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Support Needs for Caregiver of Terminally Ill Patients with Chronic Pain in Rwanda

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Abstract

Chronic and acute pain are very common among patients, especially those with chronic illnesses who are at a higher risk of experiencing untreated pain. Terminally ill patients can be effectively cared for either at home or in healthcare facilities, depending on their prognosis and the resources and preferences available. Pain management requires the collaboration of a multidisciplinary team. Patients may endure pain throughout their illness, which is highly challenging and impacts all aspects of the lives of both caregivers and patients. The study aims to identify the perceived support needs of caregivers of terminally ill patients in relation to pain management.

This quantitative research employs a non-experimental descriptive cross-sectional design. Conducted at Kibo Góra District Hospital in rural Rwanda, the study involved in-home caregivers of patients with end-of-life illnesses receiving hospice care. Participants were selected using a purposive sampling strategy. Inclusion criteria required caregivers to be involved in hospice care at the home level. The sample size consisted of 139 in-home caregivers of patients with terminal illnesses. The study found that home-based caregivers need educational support, including pain management skills, various pain relief techniques, and the ability to assess and treat pain.

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Introduction

Chronic pain is a complex phenomenon that results from a combination of biological, psychological, and social factors. Theoretically, patient-centered care aims to enhance patient outcomes and ensure effective pain assessment and management. Adequate planning and implementation of pain management are best achieved within a multidisciplinary team context [1,2].

Chronic pain is a widespread and complex issue that significantly affects both individuals and society. It often arises from diseases or injuries but is recognized as a distinct medical condition with its own classification. Understanding the prevalence and causes of chronic pain is essential for effective intervention at both individual and societal levels. Addressing chronic pain requires preventive and management strategies that consider various factors, including biological, psychological, socio-demographic, and lifestyle aspects. This review provides an overview of the current understanding of these factors [3].

Pain is a common symptom of cancer, with 30% to 50% of all cancer patients experiencing moderate to severe pain. This pain significantly negatively impacts their quality of life [4]. In developing nations, 18% to 20% of the general population experiences chronic pain. This high prevalence often results in early hospital discharge [5]. Chronic pain is a widespread condition, affecting approximately 20% of the global population. However, compared to the extensive research on its prevalence and management in developed nations, there is a notable scarcity of studies on chronic pain in developing countries. Chronic pain is recognized as a significant public health risk worldwide, impacting many adults and youth with chronic illnesses. Untreated pain can adversely affect patients' and their families' daily activities. The consequences of chronic pain extend to many areas of the patient's life, including their ability to generate income, making it a complex and multifaceted issue [6]. In 2011, Rwanda identified strategies and policies to provide high-quality healthcare for all patients suffering from terminal end-of-life illnesses. By supporting and educating caregivers through a coordinated service model, innovative methods were planned to address the needs of Rwandan society in an affordable and socio-culturally appropriate manner by 2020 [7].

Patients with chronic pain, whether cared for at home or in a hospital setting, need assistance with activities that improve their daily living. The most support typically comes from intimate caregivers, often family members. Caregivers themselves require support, educational opportunities, and mental health care to maintain their well-being. When caregivers are stable and confident in pain management, they can effectively assess, treat, and manage the patient's pain, employing the requisite knowledge and techniques for pain relief[8]. Often, the in-home caregiver is the sole source of care and support for the patient with pain in the home care context. Cancer pain management involves both physical and emotional components, which are crucial for effective patient management. Caregivers take on multiple roles that demand a diverse set of skills and determination to fulfill their responsibilities effectively [9].

Problem Statement

One primary challenge faced by home-based caregivers is pain management. The demands of end-of-life care often create significant stress for caregivers, impacting both the patient and the caregiver's ability to carry out daily activities. Inadequate pain control can result in acute issues such as depression and hopelessness, which may even lead to suicide[10]. This support must prioritize pain management. The caregiver's role has become increasingly demanding due to the aging population and the strain on hospitals. In 2016, approximately 50 million adults in the United States endured chronic pain, lasting three months or longer, resulting in significant healthcare costs and productivity losses. By 2021, an estimated 20.9% of U.S. adults, equivalent to 51.6 million individuals, experienced chronic pain, with 6.9% of them (17.1 million persons) facing high-impact chronic pain severely limiting their daily activities. This higher prevalence of chronic pain was observed among non-Hispanic American Indian or Alaska Native adults, adults identifying as bisexual, and adults who were divorced or separated [11,12] The statistics from 2017 reveal a consistent prevalence of chronic pain compared to data from 2011, with approximately 34% of respondents indicating some degree of chronic pain.

This persistent burden of chronic pain is further illuminated by its correlation with age, showing a progressive increase from 18% among individuals aged 16-34 years to a higher prevalence among those aged 75 and above. Moreover, gender differences are evident, with women reporting a higher prevalence compared to men. Additionally, there's a notable association between employment status and chronic pain, as individuals unable to work due to long-term sickness or disability, as well as those hindered by temporary sickness or injury, are more prone to experiencing chronic pain compared to those in paid employment. Furthermore, weight status emerges as another factor influencing chronic pain, with individuals classified as obese or very obese reporting a higher prevalence than those with a healthy weight. These findings underscore the complex interplay of demographic factors in the experience of chronic pain, emphasizing the need for tailored interventions and support systems to address this widespread issue effectively [13].

A comprehensive pain assessment serves as a cornerstone in formulating an effective pain management plan and ensuring continual evaluation of patients' pain experiences. Despite the availability of various clinical tools for pain assessment, their consistent utilization remains a challenge, potentially undermining the efficacy of pain management strategies. Particularly in home care and hospice settings, nurses play a pivotal role in employing these assessment tools consistently and documenting patients' pain levels along with their responses to the management plan, Patients and caregivers often harbor apprehensions and anxieties regarding the use of medications, especially narcotic analgesics. Research indicates that nurses who validate patients' concerns and provide education are most effective in pain management. This approach builds trust, empowers patients, and enhances communication, leading to better outcomes [14].

Aim of the Study

The aim of this study is to assess the perceived support needs of caregivers of terminally ill patients with chronic pain.

Specific Objectives

To identify the specific support needs of terminally ill patients with chronic pain in Rwanda

Perception of Pain

Acute and chronic pain may be associated with tissue damage or can signal a chronic terminal illness development. Physiological effects of illness may progress and become worse, or a chronic condition may become toxic and or life-threatening impacting every aspect of a patient's life. Chronic illness may lead to role changes within the family, as the patient becomes increasingly dependent on other members of the family indirectly or directly [10].Long-term illness places added strain on family members, yet they play a pivotal role in shaping the patient's psychological adaptation, managing the illness, and encouraging behaviors that contribute to recovery, functionality, and adherence to medication regimens [15].

Family members or caregivers providing in-home support may face challenges in accurately assessing and evaluating patients' pain levels. This difficulty in effectively assessing pain may stem from the emotional closeness between caregivers and the patient. Additionally, the psychological responses of family members to individuals experiencing chronic pain may vary depending on the intimacy of their relationships with the patient [16]. Caregivers who provide support during terminal illness often grapple with feelings of loss and grief. This experience of loss can manifest in a range of emotions, from profound sadness to anger, and the grieving process will differ from person to person. Even caregivers undergo stages of loss similar to those defined by Dr. Kubler-Ross, which include denial, anger, bargaining, depression, and eventually acceptance [17].

Resilience and a determined mindset provide crucial support for both patients and caregivers throughout the in-home hospice care journey. Facing fears associated with death, pain, and the dying process can be mitigated by the presence and support of loved ones, creating a comforting environment for patients and caregivers alike [18]. Caregivers play a vital role in meeting the comprehensive needs of terminal patients, including physical comfort, mental and emotional support, addressing spiritual concerns, and handling practical tasks. Central to their care is prioritizing chronic pain management and ensuring physical comfort. Chronic pain can be debilitating, and as the patient's condition progresses, issues such as respiratory problems, the risk of skin irritation and breakdown, and digestive complications from narcotic pain medications need to be addressed promptly. Additionally, terminal patients often experience heightened sensitivity to temperature changes, necessitating attention to their comfort levels regarding heat or cold. Furthermore, these patients, often with limited resources, are prone to fatigue and may require additional support in managing their energy levels [19].

In-Home Caregivers Needs Assessment

The assessment conducted by caregivers involves a methodical approach aimed at gathering comprehensive information about the caregiving scenario. Its primary purpose is to identify specific challenges, requirements, strengths, and available resources of the family caregivers, as well as their preferences and desires. Equally significant is the evaluation of the caregiver's present capacity to meet the needs of the care recipient, considering both their physical and mental capabilities[20]. Caregivers can typically be classified into one of three categories. Firstly, there are primary caregivers who bear full responsibility for the care recipient, overseeing all aspects of their care. Secondly, there are primary caregivers who receive support from either informal source such as family and friends, or formal assistance from healthcare professionals or support services. Lastly, there are caregivers who do not hold primary responsibility for the care recipient but still provide some level of support or assistance as needed [21].

Providing terminal care can be extremely stressful and demanding, often leading caregivers to experience physical and emotional challenges. Each caregiver brings their own set of personality traits, past experiences, coping mechanisms, and support networks, which can influence their ability to cope and increase the risk of emotional breakdown. Chronic pain experienced by caregivers can exacerbate these issues, leading to feelings of boredom, depression, and a decreased quality of life due to the immense stress and demands of in-home care. Socially, caregivers may face obstacles in effectively managing pain, as isolation, feelings of worthlessness, being confined to the home, difficulty in performing daily activities, and guilt about being a burden on family members can all contribute to worsening pain management [8,22]. Continual chronic pain or inadequately addressed pain can heighten a patient's anxiety and increase the risk of substance abuse disorders. Moreover, the daily stress associated with chronic pain can diminish economic productivity for both patients and caregivers [23].

The role of caregiving involves a multitude of tasks, which often results in caregivers having limited time for self-care as their responsibilities and stress grow. This lack of personal time can lead to heightened feelings of isolation and fatigue among caregivers. Many caregivers emphasize the importance of respite care as it offers a valuable opportunity for self-care, alleviating feelings of isolation and promoting physical, mental, and emotional well-being. Additionally, challenges in communication and inadequate access to information may exacerbate stress and frustration for caregivers. Communication breakdowns, particularly those related to insufficient care coordination, can exacerbate caregiver burnout and increase overall stress levels [24]. Caregivers have five primary areas of need: transitioning into hospice care, managing comprehensive responsibilities, recognizing the importance of support, accessing formal support services, and ensuring effective communication and access to information during decision-making processes [25].

Caregivers play a crucial role in managing chronic pain stemming from chronic illness and should be integrated into all patients' management strategies. The attitudes, values, and knowledge of family members or caregivers significantly influence the patient's pain medication plan, affecting medication adherence and the overall quality of pain management [26]. Caregivers rely on collaboration with medical providers to ensure medication adjustments that cater to each patient's unique needs, especially considering their specific disease process. This collaboration is essential for acquiring the necessary information to maintain their loved one's safety at home and effectively manage stress [27]. The transition into terminal care should be proactive, providing patients and families with comprehensive care options to support the disease process. It is crucial that healthcare transition prioritizes the well-being of caregivers, offering reassurance and support to ensure their needs are addressed effectively [28]. Caregivers face burdens such as excessive time demands, physical exhaustion, and financial strain [29].

A study conducted in China in 2014 revealed that caregivers faced significant mental stress and health risks while fulfilling in-home care responsibilities for their loved ones. The caregivers expressed a strong need for comprehensive knowledge about the disease process of each patient, strategies for enhancing symptom control, addressing psychological issues, and receiving support. Additionally, they emphasized the importance of healthcare providers prioritizing attention to their own health needs [30].

Each individual involved in the care of patients dealing with conditions like cancer, heart disease, diabetes, or chronic obstructive pulmonary diseases requires current information to aid in informed decision-making and effectively utilize healthcare resources to enhance patient outcomes. Access to up-to-date knowledge can help reduce the fear and anxiety often associated with chronic illnesses [31]. Enhancing support systems and implementing intensive follow-up with home services can enhance the delivery of in-home palliative care. This approach not only addresses the essential daily care routines necessary for proper care delivery but also helps overcome financial, technical, and emotional barriers to care. Additionally, it can increase the availability of care providers as required, thereby improving overall care accessibility and quality [9].

Training on pain assessment tools lacks consistency for home care nurses, caregivers, and patients grappling with pain-related issues [32]. Insufficient training in palliative care and pain management is observed in industrialized countries, with undergraduate medical studies often lacking adequate instruction on pain management [33]. Caregiving can be profoundly rewarding as it often brings partners and family members closer together. However, as the demands of caregiving escalate both physically and emotionally cognitively the care recipient then has less time to devote to the caregiver's own needs [34].

Caregivers necessitate collaboration and tailored support that adapts to the unique needs of each patient and is specifically tailored to their individual disease processes [35]. Throughout the care continuum, caregivers frequently encounter unforeseen circumstances that amplify their caregiving responsibilities, heightening emotional, physical, psychological, and financial challenges. Individuals and families must devise plans to adapt their lifestyles, involving siblings and friends, as the disease process evolves [34]. caregivers are integral members of the care team, playing dual roles as both providers and clients. This dynamic often heightens stress from two perspectives: the caregiver's responsibility to provide care and their own need for support. Family members and in-home caregivers emphasize the importance of care planning as it serves as a foundational roadmap, helping them understand the expectations placed on them as members of the health plan [36]. When caregivers feel supported, they are more capable of sustaining their roles in providing care at home. This, in turn, helps to diminish the need for expensive public and private services, ultimately reducing overall costs [36].

Methods

This study is a quantitative research project. Data was collected from care givers of patients with terminal ill cancer who experience chronic pain in their illness continuum from kibogora Study site is the Kibogora District Hospital Catchment area in Nyamasheke District, rural Rwanda. The program of interest was the palliative care program supporting rural Rwandan families and patient with chronical ends diseases. The Participants were caregivers from 77 patients enrolled in the palliative care services at Kibogora palliative care program Sampling Strategy used a convenient sampling method in order to gain samples of caregivers in nonprobability sampling method was used. Members of the target population must meet inclusion criteria and be easily accessible, geographically proximity, and have the availability and a willingness to participate. In this research, the sample size consisted of 120 caregivers. The inclusion criteria comprised caregivers of patients in a terminal illness state experiencing chronic pain, who were receiving home-based care services, and were 16 years of age or older and provided informed consent. Caregivers who did not provide informed consent, were under 16 years of age, or whose patients did not presently experience pain-related issues, and those whose patients had been in homecare services for less than 2 weeks were excluded from the study. Institutional Review Board (IRB) permission approval was obtained from relevant institutions. The data collected were analyzed descriptively using measures such as frequency, percentages, mean, and standard deviation, as well as inferential statistics including chi-square and Pearson correlation coefficient, and cross-tabulation. Data analysis was conducted using SPSS 21, and the results were presented in tables and graphs.

Results

The results section presents a description of socio-economic and demographic characteristic of participants along with statistical test for association and Pearson correlation coefficient on support needs for terminally ill patients with chronic pain in Rwanda.

Section A: Demographic Information of Participants (N=120)

Age, sex and types of vascular access (N=120)
The results of age. According to results, majority of respondents was aged 41 years old and above 19(15.8%), followed also with of people aged 21years old 15(12.5%).

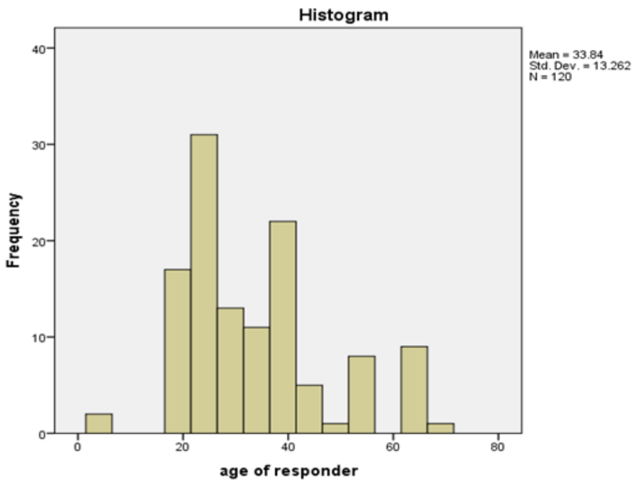

Figure 1: The distribution of respondent according to the age

The figure 2 reveals also that majority of respondents were male 72(60%),While male who responded were covering 48(40%).also the result shown that the majority of respond where no not having no formal education 48(40%),8(6.7%),we having nursery school,32(26.7%) did attend in primary school at any level .24(20%)attended secondary school and 8(6.7%) was at university lev of education, however the majority of respondents the result reveals the they were not having any form of job 88(73.3%) ,and 32(26.7%) Only where employed.

Table1: Distribution of participants according to their Gender, Education, Occupation

Occupation	n (%)
Male	48(40%)
Female	72(60)
Education of responders	
No Formal Education	48(40%)
Nursery School	8(6.7%)
Primary	32(26.7%)
Secondary School	24(20.0%)
Undergraduate	8(6.7%)
Job Distribution of respondents	
Yes	32(26.7%)
No job	88(73.3%)

According to the results, 16(13.3%) are public employed and 24(20%) of respondents were employed in private institutions and 8(6.7%) were self-employed while the majority 72(60%) were having others employers such us farmer and agriculture

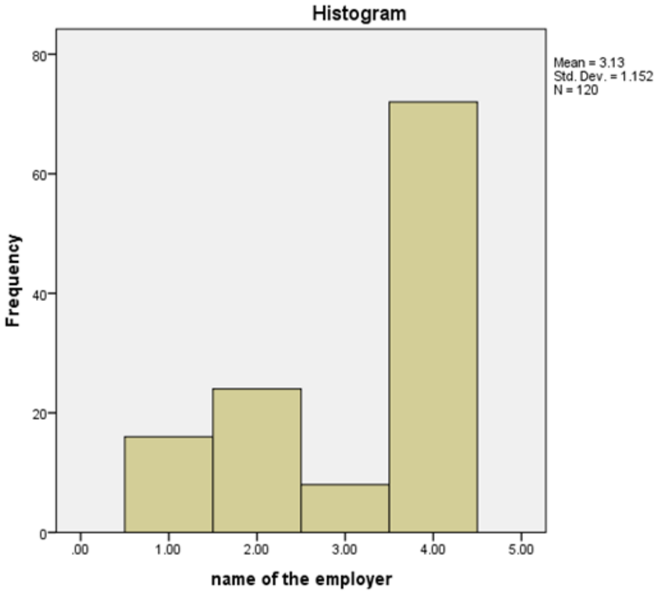

Figure 2: Distribution Of Respondents According to Working Sectors

From the analysis of results regarding information of patient diagnosis the majority of patient were diagnosed since above one year 96(80%), and 24(20%) were admitted in 6 months to 1 year before, whoever the results from responders reveals that the majority of patient are admitted in the services in the period more than 1 year 96(80%),and 21(17.5%) were admitted in 6month to 1 year ,and the 2 (1.7%) patient were spend 1 to 6 months in the services and 1(0.8%),were in the services for 1 month and below according to the patient pain history the majority of respondents confirmed that pain do experiences pain in the life illness history 112(93.3%) ,only 8(6.7%) responded that their patient do not experiences pain in the illness history.

Table 2: Distribution of Participants According Patient Time of Illness Diagnosis and the Admission Time in the Service, Pain History of Patient.

Diagnosing time	n (%)
From 6 months to 1 year	24(20%)
Above 1 year	96(80%)
Admission time in the service	
after one month	1(0.8%)
between 1 to 6 months	2(1.7%)
between 6 months to 1 year	21(17.5%)
Above 1 year	96(80%)
Distribution according to the pain History	
Yes	112(93.3%)
No	8(6.7%)
Distribution according to the age	
Between 18 to 30 years Old	63(52.5%)
Between 31 to 55 Years old	47(39.2%)
Above 55 Years Old	10(8.3%)
Job status for respondents	
yes	32(26.7%)
no job	88(73.3%)
Cared patient pain status	
mild pain	2(1.7%)
moderate pain	14(11.7%)
severe pain	104(86.7%)
Knowledge of caregivers on pain Killers	
not known	8(6.7%)
known but are forgotten the name	48(40.0%)
Only form of medications is known	64(53.3%)
Time for cared patient experiencing pain	
between six to 1 year	8(6.7%)
from 1 to 3 years	64(53.3%)
Above 3 years	48(40.0%)
Patient living condition	
living alone	8(6.7%)
living with friend	8(6.7%)
living in closed family	104(86.7%)
Relationship of caregivers to cancer cared patient	
closed relation	88(73.3%)
it is a job which is being paid	32(25.7%)
Received explanation of caregivers from health care team on patient condition	
Yes	96(80.0%)
No	24(20.0)
Received explanation of caregivers on cancer pain from health care team	
yes	112(93.3%)

No	8(6.7%)
Explanation of health care team about types of pain relate to cancer	
Yes	104(86.7%)
No	16(13.3%)
Health care team education of sign for end of life to responders	
yes	24(20%)
No	96(80%)
Experienced gap on received education	
Yes	103(86%)
No	17(14%)

In this study, the results from the analysis regarding information of patient diagnosis the most prevalent patient cared were diagnosed since above one year 96(80%) and the most patients were hospitalized more than 1 year 96(80%) in home care services, the majority of respondents said that their patients were experiencing pain in their life illness 112(93.3%) and the had several pain 104(86.7%) measured from 8-10 scores , 113(94.2%), the majority of caregivers only know the form of medication (53.3%) ,the pain to patient last long between (53.3%) prevalent number of patient live in their family 104(86.7%) , 96(80.7%) ,most of caregivers were explained on consequences related to chronic pain management 112 (93.3%), in addition the majority 104(86.7%) said that they were explained about patient condition while 112(93.3%) has explanations about cancer pain , the majority 88(73.3%) do not have explanation on assessment tools and they do not use them, most of respondents are educated on drug administration and their side effects management , 96(80%) are not educated on signs of end life, 88(73.3%) are prepared about consequences of chronic pain management .do not have that 96(80%) of respondents said they do not have same body else to support in care considering to the results ,there is a significant association between ,the education provided received on patient condition and the coping level of caregivers.

Discussion

Most of caregivers were explained on consequences related to chronic pain management 112 (93.3%). 104(86.7%) said that they were explained about patient condition while 112(93.3%) has explanations about cancer pain though Finnel and Othman said that when clinicians better understand and respond to the needs of the family caregivers, they can enhance the quality of life and care outcomes for both patients and their caregiver[37]which is related to the level of acceptance and comfort. 96(80%) were educated on drug administration this had impact on the satisfaction of caregivers .I pain management provision however signs of end of life ae not educated and this conduces to ineffective preparation on the loss and last complain for the one who is ending .This reflect on the Berry and colleagues' concerns who advised that those Caregivers will require professional support with educational opportunities, psychological and economical context to enable them to provide quality care on ill patient and also maintain their self-wellbeing [8]. 96(80%) respondents said they do not have someone else to support in care considering to the results and this may be risk factor to personal affection in caregiving moreover there is a significant association between the education provided and received on patient condition and the coping level of caregivers.

Other researchers also reported on this and said that socially caregivers face issues in pain management which can be compromised due to the increased tendency towards isolation, feelings of worthless, homebound status, difficulty in performing ADLs, feelings of guilt related to be a burden for members. All of these can all worsen pain [22]. And while caregivers are stable it has significant relation to the understanding of drug administration principles to patient, and the explanation about tools of pain assessment has significant association to the use of methods for pain management. The experience of pain to patient has also a significant relationship to their caregivers feeling and future view. The relationship is highly related to application of pain management methods; the explabout possible consequences of pain management is significantly associated on drug administration stability for caregivers and on status of resources income generation, education about cancer pain is significantly associated on stability on drug administration.

The education on assessment tools has a significant association on the caregiver's appreciation of patient end life condition, and appreciation of support reviewed with resources support. Education about side effects of drugs used on chronic pain management has a significant association on caregivers' stability as Kariuki said that caregivers need to be supported by healthcare professionals in highly confident pain assessment and management and filling satisfied even though living in a context of limited resources and infrastructure[38]. Studies have shown that educational interventions for pain management are often the first step in identifying and resolving common problems. As a result, further education and training of health professionals are recommended. Through workshops, seminars and discussions, the best practices for effective pain management for inpatients and those in homecare could be hugely beneficial. Similarly, such programs could equip professionals with the skills and knowledge to cooperate with primary caregivers to identify their beliefs [39]. The level of education has significantly associated on patient satisfaction of care. Education level is also associated on the coping with the situation and the view. The job of caregivers has a significant association on pain management and satisfaction of patient.

The preparedness on chronic pain management effects has a significant association on stability in drug administration. The patient living condition is significantly associated on how the caregivers appreciate the end life of their patient and personal affection however studies shown that for some, negative beliefs, attitudes, and misconceptions that they have about pain medication may lead them to under use pain medications. It is estimated that, worldwide, there are millions of cancer patients in need of palliative care. With careful planning of cancer palliative care within a comprehensive cancer control plan, a large proportion of advanced cancer patients could be relieved from their suffering and the quality of their lives could be improved significantly. An overall assessment of palliative care needs should be based on information about the specific requirements of the patients concerned, as well as those of health-care providers and family caregivers [40].

Conclusion

The present study shows that ,in I home based care pain management do not have formal education and most of the needs resources for supporting in caring activity, as the time for caring increases caregivers has risk to be affected the need to be e educated on self-care, also support should focus on cancer pain explanations with end of life signs ,a multi-display team should be involved in home caregivers support to enable them effectively manage all dimension patient needs, Therefore , health authorities are recommended to take into consideration to the necessity of continuous professional development in relation to cancer pain management and palliative care in general and peer education should be empowered to enable caregivers sharing experiences.

Conflict of Interest

We declare that there is no conflict of interest with this work.

Acknowledgement

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Author Contributions

JCT,EN,JPN,MRK,FM,UC,JCU1: Conceptualized the study, led data analysis, provided methodological guidance, critically reviewed the manuscript, and contributed to data interpretation, contributed to critical manuscript revisions and supported ethical compliance and quality control.

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