

# Knowledge and Home Caregiver's Experiences of Palliative Health Care Team Support in Pain Management of Cancer Patients in Rwanda

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**Abstract Background** Pain is highly prevalent in the general patient population worldwide. Persons suffering from chronic illness are at increased risk of untreated pain, including cancer patients managed in home-based care services. Pain management involves a multidisciplinary team engagement and home-based caregivers need to have educational support, as well as pain management skills for their effective contribution. **Objective** To assess the knowledge received and explore caregiver's experience in pain management for cancer patients in a home-based care service in Rwanda. **Methods** A descriptive cross-sectional design study was conducted at Kibogora hospital catchment area. The sample comprised of 120 in-home caregivers recruited from patient's cancer follow up in palliative care service. The questionnaire was developed from a study named knowledge and attitudes survey regarding pain and Descriptive statistics were used to analyze the data. **Results** The results of this study revealed that health care team supports palliative home caregivers which enabled them to care terminally ill cancer pain in home without affect. **Conclusion** Health care team support Palliative home caregivers with knowledge to care patient with cancer pain with satisfactory in Rwanda however there is still a need to increase the effort of support and follow up with involvement of a multiciliary team.

**Keywords:** knowledge, cancer, caregiver, experience, palliative

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## 1. Introduction

Pain is a complex phenomenon and is the sum of biopsychosocial factors. Patient-centered care seeks to improve patient outcomes where pain assessment and management planning and implementation are adequately addressed in a multidisciplinary team context [1]. Pain is a common symptom of cancer expressed in 30% to 50% of all cancer patients with moderate to severe pain in their illness history, which leads to the significant negative impact on the patient's quality of life [2]. Chronic cancer pain is recognized as a significant public health risk throughout the world as it affects a large number of patients who are experiencing terminal illness conditions from cancer, if untreated, it can adversely affect the activities of daily living for the patient and their family members or anybody else involved in their care at home [1]. Patients with malignant diseases especially in the

advanced stages are at risk of experiencing severe pain issues [3]. Globally people are living longer, with advanced aging population due to improved quality of life, the prevalence of chronic disease and Cancers illness has increased and will continue to increase; this translates to a higher demand being placed on the family members to participate as caregivers within the health sector development [4]. There is strong and increasing recognition of legal support as an essential aspect of comprehensive palliative care. Many palliative care professionals are addressing the legal needs they encounter by providing mediation, guidance on basic rights, or referrals to a lawyer [5]. Since 2009, the government of Rwanda has initiated a program of home based care to the terminally ill patients where they are managed at home by a family member or a relative [6]. It has also introduced levels of discomfort, leading many to prefer passing away in their own homes surrounded by family and friends [7]. Frequently, the in-home caregiver is the sole source of care and support for the patient's pain

management regimen in the home care setting. Their resilience is strengthened by the use of opioid medication, which is considered the gold standard in hospice care and the primary medication for pain control in terminal illnesses [8]. The Pain and Policy Studies Group has contributed to promoting the principle of balance and developing a unique model of technical assistance to help national governments assess regulatory barriers to essential medicines for pain relief. They assist in amending existing legislation or developing new laws to facilitate appropriate and adequate opioid prescribing according to international standards. However, we recognize that the majority of the world's population still lacks sufficient access to opioid medicines. Sustained efforts are needed to continue making policy and regulatory improvements to ultimately relieve patient suffering. The field faces challenges, including reduced funding opportunities and a lack of coordination.

[9]. Patients with end-stage cancer may benefit from various educational programs and knowledge enhancement initiatives that focus on pain assessment and management skills. These programs aim to alleviate the patient's pain effectively [10,11]. Understanding the foundational and essential aspects of pain management emphasizes the assessment and practical application of pain relief measures. This enhances communication between patients and all caregivers involved in their care [12,13,14]. Being non health professional caregivers for a terminally ill patient at home context increases the demand in knowledge and support from health care team [15,16]. Health policy reform is essential for integrating palliative care into public health systems. This reform should include drug regulatory changes to ensure essential palliative medications are available, accessible, and affordable. Palliative care also needs to be integrated into health system financing schemes, and services should be accessible for adults and children in various settings including home care, hospitals, and other inpatient facilities [17]. As health services, including home care, are being strengthened in Rwanda, there is a need to better understand how home caregivers are supported and empowered with knowledge. This understanding is crucial for improving the quality-of-service delivery in home-based care. This study aims to assess the knowledge acquired and explore caregivers' experiences in pain management for cancer patients receiving home-based care services in Rwanda.

## 2. Methods

A descriptive cross-sectional design was selected for this study to assess the knowledge and experience in management of cancer pain at home.

The study was conducted in palliative care service at Kibogora Level II Teaching Hospital community catchment area.

The target population was those caregivers involved in home-based care of cancer patients admitted in palliative care services of Kibogora Level II Teaching Hospital community catchment area, aged 18 years or above, who agreed to sign the consent were included in the study.

### Sampling size calculation

The sample size was calculated using Yamane's formula (1967:886) at level 5% cutoff. Since there were two strata (male and female groups), a stratified sampling procedure was then used to select the number of individuals representing each category of respondents of the population under study. In this analogy, a sample of 120 home caregivers for patients in palliative care service of Kibogora Level II Teaching Hospital community catchment area was used to represent the target population under study.

### Data collection instrument

The data collection instrument used in this study was a set of questionnaires containing the main questions aligned with the research objectives. To ensure the validity and reliability of this instrument, a pilot study was first conducted before distributing the questionnaires to the respondents. Subsequently, Cronbach's alpha was used to measure the internal consistency of the questionnaire items. The computed Cronbach's alpha value was 0.85, indicating a high level of reliability for the items included in the study's questionnaires.

### Data collection

Data collection took place within the home care services of the palliative care unit at KH, following the acquisition of necessary permissions from the University, MoH, and the hospital. The researcher engaged in discussions with the palliative care department, securing contact details of patients along with the most suitable ways and times to connect with caregivers in their homes.

Caregivers were approached at times convenient for them to engage with the researchers. The study's details were comprehensively explained to potential participants, underscoring its voluntary nature and the assurance that withdrawal at any stage would not result in adverse consequences. Participants meeting the defined criteria and expressing willingness to participate proceeded to sign a written consent form, formalizing their involvement in the study.

### Ethical considerations

The Institutional Review Board of the University of Rwanda, College of Medicine and Health Sciences and MoH research committee and Kibogora Hospital approved the study. Informed consent was obtained from each participant prior to the data collection.

### Data analysis

The multinomial logistic regression model was used to assess the main factors influencing the knowledge and experience of caregivers whose parameters estimates were obtained via Maximum likelihood estimation using SPSS 24 and the results presented in tables.

## 3. Results

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

in-home pain management.

**1. Demographics of Participants (N=120)**

**A. Age Distribution (n=120)**

Figure 1 describes the age distribution of respondents in the study on knowledge and home caregivers' experiences of palliative health care team support in pain management of cancer patients in Rwanda. The results are as follows: The majority of participants, 63 (52.5%), were youth. Adults accounted for 47 (39.2%) participants, while 10 (8.3%) participants were older adults. This demographic breakdown highlights that the majority of participants are youth, followed by adults, and a smaller proportion of older adult

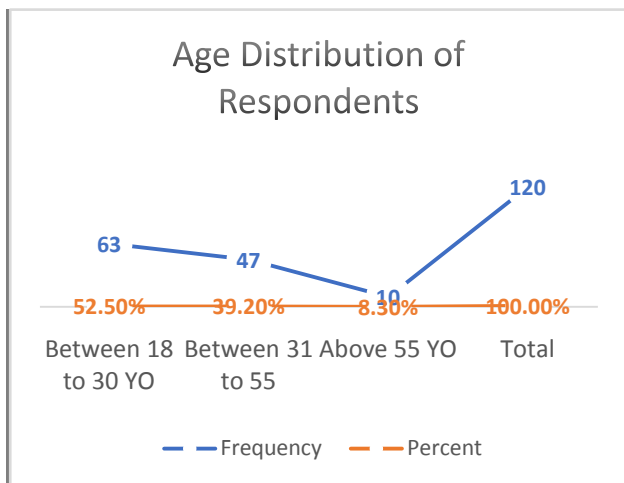


Figure 1. Age distribution of respondents

**B. Social Demographic Characteristics of The Repsosndes n120 (%)**

Table 1. Social Demographic Characteristics of The Repsosndes

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

Table 1 reveals that the majority of respondents were male, with 72 (60%) males responding to the survey, while females accounted for 48 (40%) of the respondents. The majority of respondents, 48 (40%), did not have any form of formal education. Eight respondents (6.7%) had attended nursery school, while 32 (26.7%) had attended primary school at any level. Twenty-four (20%) attended secondary school, and eight (6.7%) had a university level of education. The majority of respondents were unemployed, with 88 (73.3%) not having employment.

Only 32 (26.7%) were employed. Among the employed respondents, 16 (13.3%) were public employees, 24 (20%) were employed in private institutions, and the majority, 72 (60%), had employers in farming and agriculture.

**2. Experiences of palliative care for home caregivers in home cancer pain management**

Table 2. Experiences of palliative care for home caregivers in home cancer pain management

| Time since diagnosis                               | n 120(%)    |
|--|-------------|
| Under one 1 year                                   | 24 (20%)    |
| More than 1 year                                   | 96 (80%)    |
| Admission time in home care service                |             |
| More than one month                                | 1 (0.8%)    |
| Between 1 to 6 months                              | 2 (1.7%)    |
| Between 6 months to 1 year                         | 21 (17.5%)  |
| More than 1 year                                   | 96 (80%)    |
| Presence of pain in illness history                |             |
| Yes  | 112 (93.3%) |
| No   | 8 (6.7%)    |
| Types of pain intensity of patient from respondent |             |
| Mild pain  | 2 (1.7%)    |
| Moderate pain                                      | 14 (11.7%)  |
| Severe pain  | 104 (86.7%) |
| Pain level score according to caregivers           |             |
| 0-4: Mild pain                                     | 0 (0%)      |
| 5-7: Moderate pain                                 | 7 (5.8%)    |
| 8-10: Several pain                                 | 113 (94.2%) |
| Knowledge of patient's painkillers                 |             |
| Name of medication known                           | 8 (6.7%)    |
| Name of medication previously known but forgotten  | 48 (40%)    |
| Name of medication unknown, but form is known      | 64 (53.3%)  |
| Time for pain suffering from patients              |             |
| Less than 1 year                                   | 8 (6.7%)    |
| Between 1 to 3 years                               | 64 (53.3%)  |
| Between 3 to 5 years                               | 48 (40%)    |
| Patient's living condition                         |             |
| Living alone                                       | 8 (6.7%)    |
| Living with friend                                 | 8 (6.7%)    |
| Living with close family                           | 104 (86.7%) |
| Place preferred to care                            |             |
| Hospital   | 24 (20%)    |
| Home   | 96 (80.7%)  |
| Caregiver's relationship with patient              |             |
| Close relative                                     | 88 (73.3%)  |
| Employed   | 32 (26.7%)  |

Table 2, The analysis of respondents' answers regarding patient diagnoses showed that most patients (n=96, 80%) were diagnosed over a year ago, while 24 patients (20%) received their diagnosis 6-12 months ago. The results also indicated that a majority of patients (n=96, 80%) were admitted to home-based care more than a year ago. Additionally, 21 patients (17.5%) were admitted 6-12 months ago, two patients (1.7%) were admitted 1-6 months ago, and one patient (0.8%) was admitted for only one month.

A significant number of respondents reported that their patients experienced pain during their illness (n=112, 93.3%), with only eight (6.7%) indicating their patients did not. Regarding the intensity of pain, 104 patients

(86.7%) experienced severe pain, 14 (11.7%) experienced moderate pain, and two (1.7%) experienced mild pain. None of the respondents reported pain levels between 0 and 4. Seven respondents (5.8%) reported their patients' pain intensity scores ranged from 5 to 7, while the vast majority (n=113, 94.2%) reported scores between 8 and 10.

The majority of respondents (n=64, 53.3%) knew only the type of drug. Forty-eight respondents (40%) previously knew the name of the medication but had forgotten it. Eight respondents (6.7%) knew the exact name of the medication their patients were taking.

Eight respondents (6.7%) reported their patients had been suffering from pain for less than a year. Sixty-four respondents (53.3%) reported a pain duration of 1 to 3 years. Forty-eight respondents (40%) reported their patients had been in pain for more than 3 years.

Most patients lived with close family members (n=104, 86.7%), while eight (6.7%) lived with friends and another eight (6.7%) lived alone. Twenty-four patients (20%) received care at a hospital, while 96 (80%) appreciated the care they received at home. Most caregivers had close relationships with the patients (n=88, 73.3%), while 32 (26.7%) were professional caregivers providing care as their job.

**3. Distribution according to education on cancer pain management of home caregivers from palliative health care team**

Table 3, The majority of respondents (n=112, 93.3%) indicated that they received education on the consequences of chronic pain management, while eight (6.7%) had not received this teaching. Similarly, the majority (n=104, 86.7%) were educated on their patients' conditions, with 16 (13.3%) indicating they were not. A significant majority (n=112, 93.3%) reported being educated on cancer pain, whereas eight (6.7%) were not. Regarding pain assessment tools, the majority (n=88, 73.3%) received training on these tools but did not consistently use them, while 32 (26.7%) both received training and used them. Most respondents (n=104, 86.7%) were educated on drug administration and management of side effects, while 16 (13.3%) were not. In terms of end-of-life signs, the majority (n=96, 80%) of respondents were not educated on this topic, while only 24 (20%) had received such education.

**Table 3. Distribution according to education on cancer pain management of home caregivers from palliative health care team**

|  | n 120 (%)   |              |
|--|-------------|--------------|
|  | Yes         | No           |
| Education on pain management consequences                    | 112 (93.3)  | 8 (6.7)      |
| Education on types of pain related to cancer                 | 104 (86.7%) | 16 (13.3 %.) |
| Education on pain assessment                                 | 72 (60.0)   | 48 (40)      |
| Education on pain assessment tools uses                      | 32 (26.7)   | 88 (73.3)    |
| Education on drug administration and side effects management | 104 (86.7)  | 16 (13.3)    |
| Education on end-of-life signs                               | 96 (80)     | 24 (20)      |
| Being prepared on chronic pain management consequences       | 88 (73.3)   | 32 (26.7)    |

**4. Respondents' self-assessment of chronic cancer pain management**

Table 4, In chronic pain management education, 32 (26.7%) respondents felt unstable, with 8 (6.7%) indicating insufficient stability, and only 16 (13.3%) feeling adequately prepared. Regarding pain management techniques, 24 (20%) used some methods inconsistently, 16 (13.3%) used all methods inconsistently, and another 16 (13.3%) consistently applied all techniques taught. However, 64 (53.3%) did not consistently use the techniques they were trained in.

All 120 respondents acknowledged gaps in their education on cancer pain management. Patient satisfaction with care was reported as low by 72 (60%) caregivers, with 24 (20%) indicating dissatisfaction, 16 (13.3%) satisfaction, and only 8 (6.7%) very satisfied.

Personal impact was significant, with 80 (66.7%) caregivers deeply affected by patients' end-of-life situations. In terms of support, 72 (60%) did not feel adequately supported in patient care, although 48 (40%) appreciated the support from healthcare teams, predominantly nurses.

Financially, 88 (73.3%) lacked resources for income generation, affecting caregiving. Emotionally, 32 (26.7%) caregivers were at risk of future self-blame for insufficient patient support. Spiritually, 104 (86.7%) viewed patient passing as natural, while 16 (13.3%) were emotionally detached from end-of-life situations.

**Table 4. Respondents' self-assessment of chronic cancer pain management**

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

|   |                |        |
|---|----------------|--------|
|   | (86.7%)        | (13.3) |
| Patient satisfaction  | n (%)          |        |
| Not satisfied   | 24 (20%)       |        |
| Slightly satisfied  | 72 (60%)       |        |
| Satisfied   | 16<br>(13.3%)  |        |
| Very satisfied  | 8 (6.7%)       |        |
| <b>Type of care and domain of satisfaction for their patient</b>  | <b>n (%)</b>   |        |
| Daily life  | 15<br>(12.5%)  |        |
| Living conditions   | 51<br>(42.5%)  |        |
| Social and cognitive  | 43<br>(35.8%)  |        |
| Spiritual   | 10 (8.3%)      |        |
| <b>self-appreciation Respondent</b>   | <b>n (%)</b>   |        |
| Gaps in information received by caregivers  | 120<br>(100%)  |        |
| Success in pain management and patient satisfaction   | n (%)          |        |
| Not satisfied   | 24 (20%)       |        |
| Slightly satisfied  | 72 (60%)       |        |
| Satisfied   | 16<br>(13.3%)  |        |
| Very satisfied  | 8 (6.7%)       |        |
| <b>Appreciation of patient's end-of-life situation and effect on caregivers' lives</b>  | <b>n (%)</b>   |        |
| Yes   | 24 (20%)       |        |
| No  | 16<br>(13.3%)  |        |
| Not very affected   | 80<br>(66.7%)  |        |
| <b>Respondents appreciation of support received basing on education</b>   | <b>n (%)</b>   |        |
| Received enough support   | 24 (20%)       |        |
| Received support, but not enough  | 16<br>(13.3%)  |        |
| Did not receive support   | 80<br>(66.7%)  |        |
| Health care team member identified as most supportive   | n (%)          |        |
| Nurses  | 120<br>(100%)  |        |
| Physicians ,Social workers, Local, Government, Mental Health, nurses, Chaplain or Priest/Pastors, Traditional healers, Family ,Neighbours/friends | 0(0%)          |        |
| <b>Experience of stress in managing chronic pain for patients</b>   | <b>n (%)</b>   | n (%)  |
| Yes   | 104<br>(86.7%) |        |
| No  | 16<br>(13.3%)  |        |
| <b>Experience of challenges and incomplete information on pain management</b>   | <b>n (%)</b>   |        |
| Yes   | 120 (100)      |        |
| No  | 0(0%)          |        |
| <b>Experience of unaddressed concerns</b>   | <b>n (%)</b>   |        |
| Yes   | 120<br>(100%)  |        |
| No  | 0(0%)          |        |
| <b>Ability to cope with the caregiving situation</b>  | <b>n (%)</b>   |        |
| Yes   | 104<br>(86.7%) |        |
| No  | 16<br>(13.3%)  |        |
| <b>Current or potential future feelings</b>   | <b>n (%)</b>   |        |
| Yes   | 22<br>(26.7%)  |        |
| No  | 88<br>(73.3%)  |        |
| <b>Perception of situation as normal</b>  | <b>n (%)</b>   |        |
| Yes   | 120<br>(100%)  |        |
| No  | 0(0%)          |        |
| <b>Beliefs ascribed to situation</b>  | <b>n (%)</b>   |        |
| Traditional   | 8 (6.7%)       |        |

|  |              |  |
|--|--------------|--|
| African beliefs                          | 8 (6.7%)     |  |
| No beliefs referenced                    | 104 (86.7%)  |  |
| <b>Ability to overcome the situation</b> | <b>n (%)</b> |  |
| Yes                                      | 120 (100%)   |  |
| No                                       | 0(0%)        |  |

**5. Contributions to home caregivers' experiences in cancer pain management.**

**Table 5. Relation between home caregivers 'Knowledge of pain Killer and home caregivers experience**

| Respective contributions to home caregivers' experiences in cancer pain management.   | P-Value | Chis-square |
|---|---------|-------------|
| Knowledge on pain killers * stability of care givers on drug administration   | .000    | 0.5         |
| Knowledge of pain killers for patient by respondent * care givers appreciation of end life time for patient and are their affecting personal life                     | .000    | 0.5         |
| Knowledge of pain killers for patient by respondent * caregivers appreciation of support their from health care team  | .000    | 0.37        |
| Knowledge of pain killers for patient by respondent * caregivers assumption on the situation and probable causes and others spiritual use                             | .001    | 1           |
| Explanation of health care team to caregivers about patient's condition * stability of care givers due to received education received on drug administration          | .003    | 0.32        |
| Explanation of health care team to caregivers about patient's condition * education of pain management type and their use for caregivers                              | .000    | 0.42        |
| Explanation of health care team to caregivers about patient's condition * preparedness of about chronically pain management effects                                   | .000    | 0.4         |
| Explanation of health care team to caregivers about patient's condition * success to pain management and satisfy the patient  | 0.031   | 0.2         |
| Explanation of health care team to caregivers about patient's condition * care givers appreciation of end life time for patient and are their affecting personal life | .001    | 0.333       |
| Explanation of health care team to caregivers about patient's condition * stress of caregivers for being supporting the patient                                       | .001    | 0.28        |
| Explanation of health care team to caregivers about patient's condition * Caregivers coping with the situation  | .001    | 0.003       |
| Explanation of health care team to caregivers about patient's condition * caregivers assumption on the situation and probable causes and others spiritual use         | .000    | 0.477       |
| Explained about consequences of chronic pain management * stability of care givers due to received education received on drug administration                          | .000    | 0.56        |

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

Table 5, the analysis reveals significant associations between knowledge of painkillers and various aspects of caregivers' roles in home cancer pain management. Greater knowledge correlates with increased caregiver stability ( $\chi^2=0.5$ ,  $p=0.000$ ), heightened appreciation of end-of-life situations ( $\chi^2=0.5$ ,  $p=0.000$ ), better recognition and appreciation of support received ( $\chi^2=0.37$ ,  $p=0.000$ ), and more informed assumptions about patient conditions

( $\chi^2=1$ ,  $p=0.001$ ). This knowledge is crucial for enhancing caregivers' preparedness in managing chronic pain and adopting effective measures.

Similarly, explanations received from palliative healthcare teams about patient conditions also show significant impacts. These explanations are linked to caregivers' stability in drug administration ( $\chi^2=0.32$ ,  $p=0.003$ ), education on pain management types and their application ( $\chi^2=0.42$ ,  $p=0.000$ ), preparedness in understanding chronic pain management effects ( $\chi^2=0.4$ ,  $p=0.000$ ), success in pain management and patient satisfaction ( $\chi^2=0.2$ ,  $p=0.003$ ), appreciation of patients' end-of-life conditions ( $\chi^2=0.333$ ,  $p=0.001$ ), situational assumptions in chronic pain scenarios ( $\chi^2=0.477$ ,  $p=0.000$ ), coping mechanisms ( $\chi^2=0.003$ ,  $p=0.001$ ), stress management ( $\chi^2=0.28$ ,  $p=0.001$ ), and overall stability in managing cancer pain ( $\chi^2=0.56$ ,  $p=0.000$ ).

**4. Discussion**

The study explored the pivotal role of knowledge about painkillers and explanations regarding patient conditions from healthcare teams in influencing home caregivers' experiences in cancer pain management. The results underscore several significant associations that highlight the critical importance of these factors in shaping caregivers' capabilities, perceptions, and overall caregiving outcomes. The analysis revealed a strong association between caregivers' knowledge of painkillers and their stability in managing home-based cancer pain ( $\chi^2=0.5$ ,  $p=0.000$ ). Caregivers who possessed comprehensive knowledge of painkillers demonstrated greater stability in providing care to patients. This finding suggests that adequate knowledge equips caregivers with the necessary confidence and competence to administer medications effectively, thereby enhancing patient care and management of pain symptoms. This is supported by Gulnara Kunirova and others in their research, which highlights that when there is a lack of specific palliative care services for and the scarcity of professionals specializing in pediatric palliative care and additionally, palliative care is not integrated into mandatory medical or nursing curricula, and there is no established profession of palliative care physician or nurse in the country. Support the psychologists and social workers, to receive minimal education and training in palliative care, play a role in addressing gaps and improving the patient care situation [18]. Furthermore, caregivers' knowledge of painkillers significantly influenced their appreciation of end-of-life situations ( $\chi^2=0.5$ ,  $p=0.000$ ) and their recognition of the support they received ( $\chi^2=0.37$ ,  $p=0.000$ ). Caregivers who are well-informed about pain management strategies are more likely to understand and appreciate the challenges and emotional aspects associated with end-of-life care.

This observation is consistent with the findings of Svala Berglind Robertson, who emphasized that effective communication is fundamental to the quality of care. It plays a crucial role in establishing positive and fruitful relationships, as well as fostering a sense of security among caregivers and patients alike. The severity of symptoms and their impact on the patient significantly influence the well-being of families during end-of-life care, highlighting the importance of giving careful attention to this aspect of care [19]. This awareness not only enhances caregiver empathy but also fosters a supportive environment that positively impacts patient comfort and family satisfaction. Moreover, caregivers' knowledge of painkillers was associated with their assumptions about patient conditions ( $\chi^2=1$ ,  $p=0.001$ ) and their ability to cope with the challenges of chronic pain management ( $\chi^2=0.56$ ,  $p=0.000$ ). Educated caregivers were better equipped to assess and interpret patient needs accurately as said by Kwame that When communication in the nurse-caregiver-patient dyad is patient-centered, it becomes therapeutic. This approach fosters trust and mutual respect within the care process, leading to practices that effectively address the needs, concerns, and preferences of both patients and caregivers [20]. leading to more effective pain management strategies and improved coping mechanisms. This highlights the pivotal role of knowledge in enhancing caregivers' adaptability and resilience in managing complex caregiving scenarios as said by Sanford that Adaptations, especially those leading to culturally accepted, long-term informal practices, significantly impact patient care, healthcare quality and safety, caregiver burnout, retention of home caregivers, and overall outcomes. These adaptations may not always be evident through traditional quality improvement methods, highlighting the importance of observing daily practices as they evolve. Understanding how these local adaptations affect subsequent processes across various spatial and temporal scales is essential for improving healthcare delivery effectively [21]. The study also found significant associations between explanations received from healthcare teams regarding patient conditions and various aspects of caregiver preparedness and effectiveness. These explanations were linked to caregiver stability in drug administration ( $\chi^2=0.32$ ,  $p=0.003$ ), education on pain management types ( $\chi^2=0.42$ ,  $p=0.000$ ), and their preparedness in managing chronic pain ( $\chi^2=0.4$ ,  $p=0.000$ ). Clear and comprehensive explanations facilitated caregivers' understanding of treatment protocols and pain management strategies, thereby enhancing their ability to provide quality care and support to patients. Chi emphasizes that providing adequate pain management training can improve patient and family caregiver outcomes. Rigorous and replicable clinical trials are essential to examine the effects of educational interventions, cognitive-behavioral therapies, and technology-based interventions in this [22,23]. Findings underscore the multifaceted impact of knowledge and explanations on caregivers' emotional resilience, practical preparedness, and overall satisfaction in caregiving roles. Effective communication of medical knowledge and patient condition explanations from healthcare teams is crucial for equipping caregivers with the necessary skills, confidence, and empathy to manage cancer pain

effectively and support patients through challenging end-of-life stages.

## Study Barriers and Limitations

Due to logistical and cultural reasons, family caregivers practice information was not easily assessable and clear to the researcher.

## Recommendations

The recommendation for health care facilities, health education institutions and the public

The administration of health facilities and hospitals may support the palliative care team with the opportunity for CPD for staff. And regular Home-based visits should not be after long intervals, and education provided to those care givers should include self-care practices. It should include Support group formation to provide peer learning opportunities and experience sharing among caregivers. The education should be collaborative, integrating palliative care, home care which is from evidence-based practice.

## Public and Government

The public health leaders may support by revising the community health policy, addressing preconceived ideas among caregivers, planning a primary health level activity package for terminal ill patient in home care services. Through legislation and policy development, they must allow private sector investing in the domain, as well as allocating the funds to projects that increase the accessibility of palliative care services to the community, and integrate home based care services in all health institutions in the public and private sector.

## Conclusion

This study delved into the experiences of caregivers managing pain for cancer patients in a home-based care service in Rwanda, focusing on their knowledge and support systems. It was found that caregivers receive education and support from healthcare teams, yet they require additional financial, social, and spiritual support, alongside regular monitoring and follow-up, to effectively fulfill their caregiving responsibilities. There is a clear need for political commitment to sustainably fund these efforts.

In conclusion, the study underscores the critical role of continuous education and effective communication strategies in enhancing caregivers' capabilities and experiences in home-based cancer pain management. Future research should concentrate on developing targeted educational programs and communication frameworks tailored to the specific needs and challenges of caregivers. These efforts are crucial for improving patient outcomes and enhancing the well-being of caregivers in palliative care settings. Further studies could delve into the specifics

of required support and strategies to encompass caregivers across all age groups in this specialized field.

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## Authors' contributions

**JCT:** Study conception, proposal writing, data collection, data analysis and review and approval for submission.

**AC:** Study conception, proposal writing, data analysis and review and approval for submission.

**RW:** Study conception, proposal writing and data analysis.

## Declaration of conflict of interest

We declare no conflict of interest.

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