SOCIO-ECONOMIC FACTORS AND ACCESS TO PALLIATIVE CARE SERVICES TO CHRONICALLY ILL PATIENTS IN INDUSTRIAL CITY DIVISION MBALE CITY

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UGANDA CHRISTIAN UNIVERSITY

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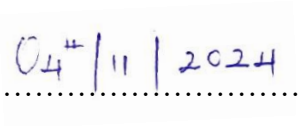
DECLARATION

I hereby declare that this research report has been written out of my own efforts and it has never been submitted to any institution of higher learning for any award.

SIGNATURE:  DATE: 

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APPROVAL

This is to certify that this research report has been completed under my supervision and submitted for approval and further examination for the award of a Bachelor's degree of Social Work and Social Administration of Uganda Christian.

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MR. WABUKYE DAVID

SUPERVISOR

DEDICATION

I dedicate this work to my family for their kind financial and moral support to my Education. In a special way I dedicate this work to my daddy and my mummy for their financial support and guidance till the completion of this research report.

ACKNOWLEDGEMENT

My great gratitude goes to God Almighty who has enabled me to successfully complete this research.

I also wish to extend my great appreciation to my supervisor Mr. Wabukye David, for all the guidance he has enkindled me with during this session amidst his busy schedules. I pray he may live to witness more great years on earth.

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LIST OF ABBREVIATIONS

EU	:	European Union
EAC	:	East Africa Corruption
DEO	:	District Education Officer
AFDB	:	African Development Bank
UNDP	:	United Nations Development Programme
US	:	United States
CVI	:	Content Validity Index
SPSS	:	Statistical Package for Social Sciences
IV	:	Independent variable
DV	:	Dependent variable
MoH	:	Ministry of health
WHO	:	World health organization
AIDS	:	Acquired immune deficiency syndrome

ABSTRACT

The study was guided by the topic socio-economic factors and access to palliative care services to chronically ill patients in Industrial City Division, Mbale City. The study was guided by the following research objectives: To find out the effect of income levels on access to palliative care services by chronically ill patients in Industrial City Division Mbale City, to investigate the effect of education levels on access to palliative care services by chronically ill patients in Industrial City Division Mbale City and lastly to examine the effect of religion on access to palliative care services by chronically ill patients in Industrial City division Mbale City. The study used both a qualitative and quantitative research design where it considered a population of 100 respondents which give rise to a sample size of 80 respondents. The study findings revealed that: that many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor, that palliative care services have not been utilized due to poverty of most patients and their families, that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness and this accounted for complications and poor quality of life, that patients with low educational attainments are not aware of available palliative care services, that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious and lastly that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services. The study findings concluded that: Many patients have continued to depend largely on external funding for palliative care as most service of these services consumers are poor and poorest of the poor, that palliative care services have not been utilized due to poverty of most patients and their families and that access to palliative care among the poor is low due to high cost of palliative care services, that patients with low levels of education often present themselves for palliative care at the advanced stage of their illness and this accounted for complications and poor quality of life. The study recommended that there is more need to invest in palliative care services in different areas in the country in order to ensure effective service delivery and lastly that there is need to change people's sociocultural backgrounds which are obstacles in provision of palliative care services.

CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter presents the background to the study, problem statement, objectives of the study, research questions, scope of the study, and significance of the study, limitations and delimitations to the research study.

1.1 Background to the study

Worldwide, only about 14% of people who need palliative care currently do not receive it. Unnecessarily restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate palliative care. British doctor Dame Cicely Saunders found out that modern hospice movement gave rise to palliative care. In 1948, as a 20-year-old nurse in London, she fell in love with a Polish patient who was dying of cancer. He left her £500 to start a home or hospital to relieve the physical and emotional suffering of people who were dying (Mwiyira, 2021). Determined to understand the best ways of controlling pain, Saunders became a doctor, against a backdrop of evolving attitudes to end-of-life care in Britain and America. An active approach was emerging, as people became more aware of the intimate connections between physical and mental states, and sought new, creative ways to care for people until the very end of their lives – and beyond, in the care of the bereaved.

In 1967, Saunders opened St Christopher's Hospice at Sydenham in south-east London, believing passionately that with the right, care, the last days of a person's life could be made dignified and happy. She said: "I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, 'For someone to look as if they are trying to understand me'. It is impossible to understand fully another person, but I never forgot that he did not ask for success but only that someone should care enough to try" (2020). Saunders built a life-affirming philosophy around the belief that dying is 'as natural as being born', and death should be free from suffering and pain. By listening carefully to patients' stories of illness, disease and suffering, Saunders evolved the concept of 'total pain', which includes not just the physical but also social, emotional and spiritual aspects of suffering. Her approach to pain management was simple: constant pain needs constant control. Analgesics according to Ojangole (2019) were to be given regularly to prevent pain,

rather than alleviate it, and they should be used progressively as needed – from mild through to strong. Each patient's needs were individual and specific, and their care was to be developed accordingly, with support extended to their family and cares.

The specialty of palliative medicine according to MoH (2021) was first recognized in the UK in 1987 – a key moment in the wider shift away from 'terminal' care towards the concept of palliative care. Alongside the realization that the benefits of holistic palliative care should be expanded to those with life-limited diseases other than cancer, the impetus emerged to move palliative care to earlier stages in disease progression, integrating it with curative and rehabilitation. The vision of 'palliative care for all' emerged as both desirable and achievable (Kofi, 2017). The difference palliative care makes to the lives of patients and their families and careers is radical, so it's easy to see why palliative care took off and is now an accepted integral part of health care policies globally. St Christopher's Hospice quickly became an inspiring model for others, differing significantly from earlier homes for people nearing death by taking a three-pronged approach, combining excellent clinical care, education and research. The success of this approach fueled palliative care development worldwide, firstly in affluent countries, then in poorer ones too, with Zimbabwe's Island Hospice Service (founded in 1979) considered to be the first in a developing country.

Today Mark et al., (2018) argued that there are more than 8,000 hospices working around the world, and many more specialist palliative care units in hospitals. But the principles of hospice care are also practiced in many different settings, such as home-based and day-care services. There are also many successful mentoring and twinning arrangements between hospices and palliative care services in developing countries and their counterparts in the West. Pioneers of palliative care have worked tirelessly to promote and develop Saunders's approach. Driven by common goals, they have built collaborative networks on national, regional and international levels, and won committed backing from key bodies such as the World Health Organization. It's now widely accepted that medical specialization, the integration of palliative care into mainstream health systems and the development of evidence-based practices are crucial to the ongoing reduction of suffering in people with life-limiting illnesses.

The World Health Organisation in 2022 estimated that over 40 million people needed palliative care and that with proper palliative care, the suffering of these people could be prevented. With people living in vast swathes of the world still unable to access any sort of

palliative care, it's vital that the expansion continues. The development by the second half of the twentieth century of new technologies and effective specific treatments for disease still left much suffering unaddressed. As Professor Patrick Wall wrote in 2021, 'Symptoms were placed on one side and therapy directed at (them) was denigrated'.

Scientific and medical advances in the last century have prolonged and facilitated life and delayed death. Advances in biomedical and clinical medicine have enabled the prevention and/or treatment of many diseases (Oite, 2019). Recently, improvements in treatment models have not significantly reduced or palliated the crucial effect of many diseases which were killing people in a short time in the past The World Health Organization (WHO, 2021) defined palliative care for the first time in 1989 as follows: "palliative care is an approach that improves the life quality of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". In 2014, the WHO added another view to the definition: "Palliative care is the responsibility of all physicians"; thus, the definition of palliative care became comprehensive. Palliative care is a multidisciplinary care that aims to prevent or palliate the symptoms, relief of suffering of patients, and improve life quality of them (Omaswa, 2016). Palliative care should not only be applied to patients in the final stages of life: it should be integrated into medical care and curative and life-long treatment, regardless of disease stage.

In Africa, a survey of hospice and palliative care services on the continent by WHO (2020) found out that 45 percent of African countries had no identified hospice or palliative care activity, and only nine percent could be classified as having services approaching some measure of integration with mainstream health provision. Palliative medicine is the continuation of the long struggle to accept life on its own terms, honestly and openly. Taking its place in academic medicine, this new subspecialty will enable future generations of physicians to gain generalist-level palliative medicine skills while advancing knowledge in the field and fulfilling our promise to patients and their families that we will not abandon them when our treatments fail and that, at all times, we will do all we can to relieve their suffering.

The goal of palliative care in Africa is to restore the functional capacity of a patient by being sensitive to the cultural and local values, beliefs, and practices of the individual, to alleviate

pain, and to improve the life quality by controlling the symptoms (Ntwale et al., 2020). In other words, the purpose is to reduce or eliminate the symptoms of the disease without any further examinations when the cure is no longer possible in the disease. Indeed, what the WHO (2020) expected from palliative care team is to respect patients and their relatives and to consider their wishes. This expectation should be interpreted as providing health care to the patient and his/her relatives that will ensure their well-being regardless of their age, economic or social status, and disease characteristics.

In Uganda, despite its vital importance, health promotion has not occupied its due place in public health in Uganda. The country is engulfed into a rising wave of both communicable and non-communicable conditions (MoH, 2019). This rising burden of both communicable and non-communicable conditions turns health promotion and palliative care essential health care packages; though there is little to show that these two important programs are getting vital support at policy and service delivery levels. A new theoretical framework that is anchored into sociocultural issues is essential in guiding the design and delivery of both health promotion and palliative care in Uganda. The autogenic theory puts socio-economic issues at the center of developing health promotion and palliative care and, seems to solve this dilemma (Tumwine, 2021). In this chapter, illustrations from indigenous communities in Uganda are employed to demonstrate the challenges to the health promotion and palliative care agenda in the country and how they can be addressed. Uganda Ministry of Health should develop robust structures within public health for development of health promotion and palliative care in the country. Research should be conducted on the effectiveness of the current strategies on health promotion and palliative care and their social-economic sensitivity and appropriateness. Given the limited resources available for development of health care in Uganda, as an overall strategy, health promotion and palliative care should be anchored in public health and its (public health) resources.

Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals (WHO, 2018). Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant

tuberculosis (Mande, 2019). Pain and difficulty in breathing are two of the most frequent and serious symptoms experienced by patients in need of palliative care in Uganda. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives. Opioids are essential for managing pain and can also alleviate other common distressing physical symptoms including breathlessness. Controlling such symptoms at an early stage is an ethical duty to relieve suffering and to respect a person's dignity.

In industrial Division Mbale City, Medications used in palliative are common medications but used for a different indication based on established practices with varying degrees of evidence. Examples include the use of antipsychotic medications, anticonvulsants, and morphine. Routes of administration may differ from acute or chronic care, as many people in palliative care lose the ability to swallow (MoH, 2021). A common alternative route of administration is subcutaneous, as it is less traumatic and less difficult to maintain than intravenous medications. Other routes of administration include sublingual, intramuscular and transdermal. Medications are often managed at home by family or nursing support. Palliative care interventions in care homes contribute to lower discomfort for residents with dementia and to improve family members' views of the quality of care. High-certainty evidence is not available to support the implementation of home-based end-of-life care programs this is because a sustainable, quality and accessible palliative care system has not been integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Therefore, higher quality research is needed to support the benefits of these interventions and this has given rise to this study by the researcher.

1.2. Problem Statement

The International Narcotics Control Board found out that in 2021, 79 per cent of the World's population, mainly people in low- and middle-income countries, consumed only 13 per cent of the total amount of morphine used for the management of pain and suffering, or 1 per cent of the 388 tons of morphine manufactured worldwide. Although that was an improvement over 2022, when 80 per cent of the world's population consumed only 9.5 per cent of the morphine used for the management of pain and suffering, the disparity in the consumption of narcotic drugs for palliative care between low- and middle-income countries and high-income countries continues to be a matter of concern.

The public has with great concern observed that socio-economic factors impend access to palliative care services of chronically ill patients in Industrial City Division Mbale City. At the World Palliative Care Management Symposium in Tokyo (2021) it was noted that socio-economic factors limit access to palliative care services by chronically ill patients in low income countries. Despite the interventions in Industrial City Division Mbale City by the Government through community awareness campaigns, increased funding from development partners and expanding outreach care centers, access to palliative care services by chronically ill patients is still limited and if nothing is done there will be a likelihood of high death rates, constant morbidity among others, therefore strong and focused strategies are needed to increase access to palliative care services by chronically ill patients which is determined by socio-economic factors such as income levels, education levels and religion

There is also lack of information regarding how socio-economic factors impend access to palliative care services by chronically ill patients in Industrial City division Mbale City, thus, this study aims to assess how socio-economic factors impend access to palliative care services by chronically ill patients in Industrial City division Mbale City.While Mwiti's study on effect of palliative care services on patients' health, concentrated on the relationship between palliation and health not access to palliative care services by chronically ill patients in Masaka and no such study has ever been conducted in Industrial City Division Mbale City hence this has given the researcher an opportunity for this study.

1.3 Objectives of the Study

1.3.1. General objective of the study

The general objective of the study was to investigate the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial City Division Mbale City.

1.3.2 Specific Objective of the study

a) To find out the effect of income levels on access to palliative care services by chronically ill patients in Industrial City Division Mbale City
b) To investigate the effect of education levels on access to palliative care services by chronically ill patients in Industrial City Division Mbale City

c) To examine the effect of religion on access to palliative care services by chronically ill patients in Industrial City division Mbale City.

1.4 Research questions

1. What is the effect of income levels on access to palliative care services by chronically ill patients in Industrial City division Mbale City?
2. How has education level affected access to palliative care services by chronically ill patients in Industrial City Division Mbale City?
3. In which ways has religion affected access to palliative care services by chronically ill patients in Industrial City division Mbale City?

1.5 Scope of the study

The study was limited to the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial City Division Mbale City of Eastern Uganda. The study scope was categorized into geographical, content and time scope as follows:

1.5.1 Geographical Scope

The study was conducted in Industrial City Division of Mbale City in Mbale district which is located in Eastern Uganda. It was carried out in the Wards of Maluku and Namatala.

1.5.2 Content scope

The study focused on information about the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial City Division Mbale City of Eastern Uganda. It specifically looked at how income and education level affects access to palliative care services by chronically ill patients in Industrial City Division Mbale City. It also looked at how religion affects access to palliative care services by chronically ill patients in Industrial City Division, Mbale City. Through this content scope, the researcher was able to collect adequate and relevant information in line with the study objectives.

1.5.3 Time Scope

The research study considered the period between 2022-2024. This period was considered because it is during this time that many lives were lost due to lack of palliative care (UHDS 2022, Ministry of Health, 2023)

1.6 Significance of the study

The results of the study may go a long way to help strengthen the implementation of policies and programs on access to palliative care by chronically ill patients.

It may also help to form a basis for future planning and negotiations with various stakeholders on how socio-economic factors affect access to palliative care by chronically ill patients.

The study may contribute to the existing body of knowledge on the effect of socio-economic factors on access to palliative care by chronically ill patients.

The study may act as a reference for future researchers who want to conduct research in a similar area of study.

1.7 Conceptual Frame work

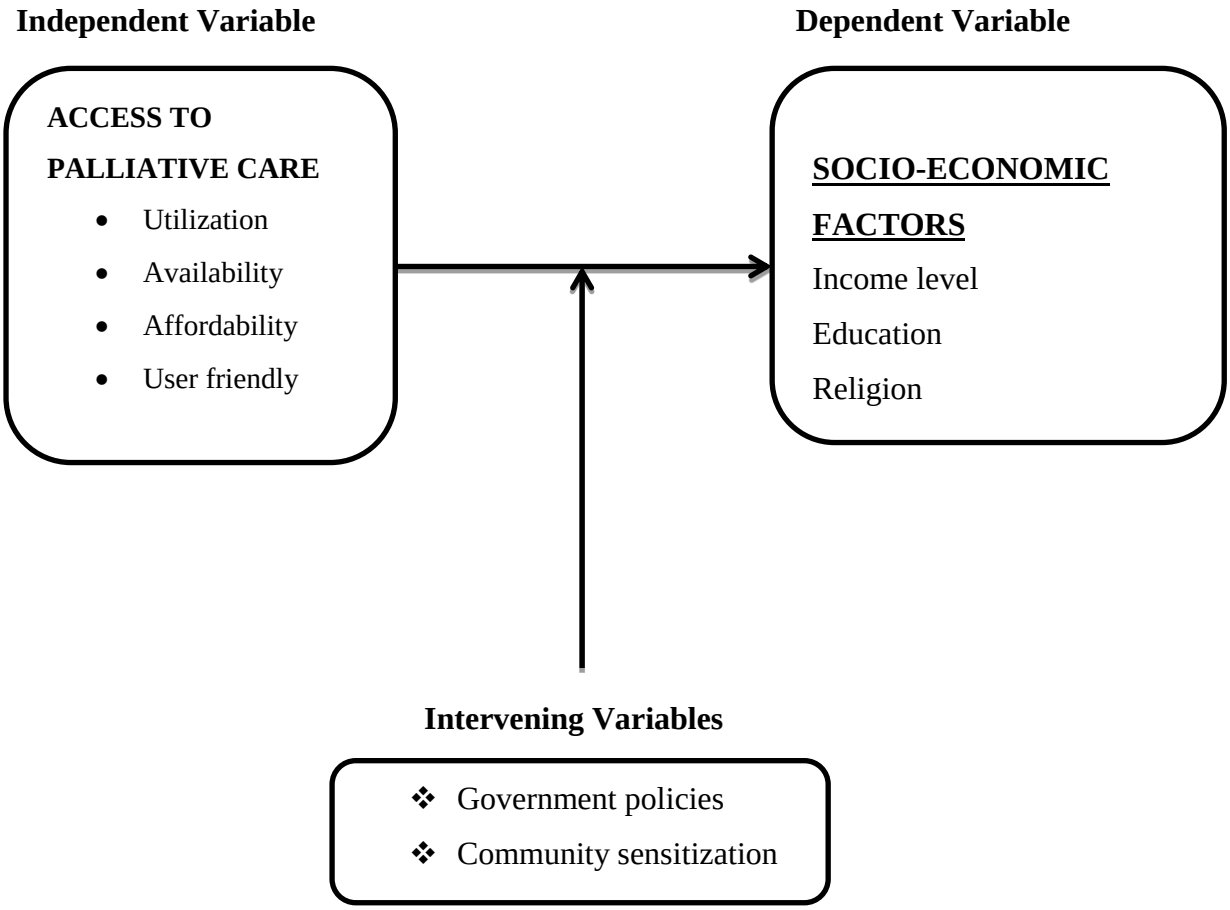

Figure 1.1 Conceptual Framework showing relationship between variables

Source: Mile s& Huberman (2009, p. 18) and modified by the researcher

Form the above conceptual framework, socio-economic factors as independent variable (IV) involves income levels, education levels and religion. The dependent variable in this case is access to palliative care by chronically ill patients. The framework assumes that when socio-economic factors are conducive, it is likely to transform access to palliative care services by chronically ill patients. Nevertheless, this may not be automatic as other factors may come into play. These may include Government policies and community sensitization. These factors have been dully coined as intervening variables by the study and are being isolated to avoid making wrong conclusions.

1.8 Operational Definitions

Palliative Care: Is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (Whitelaw and Clerk [2021], p. 4).

Chronically ill Patients: these are persons who are near death and in need of all available care including treatment (WHO, 2020)

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents the review of the past literature related to area under investigation. The review was conducted according to objectives of the research study as seen below:

2.1 Effect of income level and access to palliative care

Okodelo, (2017) found that the few patients and their families in Morocco who were knowledgeable about PC (palliative care), as well as those without knowledge of PC, often presented themselves for PC in the healthcare setting at the advanced stage of their illness, and this accounted for complications and poor quality of life. Late presentation of illness was further complicated by poverty and the religious beliefs of the patients and their families. Specifically, most of the patients perceived that PC was expensive, and therefore, they were reportedly unable to pay due to poverty and lack of health insurance coverage, leading to a high rate of patient drop-out, stoppage, or restricted access to PC. However, Okodelo study took place in Morocco not in in industrial division of City of Uganda and as such, his findings cannot be relied on making this study necessary.

WHO (2020) found that most PC services have not been utilized due to poverty of most patients and their families. But evidence from the literature has not shown that availability and provision of PC across African countries are still patchy and its access is limited to seriously and/or terminally ill and dying patients and that it has not been integrated into the mainstream of healthcare systems in almost all the African countries due to ability to pay. Other potential key factors accounting for the limited access include late presentation, inadequate referral systems, client's previous knowledge of PC, and service users' incomes. Efforts are not being made to improve access through the use of mobile phones to deliver PC and home visits by professionals as clients are poor. However, barriers (patients not having access to phones, limited mobile networks, and access to expertise and hardware) required for the use of mobile phone for PC deliver and lack of vehicles for home visits have made access to PC ineffective.

Another identified economic factor hindering PC were affordability alongside with funding and policies. The multi-method reviews that Sealey et al., (2017) mapped the level of PC development in 2017 showed that 26 out of 47 African countries with a known PC activity hugely depend on external funding for PC due to low incomes of the beneficiaries. However, the similar review by WHO (2022) conducted 4 years later showed there was no significant improvement in the commitment by the government for funding PC because majority of African countries were still reliant on the external financial aid to fund PC except Cote d'Ivoire that has established multiple sources of funding for PC to support poor beneficiaries.

Furthermore, MoH (2021) found that the healthcare professionals that participated in the empirical study conducted in Nigeria reiterated lack of access to PC services due to poverty. Likewise, the in-country experts in PC from Ghana, Kenya, Mozambique, Namibia, and South Africa unanimously reported that their countries have continued to depend largely on external funding for PC as most of PC service consumers are poor and poorest of the poor. For instance, they reported that the withdrawal of external funding for HIV/AIDS in South Africa caused closure of many hospices and death of millions of poor HIV patients. This implies that low incomes of PC beneficiaries may still be one barrier to PC development in African countries. However, these studies did not capture the underlying reasons for this client's poverty, suggesting a need for a more comprehensive and in-depth study.

Osegen (2019) argued that costs avoided by poor patients receiving palliative care are rarely redeployed to support the programs that create those savings and palliative care specialists' ability to assist those patients with long or indeterminate life expectancies will be severely constrained if a take-over model of care is dependent on ability to pay. This is going to become even more important as patients with increasingly unpredictable prognoses are included in specialist palliative care programs' mandate. Patients do best by having access to both disease-modifying treatments and palliative care simultaneously, so it makes no sense to hand over all aspects of care to a service with limited resources when a referral is made. The most efficient model of care is to have the right people delivering the care at the right time that most suits the circumstances not income levels of consumers of PC services. Who is "right" may change a number of times over the course of a long illness, and palliative care professionals can most efficiently and cost-effectively share their expertise at multiple points in the illness trajectory, stepping back when not needed, ensuring ongoing care is provided by the referring team.

Whilst some socio-economic barriers to practices thought to indicate a 'good death' have been identified, e.g. insufficient space for specialist equipment to die at home (Wahid et al., Citation2018), there is little research investigating the more nuanced ways in which poverty impacts end-of-life experiences (Lewis et al., Citation2014; Song et al., Citation2007). Whilst acknowledging ongoing debates about the definition of terms such as class (Bartley, Citation2016), this paper argues that there is an urgent need to understand how the structural, social and economic aspects of poverty, as well as cultural values of class and community, may interact with and impact upon attitudes towards preparing for end of life, as well as experiences of dying and bereavement. Most importantly, it argues for the need for research to listen to the lived experience of those living, and dying, on a low-income basis.

2.2 Effect of education and access to palliative care

According to a study by Opoku (2018) where 79 out of 115 respondents in Ghana indicated their awareness and knowledge about PC, although the majority of these participant's low educational attainments were aware of the healthcare settings that did not provide PC services, nor were they aware of persons who had received PC in Ghana. Conversely, three studies found that majority of patients and their family members had no knowledge of, and were inadequately aware of, PC and hospice care services. However, it was reported in the 2015 that no public awareness or understanding of PC exists in Ghana.

Studies by Davis et al., (2017) provided insights that the level of education impacted on whether respondents had, or had no knowledge of PC indicating that higher educational level was associated with higher level of awareness/knowledge. Remarkably, there was consensus in the literature that patients desired knowledge about PC, particularly in respect to the causes of cancer, treatment options, as well as aspects of PC, which would require decision-making. Although agreement existed in the literature about poor public knowledge of PC by PC clients with low educational levels in many of the African countries, most of the patients from Nigeria, Ghana, Uganda, and Zimbabwe demonstrated a positive attitude toward PC through their expression of acceptance and willingness to receive PC.

Onyango (2020) found that patients from Rwanda and Nigeria complained that they lacked formal knowledge about PC confirming what has been reported in the literature about the development of PC in Africa. Findings across the previous review papers about PC consistently reported that countries such as South Africa, Uganda, Botswana, Kenya, Zambia,

Swaziland, Malawi, Rwanda, Namibia, Nigeria, Ethiopia, Egypt, Cote d'Ivoire, and Tanzania had developed national PC programs which were either being implemented in collaboration with local universities or were planned to be implemented to create awareness about PC services among patients with low educational attainments. Uganda and South Africa were the two countries in the African continent recognized to have developed educational centers and academic links forged within universities. This finding revealed that there is a complete lack of PC services education or training institutions for public in most African countries, despite the demand for PC services.

The inadequate knowledge of PC among uneducated patients seems to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of PC services. In his scoping review, Tagotya (2019) found that patients with formal education were more likely to take up PC services compared to those with low educational attainments, thus explaining the inadequate knowledge of PC services held among many of the chronically ill patients. Arguably, lack/inadequate could have affected the relational factors by making healthcare professionals incompetent in communication with patients and even among themselves. However, a few African countries have been shown to be making efforts to develop national PC program to bridge the gap in knowledge and skills required for the practice of PC (Kungu, 2018). In addition, it appears that dissatisfaction with symptom management, especially pain control, experienced by the patients can also be attributable to their inadequate knowledge about PC services by both chronically ill patients and care givers

The level of education as an essential role in the efficacy and continuation of palliative care services, and its inadequacy has been reported as a challenge to obtaining these services. Public awareness about care services is another effective step in providing optimal palliative care, but despite the efforts made to raise the community's knowledge of palliative care, 15 only 20 countries in the world report a relatively good public awareness about these services. Raising awareness requires the adoption of strategies at the national level and the integration of palliative care services with national health care.

2.3 Effect of religion and access to palliative care

Ojangole (2018) argued the significance of religion, belief, and spirituality at the end of life. This study explored palliative professionals' views in this area. By means of an in-depth interviewing method, the researcher collected data from participants were recruited from five hospice and palliative care organizations, and the data were managed and analyzed with thematic analysis and NVivo (version 11). Results showed that patients who are deeply religious had a high level of PC services uptake compared to non-religious. This study will find out whether there are reasons that make religion, belief, and spirituality important for patients and their loved ones when facing imminent death and whether these reasons are independent from one another or complementary.

Notably, Lewington *et al*. (2016) reported that majority of patients and their families had faith in God, while other articles also showed that patients and their families had inclinations to religious beliefs. The study by Opoku (2018) mentioned that religious belief system and sociocultural background were cited in the minority among listed factors that Ghanaians indicated to be obstacles which affect the provision of PC. The study conducted in Nigeria which used a modified needs questionnaire, identified some spirituality concerns in which 86% of the cancer patients felt that "God is a doer," with few patients of the opinion that God was a supporter and could heal them. Further, an impression about religious belief as a barrier to PC was made in another study conducted in Nigeria where it was reported that most of the patients and their families resorted to an attempt to reconcile hope with religion, leading to hopes for miraculous cures, healing, and recovery

After a review of 26 articles published between August 2013 and August 2014 on the role of religion and spirituality at the end of life, Lópes-Síerra and Rodríguez-Sánchez (2018, p. 87) concluded that "religion/spirituality evokes in patients the resources to find the necessary inner strengths, which includes perspective thinking, rituals for transcending immediate physical condition and modalities of coping with their oncological illnesses". also Koenig reported that with the support of the spiritual community and religious faith, individuals at the end of life are able to leave it to God to control their circumstances with love and wisdom.

Bülow et al. (2019) found that patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion. It was also reported by Ford et al. (2016) that religious patients and families felt optimistic about the outcome of the illness and the efficacy of treatment. Other works include Robinson et al. (2018) who carried out a study in 3 pediatric intensive care units in Boston to explore the role of spirituality from the perspective of parents who had recently lost their children. They asked 56 parents for the advice they would like to give to anyone who is nearing the end of life. Three of the four major themes that emerged from the qualitative study were prayer, faith, and support from clergy. The fourth theme focused on the "belief in the transcendent quality of the parent child relationship that endures beyond death"

Furthermore, Kaut (2020) explained that a lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties. In order to cater to the patients' religious/spiritual needs, chaplaincy services are provided by most palliative care homes. Chaplaincy intervention has significantly contributed to patient satisfaction and increased enrolment in hospices

There have been studies looking at the spirituality of palliative care professionals as well as patients and their families but they lack a coherent and conceptually guided principle on the subject matter. In 2006, Sinclair et al. (2016) studied how palliative care professionals experience spirituality in their workplace. According to the authors, this was the first study to focus on the exploration of the "collective spirituality" of palliative care providers. Wasner et al. (2019) looked at the impact of spiritual care training on palliative care professionals and Arrieira et al. (2017) interviewed palliative care professionals to understand how they experience spirituality in their daily routine. The present study will explore palliative care professionals' views on the importance of religion, faith, belief, and spiritual identities for their client group.

Mwiti (2018) found that in some aspects, palliative care was always spiritual, and the two disciplines developed together in this environment. Still, as palliative care practitioners have increasingly clarified palliative care as a distinct discipline in medicine, yet religious and spiritual care practitioners have continued to struggle to define their place. Palliative care practitioners brought a unique lens to spiritual care from the outset, understanding that spirituality exists within dynamic extended systems of relationships. These complex relational networks and connections exist between patients, their families, personal careers, the interdisciplinary team, sociocultural and religious communities, and existential and transcendent values and beliefs. Much of the academic research on spirituality focuses on the individual. However, in reality, an individual's spirituality is embedded within a broader multivalent relational network and this study will be done to fill this gap.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter describes the methodology that was used in the study and some of the areas that were covered include: research design, area and population of the study, sample size, sample selection techniques, sources of data, data collection instruments, data quality control and data analysis

3.1 Research Design

The research study used cross-sectional design using both qualitative and quantitative research approaches to analyze the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial division of Mbale City. This design helped the researcher to generate more sufficient data and relevant information that supported the variables and objectives of the research study

3.2 Study Area

The study was conducted in the selected wards of industrial division of Mbale City in Mbale District. It was conducted in wards of Masaba, Malukhu and Central Ward. This area is chosen because it made it easy for the researcher during cases of data collection.

3.3 Sample size and Study Population

The population consisted of 40 palliative care staffs, 20 nurses and 20 local leaders. Palliative care staffs were chosen to participate in this study because of their experience in the administration of palliative care services to chronically ill patients while division were selected because of their experience in supervising and monitoring the provision of PC services and they had firsthand information regarding the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial division of Mbale City. Additionally, nurses were chosen because of their oversight roles, planning and community mobilization to increase the uptake and access to PC services.

The total population (N) was 100 participants and therefore the sample population was 80 participants which was arrived at using solvents formula of determining a sample.

$$n = \frac{N}{1 + N(e)^2}$$

Where:

$N =$ Study population

$n =$ Sample size

$e =$ Precision error at 95% confidence interval

Thus

$$n = \frac{N}{1 + N(e)^2}$$

$$n = \frac{100}{1 + 100(0.05)^2}$$

$$n = \frac{100}{1 + 100(0.0025)}$$

$$n = \frac{100}{1.25}$$

$$n = 80$$

Table 3.1 Summary of the Sample Size and Sampling Techniques

Respondents	**Study Population (N)**	**Sample Size (n)**	**Sampling Technique**
Palliative care staffs	50	40	Simple random
Division leaders	25	20	Purposive sampling
Nurses	25	20	Purposive sampling
Total	**100**	**80**	

Source: Primary data, 2023

3.4 Sampling Techniques

The researcher used the following sampling techniques:

3.4.1 Simple random sampling

The researcher used simple random sampling to select respondents from palliative care staffs category. This technique involved giving a number to every subject or member of the accessible population, placing the numbers in the container and then picking any number at random. The subject corresponding to the numbers were then be included in the sample.

3.4.2 Purposive Random Sampling

Purposive sampling technique was used because some individuals in the population have special knowledge that makes them become "privileged" to participate for the purpose of the study. According to Kothari (2010) purposive sampling is a type of sampling where the researcher purposively chooses persons who, in his judgment about some appropriate characteristic required of the sample members are thought to be relevant to the research topic and are easily available. A purposive, or judgmental, sample was used on nurses and local leaders because had enough information that helped the researcher to address the research objectives.

3.5 Research Instruments

The researcher used both questionnaires and interview guide.

3.5.1 Questionnaire

The researcher used self-administered questionnaire as research tool to collect data from the nurses and local leader's category. The questionnaire had three sections: Section A included respondents' demographic information, Section B, C and D focused on the general and closed ended statements which was in accordance with the objectives of the study.

The nature of the questions was in form of structured and closed ended questions where by a 5 Likert scale of measurement was on close ended questions based on a scale of strongly agree (5), agree (4), unsure (3), disagree (2), strongly disagree (1). A questionnaire was used because it allowed participants to provide fist hand information which is free of bias and easy to use. This instrument was used on division staffs and nurses

3.5.2 Interviews

Other data was collected using interviews with the help of interview guide. An interview guide is a research instrument that contains a set of questions on defined issues under study that are put to participants on face to face basis (Saunders, et al, 2007). These instruments contained mostly open-ended questions. The interview guide was used on palliative care staffs as respondents because this category of the study population may have in-depth knowledge and firsthand information that may not be fully captured using questionnaires.

3.6 Data quality control tools

3.6.1 Validity

The validity of an instrument is defined as the ability of an instrument to measure what it is intended to measure. To establish the validity of the instruments, the researcher used expert judgment as recommended by Gay (1997) as the best method for ensuring validity. Thus the researcher ensured that the instrument is clear, relevant, specific and logically arranged. The validity of the questionnaire was tested using the content validity test (CVI). To arrive at the relevancy of the questionnaire, the researcher designed the instrument that will yield content –valid data by first specifying the domain of indictors that are relevant to the concept being measured. A content-valid data measure contained all possible items that was used in measuring the effect of socio-economic factors on access to palliative care services by chronically ill patients in industrial City Division Mbale City.

$$CVI = \frac{R}{R + N + 1R}$$

Where, Relevant (R), Neutral (N), to Irrelevant (IR).

3.6.2 Reliability

The reliability of the instruments was tested using a test re-test method of reliability and Cron-bach alpha tests to determine the reliability index with the help of SPSS. Data was collected from 20 palliative care staffs not among those in the sample. The principle of reliability as far as research instruments are concerned, is clearly put forward by Amin (2005), an instrument is reliable if it produces the same results wherever it is repeatedly used to measure a trait or a concept from the same population and under similar circumstances. In this case of reliability, the Cronbach Alpha coefficient method of internal consistency was used to calculate the reliability co-efficient of the questionnaire.

The formula used was as follows:

$$\alpha = \frac{K}{K-1}\left(\frac{2}{1 - \Sigma Di\, S}\right)$$

SDt^2

Where:

α = the alpha coefficient

ΣSDi^2 = sum of the variance of individual items in the questionnaire

SDt^2 = variance of entire questionnaire

K = number of items in the questionnaire.

Reliability of the questionnaire will be found to be 0.911 therefore warranting the researcher to proceed.

3.7 Data Processing and Analysis

3.7.1 Quantitative data analysis

Data processing was done through editing of the data which was coded for further data analysis. After data processing, quantitative data analysis was carried out by simple frequency tabulation using a Statistical Package for Social Science (SPSS). Data was presented using different methods such as simple frequency tables which ultimately helped to measure the influence of soci0o-economic factors on access to palliative care services by chronically ill patients. This was because data presentation required clear portrayal of the findings presented, and the listed method above clearly fulfilled that purpose.

3.7.2 Regression Analysis

Regression analysis was used because the researcher is interested in finding out whether the independent variable predicts the dependent variable. The researcher used simple regression to analyze the effect of gender inequality on psychosocial wellbeing of women. This type of inferential statistics is easy to compute and interpret and it helped in making conclusions.

Descriptive statistical techniques (frequencies and percentages) will be used to analyze field data from questionnaires to assist in the interpretation of data.

3.7.3 Qualitative data analysis

On the other hand, qualitative data gathered from open-ended questions in the interview guide was summarized. A style called content analysis was used to test the validity and authenticity. Content analysis is the analysis of data which is non-empirical. In qualitative data analysis, the researcher obtained detailed information about the effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial City Division Mbale City and try to pattern trends and relationship. Then data was coded and categorized according to the sub-themes identified earlier.

3.8 Data collection procedure

The researcher selected and presents a research topic to the department of social sciences which was approved. Thereafter the researcher developed a research proposal. After approval of the research proposal, the researcher obtained an introductory letter from the Head of department which was presented to the relevant authorities in the study area for data collection. Thereafter the researcher writes a report to be presented to the department for further examination

3.9 Ethical Considerations

3.9.1 Consent

The researcher sought approval consent from the respondents. Respondents willingly decided to participate in the study after the researcher explaining to them the purpose of the study which is purely academic. It was possible that the researcher's views could influence the way the study findings were documented thus creating an ethical dilemma of failure to present exactly what the study subjects revealed in the course of the data collection. However, the prepared instruments helped the researcher to collect objective information hence fears of personal views was reduced.

3.9.2 Confidentiality

Confidentiality is looked at by Walford (2018) to mean information that is private and is not to be divulged to others. Whatever was said in confidence must remain confidential. The researcher assured the respondent that information offered by the participants was not be passed on to another party (third party) without consent of the participants. Their identity and response was made confidential.

3.9.3 Anonymity

Anonymity, termed more appropriately as pseudonymity, is defined by Wiles (2013) as a major means used by the researcher to safeguard the confidentiality of responders by using pseudonyms. The researcher ensured that all respondents were identified anonymous ly implying that their identities are not known and not salient in the study. Withholding the identity of respondents is a guarantee that their statements are authentic (Taylor, 2015).

3.9.4 Plagiarism

The researcher ensured that all written work is original and without any borrowed and manipulated texts, results or even expressions. The researcher made sure that, all words and publications of the author were given their due acknowledgement (Mugenda & Mugenda, 2016). The researcher subjected the written works to a software and make sure it is 15% or less compliant of plagiarism material.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.0 Introduction

This chapter presents data analysis and interpretation based on the study objectives identified earlier. It begins with the analysis of the demographic data as seen below;

4.1 Demographic characteristics of the respondents

The first part of this chapter is a presentation and analysis of the preliminary data obtained from the study. It involves the background information of the respondents. The variables involved are age (years), gender of respondents, educational level and marital status**.** Data obtained has been presented in tables below.

4.1.1 Age of Respondents

Table 4.1 contains the age distribution of respondents who participated in the study. The purpose was to find out the average age of respondents in the study area.

Table 4.1: Age in years

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	21-29	3	3.8	3.8	38.8
	30-39	34	42.5	42.5	46.3
	40-49	40	50.0	50.0	96.3
	50 above	3	3.8	3.8	100.0
	Total	**80**	**100.0**		

(Source: Primary data, 2024)

A close look at the Table 4.1 show that 3.8% of the respondents were 21-29 years of age, 42.5% were between 30-39 years of age, 50% who constituted the majority were 40-49 years and 3.8% of the respondents were 50 years and above.

The findings of the study imply that since majority of the respondents were 40 years above, this means that they were mature enough and information acquired from them was reliable. The above view is in the line with Amin (2005) who argued that the majority age of above 18 years adds value to the responses given that mature people are more trustable as they take time to think about a particular aspect of life.

4.1.2 Gender of Respondents

The respondents were asked to indicate their gender by ticking the appropriate column they belonged. The purpose was to find out the number of males and females who actually participated in the study.

Table 4.2: Gender of Respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	51	63.8	63.8	63.8
	Female	29	36.3	36.3	100.0
	Total	**80**	**100.0**	**100.0**	

(Source: Primary data 2024)

Table 4.2 shows that out of the 80 respondents who participated in the study, majority 63.8% were males, while the remaining 36.3% were females. The finding means that there are more male than females who participated in the study, naturally, males and females have different attitudes and views toward events and since females are home makers, they tend to remain at home and this explains their lower turn up rate (Singer, 2014).

4.1.3 Marital status of the respondents

Table 4.3 depicts the marital status of respondents who participated in the study. The purpose was to find out the status people who participated in the research study.

Table 4.3: Marital status of the respondents

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Married	62	77.5	77.5	91.3
	Single	11	13.8	13.8	13.8
	Widower/ Widow	7	8.7	8.7	98.8
	Total	**80**	**100.0**	**100.0**	

(Source: Primary data 2024)

Table 4.3 shows that 13.8% of the respondents were single, 77.5% of the respondents were married, 7.5% were widows/widower and 1.3% of the respondents indicated that they had divorced. The data show that majority of respondents were married (mature adults) and therefore their responses were trusted because they had experience in solving various socio-economic problems.

4.1.4 Educational level of the respondents

The level of education was used to demonstrate the knowledge of respondents on vocational skilling and its effect on youth wellbeing.

Table 4.4: Levels of Education

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	University	29	20.0	20.0	36.3
	Tertiary	35	36.3	36.3	80.0
	Secondary	16	43.8	43.8	100.0
	Total	**80**	**100.0**	**100.0**	

(Source: Primary data 2024)

From the research findings, 20% of the respondents had ended at University level of education, 43.8% had ended at secondary level and 36.3% had ended at tertiary level of education.

The data shows that majority of the respondents had attained some level of education whose opinions and views regarding role of vocational skilling on youth wellbeing are guided and well informed. This was in line with Uma (2000) who argued that it is important in social investigation research to involve people that have attained an acceptable level of literacy and numeracy in order to be in position to understand and interpret content in the questionnaire.

4.2 Income levels and access to palliative care services by chronically ill patients

This was the first objective of the study which was about finding out identifying how income levels and access to palliative care services by chronically ill patients. Responses are shown below:

Table 4.5: Income levels and access to palliative care services by chronically ill patients

Question statements	SD	D	N	A	SA
Many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor.	3 (3.8%)	5 (6.3%)	19 (23.8%)	39 (48.8%)	14 (17.5%)
Palliative care services have not been utilized due to poverty of most patients and their families.	1 (1.3%)	26 (32.5%)	42 (52.5%)	11 (13.8%)	11 (13.8%)
Access to palliative care among the poor is low due to high cost of palliative care services	3(3.8%)	4(5.0%)	29 (36.3%)	29 (36.3%)	15 (18.8%)
Palliative care services are unaffordable to rural patient particularly those residing in rural areas	1 (1.3%)	10 (12.5%)	19 (23.8%)	37 (56.3%)	13 (16.3%)
Poverty restrict access to information regarding palliative care services	5 (6.3%)	13 (16.3%)	24 (30%)	29 (36.3%)	9 (11.3%)

Source: Primary data, 2024

Many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor.

The study investigated whether many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor. According to the findings in table 4.5 above, 3.8% of the respondents strongly disagreed that Many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor., 6.3% disagreed, 23.8% were neutral, while 48.8% who were the majority agreed and 17.5% also strongly agreed to the statement.

Therefore from the above findings, it is noticeable that many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor. At work with similar findings obtained from interviews. In support of this finding Greinert (2019) opined that many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor.

Palliative care services have not been utilized due to poverty of most patients and their families

The study also investigated whether palliative care services have not been utilized due to poverty of most patients and their families and from the findings, only 1.3% strongly disagreed that organization provides workers with better housing and office space, 32.5% were neutral, 52.5% who constituted the majority agreed and 13.8% strongly agreed.

From the above findings it means that palliative care services have not been utilized due to poverty of most patients and their families. Even the data collected from interviews show that palliative care services have not been utilized due to poverty of most patients and their families. Greinert (2017) equally agrees with the findings where he argued that palliative care services have not been utilized due to poverty of most patients and their families.

Access to palliative care among the poor is low due to high cost of palliative care services

On whether access to palliative care among the poor is low due to high cost of palliative care services, 3.8% of the respondents strongly disagreed to the statement noting that access to palliative care among the poor is low due to high cost of palliative care services, 5% disagreed, 36.3% were neutral, the same percentage of 36.3% agreed and 18.8% strongly agreed.

The above findings imply that access to palliative care among the poor is low due to high cost of palliative care services as majority of the respondents (36.3%) agreed and data collected from interviews also show that access to palliative care among the poor is low due to high cost of palliative care services. In line with the above findings, Bray, et al. (eds) (2020) opined that access to palliative care among the poor is low due to high cost of palliative care services with similar results from interviews.

Palliative care services are unaffordable to rural patient particularly those residing in rural areas

This variable investigated whether palliative care services are unaffordable to rural patient particularly those residing in rural areas and results show that 1.3% and 12.5% of the respondents strongly disagreed to the statement noting that palliative care services are unaffordable to rural patient particularly those residing in rural areas and disagreed respectively, 23.8% were neutral, 46.3% who were the majority agreed and 16.3% strongly agreed to the statement.

Therefore, the findings of the study imply that palliative care services are unaffordable to rural patient particularly those residing in rural areas. Even findings obtained from interviews show that palliative care services are unaffordable to rural patient particularly those residing in rural areas. This is in line with the findings of Okiiria and Okiidi (2017) who opined that palliative care services are unaffordable to rural patient particularly those residing in rural areas.

The organization provides workers with transportation and they arein good condition

Respondents were also asked to find out whether organizations provide workers with transportation and they are in good condition. Table 4.6 above shows 6.3% of the respondents who strongly disagreed that organizations provide workers with transportation and they are in good condition, 16.3% of the respondents equally disagreed, 30% were neutral, 36.3% agreed and 11.3% of the respondents strongly agreed that organizations provide workers with transportation and they are in good condition.

The above findings of the study therefore imply that organizations provide workers with transportation and they are in good condition and similar results were obtained from face to face interviews. In a related study, Gupta (2009) further commented organizations provide workers with transportation and they are in good condition.

Poverty restrict access to information regarding palliative care services

The researcher further investigated whether poverty restrict access to information regarding palliative care services; the findings of the study indicate that 5% of the respondents strongly disagreed and 13.8% disagreed and neutral to the statement respectively. Meanwhile, majority who constituted 50% agreed and 17.5% strongly agreed to the statement noting that poverty restrict access to information regarding palliative care services.

It is therefore true from the findings as majority of the respondents (50%) agreed that poverty restrict access to information regarding palliative care services with similar data obtained from interviews. Even research done by Asare, (2008) further revealed that poverty restrict access to information regarding palliative care services.

4.3 Education level and access to palliative care services by chronically ill patients

The second objective in this study was to investigate the effect of education level and access to palliative care services by chronically ill patients. The findings from respondent's opinion accompanying variables under this objective were summarized as follows;

Table 4.7: Education level and access to palliative care services by chronically ill patients

Question statements	SD	D	N	A	SA
Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life	2 (2.5%)	8 (10%)	17 (21.3%)	46 (57.5%)	7 (8.8%)
Patients with low educational attainments are not aware of available palliative care services	1 (1.3%)	7 (8.8%)	26 (32.5%)	33 (41.3%)	13 (16.3%)
Inadequacy of education among patients is as a challenge to obtaining these palliative care services	0 (0.0%)	23 (28.8%)	0 (0.0%)	39 (48.8%)	11 (13.8%)
Uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services	3 (3.8%)	5 (6.3%)	16 (20.0%)	40 (50%)	16 (20%)
Uneducated patients lacked formal knowledge about palliative care services	0 (0%)	6 (7.5%)	21 (26.3%)	34 (42.5%)	19 (23.8%)
Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life	0 (0%)	8 (10%)	29 (36.3%)	36 (45%)	7 (8.8%)

Source: Primary data, 2024

Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life

The study investigated whether patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life and the findings show that majority 57.5% of the respondents agreed to the statement noting that employees follow law full instructions from my superiors, 8.8% strongly agreed, 21.3% of the respondents was neutral, 10% disagreed and 2.5% strongly disagreed.

As evidenced from the above findings, majority of the respondents (57.5%) strongly agreed that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life and similar data was obtained from interviews. As Abagi (1997) noted that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life.

Patients with low educational attainments are not aware of available palliative care services

Respondents were asked whether patients with low educational attainments are not aware of available palliative care services and only 1.3% of the respondents strongly disagreed noting that employees are not supervised regularly, 8.8% of the respondents disagreed, while other respondents who constituted 32.5% were neutral, 41.3% who were the majority agreed and 16.3% strongly agreed that employees are supervised regularly.

Therefore from above findings, patients with low educational attainments are not aware of available palliative care services with similar results obtained from interviews. This is in support of the study done by Bayrak (1999) he opined that patients with low educational attainments are not aware of available palliative care services.

Inadequacy of education among patients is as a challenge to obtaining these palliative care services

Also, respondents were asked on whether inadequacy of education among patients is as a challenge to obtaining these palliative care services according to the findings, 8.8% of the

respondents disagreed that inadequacy of education among patients is as a challenge to obtaining these palliative care services, 28.8% of the respondents were neutral, whereas 48.8% agreed and 13.8% strongly agreed that inadequacy of education among patients is as a challenge to obtaining these palliative care services.

Furthermore, results from interviews also indicated similar opinions that employee's performance is reviewed regularly and by the head of department. The above findings are in agreement with Khan (2005) where he observed that Employee's performance is reviewed regularly and by the head of department.

Uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services

The study further investigated whether uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services and from the research findings in table 4.7, 3.8% of the respondents strongly disagreed noting that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services 6.3% disagreed, 20% were neutral, while 50% of the respondents agreed and 20% of the respondents strongly agreed that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services.

The findings of the study imply that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services. This discovery is in line with the findings of Okumbe (2018) who opined that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services.

Uneducated patients lacked formal knowledge about palliative care services

The study also investigated whether uneducated patients lacked formal knowledge about palliative care services as strongly agreed and agreed by 23.8% and 42.5% of the respondents respectively. Only 7.5% of the respondents disagreed and 26.3% of the respondents were neutral.

The above findings thus show that uneducated patients lacked formal knowledge about palliative care services. Kaplan (2016) equally agrees with the findings where he opined that uneducated patients lacked formal knowledge about palliative care services.

Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life

The findings show that 10% of the respondents disagreed that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life, 36.3% of the respondents were neutral, 45% agreed and 8.8% of the respondents strongly agreed that Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life.

Therefore the above results give clear indication that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life. Similar data however was collected from face to face interviews where it was noted that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life. Prosser (2011) argued that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life.

4.4 Religion and access to palliative care services by chronically ill patients

The third objective in this study was to establish whether religion influenced access to palliative care services by chronically ill patients and the findings from respondent's opinion accompanying variables under this objective were summarized as follows:

Table 4.9: Religion and access to palliative care services by chronically ill patients

Question statements	SD	D	N	A	SA
Patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.	3 (3.8%)	8 (10%)	23 (28.8%)	34 (42.5%)	12 (15%)
Religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services	4 (5.0%)	7 (8.8%)	24 (30%)	29 (36.3%)	16 (20%)
Religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses	5 (6.3%)	10 (12.5%)	26 (32.5%)	29 (36.3%)	10 (12.5%)
Patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion.	4 (5%)	11 (13.8%)	29 (36.3%)	28 (35%)	8 (10%)
Palliative care is integrated into spiritual care	8 (10%)	5 (6.3%)	21 (26.3%)	36 (45%)	10 (12.5%)
Lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties	2 (2.5%)	9 (11.3%)	23 (28.8%)	40 (50%)	6 (7.5%)

Source: *Primary data, 2024*

Patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.

Results in table 4.9 above show that 3.8% of the respondents strongly disagreed with the statement that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious, 10% disagreed, 28.8% of the respondents were neutral, 42.5% who constituted the majority agreed and 15% of the respondents strongly agreed that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.

Thus from the above findings, it is patients who are deeply religious had a high level of palliative care services uptake compared to non-religious as majority of respondents (42.5%) agreed to the statement. Similar findings were obtained from face to face interviews where it was found out those patients who are deeply religious had a high level of palliative care services uptake compared to non-religious. In support of these findings, research by Musaazi, (2017) found that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.

Religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services

On whether religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services, the study found that 5% of the respondents strongly disagreed with the statement noting that employees are provided with safety tools at work.8.8% disagreed, 30% were not sure, 36.3% agreed and 20% strongly agreed.

The findings therefore imply that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services. Even the findings obtained from interviews show that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services. Okojie (2019) also argued that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services.

Religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses

It was strongly disagreed by 6.3% of the respondents that religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses, 18.8% disagreed, 32.5% were neutral, 36.3% agreed and 12.5% strongly agreed that religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses.

The above findings thus imply religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses. Results obtained from interviews also show that religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses. Abdullah (2017) also opined that religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses.

Patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion

Further, the study investigated whether patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion.. It was strongly disagreed by 5% of the respondents noting that patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion, 13.8% disagreed, 36.3% were not sure, while 35% agreed, and 10% strongly agreed to the statement.

From the research findings, the majority of the respondents were not sure whether patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion, as revealed by 36.3% of the respondents.

Palliative care is integrated into spiritual care

The researcher also investigated whether palliative care is integrated into spiritual care. From the findings therefore, 10% of the respondents strongly disagreed that palliative care is integrated into spiritual care, 6.3% of the respondents disagreed, and 26.3% of the respondents were neutral, 45% of the respondents agreed and 12.5% of the respondents strongly agreed.

The study findings mean that palliative care is integrated into spiritual care as agreed and strongly agreed by 45% and 12.5% of the respondents and this is in line with the data collected from face to face interviews. Research by Maria (2020) also found similar results where she argued that palliative care is integrated into spiritual care.

Lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties

Research findings in table 4.9 above show that 2.5% of respondents strongly disagreed that lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties. 11.3% of the respondents disagreed, 28.8% were neutral, 50% who constituted the majority agreed and 7.5% strongly agreed.

The above findings therefore imply that that lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties. In the same line of argument, Jonnes (2017) argued that that lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter presents the summary, conclusion, and recommendations about the study. It also presents at areas for further research.

5.1 Summary

How income levels on access to palliative care services by chronically ill patients

Firstly, study findings showed that many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor.

Secondly, palliative care services have not been utilized due to poverty of most patients and their families, access to palliative care among the poor is low due to high cost of palliative care services.

Thirdly, Palliative care services are unaffordable to rural patient particularly those residing in rural areas

Findings also show that palliative care services are unaffordable to rural patient particularly those residing in rural areas and poverty restrict access to information regarding palliative care services.

How education level affected access to palliative care services by chronically ill patients

It was discovered in the findings that patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness and this accounted for complications and poor quality of life

Also findings indicate that patients with low educational attainments are not aware of available palliative care services.

Inadequacy of education among patients is as a challenge to obtaining these palliative care services.

It was also discovered from the study that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing

Study findings revealed that the provision and utilization of palliative care services and uneducated patients lacked formal knowledge about palliative care services

How religion affected access to palliative care services by chronically ill patients

Participants of the study mentioned that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.

Study findings show that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services.

Additionally, religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses.

Other fin dings revealed that patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion.

Lastly, palliative care is integrated into spiritual care and lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties

5.2 Conclusions

How income levels affect access to palliative care services by chronically ill patients

Findings concluded that many patients have continued to depend largely on external funding for palliative care as most service of these services consumers are poor and poorest of the poor.

Findings concluded that palliative care services have not been utilized due to poverty of most patients and their families and that access to palliative care among the poor is low due to high cost of palliative care services.

Findings concluded that palliative care services are unaffordable to rural patients particularly those residing in rural areas

How education level affected access to palliative care services by chronically ill patients

Findings concluded that patients with low levels of education often present themselves for palliative care at the advanced stage of their illness and this accounted for complications and poor quality of life.

Findings concluded that patients with low educational attainments are not aware of available palliative care services,

Findings also concluded that inadequacy of education among patients is as a challenge to obtaining palliative care services as this was clearly identified in the study.

Findings concluded that uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing

How religion affected access to palliative care services by chronically ill patients

Findings of the study concluded that patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.

As findings concluded that religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services.

Findings concluded that religion evokes in patients the resources to find the necessary inner strengths like includes thinking that transcends immediate physical condition and modalities of coping with their oncological illnesses.

Findings concluded that patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion as found out by this study.

5.3 Recommendations

The study recommends that there is need for government to sensitize people in the communities to differentiate palliative care with their religious beliefs.

There is more need to invest in palliative care services in different areas in the country in order to ensure effective service delivery

There is need to change people's sociocultural backgrounds which are obstacles in provision of palliative care services.

5.4 Areas for further study

1) Culture and access to palliative care services
2) Socio-demographic factors and access to palliative care services
3) End life care and palliation

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APPENDICES

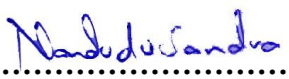
Appendix I: Consent Letter

Bachelor of Social Work and Social Administration (Candidate)

RESEARCH PROJECT-UGANDA CHRISTIAN UNIVERSITY, MBALE

I am **Nandudu Sandra** a student of Uganda Christian University, currently undertaking a research on the topic 'effect of socio-economic factors on access to palliative care services by chronically ill patients in Industrial City Division Mbale City'. You are privileged to participate in this research and your selection has been based on random sampling. Please feel free as you respond because the information you give will only be used for academics purposes, treated confidential and will be held anonymous before publication.

Thank you



NANDUDU SANDRA

(Researcher)

Appendix II: Questionnaires for division leaders, palliative care staffs and nurses

SECTION A

RESPONDENT'S BIO – DATA

INSTRUCTIONS

Please fill in the blank spaces or tick (√) in the boxes provided where necessary

1. Name:(optional)
   ……

2. Age: ……..

3. Sex: Male ☐ Female ☐

4. Marital status: Single ☐ Married ☐ Divorced ☐ Separated ☐ Widowed ☐

5. Location:
   Cell ……..…… Parish …….……..……..
   Sub – county …….

6. Class:
   P6 ☐ P7 ☐
   ……
   ……

7. Religion: Protestant ☐ Catholics ☐ Muslims ☐ Born again ☐
   Others (please specify)……

SECTION B: Income levels and access to palliative care services by chronically ill patients

In a score of 1-5, please choose the most appropriate answer where 1- strongly disagree, 2-disagree, 3- agree, 4-strongly agree and 5 uncertain

Question Statements	**1**	**2**	**3**	**4**	**5**
Many patients have continued to depend largely on external funding for palliative care as most of these service consumers are poor and poorest of the poor.					
Palliative care services have not been utilized due to poverty of most patients and their families.					
Access to palliative care among the poor is low due to high cost of palliative care services					
Palliative care specialists' ability to assist those patients with long or indeterminate life expectancies will be severely constrained if a take-over model of care is dependent on ability to pay.					
Palliative care services are unaffordable to rural patient particularly those residing in rural areas					
Poverty restrict access to information regarding palliative care services					

SECTION C: Education level and access to palliative care services by chronically ill patients

In a score of 1-5, please choose the most appropriate answer where 1- Strongly Disagree, 2-Disagree, 3- Agree, 4-Strongly Agree and 5-Uncertain

Question statements	**1**	**2**	**3**	**4**	**5**
Patients with low levels of education often presented themselves for palliative care at the advanced stage of their illness, and this accounted for complications and poor quality of life					
Patients with low educational attainments are not aware of available palliative care services					
Inadequacy of education among patients is as a challenge to obtaining these palliative care services					
Uneducated patients seem to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilization of palliative care services					
Uneducated patients lacked formal knowledge about palliative care services					

SECTION D: Religion and access to palliative care services by chronically ill patients

In a score of 1-5, please choose the most appropriate answer where 1- Strongly Disagree, 2-Disagree, 3- Agree, 4-Strongly Agree and 5-Uncertain

Question statements	**1**	**2**	**3**	**4**	**5**
Patients who are deeply religious had a high level of palliative care services uptake compared to non-religious.					
Religious belief system and sociocultural backgrounds are obstacles which affect the provision of palliative care services					
Religion evokes in patients the resources to find the necessary inner strengths which includes perspective thinking, rituals for transcending immediate physical condition and modalities of coping with their oncological illnesses					
Patients, nurses, doctors, and families that identified themselves as religious supported more aggressive treatment than those who only identified themselves as being affiliated to a religion.					
Palliative care is integrated into spiritual care					
Lack of attention to the spiritual needs of the dying might lead to physical, cognitive, and emotional difficulties					

END

Appendix III: Interview guide for palliative care patients

1) Self-introduction

2) What is your occupation?

3) What is the effect of income levels on access to palliative care services by chronically ill patients in Industrial City division Mbale City?

4) How has education level affected access to palliative care services by chronically ill patients in Industrial City Division Mbale City?

5) In which ways has religion affected access to palliative care services by chronically ill patients in Industrial City division Mbale City?

Appendix IV: Work Plan Schedule

S/NO	ACTIVITY	DURATION
01	Developing questionnaires	2 weeks
02	Data collection	1 week
03	Data processing and analysis	1 week
04	Writing draft and final report	1week
05	Submission of the report	1 week
	Total Duration	**2 (Two Months)**

Appendix V: Budgetary Estimates

S/No	ITEM (S)	Quantity (Qty)	Unit cost (Ugshs)	Total Coast (Ugshs)
01	Printing/ photo copying papers	1 ream	20,000	20,000
02	Ruled papers	1 raem	16,000	16,000
03	Flash disk	1 (2GB)	40,000	40,000
04	Pens, pencil and note book	Assorted	10,000	10,000
05	Photocopying expenses	45 PAGES	@100	4500
06	Word typesetting expenses	45 PAGES	@1000	45,000
07	Spiral binding expenses	3 BOOKS	@5000	15,000
08	Airtime		10,000	10,000
09	Transport expenses		50,000	50,000
10	Contingency		50,000	50,000
	TOTAL			**266,000**

Appendix V: **Approved research letter**

UGANDA CHRISTIAN
UNIVERSITY
A Centre of Excellence in the Heart of Africa
MBALE UNIVERSITY COLLEGE

Office of the Academic Registrar

To THE DIVISION TOWN CLERK
INDUSTRIAL CITY DIVISION.

Dear Sir/Madam,

Re: Academic Research

Christian greetings!

We are honored to introduce to you Mr. Mrs./Miss. NANDUDU SANDRA
Of Registration Number; S22/MUC/BSW/1051 pursuing a Masters' Degree/Postgraduate Diploma / Bachelor's Degree BACHELORS DEGREE IN SOCIAL WORK & ADMINISTRATION
He/ she is required to carry out an academic research on the topic
SOCIO-ECONOMIC FACTORS AND ACCESS TO PALLIATIVE CARE SERVICES TO CHRONICALLY ILL PATIENTS IN INDUSTRIAL CITY DIVISION MBALE CITY
and thereafter produce a well bound hard cover research report (**MAROON**) in color for undergraduate and three (**BLACK**) copies for Postgraduate students as a University requirement for the award of a degree/diploma in the academic discipline that he / she is pursuing.

We shall be grateful for the help you may offer to him or her accordingly.

Thank you.

Yours faithfully,

28 FEB 2024

Mr. Akampurira Timothy

Academic Registrar

Permission Granted

TOWN CLERK
03 MAY 2024
MBALE
INDUSTRIAL CITY DIVISION