AIDS in the Eastern Cape, South Africa. BMC Health Serv Res. 2008;8:271.

26. Stark LL, Tofthagen C, Visovsky C, McMillan SC. The symptom experience of patients with cancer. J Hosp Palliat Nurs [Internet]. 2012 Jan [cited 2020 Jun 21];14(1):61–70. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3358129/

27. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. Eur J Cancer. 2011 Jan;47(1):51–6.

28. Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. Eur J Cancer. 2008 Jul 1;44(10):1414–24.

29. Logie DE, Harding R. An evaluation of a morphine public health programme for cancer and AIDS pain relief in Sub-Saharan Africa. BMC Public Health. 2005 Aug 10;5:82.

30. Nayak MG, George A, Shashidhara YN, Nayak BS. Symptom Interference and Relation between the Domains of Quality of Life among Cancer Patients of Tertiary Care Hospital. Indian J Palliat Care [Internet]. 2019 Oct 1 [cited 2020 Jun 20];25(4):575–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/31673215

31. Büssing A, Koenig HG. Spiritual Needs of Patients with Chronic Diseases. Religions [Internet]. 2010 Nov 12 [cited 2020 Jun 21];1(1):18–27. Available from: http://www.mdpi.com/2077-1444/1/1/18

32. Murray SA, Kendall M, Boyd K, Worth A, Benton TF. Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers. Palliat Med. 2004;18(1):39–45.

33. Kimani KN, Murray SA, Grant L. Spiritual issues of people living and dying with

advanced heart failure in Kenya: A qualitative serial interview study. BMJ Glob Heal [Internet]. 2016 Nov 1 [cited 2020 Jun 21];1(3):e000077. Available from: https://gh.bmj.com/content/1/3/e000077

34. Vallurupalli M, Lauderdale K, Balboni MJ, Phelps AC, Block SD, Ng AK, et al. The Role of Spirituality and Religious Coping in the Quality of Life of Patients With Advanced Cancer Receiving Palliative Radiation Therapy. J Support Oncol. 2012;10(2):81–7.

35. Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. Support Care Cancer [Internet]. 2002 May 28 [cited 2020 Jun 23];10(4):272–80. Available from: http://link.springer.com/10.1007/s005200100289

36. Nikbakhsh N, Moudi S, Abbasian S, Khafri S. Prevalence of depression and anxiety among cancer patients. Casp J Intern Med. 2014;5(3):167–70.

37. LI Q, LIN Y, XU Y, ZHOU H. The impact of depression and anxiety on quality of life in Chinese cancer patient-family caregiver dyads, a cross-sectional study. Health Qual Life Outcomes [Internet]. 2018 Dec 13 [cited 2020 Jun 23];16(1):230. Available from: https://hqlo.biomedcentral.com/articles/10.1186/s12955-018-1051-3

38. Mccarthy J, Smart V. P-230 Palliative care training in rwanda – working together to effect change. In 2016 [cited 2020 Jun 21]. p. A91.3-A92. Available from: https://www.researchgate.net/publication/320636444_P-230_Palliative_care_training_in_rwanda_-_working_together_to_effect_change

39. Benemariya E, Chironda G, Nkurunziza A, Katende G, Sego R, Mukeshimana M. Perceived factors for delayed consultation of cervical cancer among women at a selected hospital in Rwanda: An exploratory qualitative study. Int J Africa Nurs Sci. 2018 Jan 1;9:129–35.

40. Rawlinson FM, Gwyther L, Kiyange F, Luyirika E, Meiring M, Downing J. The current situation in education and training of health-care professionals across Africa to optimise the delivery of palliative care for cancer patients [Internet]. Vol. 8, ecancermedicalscience. Cancer Intelligence; 2014 [cited 2020 Jul 16]. Available from: /pmc/articles/PMC4303614/?report=abstract

41. Dubale BW, Friedman LE, Chemali Z, Denninger JW, Mehta DH, Alem A, et al. Systematic review of burnout among healthcare providers in sub-Saharan Africa [Internet]. Vol. 19, BMC Public Health. BioMed Central Ltd.; 2019 [cited 2020 Jun 21]. p. 1–20. Available from:

https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7566-7

42. Commonwealth Secretariat. Rwanda | The Commonwealth [Internet]. thecommonwealth.org; 2018. Available from: http://thecommonwealth.org/our-member-countries/rwanda

43. Antunes B, Daveson B, Ramsenthaler C, Benalia H, Ferreira PL, Bausewein C, et al. The Palliative care Outcome Scale (POS) Manual for cross-cultural adaptation and psychometric validation [Internet]. 2012. Available from: http://pos-pal.org/Resources.php

44. Powell RA, Downing J, Harding R, Mwangi-Powell F, Connor S. Development of the APCA African Palliative Outcome Scale. J Pain Symptom Manage. 2007 Feb;33(2):229–32.

45. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: The APCA African Palliative Outcome Scale. Health Qual Life Outcomes. 2010 Jan 25;8:10.

46. Sakurai H, Miyashita M, Imai K, Miyamoto S, Otani H, Oishi A, et al. Validation of the Integrated Palliative care Outcome Scale (IPOS) – Japanese Version. Jpn J Clin Oncol [Internet]. 2019 [cited 2020 Jun 22];49(3):257–62. Available from: https://pubmed.ncbi.nlm.nih.gov/30668720/

47. Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): A new tool. J Palliat Care. 1996;12(1):5–11.

48. Ho F, Lau F, Downing MG, Lesperance M. A reliability and validity study of the Palliative Performance Scale. BMC Palliat Care [Internet]. 2008 [cited 2020 Jul 17];7(1):10. Available from: /pmc/articles/PMC2527603/?report=abstract

49. Wilner LS, Arnold RM. The Palliative Performance Scale #125. Vol. 9, Journal of Palliative Medicine. 2006. p. 994.

50. Lewington JR, Namukwaya E, Limoges J, Leng M, Harding R. Provision of palliative care for life-limiting disease in a low income country national hospital setting: How much is needed? BMJ Support Palliat Care. 2012;2(2):140–4.

51. Gouda HN, Charlson F, Sorsdahl K, Ahmadzada S, Ferrari AJ, Erskine H, et al. Burden of non-communicable diseases in sub-Saharan Africa, 1990–2017: results from the Global Burden of Disease Study 2017. Lancet Glob Heal [Internet]. 2019 Oct 1 [cited 2020 Jun 23];7(10):e1375–87. Available from: http://www.thelancet.com/article/S2214109X19303742/fulltext

52. Mukasahaha D, Uwinkindi F, Grant L, Downing J, Turyahikayo J, Leng M, et al.

Assessment of Palliative Care Needs in Hospital Settings in Rwanda. J Glob Oncol. 2018 Oct 1;4(Supplement 2):111s-111s.

53. Pandve HT, Fernandez K, Chawla PS, Singru SA. Palliative care - Need of awareness in general population. Vol. 15, Indian Journal of Palliative Care. 2009. p. 162–3.

54. WHO. Global Health Observatory | Life expectancy and Healthy life expecancy - Data by WHO region [Internet]. World Health Organization. World Health Organization; 2018 [cited 2020 Jun 22]. Available from: http://apps.who.int/gho/data/view.main.SDG2016LEXREGv?lang=en

55. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness [Internet]. Vol. 330, British Medical Journal. 2005 [cited 2020 Jun 23]. p. 611–2. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC554893/

56. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Prevalence, burden, and correlates of physical and psychological symptoms among HIV palliative care patients in Sub-Saharan Africa: An international multicenter study. J Pain Symptom Manage. 2012 Jul;44(1):1–9.

57 M. Young. Private vs public healthcare in South Africa. Honors Thesis. 2016 jun; 2741:1-21.

58 The Irish Hospice foundation. Hospice, Palliative and End of life care: Definitions. Hospicefoundation.ie. July 2017. retrieved from, https://hospicefoundation.ie/aboutus/hospice-palliative-and-end-of-life-care/how-to-access-specialist-palliative-care/

APPENDICES

UNIVERSITY OF RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 3rd /04/2019

Dr NGOGA Saad,
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 143/CMHS IRB/2019

Your Project Title ***"Palliative Care Needs Assessment In Patients Admitted At Butare University Teaching Hospital"*** has been evaluated by CMHS Institutional Review Board.

		Involved in the decision		
			No (Reason)	
Name of Members	**Institute**	Yes	**Absent**	**Withdrawn from the proceeding**
Prof Kato J. Njunwa	UR-CMHS	X		
Prof Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS	X		
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS	X		
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 30th March 2019, **Approval has been granted to your study.**

Please note that approval of the protocol and consent form is valid for **12 months**.

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 3rd April 2019

Expiration date: The 3rd April 2020

Professor GAHUTU Jean Bosco
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:
- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR

CENTRE HOSPITALIER UNIVERSITAIRE

UNIVERSITY TEACHING HOSPITAL

CENTRE HOSPITALIER UNIVERSITAIRE DE BUTARE (CHUB)
OFFICE OF DIRECTOR GENERAL

Huye, 20/06/2019

N° Ref: CHUB/DG/SA/06/……../2019

Saad Ngoga

Phone: +250781182264

Email: saad14ng@gmail.com

Dear Ngoga

Re: Your request for data collection

Reference made to your letter requesting for permission to collect the data within University Teaching Hospital of Butare for your research proposal entitled ***"Palliative care needs assessment in patients admitted at University Teaching Hospital of Butare"***, based to the approvals **No: 137/CMHS IRB/2019** from Institution Review Board of University of Rwanda and **No: RC/UTHB/047/2019** from our Research-Ethics committee, we are pleased to inform you that you are accepted to collect data within University Teaching Hospital of Butare. Please note that your final document will be submitted in our Research Office.

Sincerely,

Dr. Augustin SENDEGEYA
Director General of CHUB

Cc:

- Ag. Head of Clinical Education and Research Division
- Ag. Director of Research
- Chairperson of Research-Ethics Committee
- Ag. Research officer

CHUB

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B.P : 254 BUTARE
Hotline: 2030

QUESTIONNAIRE

PALLIATIVE CARE NEEDS ASSESSMENT IN PATIENTS ADMITTED AT BUTARE UNIVERSITY TEACHING HOSPITAL

1. Age:
2. Gender:
    a. Male
    b. Female
3. Marital status:
    a. Single
    b. In legal marriage
    c. In illegal marriage
    d. Divorced
    e. Separated
    f. Widowed
4. Ongoing Diagnoses:…….
5. Days since admission:
    a. 24 hours
    b. 48 hours
    c. 72 hours
    d. 7 days
    e. 2 wks
    f. 1 month
    g. 2 months
    h. >2 months
6. UBUDEHE CLASS:
    a. I
    b. II
    c. III
    d. IV
    e. HCR

7. Occupation:
    a. Farmer
    b. Monthly paying job
    c. Private paying job
    d. No job

8. Health Insurance type :
    a. MC
    b. PREMIUM
    c. NONE

9. What have been your main problems or concerns over the past week?

    1- …….
    2- …….
    3- …….

10. FOR EACH SYMPTOM PLEASE TICKIN A BOX THAT WELL DESCRIBES HOW IT AFFECTED YOU.

Symptoms	Not at all 0	Slightly 1	Moderately 2	Severely 3	Overwhelmingly 4
Pain					
Nausea					
Vomiting					
Anorexia					
Constipation					
Difficult in breathing					
Bowel incontinence					
Bladder incontinence					
Do you have fatigue					
Do you have breathing problems or cough					
Sore or dry mouth					
Drowsiness					

11. PLEASE MENTION AND DESCRIBE ANY OTHER SYMPTOMS NOT MENTIONED ABOVE

1- …….……. ☐ ☐ ☐ ☐ ☐
2- ……... ☐ ☐ ☐ ☐ ☐
3- ……... ☐ ☐ ☐ ☐ ☐

12. DESCRIBE BELOW ITEMS

Item	**Not at all 1**	**Occasionally 2**	**Sometimes 3**	**Most of the time 4**	**Always 5**
Are you anxious					
Is your family anxious					
Are you feeling depressed					
Are you feeling at peace					
Do you have as much information as you want.					
Are you able to share your feelings with family and friends as much as you wanted.					
Have any practical problems, resulting from your illness been addressed..(financial..)					

13. In the past have you ever taken herbal drugs ?
    a. Yes
    b. No

14. What were you suffering from ----------?

15. a) With illness, patients have right to consult where they feel they will be cured, with this illness where have you consulted?
    a. HC:
    b. DH:
    c. Referral Hospital:
    d. Private clinic:

Q15b. Alternative health clinics:
    1. Traditional healer using herbal drugs:
    2. using superpower:
    3. Only stayed home:
    4. church minister:

16. Do you feel more need of support than your family, friends or insurance can provide:
    a. Yes
    b. No

17. With this disease Do you feel abandoned or punished by God or **not** supported by your church/faith?
    a. Yes
    b. No

18. When people are sick they need special food to improve their appetite, do you get desired food for your disease:
    a. Yes
    b. No
19. Home composite: Number of children (……)

Husband……Wife…..Number of other family member staying with you (…….)

20. a) Do you have a care taker:
    a. Yes
    b. No

b) What relationship between you and your care taker:……

c) Are you willing for your care taker to know your disease and its natural progress:

1. Yes
2. No

21. Do you know your disease:
    a. Yes
    b. No

22. Do you know the natural progress of your disease
    a. Yes
    b. No
23. Do you know if your disease is curable:
    a. Yes
    b. No
24. Do you have resources to cover your hospital stay, Drugs, Food, and Transport ?
    a. Yes
    b. No

25. Since your admission how do you rate frequency of your family member visits in the hospital:
    a. Not yet any visit
    b. Not enough
    c. Satisfactory
26. Despite your illness do you feel your memory remains intact:
    a. Yes
    b. No

27. Do you wish more of your spiritual beliefs be discussed with ;
    a. Your primary health provider,
    b. A member of your congregation,
    c. Any one,
    d. None,
    e. Care taker
28. How often do you ever get panic that you are going to die from this disease?
    a. Never
    b. rarely
    c. sometime
    d. almost daily
29. Are you part or member of any religious or spiritual group?
    a. Yes
    b. No
30. Are you willing that your religious or spiritual group be involved to help you cope with your illness nature:
    a. Yes
    b. No

PPS TABLE BELOW TO BE COMPLETED FOR EVERY ENROLLED PATIENT

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80 %	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable to Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

IKUSANYAMAKURU K'UBUVUZI BWANYUMA

IBIBAZO KU BUSHAKASHATSI MUKUNOZA IMITANGIRE Y'UBUVUZI BWANYUMA.

1. Imyaka:
2. Igitsina:
3. Irangamimirere: Ingaragu ☐ Arubatse muburyo bwemewe na leta ☐ Muburyo butemewe na leta ☐ Yatandukanye mumategeko ☐

4. Uburwayi nyirizina:

5. Iminsi ishize Ari mubitaro: Amasaha 24 ☐ Amasaha 48 ☐ Amasaha 72 ☐ Iminsi 7 ☐ Ibyumweru 2 ☐ Igihe kirenze amezi abiri ☐

6. Ikiciro cyubudehe : I ☐ II ☐ III ☐ IV ☐
7. Icyo akora: umuhinzi ☐ akazi gahemba kukwezi ☐ arikorera ☐ Ntakazi ☐

8. Ubwishingizi mukwivuza: ubwisungane ☐ Izindi ☐ ntabwo ☐
9. Muri iki cyumweru gishize ni ibihe bibazo bikubangamiye:

   1- …….
   2- …….
   3- …….

10. KURI BURI BURWAYI KOSORA MUKAZU GASOBANURA NEZA IKIGERO CY'UBURWAYI.

Ibimenyetso	Ntabyo 0	Buhoro 1	Biringaniye 2	Bikabije 3	Birenze igipimo 4
Kubabara					
Iseseme					
Kuruka					
Guhurwa					

Gufuma					
Guhumeka nabi					
Kwirangirizaho umusarane					
Kwirangirizaho inkari					
Gucika integer					
Kubabara mukanwa no kumira					
Ibibazo byimihumekere					
Guhwekera					

11. WATUBWIRA IBINDI BIMENYETSO BY'UBURWAYI TUTAVUZE HARUGU.

1. ……0	☐	1☐	2☐	3☐	4☐
2. …….	☐	☐	☐	☐	☐
3. …….	☐	☐	☐	☐	☐

12. GARAGAZA INSHURO UGIRA IBI BIKURIKIRA.

Ikibazo.	Ntabyo	Gake cyane	Rimwe na rimwe	Kenshi	Burigihe
Guhangayika					
Umuryango wawe urahangayitse					
Ufite agahinda					
Wumva utuje					
Ufite makauru yose ukeneye					
Ubasha gusangiza ibyiyumviro byawe umuryango n'inshuti nkuko ubyifuza					

Hari ingaruka mubuzima bwa buri munsi uburwayi buguteza. (ubukene)					

13. Hambere aha wigeze ukoresha imiti yakinyarwanda ? ☐
14. Wari urwaye iki?.....
15. Iyo umuntu arwaye afite uburenganzira bwo gushaka uwo yumva wamukiza ,kuri ubu burwayi wagannye ikihe kigo cyubuvuzi? Ikigo nderabuzima, ☐ Ibitaro byakarere, ☐ Ibitaro bikuru ☐ Ikigo kigenga ☐ Ayandi mavuriro ☐ Umuvuzi gakondo ; Akoresheje imiti yakinyarwanda ☐ Akoresheje izindi mbaraga ☐ umushumba witorero ☐ wagumye murugo ☐
16. Wumva hari ubundi bufasha butari ubw'abo mumuryango,inshuti cg ubwishingizi bw'ubuzima ukeneye ? ☐
17. Muri ububurwayi, wumva waratereranywe cg warahanywe n'Imana cg ntabufasha itorero ryawe riguha ? ☐
18. Iyo umuntu arwaye akenera ibiryo Atari asanzwe abona kugirango abashe kurya, ubona ibyokurya byose wifuza muri ubu burwayi ☐
19. Abagize umuryango: ufite abana bangahe ?(…….)
    Ufite umugabo ☐ Ufite umugore ☐ vuga umubare wabandi bantu mubana(…….)
20. Ufite umurwaza ☐
    Vuga isano hagati yawe n'umurwaza wawe……
    Wemera ko umurwaza wawe yamenya uburwayi bwawe n'imiterere yabwo ☐
21. Uzi uburwayi bwawe ☐ Uzi imiterere kamere yuburwayi bwawe ☐
22. Uzi imitere kamere n'imikurire y'uburwayi bwawe ☐
23. Uburwayi bwawe burakira ☐
24. Ufite ubushobozi bwishyura ibitaro, imiti, ibiryo, n'amatike y'ingendo ☐
25. Kuva ugeze mubitaro gereranya ubwitabire bw'abo mumuryango wawe mu kugusura mubitaro :

☐ ☐ ☐

Ntanarimwe Ntibihagije Birahagije

26. Uretse uburwayi bwawe , hari ikibazo cyo kwibuka ufite ☐

27. Ninde wifuza kaganira nawe kumyemerere y'idini yawe;

Umuganga wawe wibanze ☐ Umuntu musengana ☐ Uwo ariwe wese ☐ Ntawe ☐

28. Hari ubwo uterwa ubwoba nuko uzahitanwa nubu burwayi ;

Hoya ☐ Gacye cyane ☐ Rimwe na rimwe ☐ Buri munsi ☐

29. Hari idini iryo ariryo ryose ubarizwamo ☐

30. Wifuzako abantu musengana bagira uruhare mu kugufasha kubana n'ubu burwayi ☐

TABLE BELOW TO BE COMPLETED FOR EVERY ENROLLED PATIENT

PPS Level	**Ambulation**	**Activity & Evidence of Disease**	**Self-Care**	**Intake**	**Conscious Level**
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable to Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

IMFORMED CONSENT FORM FOR PALLIATIVE CARE NEEDS ASSESSMENT AT BUTARE UNIVERSITY TEACHING HOSPITAL SOUTHERN PROVINCE.

This consent form is for those who are invited to participate in our study on "Assessment of palliative care needs in patients admitted at Butare university teaching hospital. Meaning finding out what are the patients needs as far as palliative care is concerned.

This form comprise of two sections:

1.Introduction to the study.
2.Consent form .

SECTION I : **Introduction to the study:**

We are going to explain and invite you to participate in this study. You will think about it and ask questions if necessary so that you understand the whole process, benefits and possible risks (although there are no expected risks) before you decide to accept to participate in this study.

I'm by the names **NGOGA Saad**, a medical doctor by proffesion I'm also a third year student in Internal medicine specialization program (masters degree) at University of Rwanda college of medicine and health sciences. We are carrying out a research on patient needs for palliative care program here at Butare university teaching hospital so that we can efficiently deliver our palliative care services based on what patients need most.

Objective of the study:

Palliative care program is still a new approach , it covers a big range of aspects being physical, spiritual, social, and economic problems for a patient with a life limiting condition. It is really inefficient to provide this kind of care with out a clear range of needs that need to be covered given the diversity of our society. We aim to identify those patients that need palliative care and what specific needs that should be tackled.

Methods of the study intervention:

Our study will involve using a questionaire , which will be given to participants to fill in their demographics and problems related to their illnesses including physical symptoms, social problems, spiritual and even economical issues. Which at the end will be put-together and analyzed to know the magnitude and characteristics of all patients and that that will help us to make an appropriate conclusion.

Participant selection:

We invite all patients admitted in internal medicine at BUTH with a diagnosed life limiting illness.

Right to participation:

Your participation in this study is fully voluntary. You will continue to get same treatments as you have been receiving even if you choose not to participate. You are allowed to stop your participation even during the process of the study. This will not affect in anyway your deserved treatments.

Duration of study:

This study will last for 10 months period. Survey questionnaire filling will take not more than 10 minutes. It will not delay your treatment schedules.

Risks :
This study is entirely safe there is no expected risks.

Benefits and reimbursement:

There are no reimbursement for any one's participation in this study.

Confidentiality:

The information that will be recorded from your charts or collected from you, will be highly confidential. This information will be stored on a secured file in our password protected computer. Our questionnaire files have not included a NAME to protect the participant and only the researchers will have access to them.

Sharing the results :

We plan to publish the results for academic and research purposes and we shall feed back to the treatment team for self evaluation ,your confidentiality will always be protected through out.

CONTACTS:

Door for questions is always open and in case you can contact the following:

NGOGA Saad : +250781182264, saad14ng@gmail.com.

SIBOMANA Jean pierre : +250788425104, jepisibo@gmail.com.

RWABIHAMA Jean paul : +250780859127, jeanpaulrwabihama@gmail.com.

CMHS IRB Chair Person : +250788490522.

CMHS IRB Deputy Chair Person : +250783340040.

SECTION II: **consent form.**

I have read and understood information provided or read to me above, all my questions have been answered to my satisfaction . I consent voluntarily to participate in this study.

Printed name of participant :…….

Signature of participant:…….

Dates: ……..

If illiterate

I have witnessed the accurate reading of study information and consent form to the potential participant, and the individual has had chance to ask questions and obtain satisfying responses. I confirm that the individual has given consent freely.

Printed names of witness: …….

Signature of witness:…….

thumb print of participant:……..

Dates :…….

Statement by the researcher/individual obtaining consent:

I have accurately read out the information sheet to the potential participant, and made sure that the participant understands the above information to my best of abilty.

I confirm that the participant was given opportunity to ask questions about the study,and all the questions have been answered correctly to best of my knowledge.

I confirm that the individual has not been forced into giving consent, and the consent has been given freely.

A copy of this consent form has been provided to the participant.

Print name of Researcher/ person obtaining consent:…….

Signature of Researcher/ person obtaining consent:……

Dates :…….

INYANDIKA NSABA BURENGANZIRA MU KWITABIRA UBUSHAKASHATSI KUBIKENEWE MUBUVUZI BWANYUMA MU BITARO BIKURU BYA BUTARE.

Iyi nyandiko nsaba ruhushya igenewe abantu bose batumiwe kwitabira ubu bushakashatsi " kurebera hamwe ibikenewe mu buvuzi bwanyuma bw'abarwayi barwariye mubitaro bikuru bya Butare."

Iyi nyandiko igizwe n'ibice bibiri:

1.**Iriburiro kubushakashatsi.**

2.**Inyemeza ruhushya**.

IGICE I: Iriburiro kubushakashatsi:

Tugiye kubasobanurira tunabahamagarire kwitabira ubu bushakashatsi. Mbere yogufata ikimezo musabwe kubitekerezaho mukanabaza ibibazo byose mwifuza kugirango murusheho gusobanukira uko ubu bushakashatsi buzakorwa n'ingaruka (nubwo ntazo) mwahura nazo mugihe mwaba mwemeye kwitabira.

Amazina yange ni: **NGOGA Saad**, umuganga wabigize umwuga nkaba ndi mumwaka wagatatu wikiciro cyagatatu cyakaminuza aho nitoza kuba inzobere mundwara z'umubiri muri kaminuza nkuru y'uRwanda ishami ry'ubuzima. Tukaba turimo gukora ubushakashatsi kubikenewe mubuvuzi bwanyuma mu barwayi barwariye kubitaro bikuru bya Butare mukunoza imitangire y'ubu buvuzi.

Intego yubu bushakashatsi:

Gahunda y'ubuvuzi bwanyuma ni gahunda nshya murwanda no muri Africa, I huruza hamwe ingeri nyinshi z'ibibazo umurwayi windwara zidakira ahura nazo ,hano uburwayi nyirizina bwumubiri, harimo, imibanire, ubwa roho ndetse nimibereho.ntibihagije gutanga ubu buvuzi hatazwi ingano nibikenewe mubarwayi bigomba kwitabwaho. Kubwiyo mpamvu ubu bushakashatsi bugamije kumenya ibikenewe mubarwayi ningano yaba barwayi bagomba kwitabwaho.

Uburyo ubu bushakashatsi buzakorwamo:

Muri ubu bushakashatsi tuzifashisha urupapuro nkusanyamakuru, aho ruzahabwa abitabiriye ubushakashatsi kugirango buzuzemo ibisubizo byose bizaba biriho.hanyuma bikazashirwa hamwe hakurwamo umwanzuro kuntego zubushakashatsi.

Guhitamo ryabazitabira:

Abarwayi bose barwariye mubitaro bikuru bya Butare basuzumwe mo indwara zidakira, n'izakarande.

Uburenganzira bwo kwitabira:

Kwitabira muri ubu bushakashatsi ni ubushake. Ndetse wemerewe guhagarika kwitabira mo hagati mubushakashatsi igihe icyo aricyo cyose. Ibi ntibishobora kubangamira cyangwa kugira ingaruka izo arizo zose kubuvuzi bwawe usanzwe uhabwa.

Igihe ubushakashatsi buzamara:

Ubu bushakashatsi buzamara igihe kigera kumezi 10 . naho kuzuza urupapuro nkusanyamakuru bizajya bitara iminota 10 bitabangamiye gahunda zindi zubuvuzi bukorerwa umurwayi.

Ingaruka zava muri ubu bushakashatsi:

Ntangaruka nimwe bizatera umurwayi kwitabira ubu bushakashatsi.

Ibihembo:

Nta bihembo biteganyirijwe uwo ariwe wese uzitabira ubu bushakashatsi.

Kubika ibanga:

Amakuru yose yerekeranye nubu bushakashatsi abikwa mwibanga rikomeye. Amakuru azajya abikwa kuri zamudasobwa zirinzwe numubare w'ibanga uzwi nabashinzwe ubu bushakashatsi gusa. Ikindi namazina bwite yumurwayi azagaragara kurupapuro nkusanyamakuru muburyo bwo kurinda ibanga .

Gutangaza ibyavuye mubushakashatsi:

Duteganya gutangaza ibizava muri ubu bushakashatsi kumpamvu z'imyigire n'ubushakashatsi. Tuzanamenyesha imyanzuro yavuyemo ikipe y'ubuvuzi murwego rwo kurushaho kunoza imitangire y'ubu buvuzi.

Mwaduhamagara:

Mushobora kuduhamagara igihe icyo aricyo cyose tukabaha ubusobanuro burambuye kurushaho.

Dr. NGOGA Saad: +250781182264, saad14ng@gmail.com

Dr. SIBOMANA Jean pierre: +250788425104, jepisibo@gmail.com

RWABIHAMA Jean paul : +250780859127, jeanpaulrwabihama@gmail.com

UMUYOBOZIUMUKURU W'UBUSHAKASHATSI MURI KAMINUZA Y'URWANDA: Tel +250788490522.

UMUYOBOZI MUKURU WUNGIRIJE W'UBUSHAKASHATSI MURI KAMINUZA Y'URWANDA: Tel +250783340040.

IGICE CYA II: **Urupapuro nyemeza ruhushya.**

Nasomye kandi nasobanukiwe amakuru yose nahawe , nabajije ibibazo byose nifuje kandi ibisubizo nawe byanyuze. Nemeye ntagahato kwitabira ubu bushakashatsi.

Amazina y'umurwayi :……

Umukono w'umurwayi:……

Amatariki :…….

Niba utazi gusoma no kwandika

Umurwayi yasomewe neza kandi muburyo bwumvikana amabwiriza, n'amakuru yerekeranye n'ubu bushakashatsi, kandi yahawe umwanya uhagije wo kubaza ibibazo bitandukanye ndetse yanyuzwe n'ibisubizo yahawe. Ndemeza ko umurwayi yemeye kwitabira ububushakashatsi ntagahato.

Amazina y'indorerezi :…….

Umukono w'indorerezi:……..

Igikumwe cy'umurwayi:……..

Amatariki :…….

Ubuhamya bw'umushakashatsi/uwakira uburenganzira:

Umurwayi yasomewe kandi neza amabwiriza n'andi makuru arebana nubushakashatsi mubushobozi bwange bwose ndahamya ko umurwayi yasobanukiwe.

Ndemeza ko umurwayi yahawe umwanya wo kubaza ibibazo kuri ubu bushakashatsi kandi yahawe ubusobanuro bumunyuze. Ndemeza ko umurwayi yemeye kwitabira ubu bushakashatsi ntagahato.

I kopi y'ururupapuru irahabwa buri wese witabiriye ubu bushakashatsi.

Amazina y'umushakashatsi:……..

Umukono w'umushakashashatsi:…….

Amatariki:……..