



UNIVERSITY *of*
RWANDA

**KNOWLEDGE AND HOME CAREGIVERS EXPERIENCES FROM
PALLIATIVE HEALTH CARE TEAM EDUCATION IN PAIN
MANAGEMENT OF CANCER PATIENTS IN RWANDA**

By

TWAHIRWA Jean Claude

College of Medicine And Health Sciences
School of Nursing Nursig And Midwifery
Masters's of Science in Nursing (Medical –Surgical)

Year, 2019



UNIVERSITY *of*
RWANDA

By

TWAHIRWA Jean Claude

Reg 218000527

A dissertation submitted in partial fulfilment of requirement for the degree of

MASTERS'S OF SCIENCE IN NURSING(Medical –surgical)

in the

College of Medecine And Health Sciences

Supervisor: Anita Collins

Co-supervisor: Rebecca L. White

July,2019

DECLARATION

I declare that this Dissertation contains my own work except where specifically acknowledged

TWAHIRWA Jean Claude 218000527

Signed.....

Date 20/7/2019

DEDICATION

I dedicate this work to the almighty God. To my beloved spouse, daughter, son and beloved parents, and numerous brothers, sisters, friends, lectures and classmates for their excellent support and collaboration.

ACKNOWLEDGMENTS

No-one can accomplish this kind of work alone, I humbly thank the almighty God for his unconditional love and protection from childhood to date. I am highly indebted to my co-supervisor, Rebecca and supervisor Doctor Anita for their continuous guidance, who supported, and encouraged, proofread, corrected, edited significantly and contributed to the completion of this work.

I express my gratitude to all Staff of UR/CMHS in general for the existence of the master's program and especially those of Dean of nursing and midwifery school, for the intellectual package they provided and every person who helped and guided me where was necessary. My Heartfelt appreciation goes to my spouse Nyirandayambaje Adelphine who spontaneously encouraged during the completion of my masters.

I thank also kibogora Polytechnic Leaders who allowed me to attend Master's program.

I thank Professor Janet Stewart for inspiration in this research and Dr .David Slack

I thank Dr Eric RUVUNA for support in data interpretation, analysis and results presentation process

I thank Dr Katende Goldfery i for his support throughout questionnaire review, data analysis, interpretation.

I also thank my colleagues whom we are struggling and helping each other in one way or another and contributed to the achievement of my daily life objectives in medical surgical Nursing

I attribute also my thanks to caregivers, nurses and palliative health care working at Kibogora Hospital Catchment area who supported me during data collection

May all almighty God bless you all!

ABSTRACT

Chronic and acute pain is highly prevalent in the general patient population, and those suffering from chronic illness are at increased risk of untreated pain including cancer patients. Terminally ill cancer patients can be managed well at home or in healthcare institutions such as a hospital. Pain management must involve a multidisciplinary team. Home-based caregivers need to have educational support including pain management skills including different techniques for pain relieve and the skills of pain assessment and treatment modalities.

Aim: The study is aimed is to assess the knowledge and perceived experience of home caregivers of cancer patients related to pain management in a home-based care environment in the context received from health care team.

Methodology This is a quantitative research uses a non-experimental descriptive cross-sectional design. A purposive sampling strategy was used to identify participants for 120 in-home caregivers for patients cancer followed in palliative care service at Kibogora Catchment area.

The instrument used was the adopted questionnaire and was pilot tested for reliability and validity and the questionnaire used was adapted to the context of Rwanda.

Results: in the results of this study shows that the caregivers were educated on chronic cancer pain and had same information relating to pain management however those information are not really applied in their daily care life for patient and the do not have efficient knowledge on pain assessment and tools to assessment pain which can have a negative impact on success to pain reliever ,most caregivers are family relatives to patients who are caring patient for considerable time but through the support from palliative health care team they arrived to cope with the situation and they are not affected.

Conclusion: The present study shows that there was a significant association between palliative health care team education to the knowledge and appreciation of caregivers in case of chronic cancer pain management at home based care service in Rwanda however the still a need to improve the service and empower those caregivers in terms of skills for pain assessment and the tools to use with a continuous follow up and monitoring of home care services as well as caregiver's needs has to be considered in every care component in health care system in

Key Words: Knowledge, palliative health care team, home caregivers, pain, cancer.

V. LISTS OF SYMBOLS AND ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ADL:	Activity of Daily Life
BPI:	Brief Pain Inventory
CNS:	Central Nervous System
CP:	Chronic Pain
EBP:	Evidence-based practice
EL:	End of Life
FGC:	Family Caregiver
HIV:	Human Immunodeficiency Virus
IAHPC:	International Association for Hospice and Palliative Care
KH:	Kibogora Hospital
NC:	Communicable diseases
NRS:	Numerical Rating Scale
NCDs:	No communicable diseases
NH:	Nursing home
PC:	Palliative care
PCC:	Patient-centered care
VAS:	Visual Analog Scale
WHO:	World Health Organization
Y/O:	Years Old
Dr	Doctor
SPSS	Statistical Package for the Social Sciences
MoH	Ministry of Health

TABLE OF CONTENTS

6DECLARATION	i
DEDICATION.....	ii
ACKNOWLEDGMENTS	iii
ABSTRACT.....	iv
V. LISTS OF SYMBOLS AND ABBREVIATIONS	v
CHAPTER1. INTRODUCTION	1
1.2 BACKGROUND	1
1.3 RESEARCH OUTLINE	2
1.4 PROBLEM STATEMENT.....	2
1.5 AIM OF THE STUDY.....	3
1.6 SPECIFIC OBJECTIVES	4
1.7 RESEARCH QUESTION.....	4
1.8 STUDY SIGNIFICANCE	4
1.9 .DEFINITION OF KEY TERMS	4
2.1. INTRODUCTION	6
2.2 THEORETICAL LITERATURE	6
2.2.1 PATHOPHYSIOLOGY OF CANCER PAIN	8
2.2.2 PERCEPTION OF PAIN.....	8
2.2.3. PAIN ASSESSMENT.....	9
2.2.4. PAIN TREATMENT	9
2.3. EMPIRICAL LITERATURE	10
2.3.1. IN-HOME CAREGIVERS ASSESSMENT.....	11
2.3.2. CAREGIVERS ISSUES AND CONTEXT IN CASE OF PAIN.....	11
2.3.3 CAREGIVERS NEEDS AND CHALLENGES.....	12
2.3.4. APPROACHES TO SUPPORT CAREGIVERS IN PAIN MANAGEMENT	13
2.3.5 CAREGIVER'S RESPONSIBILITIES.....	14
2.4. CRITICAL REVIEW AND RESEARCH GAP IDENTIFICATION	15
2.4.1. IN HOME CARE GIVERS NEEDS ON PAIN MANAGEMENT	16
2.4.2. INTERVENTIONS TO IMPROVE COMPETENCE AND CONFIDENCE OF HOME CAREGIVER.....	17
2.5 .CONCEPTUAL FRAMEWORK FOR CAREGIVERS KNOWLEDGE AND EXPERIENCES ON CANCER PAIN MANAGEMENT.....	18
CHAPTER 3: METHODOLOGY	20
3.1. INTRODUCTION	20
3.2. STUDY DESIGN.....	20

3.3. STUDY APPROACH.....	20
3.4. STUDY SETTING.....	20
3.5. STUDY POPULATION	20
3.6. SAMPLING	20
3.6.1. SAMPLING STRATEGY	20
3.6.2. SAMPLE SIZE	21
3.6.3 INCLUSION AND EXCLUSION CRITERIA	21
3.7. DATA COLLECTION	21
3.7. 1. DATA COLLECTION INSTRUMENT.....	21
3.7.2. DATA COLLECTION PROCEDURE.....	22
4.1. INTRODUCTION	24
4.2. PRESENTATION OF DATA.....	24
4.2.1: DEMOGRAPHICS OF PARTICIPANTS (N=120).....	24
Age (n=120).....	24
6.1. INTRODUCTION	45
6.2. CONCLUSION.....	45
6.3. RECOMMENDATIONS	46
APPENDICES	52

LIST OF FIGURE

Figure 1: Conceptual Framework for knowledge and home Caregivers experiences on 19

Figure 2: Age distribution of respondents 24

LIST OF BABLE

Table 1: Conceptual Framework for knowledge and home 19

Table 2: Age distribution of respondents..... 24

Table 3:Distribution of participants according..... 26

Table 4:Distribution according to edication 28

Table 5: Respondents' self-assessment of chronic 30

Table 6: Bivariate analysis for contribution 35

Table 7:Bivariate analysis of contribution of explanation 37

Table 8:Bivariate analysis of education on pain assessment..... 38

Table 9:Bivariate analysis of Education for drug administration 39

CHAPTER1. INTRODUCTION

Pain is a complex phenomenon and is the sum of bio-psycho-social factors. Theoretically, patient-centered care seeks to improve patient outcomes and achieve effective pain assessment and management. Pain assessment and management planning and implementation are adequately addressed in a multidisciplinary team context(Paul-savoie, Rn and Rn, 2015, p. 17) .This chapter includes the definitions of key terms and concepts, the background to the study, the research problem statement, objectives of the study, research questions, and significance of the research.

1.2 BACKGROUND

Pain is a common symptom of cancer, 30% to 50% of all patients with cancer will experience moderate to severe pain in their illness history , which leads to the significant negative impact on the patient's quality of life outcome (Wiffen *et al.*, 2017, p. 41). Chronic pain is recognized as a significant public health risk throughout the world it affects a large number of adults or youth who are experiencing chronic terminal illness such as cancer, if untreated, it can then adversely affect the activities of daily living for the patient and their family members or anybody else who are involved in care for them (Paul, 2015, p. 23). Patients with malignant diseases especially in the advanced stages are at risk of experiencing severe pain issues (Connor and Sepulveda Bermedo, 2014, p. 15).

Globally people are living longer, and with this advanced aging population, the prevalence of chronic disease has increased and will continue as well; this increase translates to a higher demand being placed on the family members to participate as caregivers within the health sector development (Kariuki et al., 2013,p. 26). Since 2009, the government of Rwanda has initiated a program to manage patients with progressive terminal illness including the use of medications specifically opioids as gold standard in hospice care and primary medication for pain control in terminal illnesses (Krakauer *et al.*, 2018, p. 23).

In advanced terminal cancer illnesses patient may feel more comfortable prefer passing away in their own homes (Niemeyer-guimarães and Schramm, 2017, p. 21). However Low-and middle-income countries in East Africa are facing challenges in the health sectors relating to health care service delivery a minimum standard application of pain control measures needs to be adopted at all levels of the healthcare sector by empowering caregivers by supporting in highly confident pain assessment technics and management however those needs to fill satisfied and confident and not affected and vulnerable eventhough living in a context of limited resources and infrastructure (Kariuki et al., 2013 ,p.43).

Frequently the in-home caregiver is only the source of care and support for the patient with pain in the home care context. Caregiver's resilience will be enhanced by educational knowledge relating to pain management and assessment skills, understanding treatments to alleviate the patient's pain. The primary and necessary knowledge to assess and effective application of pain relief measurement and techniques is paramount for care providers (Berry, Dalwadi and Jacobson, 2018, p. 35). Caregivers play multiple roles which require a complex set of skills, extensive knowledge, and self determination to fulfill their obligations effectively as in-home end of life support for patients (Kunsch, 2016 , p. 17).

1.3 RESEARCH OUTLINE

This thesis is composed of two main parts. The initial section includes the title page, declaration, dedication, acknowledgments, abstract and summary, table of contents, a list of symbols and abbreviations and a list of tables, and a list of figures. The second section includes an introduction, literature review, and methodology. The analysis of data, discussion ,conclusion and recommendation.

1.4 PROBLEM STATEMENT

A primary challenge for the home-based caregivers is pain management. End of life care needs creates considerable stress for caregivers who may affect both the patient and the caregiver's ability to perform activities daily living. Lack of adequate pain control can leads to acute issues of depression and hopelessness which can turn or lead to even self-suicide (Rokach *et al.*, 2016, p. 43). Family members in the United States currently have been seen to provide the majority of care (75%-80%) of the home care for terminally ill patients, highly dependent on family in-home care providers, warrants extensive educational programs, and enhanced support to ensure optimal health and well-being for terminally ill patients.

Caregiver's responsibilities have increased due to the growing elderly population and the overcrowding of hospitals which in turn leads to early hospital discharge (Kariuki *et al.*, 2013, p. 19), 2013). End of life in-home care is stressful both for the caregiver as well as patient, and these demands place a high risk of injury and risk for occurrence of adverse events. Family caregivers are many times unpaid providers who often need support and assistance to become competent, efficient, and safe who can protect their family members (Reinhard *et al.*, 2018, p. 24).

Africa has a significant burden related to the growing number of NCDs and communicable diseases such as HIV. In the Sub-Saharan region, indicates 68% of the global burden of HIV in 2030 will be from the region. Cancer is emerging in the low to middle-income countries as a public health problem. Cancer rates are expected to double to 1.28 million in 2030. Prevalence rate of 5 to 10 million people currently has cancer, and other life-limiting illnesses at risk for chronic pain. Those growing cancer rates support the increase involvement of family members in palliative care and for their family members education and support is imperative due to the growing burden of disease.

This research helped to define the knowledge got from palliative health care team support and experiences resulted from the support for enhancing the in-home caregivers' participation in end of life care pain management mainly for patient with terminal cancer illness (Kariuki *et al.*, 2013,p.18). Worldwide roughly 40 million caregivers provided an estimated 37 billion hours of care to adults with limitations in daily activities. (Reinhard, Fox-grage and Feinberg, 2016, p. 23) In Rwanda, there is limited data and research studies exploring the knowledge, experience, and perceived needs of caregivers in hospice or end of life cancer care. This study highlighted the knowledge and experience of home caregivers on cancer pain management in patients enrolled in the palliative care service at Kibogora Hospital catchment area.

1.5 AIM OF THE STUDY

The aim of this study was to assess the knowledge received and exploring caregiver's experience in pain management for cancer patients in a home-based service.

1.6 SPECIFIC OBJECTIVES

1. To assess knowledge that caregivers received from the palliative health care team concerning cancer pain management in home-based care.
2. To assess caregivers self-experience relating to cancer pain management support in home-based care from palliative health care team.

1.7 RESEARCH QUESTION

1. What is the knowledge received by caregivers from palliative care team about cancer pain management?
2. What are the experiences of caregivers relating to pain management while managing pain for cancer patient at home?

1.8 STUDY SIGNIFICANCE

This study will allow educators in nursing domain to enhance and upgrade educational materials. This study will also inform national health policymakers to understand and recognize the needs of caregivers support in home-based context however this research will also serve as an EBP tool relating to caregiving in home-based care systems in Rwanda; The findings may have an impact on nursing research as new resource of new knowledge .

1.9 .DEFINITION OF KEY TERMS

Knowledge is the fact or condition of knowing something with the familiarity. Knowledge is gained through the experience or associations, or acquaintance with or understanding of science, art, or techniques, the condition of being aware of something (Gulik *et al.*, 2017, p. 23).

Palliative Health Care Team is defined As all health professionals who are involved in caring for people with life-threatening illnesses which focuses on quality of life (Hawley, 2017, p. 1).

Experience, an event or occurrence which leaves an impression on someone or on something (Kova *et al.*, 2018, pp. 1–8).

Home-Based Caregiver is a person involved in any form of care given to chronically ill people in their homes, including activities that provide physical, psychological, social, and

spiritual support. Families are the central focus and form the basis of this in home community (Health and Welfare, 2010, p. 17).

Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. The subjective part of pain is an individual's experience modulated by physiological, psychological, and environmental factors such as previous events, culture, prognosis, coping strategies, fear and anxiety (Rwanda Ministry of Health, 2012, p. 2).

Cancer abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases cancer spread other parts of the body through the circulation systems (Rn *et al.*, 2015, p. 14).

CHAPTER2. LITERATURE REVIEW

2.1. INTRODUCTION

Home caregivers of patient in terminally cancer period experience multiple complex transitions concerns resulting in diversity of needs and required support(Parmar, 2015, p. 25).They may include caring for a loved one in home, the care recipient's home or in an institutional setting.(Astolfi, 2014, p. 23) a Millions of working people provide care including people with cancer at end stages who are experiencing pain and who are critically ill; Many of these are struggling to manage both their caregiving responsibilities and their daily living life(Shiro *et al.*, 2017, p. 1).it encompasses a wide range of experiences and situations their needs are expressed in different areas of which should be addressed in nursing interventions(Fernandes and Angelo, 2016, p. 672). Caregivers expressed the need to maintain the identity of their cancer patient, a familial responsibility for caregiving, and change in their family relationship over time. Appreciating caregivers' challenges and needs gives health care professionals a better understanding for how to provide assistance for a smoother nursing home transition.(Koplow *et al.*, 2015, pp. 1–2).The findings indicate that family caregiving requires collaboration with formal care to get support adjusted to individuals' needs specific to individual disease process through expressing a transition in the process of the disease. Interventions should focus on facilitating the transition to assure caregivers' wellbeing.(Hallberg, 2016, p. 11) because they are central members of the care team. They can be both providers of care and clients in need of supportive services(Reinhard, Fox-grage and Feinberg, 2016, p. 1)

2.2 THEORETICAL LITERATURE

Acute and chronic pain may be associated with tissue damage or can signal a chronic terminal illness development. Physiological effects of illness may progress and become worse, or a chronic condition may become toxic and or life-threatening impacting every aspect of a patient's life. Chronic illness may lead to role changes within the family, as the patient becomes increasingly dependent on other members of the family indirectly or directly (Rokach *et al.*, 2016, p. 26).

Pain may have a predictable or unpredictable course. Pain issues may result in changes both in physical and psychological functioning; but also changes in professional and social roles at

work, in family life, within friendships, education, and leisure time activities.(Rokach *et al.*, 2016, p. 32). The issues of pain management in Rwanda in the realm of hospice care are a vital avenue to allow patients to die at home with dignity in their well-known surroundings. The ability to be at home in the village, in familiar surroundings will allow those patients faced with death a calm, supportive environment.

The issue of pain uncontrolled is a barrier to this care. Issues of uncontrolled and ever-changing pain can also occur when a patient faces chronic illnesses. Chronic conditions such as diabetes, cardiovascular disease, stroke, hypertension, Sickle Cell Disease, and Human Immunodeficiency Virus are just a few of chronic disease states which can result in death.

Having the conversation around death and dying is also of an issue in the Rwandan context. The ability for a healthcare provider to state the obvious of impending death may be limited, and many times Rwandans feel “it is in the hands of God.” Research by ramia et al. (2017) found that communities with limited hospice or end of life support felt that cancer was perceived as a punishment from God. The issues of pain were seen as unavoidable and sad but yet were the plan set down by(Ramia *et al.*, 2017, p. 21).The dysfunctional hierarchical relationships among health practitioners, nurses, families, and patients contribute to unmet needs for those facing end of life issues (Kobayakawa,. 2016,p.18).

These chronic illnesses may affect the patient’s moods, so mental health status needs to also be assessed areas of anxiety and depression and also needs to be addressed in those with chronic pain who are facing the end of life issues. The stigma around mental health and seeking care in psychiatry is also a problem. Though all district hospitals have Mental Health services, the care is not stable at the district level as limited access to medications such as serotonin reuptake inhibitors which work well for the care of depression. The use and availability of tricyclic antidepressants are common and these medications are also useful in pain management as well as mental health.

It is important not always to align the end of life issues with a diagnosis cancer; as many NCD as mentioned above, can and will be a cause death for people. Through both their physical and emotional status; it increases stress on family members, though they can influence patient psychological adjustment, illness management and adoption of behavior that influences recovery, functionality, and adherence to medications regimes (Goldberg and Rickler, 2011, p. 42).

2.2.1 PATHOPHYSIOLOGY OF CANCER PAIN

In cancer patients' pain is complex and involves inflammation, neuropathic, ischemic and compression mechanisms at variable sites in the body and this background will assist in the determination of pain and its classification. (Londhey, 2015, p. 16). The pathophysiology of pain is complex and the basics of its generation are occurs when there is a damage of peripheral neuroreceptors in tissues after this damage there is a transmission of the pain signal from peripheral to the central of the brainstem where the influx is modulated which will conduct to the cognition of the final summed sensation of the pain and modify the influence as experienced by the person(Anderson, 2002, p. 18).

2.2.2 PERCEPTION OF PAIN

Family members or in-home caregivers may be limited in their ability to assess and judge patients' pain levels. This lack of critical pain assessment skills may be related to the fact that caregivers may be close emotionally to the patient and their psychological reactions to individuals suffering from chronic pain may vary by the closeness of their relationships(Riffin *et al.*, 2017, p. 7). Caregivers will experience issues of loss and grief reactions relating to terminal caregiving situation. This loss can vary from deep sadness to anger, and the loss and grief process will vary from individual to individual. Even caregivers experience the stage of loss of loss defined by Dr. Kubler Ross; include denial, anger, bargaining, depression, and acceptance. (Lynch *et al.*, 2011, p. 8).

Strength and mindedness help patients and caregivers during the journey of in-home hospice care the experiences of fear related to death, fear of pain, and dying can be lessened by being surrounded by relatives and friends (Nissim *et al.*, 2016, p. 13). Caregivers need support, education and fulfill the following foundational needs for the terminal cancer patient including physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Chronic pain and physical comfort must be a paramount focus as pain may be debilitating but also as the patient progresses respiratory problems, the risk for skin irritation and breakdown, digestive issues such as constipation with narcotic pain medications must be addressed. Terminal patients experience increased sensitivity to temperature changes, where the patient is more sensitive to heat or cold must be noted. These patients with limited resources also become easily fatigued(Larkin, Hasselaar and Payne, 2016, p. 11).

2.2.3. PAIN ASSESSMENT

Caregivers' education on pain management must support by both the caregivers and patients to understand the patient classifications of pain levels the categorization which helps to guide treatment modalities by classifying pain as nociceptive, neuropathic and visceral pain; Neuropathic is a pain accompanied by tissue injury or disease affecting the somatosensory nervous system(Kumar and Elavarasi, 2016, p. 14). Nociceptive pain are the most experienced and develops when nerve fibers triggered by inflammation, chemicals, or physical events, such as stubbing a toe on a piece of furniture (Heinricher and Ph, 2014, p. 8). Visceral pain results from the activation of nerve fibers of visceral organs.(Rishikesan, Mark and Hamish, 2013, p. 9).

Nevertheless, pain can be acute or chronic depending on how long it is last harming the patient. (Groenewald and Palermo, 2015, p. 7). Additionally, breakthrough pain can occur while there is no sufficient dose to manage pain and can worsen at different times of the day, it can also relate to depressive illness which is harming tissues. Even phantom pain also can exist, this pain occurs in the area of the amputated limb area(Lamont, Tranquilli and Grimm, 2000, p. 14). The caregivers and healthcare providers need to have a comprehensive understanding of the underlying causes of pain this will help guide best practices in pain management.

2.2.4. PAIN TREATMENT

Prolonged opioid use may lead to the development of tolerance, hyperalgesia, dependency or addiction (Twycross, 1996). WHO recommends opioid narcotic medications to treat moderate or severe cancer pain and the most commonly-used pain medications include buprenorphine, codeine, fentanyl, hydrocodone, hydromorphone, methadone, morphine, and oxycodone.

Non-narcotic pain medications include tramadol, tapentadol, aspirin, and other related compounds constitute a class of drugs known as non-steroidal anti-inflammatory drugs (NSAIDs). (Wiffen *et al.*, 2017, p. 14). Those medications help pain and comfort in cancer in three areas, anti-inflammatory, analgesic, and antipyretic or fever-reducing properties however non-narcotic analgesic medications such as aspirin, ibuprofen, naproxen, ketorolac, meloxicam, and piroxicam run the risk of gastrointestinal irritation. These medications are also renally secreted patient with renal failure, marginal creatinine or renal function and dehydration may even issue with these medications(Mirabile *et al.*, 2016, p. 21) . Oncological

based pain treatment includes pharmacological and non-pharmacological interventions including radiotherapy, chemotherapy, hormones, bisphosphonates, and surgical interventions(British and Society, 2013, p. 16).

2.3. EMPIRICAL LITERATURE

Pain is a subjective experience based on the self-report of each patient (Mirabile *et al.*, 2016, p. 5). Inadequate assessment of pain and a lack of documentation of pain levels are significant barriers to effective pain control. Oncology patients need frequent assessments of their pain levels, and this assessment of pain is a pillar for effective pain management. Pain management needs to be fruit based on pain severity and pain characteristics(National Cancer Institute, 2014, p. 15).

The description of pain varies dramatically between individual, these differences in pain supports examination of care providers experiences and knowledge related pain assessment and management (Stewart, 2014, p. 21). Systematic evaluation of pain involves the assessment of pain severity, history of the pain, medications and treatments, pain intensity, and characteristics. A comprehensive pain assessment must include the patient's mental health status or psychological state of the patient, including mood , support systems, and coping skills.

There are several validated rating scales available to assess pain. Many patients rate their pain using a verbal assessment score (VAS) which is easy to use but is limited in the evaluation of chronic pain(Borda *et al.*, 2013, p. 16). A Visual Analog Scale (VAS) which is a unidimensional measure of pain intensity, usually 10 centimeters in length. The VAS is anchored by two verbal descriptors of pain intensity, with the words 'no pain' at the left end, and 'worst pain imaginable' at the right(Gregory and Richardson, 2014, p. 18).

Numerical rating scales (NRS) have both written and verbal form. The Verbal Numeric Rating Scale (VNRS) allows patients to rate their pain intensity on the scale of 0 to 10, where 0 represents 'no pain' and 10 represent 'worst pain imaginable severity(Rwanda Ministry of Health, 2012, p. 25) . Patients who able to communicate may utilize more comprehensive tools including the Brief Pain Inventory (BPI)(Stewart, 2014, p. 8) . The BPI uses verbal descriptors and the Wong-Baker Smiley Faces (WBSF) multi-dimensional scales includes the McGill pain questionnaire (MPQ) which is used in palliative care and for the assessment of on-going or chronic pain those tools require cognitive ability(Analog *et al.*, 2011, p. 28).

For child and other acutely ill patients with the impaired consciousness levels, the behavioral pain assessment tools are the next best alternative for their pain assessment. Behavioral pain assessment tools developed for patients who are unable to self-report pain. These scales consist of four items (scores range from 0-8) areas of assessment include verbalization, facial expressions, body movements, changes in the ability to communicate or interact, and changes in activities of daily living including mental status changes. For example, the Abbey Scale includes six items, producing a score ranging from 0 to 18.

(Gregory and Richardson, 2014, p.23) .

2.3.1. IN-HOME CAREGIVERS ASSESSMENT

The caregivers' assessment is a systematic process of gathering information about the caregiving situation and identifying specific problems, needs, strengths, and resources of the family caregivers need or desire it also assess the caregiver's current ability to contribute to the needs of the care recipient both physically and mentally (Reinhard, Fox-grage and Feinberg, 2016, p. 9). they are three Classification of caregivers as the follow categories, as primary caregivers who have complete responsibility for the care recipient, following as primary caregivers whose efforts are supplemented by either informal or formal assistance, and finally as caregivers who do not have primary responsibility for the care recipient (Astolfi, 2014, p. 17).

2.3.2. CAREGIVERS ISSUES AND CONTEXT IN CASE OF PAIN

Terminal care is stressful and taxing, and caregivers may experience physical and emotional issues. Each caregiver has personality traits, historical issues, coping skills, and support systems which may increase the risk for decompensating. Chronic pain may lead caregivers to experience boredom, depression, and a decreased quality of life due to the high stress and demands of in-home care. Socially caregivers face issues in pain management which can be compromised due to the increased tendency towards isolation, feelings of worthless, homebound status, difficulty in performing ADLs, feelings of guilt related to be a burden for members for example can exacerbate pain (Manoochchri *et al.*, 2014, p. 13) (Berry, Dalwadi and Jacobson, 2018, p. 32) .

Persistent chronic pain or inadequately treated pain may heighten the patient's anxiety or increase the risk of substance abuse disorders. Daily stress decreases economic productivity

for patients and caregivers(Tracy, 2017, p. 23) . Caregiving involves managing a multitude of tasks and does not allow caregivers to personal care for themselves as the demands and stress mounts.

Caregivers lacking personal time may become more and more isolated and fatigued. Caregivers state that respite supports time for self-care which can decrease issues of isolation they feel and support renewal of physical, mental, and emotional stability. Poor communication and lack of information may increase stress and frustration. Communication breakdown associated with a lack of care coordination also increases caregiver burnout and stress(Parmar, 2015, p. 12).

2.3.3 CAREGIVERS NEEDS AND CHALLENGES

Care givers are those persons involved in care for the sick person, they may experience needs and challenges at different levels. The stress experienced buy caregivers will differ from person to person and will be expressed differently with each person. The caregivers' needs are divided into five key areas: including transition into hospice care, mounting responsible for entire care or both physical and psychological and at time financial, the importance of support services, access to formal support in terms of all care needs of the patient and caregiver communication, and valid up to date information in the decision-making processes(Fernandes and Angelo, 2016, p. 16).

Caregivers are an essential part of chronic cancer pain management team approach. The need for caregivers results from the chronic nature of the illness and caregivers must be a central player in all the care management planning. The impact of the family or caregivers' attitudes, values, and knowledge will affect the patient's comfort, pain medication regimen, including medication adherence, and the quality of pain management(Lee *et al.*, 2015, p. 24) . Caregivers require respectful collaboration with medical providers to support adjustment of medication to align with the patient 's needs. These medication changes are specific to the individuals' disease process and the need common goals between the medical provider, patient, and family to keep the patient safe at home, relatively pain free and able to manage stress (Hunt and Alliance, 2016, p. 15).

Transition into terminal care must be proactive and deliver care options to patients and family to support the disease process. Health care transition with a focus on the reassurance of caregivers' well-being is imperative(Hallberg, 2016, p. 8). Caregivers' burdens include excessive time demands, issues of physical exhaustion, and financial burdens (Gibson, Kelly

and Kaplan, 2012, p. 18) . A 2014 study in China indicated mental stress and personal health risks when faced with in-home care needs for their loved ones. The caregivers indicated in the study a strong desire for knowledge about each patient's disease process, how to allocate improved symptom control, psychological issues, and support, and how each provider can allocate attention to their own health and support caregiver's resilience(Cui, Military and Song, 2014, p. 15).

Every person involved with a patient suffering from illnesses such as cancer needs up to date information to help them through education. This education will help the caregiver to make informed decision planning. The caregiver needs to know how to utilize healthcare resources to optimize the patients' outcomes. The caregiver needs to have increased knowledge which will prevent fear and anxiety associated with chronic illness(Info, 2018, p. 16) .

2.3.4. APPROACHES TO SUPPORT CAREGIVERS IN PAIN MANAGEMENT

Strengthened support systems and intensive follow up with home services will improve in-home palliative care delivery. Not only necessary daily care regimes inherent to the proper delivery of care but also may help financial, technical, and emotional barriers to care and increase the availability of care providers as needed (Kunsch, 2016, p. 23).

Training about pain assessment tools will also support the care provider in the in-home setting. (Torvik *et al.*, 2015, p. 27). There is inadequate training in palliative care and pain management seen in industrialized countries. (Lohman, Schleifer and Amon, 2010, p. 15) .But if they are well trained, caregivers can be deeply satisfied as care partners, and family members will be drawn closer together. However, as the care demands increase physically, emotionally, and cognitively the care recipient then has less time to devote to the caregiver's own needs (Sullivan, 2015, p. 12).

Research indicates that most of the caregivers' duties include assisting with the activity of daily living. The in-home caregivers are responsible for the coordination of medical care, most hands-on nursing activities, and as emotional support on a day to day basis. These tasks can be all-consuming, and caregivers may neglect their own health and not take time to stay healthy.

Additional challenges were noted when end of life patients become hospitalized; as caregivers related that upon discharge interacting with physicians, nurses and another healthcare team members was difficult for them. There are limits on the amount of support that the health care professionals can give in the form of managing tasks and giving increased support where there is limited emotional support demands for the caregiving family members(Reinhard *et al.*, 2018, p. 18). Caregivers relate they needed to be acknowledged, valued, and better understood within the care process. In-home care providers felt support need tailoring to each patient and family's needs, values, and preferences in the context of ongoing support and monitoring of the home care situation they faced daily (Reinhard, Fox-grage and Feinberg, 2016, p. 23).

The home care situation is not static, and caregivers expressed a desire for nurses and medical healthcare providers needed to develop care strategies and planned interventions with a focus on caregiver empowerment. Moreover, new public policies and educational programs should be developed and directed at family caregivers to help reduce the risk of harm or abuse for the dependent, vulnerable terminally ill patient (Bierhals *et al.*, 2017, p. 13).

2.3.5 CAREGIVER'S RESPONSIBILITIES

However, caregivers do experience needs there also having responsibilities through which they need to function well, to execute fruitful care and be effective and efficient. Caregivers may require collaboration and support that needs to be adjusted with each patient's needs and designed explicitly towards the individual disease processes(Hallberg, 2016, p. 23). Throughout the care continuum, caregivers are dealing with uncontrolled and everchanging situations which increase caregiving responsibilities in emotional, physical, psychological, and financial areas. Individuals and families need to plan how they will adjust their lifestyle, along with their siblings and friends as the disease process progresses(Sullivan, 2015, p. 15) . In home caregivers are critical members of the care team. The central key role of caregivers increases stress in two ways- caregiver as providers and the caregiver as a client. Family members and in-home caregivers relate that the care planning is the fundamental roadmap to understanding the expectations placed on them as a member of the health plan

(Reinhard *et al.*, 2018, p. 14). When family caregivers feel supported, they are better able to continue in the caregiving roles at home, thereby reducing the cost of both public and private services(Reinhard, Fox-grage and Feinberg, 2016, p. 13).

2.4. CRITICAL REVIEW AND RESEARCH GAP IDENTIFICATION

Caregivers often feel a significant demand and burden to their endurance and coping mechanisms and report a plethora of their own physical and psychological symptoms. Caregivers often are forced into the role of care provider out of necessity and have no previous knowledge or caregiving skill(Sullivan, 2015, p. 17).

Caregivers relate gaps in attention to potential emergencies and barriers in home terminal care. Caregivers are the forgotten patients, running a risk of adverse, severe physical and mental health consequences due to the demanding role they play as the home caregiver, they may not pay attention to their own healthcare needs.

As their duties to the patient increases; the caregiver may face decreasing personal physical health and even at the extreme premature death (Reinhard *et al.*, 2018, p. 24). Issues such as anticipatory grief, caregiver's emotional burden, lack of preparation to deal with the patient's suffering, pain management, financial hardships, and lack of support from the health institutions are challenges faced by caregivers in chronic in-home care conditions(Kunsch, 2016, p. 23).

Task shifting, communication, and care coordination are essential to assign tasks associated with the care regime; New tasks may cause an imbalance in the family caregiver unit related to the time requirements necessary to perform these various activities. The emotional needs described are essential to support for this new role and must be addressed to reduce the caregiver burdens (Fernandes and Angelo, 2016, p. 13).

The burdens of care may include time spent providing care to another person, domestic chores, being unprepared to care for a bedridden patient, the caregiver's physical burden, a lack of proper equipment, limited physical structure within the home, and marginal support on the part of the health professionals(Kunsch, 2016, p. 14). Nurses and other healthcare professionals are involved at multiple points within the context and have a crucial role as advocates. Healthcare providers can assist families and patients through the illness continuum by educating members of the interdisciplinary team concerning the unique situations faced by families. The education about what families and care providers are facing

is imperative and influencing the development and implementation of family-centered programs with interventions with foster partnerships between nursing home staff and caregivers and their families.(Koplow *et al.*, 2015, p. 21) .The in-home treatment of chronic pain with opioids may increase issues such as misuse, abuse, addiction, overdose, and death.(Majeed, Muhammad Hassan; Sudak, 2017, p. 26).

2.4.1. IN HOME CARE GIVERS NEEDS ON PAIN MANAGEMENT

An individual caregivers' perception of needed and desired levels of social support can be an important factor in decreasing the potential for depression and anxiety. Supportive groups offer empathetic mutual understanding from persons facing the same issues and problems.(Info, 2018, p. 8) . Supporting care givers includes assessment and determination who will exactly be in charge of the patient communication and interaction within the healthcare system. Communication about educational programs which defines the roles, responsibilities, and gaps in knowledge will increase skills and enhance comfort at the bedside to enhance caregiving techniques.

Caregivers need empowerment and assistance to strengthened and help align control over their lives and provide greater peace of mind. Assisting and educating family caregivers on how and where they can receive assistance, ranging from getting a medication question answered to dealing with an emergency is imperative.(Berry, Dalwadi and Jacobson, 2018, p. 19) .Therefore, nurses and other healthcare professionals need to partner with hospital administration, patients, and their families to urge for the development of standards and training for engaging families or in-home caregivers to assess their personal needs routinely. (Perez, 2018, p. 21) Family caregivers need education training in problem-solving skills, and recognition from providers about their role in pain management(Republic of Rwanda, 2018, p. 45). Interventions targeted to caregivers and trained home care teams may improve the quality of cancer care in these settings (Konstantis and Exiara, 2019, p. 13). Though the effects of cancer most directly affect the individual with cancer, its impact extends to the relatives or friends who care for the person with cancer. Family and friends are often central in providing care or assistance in both the immediate and long- term management of cancer. Furthermore, as a result of advances in treatment and health care changes, much of cancer care is offered on an outpatient basis and is performed at home by caregivers. Research indicates that caregiving can be both demanding and burdensome – physically, emotionally, and financially for many cancer caregivers(Hunt and Alliance, 2016, p. 12). Risk factors for

caregiver burden include female sex, low educational attainment, residence with the care recipient, the higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver(Adelman *et al.*, 2015, p. 18) .

2.4.2. INTERVENTIONS TO IMPROVE COMPETENCE AND CONFIDENCE OF HOME CAREGIVER

The provision of service and access to the home care team, a collaborative home care dossier or case file, and care protocols need to be used in improving caregivers' competences. These items will assist with communication and coordination system between caregivers and health professionals by empowering family members and decrease moderate caregiver stresses. (Reinhard *et al.*, 2018, p. 17). Then home care giving does require protocols and multidisciplinary teams to reach the objective of pain relieves and decrease the caregiver's issues related. (Writer *et al.*, 2017, p. 14).

Research indicates the importance of the contributions to improving quality of caregiver's life based on enhancing the ability to offer pain management at home and to ensure adequate availability of adequate materials, relevant structure, financial support, technical support, and emotional support. (Kunsch, 2016, p. 31).

Caregivers require access to a wide range of community services and resources such as education, training in emergency care specific to the care recipient, and respite supportive services. Research has shown that caregivers need to understand the implications of each diagnosis better, prepare for the future, and have a safe space to address concerns when appropriate support. Provision of emotional support was noted to result in decreased distress, improved coping and increased caregiver quality of life-enhancing (Parmar, 2015, p. 16)

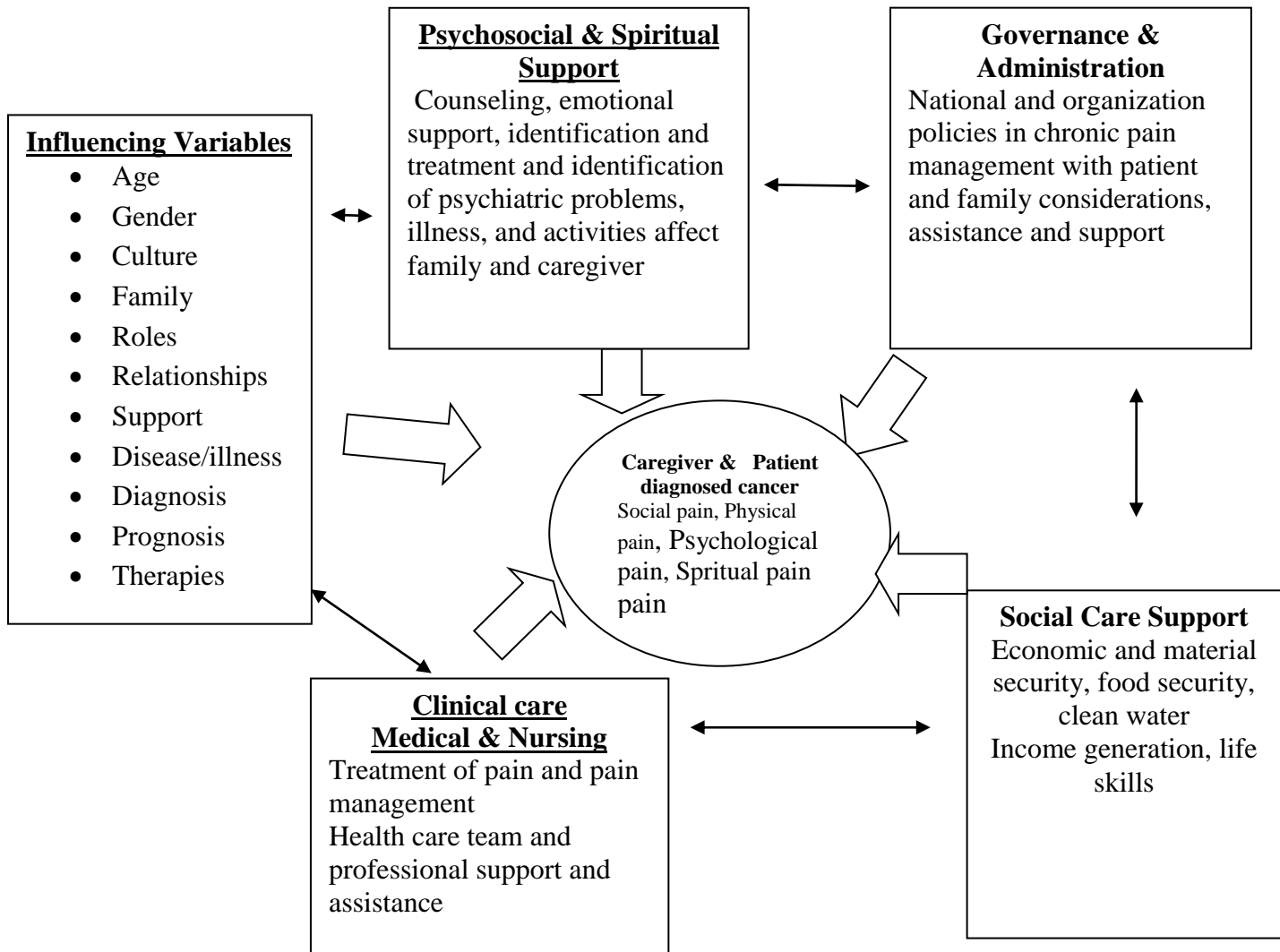
2.5 .CONCEPTUAL FRAMEWORK FOR CAREGIVERS KNOWLEDGE AND EXPERIENCES ON CANCER PAIN MANAGEMENT

Figure 1 is the application of multidisciplinary team of medical professionals in pain management, every member within the health care team should take a moment to assess and address caregiver needs while facing a cancer patient with pain and provide appropriate care concerning the illness of the client to the context of care and available resources which can be useful. An interdisciplinary teamwork will involve the health care team, administration caregiver-patient and other organization approaches to care has adopted and support throughout the healthcare home care context (Berry, Dalwadi and Jacobson, 2018; Sullivan, 2015).

The pain has psycho-social and spiritual components there is a need to consider or this so that the patient will be managed effectively, however there are several variables which can contribute to patient demographic status.

Therapies this will contribute to the Health care team and professional support and assistance for patient, the national organization policies in chronic pain management with patient and family considerations will highlight the assistances and support guidelines with pain management key point to be emphasize on with training requirements and protocols ,the social economic status of the patient will contribute to the effective implementation of the protocols and its efficiency by considering both caregivers and patient roles in the implementation of pain management for diagnosed cancer patient .

Table 1: Conceptual Framework for knowledge and home Caregivers experiences on cancer pain management



Adopted from (Berry, Dalwadi and Jacobson, 2018, p. 24)and (Sullivan, 2015, p. 26)

CHAPTER 3: METHODOLOGY

3.1. INTRODUCTION

This chapter explains the process and methods which was used to conduct this study. This research project includes a study area, study population, study design, sample size and sampling methods, data collection methods and procedures, data analysis, study limitation and problems, and ethical consideration.

3.2. STUDY DESIGN

This research study used a non-experimental descriptive cross-sectional design which to collect data from participants. This study design was selected because it allows collecting all information at one point in time.

3.3. STUDY APPROACH

This research study used a quantitative research Approach. Data was collected from care givers of patients with terminal ill cancer who experience chronic pain in their illness continuum from Kibogora catchment area. The data was collected by the researcher.

3.4. STUDY SETTING

This research study setting was conducted in the Kibogora District Hospital Catchment area, in Nyamasheke District, in rural Rwanda. The point of interest was the palliative care service.

3.5. STUDY POPULATION

The study participants are a selected group of 221 caregivers , for 77 patients enrolled in the palliative care services from Kibogora Palliative Care Program.

3.6. SAMPLING

3.6.1. SAMPLING STRATEGY

A convenience sampling method was used in this study in order to gain samples of caregivers, nonprobability or nonrandom sampling. Members of the target population must meet inclusion criteria and be easily accessible, geographically proximity, and have the availability and a willingness to participant. (Dornyei, Z, 2007, p.1).

3.6.2. SAMPLE SIZE

Sample size in the quantitative study must be the biggest so that it is representative of the target population (Polit & Beck, 2010, p.49). In this research the sample size 120 caregivers from 221 of caregivers who ever participated in the care for the patient and has ever contacted with health care team in patient care period as for one patient they may have or more persons who has cared for her/him.(According to Yamane (1967, p.886), sample sizes is 120

3.6.3 INCLUSION AND EXCLUSION CRITERIA

Participants sampling inclusion criteria was available caregivers of patient whose patients are in terminal illness cancer state with pain complains and are receiving in home-based care services. Participants must be 16 years of age or older. Participants will be included that give informed consent to participate in the study.

Exclusion criteria are caregivers who do not give informed consent for the study, caregivers with obvious mental health disorders. Also, caregivers aged less than 16 years whose patients has other caregivers older than 16 years old and, caregivers whose patient's do not have cancer, and caregivers whose patients are cared in homecare service less than two weeks

3.7. DATA COLLECTION

3.7.1. DATA COLLECTION INSTRUMENT

The tool is a questionnaire format and focused on the assessment of knowledge and experience of home caregivers for cancer pain management in Rwanda. Data collection used structured questionnaire, the first section was containing questions on patients' family caregiver's demographic information, the knowledge, and experience of chronic pain management related to caregiving context analysis. Currently, there is no tool used in the Rwandan context to examine the caregivers' experiences with pain management in the in-home care context the used tools tested and was modified and adapted to Rwandan Context (Ferreira, Sa and Orth, 2014, p. 16).

These tool was developed in 1987 and has been used extensively from 1987 to present.it has been revised over the years to reflect changes in pain management practice. Content validity has been established by reviewer of pain experts. Test-retest Reliability was established.

Internal consistency reliability was established with items reflecting both knowledge and attitude domains. The pilot test was done with experts in the field of nursing.

3.7.2. DATA COLLECTION PROCEDURE

After approval from the CMHS IRB, this researcher contacted the Ministry of Health in department National Health research community for approval. The researcher also contacted Kibogora District Hospital and administration to request for permission to conduct the study in their institution. Once approval from authorities received, introduce himself to nurses in charge of the services to get contacts of participants who signed consent form before participating after being explained on the study, on the importance of their participation, the procedures to be followed and the purpose of the study was also shared. The data were collected during one month by the researcher himself

3.8. DATA ANALYSIS

Quantitative data was used to analyze data descriptively (frequency, percentages) and inferential statistics (chi-square and Pearson correlation coefficient, and cross-tabulations were done). Data analysis with SPSS 20 and the results presented in tables and graphs.

3.9. ETHICAL CONSIDERATIONS

Before conducting this study, the researcher requested written permission from CMHS researcher center, National Health Research community, and Kibogora District Hospital and the researcher ensured the participants that their participation in the study was voluntary. No names were attached to the questionnaires to ensure anonymity to encourage respondents to give full and correct information. The participants was assured that the information for the study will be confidential and used for study purposes of this study alone, and a signed consent form will be used to allow the researcher to conduct the study. Participants were instructed that they might withdraw at any stage of the study without any consequences.

3.10. DATA MANAGEMENT

All data was collected, quantified, entered in SPSS, and analyzed. All paper documents are kept in a locked cabinet in the PI office and will be destroyed in 10 years. The soft data stored on a password-protected computer that only the PI had the password the computer.

3. 11. DATA DISSEMINATION

The results of this study will be disseminated to the Ministry of Health, the University of Rwanda, School of Nursing and midwifery, Hospice organizations within Rwanda, and students. The researcher will seek to publish this work. The researcher will provide feedback to the study setting in order to facilitate them to set strategies to improve chronic pain management by involving caregiver's context at home-based care.

3.12. STUDY BARRIERS AND LIMITATIONS

Due to logistic and cultural reasons, family caregivers practice information was not easily assessed and clear to the researcher. Other barriers included the issue of getting approval for the project which was held up at the MoH level and at the hospital level. The researcher had limited time to complete the study and had to travel for long distances to meet with participants in the region which not geographically accessible and the data well collected in winter period which was not easy. In spite, the listed limitations of the study we provided critical information that will contribute to nursing research in Rwanda.

CHAPTER 4: RESULTS PRESENTATION AND INTERPRETATION

4.1. INTRODUCTION

This section presents the socio-economic and demographic characteristics of participants, along with the results of statistical tests for association (Chi-square, Fisher's exact test, and Pearson) and the Pearson correlation coefficients between knowledge received from the palliative care team and caregivers' experiences with in-home pain management.

4.2. PRESENTATION OF DATA

4.2.1: DEMOGRAPHICS OF PARTICIPANTS (N=120)

Age (n=120)

Figure 1 describes the results from respondents; the majority 63(52.5%) were youth and 47(39.2%) were in adult age and 10(8,3%) were old people who are involved in care

Table 2: Age distribution of respondents

Age of responder		Frequency	Percent
Age of responder	Between 18 to 30 YO	63	52.5%
	Between 31 to 55	47	39.2%
	Above 55 YO	10	8.3%
	Total	120	100.0%

Table 2 reveals that the majority of respondents were male (n=72, 60%), while males who responded were (n=48, 40%). The majority of respondents did not have any form of formal education (n=48, 40%). Eight respondents (6.7%) had attended nursery school, while 32 (26.7%) had attended primary school at any level. Twenty-four (20%) attended secondary school, and eight (6.7%) had a university level of education. The majority of respondents were unemployed (n=88, 73.3%), with only 32 (26.7%) employed

The results show that 16 (13.3%) of the respondents were public employees, 24 (20%) were employed in private institutions, and were self-employed. The majority (n=72, 60%) had employers in farming and agriculture.

Table 2: Distribution of participants based on gender, education, and occupation

Gender	n120 (%)
Male	48 (40%)
Female	72 (60%)
Education of respondents	
Primary school	32 (26.7%)
Secondary school	24 (20.0%)
University level	8 (6.7%)
Employment status of respondents	
Employed	32 (26.7%)
Unemployed	88 (73.3%)
Service of employers for respondents	
Public	16(13.3%)
Private	24(20%)
Self employed	8 (6.7%)
Other employers/agriculture	72 (60%)

4.2.2. Distribution of participants according to time of cancer diagnosing, time for services admission, and presence of pain in illness back ground for patients type of pain and score level and pain treatment Knowledge.

Analysis of respondent responses on patient diagnosis indicated that the majority of their patients were diagnosed more than one year ago (n=96, 80%), and 24 (20%) were admitted 6-12 months ago. However, the admission results reveal that the majority of patients were admitted to home-based care than one year ago (n=96, 80%), 21 (17.5%) were admitted 6-12 months ago, two (1.7%) patients were admitted 1-6 months and one (0.8%) were admitted for 1 month. The majority of respondents reported that their patients experienced pain during the illness (n=112, 93.3%), while only eight (6.7%) patients did not.

The majority of patients cared for experienced severe pain (n=104, 86.7%), and 14 (11.7%) experienced moderate pain. Two respondents (1.7%) reported that their patients had mild pain. No respondents said that their patients experienced pain level score between 0 and 4. Seven (5.8%) respondents indicated that their patients' pain intensity scores ranged from 5 to 7. However, the majority (n=113; 94.2%) responded that their patients' pain intensity scores

ranged from 8 to 10. Regarding painkillers taken by the patients, the majority of respondents (n=64, 53.3%) knew only the form of drug. Forty-eight (40%) previously knew the medication name but had forgotten it, and eight (6.7%) knew the name of the medication taken by the patient

Table 3: Distribution of participants according to time of cancer diagnosing, time for services admission, and presence of pain in illness back ground for patients type of pain and score level and pain treatment Knowledge.

Time since diagnosis	n (%)
Under one 1 year	24 (20%)
More than 1 year	96 (80%)

Admission time in home care service

More than one month	1 (0.8%)
Between 1 to 6 months	2 (1.7%)
Between 6 months to 1 year	21 (17.5%)
More than 1 year	96 (80%)

Presence of pain in illness history

Yes	112 (93.3%)
No	8 (6.7%)

Types of pain intensity of patient from respondent

Mild pain	2 (1.7%)
Moderate pain	14 (11.7%)
Severe pain	104 (86.7%)

Pain level score according to caregivers

0-4; mild pain	0 (0%)
5-7; moderate pain	7 (5.8%)
8-10; several pain	113 (94.2%)

Knowledge of patient's painkillers

Name of medication known	8 (6.7%)
Name of medication previously known but forgotten	48 (40%)
Name of medication unknown, but form is known	64 (53.3%)

4.2.3. Distribution of respondents according to length for pain suffering time, living conditions, patient relationship and place for care appreciation.

From respondents 8(6.7%) were suffering for pain in the time below 1 year, 64(53.3%) were suffering for pain from 1 to 3 years; 48(40%), the pain suffer range more than 3 years, the majority of patients lived with close family members (n=104, 86.7%), eight (6.7%) were living with friends, and eight (6.7%) were living alone. Twenty-four (20%) of the patient’s caregivers received care at the hospital, and 96 (80.7%) were appreciating the care from home. The majority of caregivers had close relationships with the patients (n=88, 73.3%), and 32 (26.7%) were caring for the patients as a job.

Table 4: Distribution of respondents according to length of time for pain suffering, living conditions, and relationship and place for care.

Time for pain suffering from patients	n (%)
Less than 1 year	8 (6.7%)
Between 1 to 3 years	64 (53.3%)
Between 3 to 5 years	48 (40%)
Patient’s living condition	
Living alone	8 (6.7%)
Living with friend	8 (6.7%)
Living with close family	104 (86.7%)
Place preferred to care	
Hospital	24 (20%)
Home	96 (80.7%)
Caregiver’s relationship with patient	
Close relative	88 (73.3%)
Employed	32 (26.7%)

4.2.4: DISTRIBUTION OF RESPONDENTS BASED ON EDUCATION RECEIVED FROM THE PALLIATIVE HEALTH CARE TEAM

The majority of respondents (n=112, 93.3%) indicated that they were educated on the consequences of chronic pain management, while eight (6.7%) had not received this teaching. Additionally, the majority (n=104, 86.7%) were educated on their patients' conditions, while 16 (13.3%) did not. The majority of respondents were educated on cancer pain (n=112, 93.3%), while eight (6.7%) did not. The majority (n=88, 73.3%) received training on pain assessment tools but did not use them, while 32 (26.7%) were trained on the tools and did use them. The majority of respondents were educated on drug administration and management of side effects, while a small number of respondents were not educated (n=16, 13.3%). The majority of respondents (n=96, 80%) were not educated on end-of-life signs; only 24 (20%) were educated. The majority of people were informed of the consequences of chronic pain management (n=112(93%), and 32 (26.7%) were not.

Table 4: Distribution according to education on cancer pain, consequences, condition, pain on assessment and tools uses with their availability, drug administration and side effects management, end-of-life signs and being prepared for chronic pain management effects

	Yes	n (%) No
Education on pain management consequences	112 (93.3)	8 (6.7)
Education on types of pain related to cancer	104 (86.7%)	16 (13.3 %.)
Education on pain assessment	72 (60.0)	48 (40)
Education on pain assessment tools uses	32 (26.7)	88 (73.3)
Education on drug administration and side effects management	104 (86.7)	16 (13.3)
Education on end-of-life signs	96 (80)	24 (20)
Being prepared on chronic pain management consequences	88 (73.3)	32 (26.7)

4.2.5: RESPONDENT SELF-ASSESSMENT OF KNOWLEDGE RECEIVED ABOUT CHRONIC PAIN MANAGEMENT FROM PALLIATIVE CARE TEAM

32 (26.7%) were not stable with education had low level of comfort stability in chronic pain management, eight (6.7%) were stable but not enough, while only 16 (13.3%) were stable with the education given to them, from education based uses on pain management ; 24 (20%) indicated that they used some but not all forms of management, 16 used by all of them but not always (13.3%), and 16 (13.3%) used all methods taught to manage pain for the patient, . The majority of respondents (n=64, 33.3%) did not use the different methods they were trained in to manage pain. Twenty-four (26.7%) used some but not all of the pain management techniques. Sixteen (13.3%) used the techniques but not always, and only 16 (13.3%) always used the pain management techniques thought. The majority of respondents had gaps in their education (n=104, 86.77%), while 16 (13.3%) did not. Most respondents (n=51; 42.5%) provided support with living conditions. 43(35.8%) provided support in social and cognitive domains, and 10 (8.3%) supported their patients in spirituality. All respondents (n=120, 100%) had gaps about the information received on cancer pain management.

On assessment of patient satisfaction according to the caregiver's own view, the majority of respondents said that their patients had low satisfaction level on their intervention n=72 (60%). 24 (20%) had patients who were not satisfied with their care, 16 (13.3%) had satisfied patients, and only eight (6.7%) had very satisfied patients. The majority (n=80, 66.7%) of respondents were personally affected by the ending situation of their patients. 24 (20%) where not significantly affected by how their patient's ending situation is; whoever 16 (13.%) did not appreciate their patients' end-of-life situations.

On assessment of support, the majority of respondents did not appreciate the support they received in caring for their patient and felt that it was not enough (n=72, 60%), while 48 (40%) did appreciate the support they received from the health care team. All respondents n=120(100%) identified nurses as the most health care team members who provided support more than others. The majority of respondents had stress related to chronic management of the patient's pain (n=104, 86.7%), while few respondents did not have stress relating to care (n=16, 13.3%). All 120 respondents had challenges and were missing information that could have contributed to the care provided to patients.

All respondents had unaddressed concerns that required advocacy on their behalf. The majority of respondents (n=88, 73.3%) did not have the resources to generate income to support care, while 32 (26.7%) had resources income generation. There were 104 respondents (87.7%) who coped with their patients' situations, while 16 (13.3%) did not. (n=88, 73.3%) did not have any negative feelings and were unlikely to self-blame in the future for insufficient support of the patient. However, 32 did not appreciate how they cared for their patient and were at risk of self-blame in the future. All respondents viewed the patient's passing as normal; 104 (86.7%) did not attribute it to any spiritual beliefs, eight (6.7%) referenced ideas in traditional health, and eight (6.7%) found support in African beliefs. All respondents overcome the situation and they are coped with the had an assistant with whom they could rotate and thereby find time to rest

From results , 96 (80%) did not have anyone to support them in patient care; only 24 (24%)

situation of cancer pain management they are doing in home-based care with terminally ill patient.

Table 5: Respondents' self-assessment of chronic cancer pain management

Caregivers' stability with received education	n (%)	
Stable with education received	16 (13.3)	
Not stable	32 (26.7)	
Stable, but not enough	8 (6.7)	
Slightly stable	64 (53.3)	
Use of pain management methods	n (%)	
Not used	64 (33.3)	
Used but not all	24 (26.7)	
Used but not always	8 (6.7)	
All methods used to manage pain	64 (53.3)	
Gaps in pain management education	n (%)	
	Yes	No
Presence of gaps	104 (86.7)	16 (13.3)
Patient satisfaction	n (%)	
Not satisfied	24 (20)	

Slightly satisfied	72 (60)
Satisfied	16 (13.3)
Very satisfied	8 (6.7)
Type of care and domain of satisfaction for their patient	n (%)
Daily life	15 (12.5)
Living conditions	51 (42.5)
Social and cognitive	43 (35.8)
Spiritual	10 (8.3)
	n (%)
self-appreciation Respondent	
Gaps in information received by caregivers	120 (100)
Success in pain management and patient satisfaction	n (%)
Not satisfied	24 (20)
Slightly satisfied	72 (60)
Satisfied	16 (13.3)
Very satisfied	8 (6.7)
Appreciation of patient's end-of-life situation and effect on caregivers' lives	n (%)
Yes	24 (20)
No	16 (13.3)
Not very affected	80 (66.7)
Respondents appreciation of support received basing on education	n (%)
Received enough support	24 (20)
Received support, but not enough	16 (13.3)
Did not receive support	80 (66.7)
Health care team member identified as most supportive	n (%)
Nurses	120 (100)

Physicians ,Social workers, Local,	0(0%)
Government, Mental Health, nurses, Chaplain	0(0%)
or Priest/Pastors, Traditional healers, Family	0(0%)
,Neighbours/friends	
Experience of stress in managing chronic pain for patients	n (%)
Yes	104 (86.7)
No	16 (13.3)
Experience of challenges and incomplete information on pain management	n (%)
Yes	120 (100)
No	0(0%)
Experience of unaddressed concerns	n (%)
Yes	120 (100)
No	0(0%)
Ability to cope with the caregiving situation	n (%)
Yes	104 (86.7)
No	16 (13.3)
Current or potential future feelings	n (%)
Yes	22 (26.7)
No	88 (73.3)
Perception of situation as normal	n (%)
Yes	120 (100)
No	0(0%)
Beliefs ascribed to situation	n (%)
Traditional	8 (6.7)
African beliefs	8 (6.7)
No beliefs referenced	104 (86.7)
Ability to overcome the situation	n (%)
Yes	120 (100)
No	0(0%)

4.2.5: BIVARIATE ANALYSIS FOR CONTRIBUTION OF KNOWLEDGE OF PAIN KILLER FROM HEALTH CARE TEAM TO HOME CAREGIVERS' S EXPERIENCE IN CANCER PAIN MANAGEMENT

According to the results, adjusting corrected shows that pain killer knowledge is significant associated to stability of caregivers in home cancer pain management (chi-square,0.5,p=0.000).it means that more pain killers are known , more they will be stable in providing care to their patients ,the is also a significant association on the knowledge of caregivers with end of life appreciation to the patient(chi-square,0.5,p=0.000), pain killer knowledge is significantly associated to appreciation of support their receiving in cancer pain management at home (chi-square,0.37,p=0.000), pain killer knowledge is significantly is significantly associated to the caregivers assumption of the situation (chi-square,1,p=0.001), more caregivers will be having a knowledge on pain killer will highly contribute to their stability in providing care for their patient with cancer pain and they will also be room of appreciation for support that they are receiving and will also determiner how they are affected by the end of life for their relatives however also will contribute to assumption of the situation and adoption of others measures to support in pain management .

Table 6: Bivariate Analysis for Contribution of Knowledge of Pain Killer From Health Care Team to Home Caregivers' Experience

BIVARIATE ANALYSIS FOR CONTRIBUTION OF KNOWLEDGE OF PAIN KILLER FROM HEALTH CARE TEAM TO HOME CAREGIVERS' EXPERIENCE IN CANCER PAIN MANAGEMENT	P-Value	Chis-square
Knowledge on pain killers * stability of care givers on drug administration	000	0.5
Knowledge of pain killers for patient by respondent * care givers appreciation of end life time for patient and are their affecting personal life	.000	0.5
Knowledge of pain killers for patient by respondent * caregivers appreciation of support their from health care team	.000	0.37
Knowledge of pain killers for patient by respondent * caregivers	.001	1

assumption on the situation and probable causes and others spiritual use		
--	--	--

N=120 outcome; Knowledge of pain Killer to home caregivers experience ***p<0.05**

4.2.6: BIVARIATE ANALYSIS FOR CONTRIBUTION OF EXPLANATION ABOUT PATIENT CONDITION FROM HEALTH CARE TEAM TO HOME CAREGIVERS' S EXPERIENCE IN CANCER PAIN MANAGEMENT

From the results analysis of contribution for explanation received from palliative health care team shows that explanation on patient condition is significantly associated to the stability of caregivers in drug administration to patient (chi-square,0.32,p=0.003),the explanation has also a significant association to the education of pain management types and their use for patient(chi-square,0.42,p=0.000),explanation will highly contribute to the preparedness of caregivers on chronically pain management effects (chi-square,0.4,p=0.000),explanation to patient condition is significantly associate to the success in pain management and patient satisfaction (chi-square,0.2,p=0.003),explanation on patient condition is highly associated to the appreciation of end of life patients conditions (chi-square,0.333,p=0.001) ,caregivers explanation on patient condition has a significant association on situational assumption on chronic pain (chi-square,0.477,p=0.000), explanation on patient condition is also significantly associated to the caregivers coping with situation(chi-square,0.003,p=0.001), ,patient's health condition explanation is significantly associated to the stress management for caregivers (chi-square,0.28,p=0.001),the explanation to caregivers on pain management will contribute to the stability in chronic pain cancer pain management(chi-square,0.56,p=0.000),these shows that while caregivers will explain to caregivers the condition of patient's life this will contribute to their stability in care for the patient ,knowledge of pain management methods and their application ,success in pain management and satisfying the patient with caregivers appreciation and valuing the end of life period of patient,wil also contribute to the stress management relating to chronic pain management will also contribute on how caregivers will cope with situation and the meaning that they are providing to the situation in which their patients is passing through.

Table 7: Bivariate analysis for contribution of explanation about patient condition from health care team to home caregiver’s experience in cancer pain management

BIVARIATE ANALYSIS FOR CONTRIBUTION OF EXPLANATION ABOUT PATIENT CONDITION FROM HEALTH CARE TEAM TO HOME CAREGIVERS’ S EXPERIENCE IN CANCER PAIN MANAGEMENT	P-Value	Chis-square
Explanation of health care team to caregivers about patient’s condition * stability of care givers due to received education received on drug administration	.003	0.32
Explanation of health care team to caregivers about patient’s condition * education of pain management type and their use for caregivers	.000	0.42
Explanation of health care team to caregivers about patient’s condition * preparedness of about chronically pain management effects	.000	0.4
Explanation of health care team to caregivers about patient’s condition * success to pain management and satisfy the patient	0.031	0.2
Explanation of health care team to caregivers about patient’s condition * care givers appreciation of end life time for patient and are their affecting personal life	001	0.333
Explanation of health care team to caregivers about patient’s condition * stress of caregivers for being supporting the patient	.001	0.28
Explanation of health care team to caregivers about patient’s condition * Caregivers coping with the situation	.001	0.003
Explanation of health care team to caregivers about patient’s condition * caregivers assumption on the situation and probable causes and others spiritual use	.000	0.477
Explained about consequences of chronic pain management * stability of care givers due to received education received on drug administration	.000	0.56

N=120 outcome; explanation about patient's condition to home caregivers experience
*p<0.05

4.2.7: BIVARIATE ANALYSIS OF CONTRIBUTION OF EXPLANATION ON PAIN ASSESSMENT TO THE EXPERIENCE OF HOME CAREGIVERS IN CHRONIC CANCER PAIN MANAGEMENT

The explanation on pain assessment is significantly associated to the relaxation during pain management (chi-square,0.37,p=0.000), The explanation on pain assessment is significantly associated to gaps of education on pain management The explanation of pain assessment is significantly associated to the relaxation during pain management (chi-square,0.433,p=0.000),explanation on pain assessment is significantly associated to the success of pain management and patient satisfaction (chi-square,0.406,p=0.000),pain assessment explanation is significantly associated to the caregivers appreciation (chi-square,0.362,p=0.000), pain assessment explanation is significantly associated to the caregivers coping (chi-square,0.305,p=0.000), pain assessment explanation is significantly associated to the caregivers personal feeling and future regret(chi-square,0.44,p=0.000), pain assessment explanation is significantly associated to the caregivers assumption on the situation and probable causes and others spiritual use (chi-square,0.35,p=0.000).from the results the explanation of pain assessment to caregiver will highly contribute to having same body else to assist and the caregivers will shift for relaxation ,this will also contribute to address of gaps in chronic cancer pain management, success in cancer pain management ,caregivers coping ,caregivers personal feeling, future concern and avoidance of regret and assumption of patients condition with spiritual concern .

Table 8: Bivariate analysis of contribution of explanation on pain assessment to the experience of home caregivers in chronic cancer pain management

BIVARIATE ANALYSIS OF CONTRIBUTION OF EXPLANATION ON PAIN ASSESSMENT TO THE EXPERIENCE OF HOME CAREGIVERS IN CHRONIC CANCER PAIN MANAGEMENT	P-Value	Chis-square
Health care team ‘ explanation of pain assessment to respondents * presence of same body else who can assisted and helps to relax	.000	0.37
Health care team ‘ explanation of pain assessment to respondents * gaps on received education on pain management	0.000	.0433
Health care team ‘ explanation of pain assessment to respondent * success to pain management and satisfy the patient	.000	0.406
Health care team ‘ explanation of pain assessment to respondents * caregivers appreciation of support their from health care team	0.000	0.362
Health care team ‘ explanation of pain assessment to respondents * Caregivers coping with the situation	.000	.305
Health care team ‘ explanation of pain assessment to respondents * caregivers feeling and concern on their personal life and future regret	0.000	0.44
Health care team ‘ explanation of pain assessment to respondents * caregivers assumption on the situation and probable causes and others spiritual use	.000	0.35

N=120 outcome; explanation about pain assessment to home caregivers experience ***p<0.05**

4.2.9: BIVARIATE ANALYSIS OF EDUCATION ON PAIN ASSESSMENT TOOLS TO EXPERIENCES OF HOME CAREGIVERS IN CHRONIC CANCER PAIN MANAGEMENT

Education of pain assessment tools is significantly associated to care givers stability (chi-square,0.467,p=0.000), Education of pain assessment tools is significantly associated to the application on different pain management methods (chi-square,0.45,p=0.000), Education on pain assessment tools is significantly associated to present of same body else to support and

relax (Chi-square,0.412,p=0.000),education on assessment tools is significantly associated to appreciation of support (Chi-square,0.396,p=0.000), education on assessment tools is significantly associated to caregivers feeling and future personal regret (Chi-square,0.30,p=0.000).education on pain will contribute to the stability of home caregivers in chronic pain management and drug administration ,will also contribute to the application of pain management methods ,this will also help to get many people whenever possible who are able to support each other and helping and giving room for relaxation ,will also enhance the appreciation of caregivers on support received ,it will also have an impact on personal feeling and future affection of situation passed through.

Table 9: Bivariate analysis of education on pain assessment tools to experiences of home caregivers in chronic cancer pain management

BIVARIATE ANALYSIS OF EDUCATION ON PAIN ASSESSMENT TOOLS TO EXPERIENCES OF HOME CAREGIVERS IN CHRONIC CANCER PAIN MANAGEMENT	P-Value	Chis-square
Education of pain assessment tools for health care team to respondents * stability of care givers due to received education received on drug administration	0.000	0.46
Education of pain assessment tools for health care team to respondents * education of pain management type and their use for caregivers	0.000	0.45
Education of pain assessment tools for health care team to responders * presence of same body else who can assisted and helps to relax	.000	0.412
Education of pain assessment tools for health care team to responders * care givers appreciation of end life time for patient and are their affecting personal life	0.000	0.47
Education of pain assessment tools for health care team to responders * caregivers appreciation of support their from health care team	0.000	0.396
Education of pain assessment tools for health care team to responders * caregivers feeling and concern on their personal life and future regret	0.000	0.30

N=120; explanation about pain assessment tools to home caregivers experience ***p<0.05**

4.2.10. BIVARIATE ANALYSIS OF EDUCATION FOR DRUG ADMINISTRATION AND SIDE EFFECTS MANAGEMENT TO THE CAREGIVERS EXPERIENCES

The results shows that there is a significant association to education of drug administration and side effects management to the stability of caregivers (Chi-square,0.467,p=0.000), Education of drug administration and side effects management is significantly associated to the preparedness on chronic pain management effects (Chi-square,0.054,p=0.000), drug administration and side effects management is significantly associated to existence of support and relax (Chi-square,0.28,p=0.04), drug administration and side effects management is significantly associated to caregivers appreciation of end life time for patient and personal life affection (Chi-square,0.26,p=0.010), drug administration and side effects management is significantly associated to caregivers stress (Chi-square,0.390,p=0.000), drug administration and side effects management is significantly associated to caregivers coping with situation(Chi-square,0.000,p=0.000) .the education of drug administration and their side effects management is contribute to stability and personal confidences for home caregivers on cancer pain management at home ,it is also important for preparedness of them on possible effects on chronic pain management of ill patients ,will also contribute to caregivers appreciation on the support there are receiving and this education will be shared and will let having many people who can support each other to help the patient and will also contribute to the stress management and enhance the coping of home caregivers to the situation .

Table 10: Bivariate analysis of Education for drug administration and side effects management to the caregiver's experiences

Bivariate analysis of Education for drug administration and side effects management to the caregivers experiences	P-Value	Chis-square
Education of drug administration and side effects management * stability of care givers due to received education received on drug administration	0.000	0.467
Education of drug administration and side effects management * preparedness of responders about chronically pain management effects	0.000	0.054
Education of drug administration and side effects management * presence of same body else who can assisted and helps to relax	0.04	0.28
Education of drug administration and side effects management * caregivers appreciation of end life time for patient and are their affecting personal life	0.010	0.26
Education of drug administration and side effects management * stress of caregivers for being supporting the patient	.000	0.390
Education of drug administration and side effects management * Caregivers coping with the situation	000	000

N=120 outcome ;Education of drug administration and side effects management to home caregivers experience ***p<0.05**

CHAPTER 5: DISCUSSION

This study is aimed to assess the knowledge and perceived experience from palliative health care team in cancer pain management in home, we contacted 120 caregivers and here we discuss key findings retrieved from respondents presented in the previous chapter which shows the gaps in knowledge education on pain management and perceived experience from cancer pain management at home .

Most study respondents cared for 80% (N=96) patients who were diagnosed in more than one year period most as of patients cared for by respondents have been part of in-home hospice care for greater than one year period was 80% (N =96). According to Niemeyer, patients with advanced terminal cancer illnesses may feel more comfortable passing away in their own homes and being cared with close relatives(Niemeyer-guimarães and Schramm, 2017, p. 24). This is also motivated by the Rwandan culture and social context where family is the central of life and nothing can replace staying together in addition the household matrix in this study found that 86.7% (N=104) of patients lived with their family. This result also supports the concept from Hunt and Alliance who reported that family and friends are often central in providing care or assistance in both the immediate and long- term management of cancer patients (Hunt and Alliance, 2016, p. 13).

93.3% (N=112) of respondents, stated that their patients were experiencing pain during their illness and severe pain on the pain scale from 8 to 10 were complained on 86.7% (N=110) of caregivers who had to manage this kind of pain. 94.2% (N=113) of caregivers had patient whose pain were lasting six months complaining such this goes in line with the expression of Twycross (1996) who said that cancer patients experience severe chronic pain due to that cancer is not acute and as it will progress as well as it will continue to increase and grow; as well as caregivers knew only the form of medication but do not knew their dosing and side effects. This can compromise the effective management of patient and can leads to medication errors however some medical related problems can be miss diagnosed and delayed in intervention and management which can even aggravate the severity of pain as Parmer (2015) reported that caregivers lacked scientific based information about pain medication . Finnel and Othman (2011) stated that family caregivers need education about pain and its management, training in problem-solving skills, and recognition from providers about their

role in pain management which can't be successfully applied if patient do not know how to assess the pain as a pillar for its effective management, they also need to be trusted in this and confidentially ensured in their performance so that they feel confident. Berry, Dalwadi & Jacobson (2018) found that caregivers needed professional support with educational opportunities by enabling them to arrive at perfection level for effective pain management however they not professionally trained but they can contribute as people who are in daily contact with patient.

Most of the caregivers, 93.3% (N=112), shared many consequences related to chronic pain management. Respondents stated they had received some education for respondents from the healthcare systems was 86.7% (N =104).

A majority of 93.3% (N=112) of respondents had received education about their patient's conditions and had explanations describing cancer pain and this might probably contributed to the feeling and securing state of caregivers and safety with confidence in care .

There was a gaps in pain assessment were 73.3% (N=88), did not have an explanation of assessment tools and did not use them however those tool were not disposed on their sides to be used this shows that there something to improve in the home based care. The research reported on this and said that caregiver's stability and increased comfort levels with pain management supported pain assessment skills, treatment, and maintenance of the patient's pain with the necessary knowledge to assess and practical application of pain relief measurement and techniques (Manoochehri et al., 2014).

Most of caregivers were explained on consequences related to chronic pain management 112 (93.3%). 104(86.7%) said that they were explained about patient condition while 112(93.3%) has explanations about cancer pain though Finnel and Othman said that when clinicians better understand and respond to the needs of the family caregivers, they can enhance the quality of life and care outcomes for both patients and their caregiver(Finnell and Othman, 2011, p. 17)which is related to the level of acceptance and comfort .

96(80%) were educated on drug administration this had impact on the satisfaction of caregivers .I pain management provision however signs of end of life are not educated and this conduce to ineffective preparation on the loss and last complain for the one who is ending .This reflect on the Berry and colleagues' concerns who advised that those Caregivers will require professional support with educational opportunities, psychological

and economical context to enable them to provide quality care on ill patient and also maintain their self-wellbeing (Berry, Dalwadi & Jacobson, 2018 ,p.8). 96(80%) respondents said they do not have someone else to support in care considering to the results and this may be risk factor to personal affection in caregiving moreover There is a significant association between the education provided and received on patient condition and the coping level of caregivers. Other researchers also reported on this and said that socially caregivers face issues in pain management which can be compromised due to the increased tendency towards isolation, feelings of worthless, homebound status, difficulty in performing ADLs, feelings of guilt related to be a burden for members. All of these can all worsen pain (Manoochehri et al., 2014 ,p.14). And while caregivers are stable it has significant relation to the understanding of drug administration principles to patient, and the explanation about tools of pain assessment has significant association to the use of methods for pain management. The experience of pain to patient has also a significant relationship to their caregivers feeling and future view.

The relationship is highly related to application of pain management methods; the explanation about possible consequences of pain management is significantly associated on drug administration stability for caregivers and on status of resources income generation, education about cancer pain is significantly associated on stability on drug administration. The education on assessment tools has a significant association on the caregiver's appreciation of patient end life condition, and appreciation of support reviewed with resources support. Education about side effects of drugs used on chronic pain management has a significant association on caregivers' stability as Kariuki said that caregivers need to be supported by healthcare professionals in highly confident pain assessment and management and filling satisfied even though living in a context of limited resources and infrastructure (Kariuki et al., 2013,p .9). Studies have shown that educational interventions for pain management are often the first step in identifying and resolving common problems. As a result, further education and training of health professionals are recommended. Through workshops, seminars and discussions, the best practices for effective pain management for inpatients and those in homecare could be hugely beneficial. Similarly, such programs could equip professionals with the skills and knowledge to cooperate with primary caregivers to identify their beliefs (Konstantis and Exiara, 2019 ,p.23). The level of education has significantly associated on patient satisfaction of care. Education level is also associated on the coping with the situation and the view. The job of caregivers has a significant association on pain management and satisfaction of patient.

The preparedness on chronic pain management effects has a significant association on stability in drug administration. The patient living condition is significantly associated on how the caregivers appreciate the end life of their patient and personal affection however studies shown that for some, negative beliefs, attitudes, and misconceptions that they have about pain medication may lead them to under use pain medications. It is estimated that, worldwide, there are millions of cancer patients in need of palliative care. With careful planning of cancer palliative care within a comprehensive cancer control plan, a large proportion of advanced cancer patients could be relieved from their suffering and the quality of their lives could be improved significantly. An overall assessment of palliative care needs should be based on information about the specific requirements of the patients concerned, as well as those of health-care providers and family caregivers (WHO, 2007, p .26).

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. INTRODUCTION

This chapter comprises the conclusion from the analysis of data collected and the literature review relating to knowledge and home caregivers experience in home caregivers and recommendation identified to different institution involved in care for patient with cancer pain

6.2. CONCLUSION

The present study shows that there was a significant association between palliative health care team education to the knowledge and perceived experience of caregivers in case of chronic pain management for cancer patient in Rwanda . from the explanation provided by health care team the study showed that home caregivers has got basic knowledge on cancer, how to provide support to patient with cancer pain using different method for pain relieve including medication, however the still need to put emphasize on specificity for each medication being used and follow-up of the implementation and the applicability of that knowledge received ,therefore home caregivers do not have all necessary components of pain assessment and they do not have exposures on different tools used in pain assessment so that they can apply objectively to patient cancer pain assessment for effective management .They do not have education on cancer prognosis and end of life sign and symptoms so that they may acknowledge each complain to patient and locate each in its own place timely .

From the results the there is a luckage of education on medication side effects and they are not explained on end of life signs with their concerns, the most stone pallor in home caregivers support were nurses and contributed to caregivers support however Caregivers are suffering with stress relating to chronic pain management and have challenges and missed information which can contribute to the effective of care there providing to their patients. They have unsatisfied concern and need to advocate. As they do not have resources to generate income for support in care, but they have copied with their patient's situation but through the education received from health care team the in home caregivers whom are caring cancer patient with chronic pain have coped with the situation and are spiritually stable and understand the process of illness conditions for their patient.

The results showed that there still need to improve he education provided to home care givers with cancer patient who are cared in home care services ,this education should be

based on pain cancer related explanations, its ways of assessment and manifestation ,medications used ,the side effects related and how to intervene .There is also a need to improve the interaction with health care team with come caregivers and organize experiential sharing meeting for home caregivers to share their experiences and for peer leaning ,additionally home caregivers needs financial support and materials to easier their caregiving especially for those with pain ,the results also showed that the education and knowledge of home caregiver on cancer pain prognosis ,pain assessment and management and availability of all necessary means will highly contribute to their views and perception ,stability and coping while caring cancer patient with chronic pain at home based care and will higly contribute to the resistance of bio-psycho –socials effects related long time caregiving for critically ill patient with pain .

6.3. RECOMMENDATIONS

KIBOGORA DISTRICT HOSPITAL

The administration of Kibogora District Hospital should provide palliative care team the opportunity to take over continuous professional development in relation to chronic pain management as well as increase caregivers' health education regarding self-care practices while caring a patient with chronic pain and provide peer learning sessions to caregivers for learning opportunity and experience sharing, the administration also should increase the coordination and supervision of care for people in home based care services mainly those who experience cancer pain.

TO UNIVERSITY OF RWANDA/COLLEGE OF MEDICINE AND HEALTH CARE SCIENCES

It is very necessary to integrate home based care courses into curriculum for undergraduates and organize continuous professional development in relation to this field and emphasize on chronic pain management for terminally ill patient especially those with cancer.

TO THE MINISTRY OF HEALTH

It is recommended that the Ministry Of Health should revise community health activities and include caregiving among primary level activity package and put their activities in insurance scheme policy and allow home cared patients using it to access to health care services easily more than it is in order to improve quality of life for cancer patients and contribute to the prevention of effects and complications related to caregiving of chronic ill patient and reduce mortality and morbidity related to caring complications and the information relating to

caregiver for these patient should be recorded and monitored to make sure the safety of their lives .

There is a need also to increase palliative care services in health institutions and provide professional specialists in this field and integrate those services within all district hospitals so that the population can access to .these will contribute to the provision to quality health care for all and contribute in reduction hospital delay and overloading

It is very necessary to allocate funds to support researcher in this field and further researcher are more needed to identify all factors concern associated to caregiving.

The Ministry of health should also empower and support home based care services to extend the accessibility of health care services easier to community

REFERANCE:

- Adelman, R. D. *et al.* (2015) 'Caregiver Burden A Clinical Review'. doi: 10.1001/jama.2014.304.
- Analog, V. *et al.* (2011) 'Measures of Adult Pain', 63(November), pp. 240–252. doi: 10.1002/acr.20543.
- Anderson, C. M. (2002) 'Scientific Pain Relief at the End-of-life : A clinical guide', 99(10), pp. 546–549.
- Astolfi, J. (2014) 'Palliative Care', pp. 119–132.
- Berry, L. L., Dalwadi, S. M. and Jacobson, J. O. (2018) 'Supporting the Supporters : What Family Caregivers Need to Care for a Loved One With Cancer', 13(1), pp. 35–42. doi: 10.1200/JOP.2016.017913.
- Bierhals, C. C. B. K. *et al.* (2017) 'Needs of family caregivers in home care for older adults', *Revista Latino-Americana de Enfermagem*, 25(0). doi: 10.1590/1518-8345.1511.2870.
- Borda, A. P. *et al.* (2013) 'Guidelines on Pain Management & Palliative Care', *European Association of Urology*, pp. 1–96. Available at: http://www.uroweb.org/gls/pdf/24_Pain_Management_LR.pdf.
- British, T. and Society, P. (2013) 'The British Pain Society Understanding and managing pain : information for patients', (January).
- Connor, S. R. and Sepulveda Bermedo, M. C. (2014) *Global atlas of palliative care at the end of life*, World Health Organization.
- Cui, J., Military, S. and Song, L. J. (2014) 'Needs of family caregivers of advanced cancer patients : a survey in Shanghai of China'. doi: 10.1111/ecc.12174.
- Fernandes, C. S. and Angelo, M. (2016) 'Family caregivers: What do they need? An integrative review', *Revista da Escola de Enfermagem*, 50(4), pp. 672–678. doi: 10.1590/S0080-623420160000500019.
- Ferreira, N., Sa, F. C. O. and Orth, M. (2014) 'The management of chronic osteomyelitis : Part II – Principles of post-infective Correspondence ', 13(3), pp. 32–39.
- Finnell, D. and Othman, A. (2011) 'of Family Nursing', (February). doi: 10.1177/1074840710396091.
- Gibson, M. J., Kelly, K. A. and Kaplan, A. K. (2012) 'Family Caregiving and Transitional Care : A Critical Review', (October).
- Goldberg, A. and Rickler, K. S. (2011) 'The Role of Family Caregivers for People with

Chronic Illness’.

Gregory, J. and Richardson, C. (2014) ‘Journal of Pain & Relief The Use of Pain Assessment Tools in Clinical Practice : A Pilot Survey’, 3(2). doi: 10.4172/2167-0846.1000140.

Groenewald, C. B. and Palermo, T. M. (2015) ‘The price of pain : the economics of chronic adolescent pain’, 5(2), pp. 61–64. doi: 10.2217/pmt.14.52.The.

Gulik, L. Van *et al.* (2017) ‘Adherence to All Steps of a Pain Management Protocol in Intensive Care Patients after Cardiac Surgery Is Hard to Achieve’. Hindawi Publishing Corporation, 2017, pp. 1–7. doi: 10.1155/2017/7187232.

Hallberg, R. (2016) ‘Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease .’ doi: 10.1111/scs.12275.

Hawley, P. (2017) ‘Barriers to Access to Palliative Care’. doi: 10.1177/1178224216688887.

Health, M. O. F. and Welfare, S. (2010) ‘THE UNITED REPUBLIC OF TANZANIA MINISTRY OF HEALTH AND SOCIAL WELFARE NATIONAL GUIDELINES FOR’, (May).

Heinricher, M. M. and Ph, D. (2014) ‘Anatomy and Physiology of Pain Anatomy and Physiology of Pain’, (January 2011). doi: 10.1007/978-1-60761-145-5.

Hunt, G. G. and Alliance, N. (2016) ‘CANCER CAREGIVING IN THE U . S .’, (June).

Info, E. (2018) ‘Expanding needs of family caregivers Zufällige TV-’, pp. 1–2.

Kariuki, H. *et al.* (2013) ‘Palliative care research in eastern Africa’, 20(6).

Konstantis, A. and Exiara, T. (2019) ‘patients in home care settings Family caregiver beliefs and barriers to effective pain management of cancer patients in home care settings’, (January).

Koplow, S. M. *et al.* (2015) ‘Family Caregivers Define and Manage the Nursing Home Placement Process’, *Journal of Family Nursing*, 21(3), pp. 469–493. doi: 10.1177/1074840715571365.

Kova, I. *et al.* (2018) ‘Self-care of chronic musculoskeletal pain – experiences and attitudes of patients and health care providers’, pp. 1–10.

Krakauer, E. L. *et al.* (2018) ‘Palliative Care in Rwanda : Aiming for Universal Access’, 55(2), pp. 77–80. doi: 10.1016/j.jpainsymman.2017.03.037.

Kumar, K. H. and Elavarasi, P. (2016) ‘Definition of pain and classification of pain disorders’, 3(June), pp. 87–90. doi: 10.15713/ins.jcri.112.

Kunsch, K. (2016) ‘Dificuldades De Cuidadores De Pacientes Em Cuidados Paliativos Na Estratégia Da Saúde Da Família’, *Texto & Contexto - Enfermagem*, 25(1), pp. 1–7. doi: 10.1590/0104-0707201500003360014.

- Lamont, L. A., Tranquilli, W. J. and Grimm, K. A. (2000) 'Physiology of Pain', *The Veterinary Clinics of North America: Small Animal Practice*. Elsevier Inc., 30(4), pp. 703–728. doi: 10.1016/S0195-5616(08)70003-2.
- Larkin, P., Hasselaar, J. and Payne, S. (2016) *Integrated palliative care Integrated palliative care Integrated palliative care*. Available at: <http://www.insup-c.eu/IntegratedPalliativeCare2016.pdf>.
- Lee, B. *et al.* (2015) 'Mediating Effect of Family Caregivers ' Hesitancy to Use Analgesics on Homecare Cancer Patients ' Analgesic Adherence', *Journal of Pain and Symptom Management*. Elsevier Inc, 50(6), pp. 814–821. doi: 10.1016/j.jpainsymman.2015.06.014.
- Lohman, D., Schleifer, R. and Amon, J. J. (2010) 'Access to pain treatment as a human right'.
- Londhey, V. A. (2015) 'Pathophysiology of Pain " W', pp. 5–7.
- Lynch, M. *et al.* (2011) 'Palliative care nursing: defining the discipline?', *Journal of Hospice & Palliative Nursing*, 13, pp. 106–111. doi: 10.1097/NJH.0b013e3182075b6e.
- Majeed, Muhammad Hassan; Sudak, D. (2017) 'Cognitive Behavioral Therapy for Chronic Pain—One Therapeutic Approach for the Opioid Epidemic', *Journal of Psychiatric Practice*, 23(6), pp. 409–414. doi: 10.1097/PRA.0000000000000262.
- Manoochehri, H. *et al.* (2014) 'Chronic Pain Management and Being Vulnerable in Older People : A Qualitative Study', 3(4). doi: 10.5812/jjcdc.23368.
- Margot Phaneuf, R.N., P. (2012) 'CLINICAL EDUCATION : Organization'.
- Mirabile, A. *et al.* (2016) 'Critical Reviews in Oncology / Hematology Pain management in head and neck cancer patients undergoing chemo-radiotherapy : Clinical practical recommendations', *Critical Reviews in Oncology / Hematology*. Elsevier Ireland Ltd, 99, pp. 100–106. doi: 10.1016/j.critrevonc.2015.11.010.
- National Cancer Institute (2014) 'Pain Control'. Available at: <https://www.cancer.gov/publications/patient-education/paincontrol.pdf>.
- Niemeyer-guimarães, M. and Schramm, F. R. (2017) 'The Exercise of Autonomy by Older Cancer Patients in Palliative Care : The Biotechnoscientific and Biopolitical Paradigms and the Bioethics of Protection'. doi: 10.1177/1178224216684831.
- Nissim, R. *et al.* (2016) 'Motivations , Satisfaction , and Fears of Death and Dying in Residential Hospice Volunteers : A Prospective Longitudinal Study', 33(4), pp. 335–339. doi: 10.1177/1049909114559830.
- Parmar, J. (2015) 'Supporting Family Caregivers of Seniors', (December). Available at: <https://www.covenanthealth.ca/media/121957/discovery-toolkit-supporting-family->

caregivers-of-seniors-web.pdf.

Paul-savoie, E., Rn, P. B. and Rn, E. G. (2015) 'Assessing patient-centred care for chronic pain : Validation of a new research paradigm', 20(4), pp. 183–188.

Perez, G. A. (2018) 'Position statement: Policies to support family', *Nursing Outlook*. Elsevier Inc., 66(3), pp. 337–340. doi: 10.1016/j.outlook.2018.04.009.

Ramia, E. *et al.* (2017) 'Patient Perception of Acute Pain Management : Data from Three Tertiary Care Hospitals'. Hindawi, 2017. doi: 10.1155/2017/7459360.

Reinhard, S. C. *et al.* (2018) 'Chapter 14 Supporting Family Caregivers in Providing Care', (Md), pp. 1–22.

Reinhard, S. C., Fox-grage, W. and Feinberg, L. F. (2016) 'Family Caregivers and Managed Long-Term Services and Supports', (November).

Republic of Rwanda (2018) 'THE REPUBLIC OF RWANDA E', (May 2013).

Riffin, C. *et al.* (2017) 'HHS Public Access', 32(4), pp. 663–675. doi: 10.1016/j.cger.2016.06.010.Impact.

Rishikesan, R., Mark, S. G. and Hamish, A. R. W. S. (2013) 'Chronic osteomyelitis of the pelvis', 79, pp. 280–286.

Rn, F. D. *et al.* (2015) 'Development of the Adolescent Cancer Suffering Scale', 20(4), pp. 213–219.

Rokach, A. *et al.* (2016) 'Caregivers of chronic pain patients : Their loneliness and burden', 1(5), pp. 111–117. doi: 10.15761/NPC.1000128.

Rwanda Ministry of Health (2012) 'Pain management guidelines', (September), pp. 1–62.

Stewart, J. (2014) 'The Challenges of Cancer Pain Assessment', 83(July 2013), pp. 44–46.

Sullivan, A. B. (2015) 'Who is taking care of the caregiver?', 2(1), pp. 7–12.

Torvik, K. *et al.* (2015) 'Original Article Pain Assessment Strategies in Home Care and Nursing Homes in Mid-Norway : A Cross-sectional Survey', *Pain Management Nursing*. American Society for Pain Management Nursing, 16(4), pp. 602–608. doi: 10.1016/j.pmn.2015.01.001.

Tracy, L. M. (2017) 'Psychosocial factors and their influence on the experience of pain', 2, pp. 2–4.

Wiffen, P. *et al.* (2017) 'Cochrane Database of Systematic Reviews Opioids for cancer pain - an overview of Cochrane reviews (Review)', *Cochrane Database of Systematic Reviews*, 2017(7), p. CD012592. doi: 10.1002/14651858.CD012592.pub2.

Writer, N. *et al.* (2017) 'Caregivers ' experiences of unmet needs during palliative care'.

APPENDICES

APPENDIX A- INDIVIDUAL INFORMED CONSENT FORM

My name is TWAHIRWA Jean Claude, a student in Master of Science in Nursing, University of Rwanda, School of Nursing and Midwifery. My master's research dissertation is **“Knowledge and home caregivers experiences from palliative health care team education in pain management of cancer patients in Rwanda”** as partial fulfillment of my studies. This study will help to increase the knowledge and enhance support through identification of the needs identified by in-home caregivers to enhance care and support in the Rwandan context.

The study seeks to inform and improve care for terminally ill cancer patients related to pain management and experience for pain management in the home care.

This study aims to identify Knowledge and experiences of new strategies which can be applied in-home caregivers of patients in the context of cancer pain management. With your permission, I kindly request you to give as much information as possible seek by responding to the questions in the questionnaire will be addressed to you. There are no anticipated risks associated with this study. Your decision whether or not to participate in this study will not affect you at all. The participation in this study is voluntary, and there is no penalty for early withdrawal.

The information you provide will be confidential. Your identity will not be disclosed in any published and written material resulting from the study and will be shared only with the research team.

I agree to participate in this study.

Signature_____

Date and Signature of Participant __/__/_____

Witness_____

APPENDIX B- CONSENT FORM FOR RESEARCHER

Introduction

The study seeks to inform about knowledge and experiences of home caregivers for patient with cancer pain in Rwanda.

Purpose of the Study

This study aims to identify knowledge of home caregivers and their experiences in the context of cancer pain management and retrieve solutions in provided care to patients.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. All the services you receive in this context of care will continue, and nothing will change. If you choose not to participate in this research project, you may withdraw at any time without risk of penalty. May change your mind later and stop participating even if you agreed earlier.

Confidentiality

The information that we collect from this research project will be kept confidential. Information about you that will be collected during the research will be put away, and no-one but the researchers will be able to see it. Any information about you will have a number on it instead of your name. Only the researcher will know what your number is, and we will lock that information up with a lock and key. It will not be shared with or given to anyone except who will have access to the information

The knowledge that we get from doing this research will be shared with you through community meetings before it is made widely available to the public. Confidential information will not be shared. If you have any questions, you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact any time on 0784810644

I have read the foregoing information/ it has been read to me. I have had the opportunity to ask questions about it, and any questions that I have asked to ,have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Signature of Participant _____

Date _____ Witness _____

APPENDIX A- IFISHI ISABA UBURENGANZIRA BWO GUKUSANYA AMAKURU

Nitwa TWAHIRWA Jean Claude, Ninga Muri Kamnuza Nkuru Y'urwanda Ishami Ryubuganga Mukiciri Cyagatatu Cya Kaminuza Mubuforomo, Ndigukora Ubushakashatsi Kugitabo Gisoza Amashuri' Bugamije Kumenya Amakuru Ahabwa Abarwaza Bababarwayi Ba Kanseri Nubumenyi Nuburyo Bakiriye Ubwo Bufasha Mukurwariza Abarwayi Mungo. Ubu Bushakashatsi Buzafasha Mukongera Ubumenyi Ndetse N'ubufasha Mugufasha Ndetse Nokuvura Abarwayi Bafite Kanseri Kandi Bababara.Ndabasaba Gutanga Amakuru Yose Ashoboka Musubizi Ibibazo Byanditse Turi Bubahe Kumpapuro. Ntangeruka Cyangwa Imbogamizi Ubu Bushakashatsi Bwagira Kandi Nuburenganzira Kwemera Cyangwa Kwanga Kugira Uruhare Murubu Bushakashatsi Kuko Nubushake Igihe Cyose Ushakiye Wemerewe Kubyihorera.

Amakuru Muraduha Nibanga Ntamwirondoro Wawe Uzerekanwa Ahantu Aho Ariho Hose Kereka Kubo Bireba Mugushyira Igitabo Ahagaragara Cyangwa Mwihuriro Ry'abashakatsi

NDABYEMEYE.....Umukono.....Itariki

**APPENDIX B- CONSENT FORM FOR RESEARCH/IFISHI YO KWIYEMEZA
KUGIRA URUHARE MUBUSHAKASHATSI KUBUSHAKE**

Iriburiro

Ubu bushakashatsi bugamije guteza imbere ubuvuzi bw'abarwayi ba kanseri bavurirwa murugo hagendewe kubufasha buhabwa abarwaza

Intego y'ubushakashatsi

Nukumenya inyigisho zihabwa abarwaza nicyo zabamariya mukwirinda ingaruka mbi zimomoka kukurwaza umuntu ufite ububabare

Kugira uruhare kubushake

Kugira uruhare murubu bushakashatsi nubushake kandi niwowe uhitamo iba usubiza cyangwa udasubiza ibi bibazo. Wumva bidakunda ko ugira uruhare murubu bushakashatsi wabihagarikira igihe cyose ushakiye ntankurikizi.

Ibanga

Amakuru uri buduhe nibanaga kandi ntawundi azerekwa cyangwa azasangizwe cyeretse umushakashatsi, ntazina cyangwa umwirondoro wawe uragaragara kuri iyi fishi

Uramutse ugize ikibazo wahamagara kuri: 0784810644

Namaze gusobanurirwa amabwiriza yose agenga ububushakashatsi kandi nyuma kumvaneza no kugira umwanya WO guhabwa ibisobanuro ndetse nibisubizo kubibazo nabajije

Ndemera kugira uruhare kubushake

Umukono

Itariki _____

APPENDIX C. DEMOGRAPHIC QUESTIONNAIRE

Day/month/year

Appendix C. DEMOGRAPHIC QUESTIONNAIRE

Date of interview: _____

Participant ID number: _____

1. What is your age? _____
2. Gender
 - a. Male _____
 - b. Female _____
3. What is your highest level of education?
 - a. No formal education _____
 - b. Less than Primary School _____
 - c. Primary School _____
 - d. Secondary School _____
 - e. Bachelor's degree _____
 - f. Graduate School _____
4. Are you currently employed? Yes ____ No _____
5. If yes where are you employed please specify:
 - a) Public ...
 - b) Private
 - c) Self employed.....
 - d) others

Information related to patients' condition

6. Date of diagnosis:
 - a. Last 4 weeks
 - b. 1-month ago
 - c. From 1 to 6 months
 - d. From 6 month to 1 year
 - e. Above 1 y
7. Date of referral to Home Care? Hospice
 - a. Last 4 weeks
 - b. 1-month ago
 - c. From 1 to 6 months

d. From 6 month to 1 year

e. Above 1 year

8. Do your patient experience pain?

a. Yes

b. No

9. Type of pain suffered by patient

a. Mild pain

b. Moderate pain

c. Severe pain

10. Current Pain level intensity do usually experience by your patient is

Scored from:

a. 1-2-3-4

b. 5-6-7

c. 8-9-10

11. Current Medications:

a. Known

b. Not known

c. Known but forget the name

d. Not known but know the form and color

12. Duration of pain to patient

a. < 6 months

b. <1 year

C. 1-3 years,

d. 3-5 years;

e. > 5 years

13. The Current Living Situation of patient

a. Alone

b. Friends

c. Family

d. Other not closed relation cheep

14. Patient Care is delivered at

a. Clinics

- b. Hospital
- c. In Home
- d. Other

15. Participant's relationship to patient whom he/she is caring for:

- a. Not related
- b. Family _____ (specify for example, sister, son, spouse)
- c. Hired care provider
- d. Other (any volunteers)

Content of teaching by palliative health care team about cancer and its pain management

16. Has the Healthcare team explained me about type of Cancer and other multiple conditions relating to my patient

- a. Yes
- b. Not

17. Has the palliative Health care team discussed about association the diagnosis and prognosis with you as a caregiver?

- a. Yes
- b. No
- c. Somewhat
- d. Never

18. Has the Healthcare team explained the issues of Cancer pain?

- a. Yes
- b. No

20. Has the Healthcare team explained about Pain types

- a. Yes
- b. No

21. Has the Healthcare team explained the issues of Assessment pain assessment?

- a. Yes
- b. No

22. Has the Healthcare team explained the issues of Scales- and scoring principles in pain assessment and different tools used?

- a. Yes
- b. No

23. Medications-Have you as a caregiver been educated in different types of medications dosages and how they are administrated and the potential side effects and when and how to intervene?

- a. Yes
- b. No
- c. Somewhat
- d. Never

24. Has the Health team trained you about End of Life related issues and the Stages of Death and Dying?

- a. Yes
- b. No
- c. Somewhat
- d. Never

25. Have been you been taught on the effects relating on caring a patient with such condition and are aware on what can happen on self and you are prepared enough, and do you consider it in your daily life

- a. Yes
- b. No

26. Has the Health team trained you on different alternative of pain relief methods?

- a. Yes
- b. No

27. Do you have as the primary caregiver has anyone else in the home trained to take care of the patient allowed you time away to relax?

- a. Yes
- b. No

Section III: Experiences of In-Home Caregivers on Cancer Pain Management

28. Do you feel the education you received for example: on how to administer drugs and training was enough to make you comfortable with pain management?

- a. Comfortable
- b. Not at all comfortable
- c. Slightly uncomfortable
- d. Somewhat comfortable

e. Very comfortable

29. If the Health care team trained you on different alternative of pain relief methods do you use them?

- a. Not
- b. Not At All
- c. Rarely
- d. Sometimes
- e. Frequently

30. In addition to the education you have received do you see gaps or needs that have not been addressed?

- a. Yes
- b. No

31. Are you able to achieve pain relief, and feel your patient is satisfied fully?

- a. Not at all satisfied
- b. Somewhat satisfied
- c. Satisfied
- d. Very satisfied.

32. I have been an effective caregiver for the patient in terms of:

Physical Needs

- a. Yes
- b. No
- c. Somewhat
- d. Never

Social Needs

- a) Yes
- b) No
- c) Somewhat
- d) Never

Psychological Needs

- a) Yes
- b) No
- c) Somewhat
- d) Never

Spiritual Needs

- a) Yes
- b) No
- c) Somewhat
- d) Never

33. Are there particular educational needs or information you are lacking related to pain management?

- a. Yes
- b. No

Section IV: In home Caregivers self-experience about cancer pain management

34. End of Life in-home pain management challenges me and I feel stressed and burdened by the situation, and I am struggling.

- a. Yes
- b. No
- c. Sometimes
- d. Never

35. I feel supported enough by facilitation from various palliative caring team members.

- a. Yes
- b. No
- c. Somewhat
- d. Never

36. The following possible team members assist me most of the time:

- a. Nurses
- b. Physicians
- c. Social workers
- d. Local Governance
- e. Mental Health nurses
- f. Chaplain or Priest/Pastors
- g. Traditional healers
- h. Family
- i. Neighbors/friends

37. Do you feel depressed and alone due to the context of the care you are performing?

- a. Yes
- b. No

38. Do you need more support?
- Yes
 - No
39. Are there any challenges and any missing information that if you had it could have helped you?
- Yes
 - No
40. Is there any needs and feeling that health care providers need to advocate or help achieve for your goal as a caregiver?
- Yes
 - No
41. Do you have any resources which are supporting you within the context of in-home caregiving to respond to patients need in case of pain management and are they enough?
- Yes
 - No
- 42 .Did you cope with the difficult situations that you are experiencing by the patient care?
- Yes
 - No
 - Somewhat
 - Never
43. Do you have main concerns, worries, and fears about the future's life you think any blame will rise at the end due to unfulfilled task or not completed task?
- Yes
 - No
 - Somewhat
 - Never
44. Do you think this is a real situation relating to explanation and hope clinical support will fully assist you in all components of your life and life of others in the family?
- Yes
 - No
 - Somewhat
 - Never

45. Do you think it might be another factor associated and trying to associate with other measures and seek additional support and beliefs outside of those given by palliative health care team?

- a. Traditional Healers
- b. West Religion
- c. African Religion
- d. Nothing

46. I tried to overcome these issues and am doing my own activities of daily living, and everyone needs in the family to understand and cope with the situation.

- a. Yes
- b. No
- c. Somewhat
- d. Never

Thank you for your participation

Adopted from (Betty and Margot , R.N., 2012, p. 65)

APPENDIX D. DEMOGRAPHIC QUESTIONNAIRE

UMUNSI/UKWEZI/UMWAKA

Appendix IBIBAZO KUMWIRONDORO W'UMURWAZA

Itariki yamavuko: _____

Urutonde rw'ibazwa: _____

1. ufite imyaka ingahe? _____
2. igitsina
 - a. Gabo _____
 - b. Gore _____
3. Nayahe mahuri wize?
 - a. ntamashuri nigeze nig _____
 - b. ashuriyincuke _____
 - c. amshuri abanza _____
 - d. ayisumbuye _____
 - e. ikiciri kibanza cya kaminuza _____
 - f. amashuri ahanitse _____
4. hari akazikumushara ufite? Yego ____ oya _____
5. niba ufite akazi ukorahe:
 - e) Ukorera leta
 - f) Ukorera abigenga
 - g) Ukorakugiti cyawe
 - h) Ukora ahandi

Amakuru ajyanye nuburwayi bw'uwo arwaje

6igihe uburwayi bwamenyekniye:

- f. Mubyumweru bine bishize
- g. Hashize ukwezi kuzuye
- h. Hagati yamezi 1 na 6
- i. Kuva kumezi 6 kugera kumwaka 1
- j. Birenze hejuru yumwaka

7. igihe yohererejwe muryi gahunda
- Mubyumweru bine bishize
 - Hashize ukwezi kuzuye
 - Hagati yamezi 1 na 6
 - Kuva kumezi 6 kugera kumwaka 1
 - Birenze hejuru yumwaka
8. ese umurwayi wawe ajya ajyira ububababare?
- Yego
 - Oya
9. nubuhe bubabare akunda kugira
- Bukeya
 - Bugerereye
 - Bukabije
10. nikihe gipimo cyububabare akunda kuba afite?
- :
- Hagati 1-2-3-4
 - Hagati 5-6-7
 - Hagati 8-9-10
11. ibiti ariho afata:
- Ndayizi
 - ntayonzi
 - ndayizi ariko narayibagiwe
 - sinzi uko yitwa ariko nzi isura yayo
12. hashize igihe kingana iki umurwayi afite ububababare?
- minsi yamezi 6
 - hagati yamezi 6 kugera kumwaka 1
 - hagati yimyaka 1-3
 - hagati yimyaka 3-5
 - hejuru yimyaka 5

13. uko umurwayi abayeho
- a. Aba wenyine
 - b. Kunshuti
 - c. mumuryango wabugufi
 - d. undi bafitanye isano
-

14. Ubufasha butangirwa

- a. mwivuriro
- b. Mubitaro
- c. Murugo
- d. Ahandi

15. isano bafitanye nuwo arwaje:

- a. Ntasano
- b. bafitanye isano _____ (specify for example, sister, son, spouse)
- c. nakazi yahawe
- d. numukorera bushake (any volunteers)

Inyigisho itsinda ryabaganga bahaabarwaza

16. ese babaganga baguhaye inama nibisobanuro kuri kanseri nibishamikiyekuriyo biri kumurwayi wawe

- c. Yego
- d. Oya

17.itsinda ryabaganga bakuganirije kubyakurikira nyuma yokuba uri kurwaza umugtu uri kuri iki kiciro bikureba?

- a. Yego
- b. oya
- c. bimwenabimwe
- d. habe namba

18. Ese abaganga bagusobanuriye kububababre buturuka kuri kanseri?

- a. Yego
- b. oya

20 .ese abaganga bagusobanuriye kubwoko bwububbare

- c. Yego
- d. Oya

21. Ese abaganga bagusobanuriyee uko wasuzuma ko umurwayio afite ububabare?

- c. Yego
- d. Oya

22. Ese abaganga bagusobanuriye uko ibipimo bipima ububbare bikoreshwa ndetse birahari kuburyo bigufasha?

- c. Yego
- d. Oya

23. Nkurwaza wasobanuriwe ndetse unigishwa imiti umurwayi akoresha, uko wayimuha ibipimo ingaruka igira nacyo wakoa igihe bibabaye

- a. Yego
- b. oya
- c. bidahagije
- d. Ntanarimwe

24. Ese abaganga bakwigishije kubijyanye nibihe byanyuma byumuntu urebye?

- a. Yego
- b. oya
- c. ntibihagije
- d. Ntanarimwe

25. Wigeze se wigishwa kubijyanye ningaruka zishobora kuba kumurwaza, ubwitaho burigihe kandi wamaze kwitegura guhangan a

A nabyo

- c. Yego
- d. Oya

26. Ese ikipe yabaganga yakwigishije uburyo butandukanye bwo kuvura ububabare?

- c. Yego
- d. Oya

27. Nkumurwaza ufite undi mufatikanaya kuburyo nawe ushobora kubona akanya ko wiyitaho no kuruhuka?

- a. Yego
- b. Oya

SECTION III: EXPERIENCES OF IN-HOME CAREGIVERS ON CANCER PAIN MANAGEMENT

28. Ubona inyigisho wahawe nko gutera umuti byaratumye wumva utekanye mukugabanya ububabare bwu'umurwayi.

- f. Ndatekanye
- g. Numva ndatekanye
- h. Ndatekanye buhoro
- i. Numva ntekanye bidahagije
- j. Ndatekanye cyane

29. Niba ikipe yabaganga yarakwigishije kuburyo butandukanye wakoresha ugabanya ububabare ,urabikoresha?

- f. Hoya
- g. Sibyose
- h. Rimwe narimwe
- i. Siburigihe
- j. Byose

30. Kunyigisho wahawe ahricyo ubona kitagezweho cyangwa wifuza kitagezweho munyigisho wahawe?

- c. Yego
- d. Oya

31. Ese ujya ubasha kugabanya uburibwe kumurwayi wawe ukabona umurwayi wawe anyuzwe neza?

- e. Ntago anyurwa
- f. Aranyurwa bitarineza
- g. Aranyurwa
- h. Aranyurwa ndetse cyane.

32. Mbona ndwaza neza umurwayi wanjye muri iki kiciro cy'ubuzima:

Mubijyanye nubuzima bwe bwaburimunsi

- e. Yego
- f. oya
- g. sineza
- h. Ntanarimwe

Mubyimibereho

- e) Yego
- f) oya
- g) Sineza
- h) Ntanarimwe

Mubyimitekerereze nibiyumviro

- e) Yego
- f) oya
- g) Sineza
- h) Ntanarimwe

Mubiyanye nimyemerere

- e) Yego
- f) Oya
- g) Sineza
- h) Ntanarimwe

33. Wumva hari amakuru yihariye kukugabanya ububabare waba ukeneye?

- c. Yego
- Oya

**Ikicro cya 4: UKO ABARWAZA BIYUMVA NYUMA YOGUFASHA
MUKUGABANYA**

UBUBABARE BWAKANSERI

34. Ibi bihe byanyuma kumurwayi numva bayarangoye cyane gukurikiranira umuntu murugo kandi byantesheje umutwe kuburyo umva mpangayitse.

- a. Yego
- b. oya
- c. Sicyane
- d. ntacyo bitwaye

35. Umva narahawe ubufasha buhagije nikipe yabaganga batandukanye

- a. Yes
- b. Oya
- c. Sineza
- d. Ntanarimwe

36. Abantu bakurikira mwikipe yabaganga bajyiye bamfasha cyane kukurwaza uyu murwayi wanjye:

- j. Umuforomo
- k. Umuganga
- l. Ukora mubijyanye nimiberho myiza
- m. Abomunzego zibanze
- n. Abo mundwara zomumutwe
- o. Mwarimu witorero, pasitoro /padiri
- p. Umuvuzi gakondo
- q. Abo mumuryango
- r. Umaturanyi /inshuti

37. Wumva uhangayikishijwe nibyo ukora kuburyo byaguhunganayije kandi wumva uri wenyine?

- c. Yego
- d. Oya

38. Hari ubundi bufasha ukeneye?

- c. Yego
- d. Oya

39. Hari imbogamizi cyangwa ibibazo namakuru udafite ubona iyo uzakuyajyira byari kugufasha?
- c. Yego
 - d. Oya
40. Haricyo ubona kitagenze neza kumurwayi, ukaba wumva hari ubuvugizi wakorerwa kugirango bigende neza
- c. Yego
 - d. Oya
41. Ufite aho ukura ubushobozi bugufasha mukurwariza umurwayi wawe imuhira
- c. Yego
 - d. Oya
- 42 .Wakiriye ubuzima urigucamo kandi wumva warabyakiriye?
- e. Yego
 - f. Oya
 - g. Sineza
 - h. Ntanarimwe
43. Hari icyo wiyumvira, ubwobase cyangwa impungenge kuhazaza hubuzima bwawe kuburyo
- hari ukwicuza wazagira kucyo utazaba waramukoreye?
- e. Yego
 - f. Oya
 - g. Sicyane
 - h. Ntanarimwe
44. Ese wumva ariko byagakwiye kugenda kandi ubufasha uhabwa nabaganga nibisobanuro wahawe ubona bizagufasha wowe numuryango wawe mukugira ubuzima bwiza ahazaza?
- e. Yego
 - f. Oya
 - g. Sineza
 - h. Ntanarimwe

45. Utekereza ko hari ikindi cyaba kihishe inyuma yubu b urwayi kandi ugerageza gushaka ubundi bufasha ahandi nimyemerere bitandukanye nibyo uhabwa nabaganaga kuburyo wifashisha?

- e. Abavuzi gakondo
- f. Imyemerere yamahanga
- g. Ubuvuzi nyafurika
- h. Ntacyo ubikoraho

46. Nagerageje kurengera byose kandi ndimubuzima busanzwe bwaburimunsi kandi buriwese mubo dufatanyije yariyakiriye.

- e. Yego
- f. Oya
- g. Sineza
- h. Ntanarimwe

Murakoze

Adopted from (Betty and margo,2012)

APPENDIX D: APPROVAL FROM MINISTRY OF HEALTH

REPUBLIC OF RWANDA

26 MARS 2019
Kigali,
N° 20/1770/DGPHFIS/2019



MINISTRY OF HEALTH
P.O. BOX: 84 KIGALI
www.moh.gov.rw

MUKASHYAKA Joëlla/ Tel: 0788489231
MUJAWAMARIYA Françoise/ Tel: 0783302009
MUREKATETE Claudine/ Tel: 0788545982
School of Nursing
University of Rwanda/CMHS
KIGALI

Re: Authorization of research

Reference is made to the letters requesting authorization of research for completion of your master's program in Nursing;

I hereby authorize your research as well as those of your colleagues in same situation to facilitate the entire cohort to speed up their academic activities. The students will have to present the CMHS/IRB research approval letter with this one to any health facility to have access of data.

Sincerely,



[Handwritten Signature]
Dr. Diane GASHUMBA
Minister of Health

Cc:
- Principal of College of Medicine Health Sciences
- Dean of School of Nursing and Midwifery/CMHS/UR

APPENDIX E: ETHICAL CLEARANCE FROM IRB



COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 14/01/2019
Ref: CMHS/IRB/019/2019

Twahirwa Jean Claude
School of Nursing and Midwifery, CMHS, UR


Dear Twahirwa Jean Claude

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled "Caregivers Knowledge and Perceived Support Needs for Terminally Ill Patients with Chronic Pain in Rwanda "

Having reviewed your protocol and found it satisfying the ethical requirements, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.


Professor Jean Bosco GASHUTU
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

APPENDIX F: REQUEST FOR RESEARCH MOH

12th March 2019
TWAHIRWA Jean Claude
School of Nursing and Midwifery
College of Medicine and Health Sciences
University of Rwanda

To
The Minister of Health
Rwanda

RE: Request to carry out research and Data collection at Kibogora district hospital.


Dear Minister,

I am TWAHIRWA Jean Claude a student in Masters in Nursing Science, Medical Surgical track at the college of Medicine and Health Sciences. As a prerequisite to complete masters' degree, I am supposed to carry out research and my study is entitled "Caregivers Knowledge and Perceived care Support Needs for terminally ill patients with chronic pain in Rwanda"

My research will contribute to assess knowledge and care support needs of caregivers for terminally ill patients with chronic pain in the context of home based care in Rwanda. I have submitted the requirements to the CMHS institutional Review board and an Ethical Clearance Letter has been granted to me Ref: CMHS/IRB/019/2019 dated 14/01/2019. The tool to be used and the ethical standards to be followed have been accepted. It is Due to this background that I am seeking authorisation to carry out research and collect data at Kibogora district hospital. Kindly find attached the letter from CMHS institutional Review Board and my research proposal.

I hope my request will be put under your kind consideration.

Sincerely yours,

TWAHIRWA Jean Claude 
Masters in Nursing Science Medical Surgical Track
School of Nursing and Midwifery
College of medicine and health sciences
University of Rwanda
Email:twahirwajeClaude1@gmail.com
Tel: +250784810644

APPENDIX G: QUESTIONNAIRE



October 2012

The "Knowledge and Attitudes Survey Regarding Pain" tool can be used to assess nurses and other professionals in your setting and as a pre and post test evaluation measure for educational programs. The tool was developed in 1987 and has been used extensively from 1987 - present. The tool has been revised over the years to reflect changes in pain management practice.

Regarding issues of reliability and validity: This tool has been developed over several years. Content validity has been established by review of pain experts. The content of the tool is derived from current standards of pain management such as the American Pain Society, the World Health Organization, and the National Comprehensive Cancer Network Pain Guidelines. Construct validity has been established by comparing scores of nurses at various levels of expertise such as students, new graduates, oncology nurses, graduate students, and senior pain experts. The tool was identified as discriminating between levels of expertise. Test-retest reliability was established ($r > .80$) by repeat testing in a continuing education class of staff nurses ($N = 60$). Internal consistency reliability was established ($\alpha r > .70$) with items reflecting both knowledge and attitude domains.

Regarding analysis of data: We have found that it is most helpful to avoid distinguishing items as measuring either knowledge or attitudes. Many items such as one measuring the incidence of addiction really measures both knowledge of addiction and attitude about addiction. Therefore, we have found the most benefit to be gained from analyzing the data in terms of the percentage of complete scores as well as in analyzing individual items. For example, we have found it very helpful to isolate those items with the least number of correct responses and those items with the best scores to guide your educational needs.

Enclosed for your use is a copy of our instrument and an answer key. You may use and duplicate the tool for any purpose you desire in whole or in part. References to some of our studies which have included this tool or similar versions are included below. We have received hundreds of requests for the tool and additional use of the tool can be found in other published literature. We also acknowledge the assistance of several of our pain colleagues including Pam Kedziera, Judy Paice, Deb Gordon, June Dahl, Hob Osterlund, Chris Pasero, Pat Coyne and Nessa Coyle in the revisions over the years. If using or publishing the tool results please cite the reference as "Knowledge and Attitudes Survey Regarding Pain" developed by Betty Ferrell, RN, PhD, FAAN and Margo McCaffery, RN, MS, FAAN, (<http://prc.coh.org>), revised 2012.

We hope that our tool will be a useful aid in your efforts to improve pain management in your setting.

Sincerely,

Handwritten signature of Betty R. Ferrell in black ink.

Betty R. Ferrell, RN, PhD, FAAN
Research Scientist

Handwritten signature of Margo McCaffery in black ink.

Margo McCaffery, RN, MS, FAAN
Lecturer and Consultant