

## ORIGINAL RESEARCH ARTICLE

## Caregivers' knowledge of palliative care for cancer patients at Bhaktapur Cancer Hospital in Nepal

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## Abstract

Cancer is a major global public health problem and a leading cause of mortality. According to the GLOBOCAN estimates, Nepal recorded 22,008 new cancer cases, 14,704 cancer deaths, and 44,803 five-year prevalent cancer cases. Despite various public health initiatives, palliative care services in low-income countries remain inadequate. Knowledge of palliative care among family members caring for cancer patients is often insufficient. The demand for palliative care in Nepal has increased to provide essential care and support to cancer patients. This article aims to assess the level of knowledge among family caregivers regarding palliative care for cancer patients at Bhaktapur Cancer Hospital, Nepal. An analytical cross-sectional study was conducted among 251 family caregivers. Data were collected using a structured quantitative survey questionnaire, which included the validated Palliative Care Knowledge Scale. Bivariate and multivariate logistic regression analyses were performed. Only 26.0% of the family caregivers had adequate knowledge about palliative care. Around 14.3% of the family caregivers had been informed about palliative care, mostly by health workers (86.1%). The mass media and social networking sites did not have an important role in providing information about palliative care. Family caregivers with secondary and higher secondary education, as well as those who had received information on palliative care, were more likely to have adequate knowledge. Public awareness campaigns, community dialogue, and media-based health promotion strategies may help improve family caregivers' knowledge.

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## 1. Introduction

Non-communicable diseases (NCDs) account for approximately 75% of all deaths worldwide, with three-quarters of them recorded in low- and middle-income countries, including in Nepal.<sup>1</sup> Cancer is one of the most rapidly growing public health problems, doubling since 1990 and reaching 18.5 million newly diagnosed cases in 2023, and approximately 10 million cancer deaths occur annually.<sup>2,3</sup> A total of 53.5 million cancer cases occurred over the last five years, and 32.2% of them died.<sup>4,5</sup> The prevalence of lung cancer and breast cancer remains high (16.8% and 12.7%, respectively) in terms of cancer-causing deaths.<sup>6</sup>

In Nepal, the prevalence of NCDs have risen from 60.0% in 2016 to 66.0% in 2019 and 66.8% in 2022.<sup>5,7</sup> This calls for urgent palliative care services for individuals with cancer because these diseases have complex symptoms, resulting in poor quality of life.<sup>8,9</sup> Although Nepal's estimated cancer incidence is relatively low compared with global figures, GLOBOCAN 2022 estimated 22,008 new cancer cases, 14,704 cancer deaths, and 44,803 five-year prevalent cases in Nepal.<sup>7</sup> The major risk factors of cancer include tobacco consumption, including vaping, indoor air pollution, excessive alcohol consumption, low physical activity, obesity, unhealthy diets, and low intake of fruits and vegetables, which are preventable.<sup>10,11</sup>

Palliative care services provide holistic support to patients diagnosed with cancer, since the service addresses the patients' physical, psychological, social, and economic issues.<sup>12</sup> Palliative care is often misconstrued as end-of-life care.<sup>13</sup> However, early integration of palliative care at the onset of diagnosis helps address these problems effectively.

Family care practices have proven beneficial in caring for the elderly and ill individuals.<sup>14</sup> However, professional palliative care services should be integrated into the healthcare system to meet the increasing demands. Despite the critical role of family caregivers, research focusing on their knowledge of palliative care has been limited, owing to the focus being on the role of health workers. Family caregivers' knowledge about palliative care plays an important role.<sup>15</sup> Palliative care offered to patients diagnosed with cancer seeks to alleviate their health challenges, improve their quality of life, and support symptom management. Provision of physical, mental, social, and economic support, along with engaging the patients, creates hope and enables them to overcome any form of discrimination. However, caregivers may lack adequate knowledge about palliative care, leading to poor-quality support.

Furthermore, challenges such as caregivers' hesitancy to discuss and share information about the diagnosis and prognosis create difficulties, resulting in the patients remaining ignorant of their illness status.<sup>16,17</sup> There is a high demand for palliative care in Nepal, which is not adequately met by the hospitals.<sup>9</sup> This paper aims to assess the level of knowledge among family caregivers regarding palliative care for cancer patients at Bhaktapur Cancer Hospital, Nepal.

## 2. Materials and methods

### 2.1. Study design and setting

A cross-sectional study design was used in this study. The study took place at Bhaktapur Cancer Hospital, which is

a government referral hospital with 150 beds located in Bagmati Province, Nepal.

### 2.2. Study population and sampling technique

The study population consisted of family caregivers of cancer patients who provided care and support in the hospital. A convenience sampling technique was applied. Eligible participants were family caregivers of cancer patients at the Bhaktapur Cancer Hospital. A formative assessment was conducted before data collection to assess the cancer patients' flow in the hospital. Caregivers of patients admitted for cancer treatment were eligible for inclusion. A total of 251 family caregivers were selected for data collection.

### 2.3. Data collection tools and techniques

The Palliative Care Knowledge Scale (PaCKS) was used in this study.<sup>18</sup> The tool was pretested among 10% of the total sample population in a non-study hospital (Tribhuvan University Teaching Hospital, Maharajgunj, Kathmandu, Nepal). This hospital is also a tertiary-level referral center that provides care and support for cancer patients, including other diagnoses and treatment of other diseases. Necessary modifications were made to the tools according to the findings of the pretesting. Data were collected using structured quantitative survey questionnaire through face-to-face interviews for one month in 2023. The questionnaire included socio-demographic characteristics and PaCKS. Duty nurses helped identify patients who had recently arrived and those who were about to be discharged from each ward. Caregivers of patients who were about to be discharged were interviewed first, while data collection continued simultaneously.

### 2.4. Data coding and management

Completed questionnaires were carefully reviewed for completeness and consistency. The entered data were organized systematically, double-entered to minimize entry errors, cleaned, and checked for missing or inconsistent values. Any discrepancies were verified and corrected where appropriate. The final dataset was exported from Microsoft Excel (Microsoft, United States of America [USA]) to the Statistical Package for Social Sciences (SPSS) version 26 (IBM Corp., USA).

### 2.5. Data analysis

The data analysis was carried out in three stages: univariate, bivariate, and multivariate analyses. In the univariate analysis, descriptive statistics were used to summarize socio-demographic and clinical characteristics of the study participants, with results presented as frequencies and percentages. For the bivariate analysis, the study examined

the association between socio-demographic and clinical variables and palliative care knowledge, using crude or unadjusted odds ratios (UORs) and 95% confidence intervals (CIs) to quantify the relationships between explanatory variables and outcomes. A multivariate analysis was applied after adjusting for possible covariates (confounders) to estimate the adjusted odds ratios (AORs) and 95% CI, with statistical significance determined at the 5% level. Variables were selected for the multivariable model based on a bivariate *p*-value threshold of <0.20 and theoretical relevance from the literature. The presence of multicollinearity between independent variables was determined by the variance inflation factor. No evidence of multicollinearity was observed.

## 2.6. Definition of study variables

The study variables were defined as follows:

- (i) Knowledge about palliative care: The degree of information that participants possess regarding palliative care. Knowledge was categorized as dichotomous, where adequate knowledge was defined as >75% of the total score, and inadequate knowledge was defined as ≤75% of the total score.<sup>19</sup> The cut-off threshold is yet to be validated in the caregiver population in Nepal.
- (ii) Family caregivers: Family members, relatives, or friends who provide assistance related to the cancer care delivery and assist in the activities of daily living, who are unpaid and have no formal training to provide those services.
- (iii) Duration of illness: The length of time from the initial diagnosis of cancer to the time of data collection. It was categorized as <6 months and ≥6 months.
- (iv) Age: An age group refers to a categorical classification of participants based on their age into specific ranges. Participants' ages were categorized as 18–25, 26–40, 41–55, and over 55 years.
- (v) Sex: Sex refers to the physical differences between people and is categorized as male and female.<sup>20</sup>
- (vi) Ethnicity: The cultural or racial identity of an individual based on factors such as ancestry, national origin, language, religion, and customs, and was categorized as Brahmin and Chhetri, Dalit, Janajati, Madhesi, and Muslim.<sup>20</sup> From the socio-cultural and economic perspective, the Brahmin and Chhetri are normally referred to as privileged groups, while the Dalit, Janajati, Madhesi, and Muslim are considered as marginalized groups in Nepal.
- (vii) Marital status: A person's relationship status in terms of whether they form a couple relationship with another person living in the same usual residence,

which was categorized as married, single, or divorced. Divorced was later removed due to the lack of available data.<sup>20</sup>

- (viii) Education level: Educational level of the participants categorized as no education, primary education, secondary education, and higher secondary education.<sup>20</sup> No education and primary level education was merged in regression model.
- (ix) Type of family: A type of family was categorized as nuclear or joint family.<sup>21</sup> The nuclear family is comprised of married partners and their offspring, where the joint family is comprised of three or more generations, living together under the same roof, sharing the same kitchen and economic expenses.
- (x) Relationship with cancer patient: Familial or social connections individuals have with the patient diagnosed with cancer, and were categorized as spouse, parents, children, siblings, and relatives.<sup>22</sup>
- (xi) Residence: The participants' place of residence was categorized into urban and rural.<sup>20</sup>
- (xii) Occupation: Participants' occupation was categorized as agriculture, business, service holder, labor, studying, or builders or construction.<sup>23</sup>
- (xiii) Income: Average salary or wages from any job or profession in a family, which was further categorized as less than NPR 25,000 and NPR 25,000 or more.<sup>23</sup>
- (xiv) Health insurance coverage: Health insurance coverage was defined as whether the cancer patient had government health insurance that covered part of the total treatment expenditure.
- (xv) Information about palliative care: The communication of knowledge regarding palliative care was categorized into yes and no.
- (xvi) Source of health information: The source of health information was categorized into newspapers, health workers, family/friends/ relatives, radio/television, and social media.<sup>22,24-26</sup>

## 2.7. Reliability and validity of tools

The data collection tool was developed after a detailed literature review. The data collection tool addressed all the variables that are supposed to measure the information needed for this study. The standard and validated questionnaire PaCKS in the English language was translated into Nepali, and then further back-translated into English to ensure validity. Validity of the tool was ensured through a literature review and consultation with supervisors and experts. The tool was pretested by 10.0% of the total sample population to assess its reliability, consistency, and applicability. Necessary modifications to the tools, based on the findings of the pretesting, were made to make them easier for participants to understand.

### 3. Results

#### 3.1. Socio-demographic characteristics of the study participants

Table 1 shows the distribution of socio-demographic characteristics of family caregivers. Approximately 47.4% of the study participants were between 26 and 40 years old. More than half of the participants (51.0%) had an illness duration of less than six months. About 55.8% of the study participants were males, and 57.8% belonged to marginalized ethnic groups, including Janajati, Dalit, Madhesi, and Muslim participants. Approximately 68.5% of the study participants were residing in urban areas. More than half of the caregivers (57.8%) were children of the patient. More than two-thirds of the participants (71.7%) were married. Most of the participants (54.2%) lived in a joint family. Approximately 87.3% of the participants were educated. More than half of the participants (51.0%) reported that the patient had health insurance coverage, and only 14.3% of participants had received health information about palliative care. Health workers were the most commonly reported source (86.1%).

#### 3.2. Knowledge regarding palliative care among caregivers

Most of the participants (84.5%) believed that palliative care is specifically for people with cancer. Nearly two-thirds of the participants (62.9%) stated that palliative care is exclusively for people who are in the last six months of life. Almost three-quarters of the participants (74.5%) understood that palliative care can help people manage the side effects of their medical treatments. A minority of the participants (33.5%) considered that when people receive palliative care, they must give up their other doctors. Additionally, 37.5% of the participants stated that palliative care is designed specifically for older adults. More than half of the participants (59.8%) considered one goal of palliative care to be addressing any psychological issues brought up by serious illness. Almost three-quarters of the participants (74.1%) stated that people must be in the hospital to receive palliative care. Most of the participants (69.7% and 68.9%) understood that stress from serious illness can be addressed by palliative care and that palliative care is a team-based approach to care, respectively. Three-quarters of the participants (75.3%) considered a goal of palliative care to be helping people better understand their treatment options. A total of 85.3% of the participants believed that palliative care encourages people to stop treatments aimed at curing their illness. More than three-quarters of the participants (76.9% and 78.1%) considered that the goal of palliative care is to improve a person's ability to participate in daily activities and that palliative care helps the whole

family cope with a serious illness, respectively. The overall score of the study findings revealed that slightly more than one-fourth (26.0%) of the participants had adequate knowledge about palliative care.

#### 3.3. Factors associated with caregivers' knowledge in palliative cancer care

Table 2 shows the effects of explanatory variables on knowledge about palliative care. Being single was associated with a lower odds of having adequate knowledge compared to being married (AOR = 0.334; 95% CI: 0.121–0.923). Compared with caregivers who had primary education plus no formal education, those with secondary education was associated with higher odds of adequate knowledge of palliative care (AOR = 3.578; 95% CI: 1.411–9.072), as did those with higher secondary education (AOR = 5.227; 95% CI: 1.860–14.687). Additionally, having information on palliative care was significantly associated with higher odds of having adequate knowledge (AOR = 3.942; 95% CI: 1.684–9.229) compared with those who did not receive information on palliative care. However, age, duration of an illness, sex, ethnicity, residence, caregiver's relationship with patients, type of family, occupation, annual family income, and health insurance coverage were not statistically significant.

### 4. Discussion

This study examined the level of knowledge among family caregivers regarding palliative care for cancer patients. To the best of our knowledge, this is the first study conducted in Nepal.

The results show that only one-fourth of participants had adequate knowledge about palliative care of cancer caregivers, highlighting a substantial knowledge gap. A similar trend of inadequate knowledge, ranging from 1 in 10 to 1 in 4 participants, has been reported in studies from Iran,<sup>27</sup> the USA,<sup>28</sup> Turkey,<sup>24</sup> and India.<sup>22</sup> The present findings must be interpreted within the context of the distinct social and cultural background and the health care system of Nepal. The low knowledge level observed in this study may reflect limited integration of palliative care into Nepal's routine healthcare services and insufficient health promotion activities targeting caregivers. In the country, palliative care is not well developed, and in most cases, it is concentrated in urban areas and is less accessible in rural areas. As a result, caregivers may become involved with palliative care services only after the cancer has progressed substantially. Additionally, limited insurance coverage may further restrict access to palliative care services.

More than half of the participants were male, paralleling the findings in India, where a similar proportion of

**Table 1. Socio-demographic characteristics of the study participants (*n* = 251)**

| Characteristics                                       | Frequency | Percentage |
|---|-----------|------------|
| Age   |           |            |
| 18–25   | 44        | 17.5       |
| 26–40   | 119       | 47.4       |
| 41–55   | 63        | 25.1       |
| Over 55   | 25        | 10.0       |
| Duration of an illness                                |           |            |
| <6 months   | 128       | 51.0       |
| ≥6 months   | 123       | 49.0       |
| Sex   |           |            |
| Male  | 140       | 55.8       |
| Female  | 111       | 44.2       |
| Ethnicity   |           |            |
| Brahmin and Chhetri (privileged group)                | 106       | 42.2       |
| Janajati, Dalit, Madhesi, Muslim (marginalized group) | 145       | 57.8       |
| Residence   |           |            |
| Urban   | 172       | 68.5       |
| Rural   | 79        | 31.5       |
| Relationship with the patient                         |           |            |
| Spouse  | 48        | 19.1       |
| Parents   | 8         | 3.2        |
| Children  | 145       | 57.8       |
| Siblings  | 35        | 13.9       |
| Relatives   | 15        | 6.0        |
| Marital status  |           |            |
| Married   | 180       | 71.7       |
| Single  | 71        | 28.3       |
| Type of family  |           |            |
| Nuclear   | 115       | 45.8       |
| Joint   | 136       | 54.2       |
| Educational Status                                    |           |            |
| No education  | 32        | 12.7       |
| Primary   | 61        | 24.3       |
| Secondary   | 73        | 29.1       |
| Higher secondary                                      | 85        | 33.9       |

(Cont'd...)

**Table 1.(Continued)**

| Characteristics   | Frequency | Percentage |
|---|-----------|------------|
| Occupation  |           |            |
| Agriculture   | 44        | 17.5       |
| Business  | 41        | 16.3       |
| Service holder  | 66        | 26.3       |
| Labor   | 19        | 7.6        |
| Student   | 42        | 16.7       |
| Builders or construction  | 39        | 15.5       |
| Annual family income (NPR)  |           |            |
| <25,000   | 97        | 38.6       |
| ≥25,000   | 154       | 61.4       |
| Insurance   |           |            |
| Yes   | 128       | 51.0       |
| No  | 123       | 49.0       |
| Information   |           |            |
| Yes   | 36        | 14.3       |
| No  | 215       | 85.7       |
| Sources of the information <sup>a</sup> (those who responded “yes” to the above question) |           |            |
| Newspaper   | 3         | 8.3        |
| Health workers  | 31        | 86.1       |
| Family/Friends/Relatives  | 7         | 19.4       |
| Television/ Radio/ FMs  | 3         | 8.3        |
| Social media  | 6         | 16.6       |

Note: <sup>a</sup> Percentages for sources of information were calculated among participants who had received information on palliative care (*n* = 36); multiple responses were allowed.

participants were male.<sup>22</sup> The demographic trend observed in this study, characterized by predominantly young male carers, may also reflect transformations occurring within Nepali society. In this study, only a small proportion of participants had adequate knowledge of palliative care. This finding differs from that of McIlfatrick *et al.*<sup>25</sup>, who reported greater public awareness of palliative care in 2013 in Northern Ireland. The discrepancy may be partly attributable to limited access to palliative care information, as reflected by the small number of information sources reported by participants in this study. The limited emphasis on health awareness campaigns may have contributed to insufficient dissemination of information about palliative care.

**Table 2. Bivariate and multivariate logistic regression analysis of factors associated with adequate knowledge of palliative care among cancer caregivers**

| Variables   | UOR (95% CI)         | <i>p</i> -value | AOR (95% CI)         | <i>p</i> -value |
|---|----------------------|-----------------|----------------------|-----------------|
| Age   |                      |                 |                      |                 |
| 18–25   | 1                    |                 | 1                    |                 |
| 26–40   | 0.690 (0.323–1.476)  | 0.339           | 0.446 (0.138–1.568)  | 0.217           |
| 41–55   | 0.729 (0.311–1.709)  | 0.468           | 0.789 (0.181–3.433)  | 0.752           |
| ≥55   | 0.677 (0.222–2.065)  | 0.493           | 0.492 (0.087–2.787)  | 0.723           |
| Duration of illness                                   |                      |                 |                      |                 |
| <6 months   | 1                    |                 | 1                    |                 |
| ≥6 months   | 0.932 (0.529–1.640)  | 0.806           | 0.909 (0.466–1.773)  | 0.779           |
| Sex   |                      |                 |                      |                 |
| Male  | 1                    |                 | 1                    |                 |
| Female  | 0.666 (0.373–1.190)  | 0.170           | 0.545 (0.251–1.181)  | 0.124           |
| Ethnicity   |                      |                 |                      |                 |
| Brahmin and Chhetri (privileged group)                | 1                    |                 | 1                    |                 |
| Janajati, Dalit, Madhesi, Muslim (marginalized group) | 0.690 (0.390–1.220)  | 0.440           | 0.920 (0.300–2.830)  | 0.690           |
| Residence   |                      |                 |                      |                 |
| Urban   | 1                    |                 |                      |                 |
| Rural   | 0.572 (0.298–1.097)  | 0.093           | 0.687 (0.318–1.485)  | 0.340           |
| Caregiver's relationship with the cancer patient      |                      |                 |                      |                 |
| Spouse  | 1                    |                 | 1                    |                 |
| Parents   | 0.897 (0.160–5.023)  | 0.902           | 0.673 (0.100–4.543)  | 0.685           |
| Children  | 1.061 (0.510–2.207)  | 0.873           | 0.633 (0.216–1.858)  | 0.405           |
| Siblings  | 0.557 (0.188–1.649)  | 0.291           | 0.584 (0.163–2.097)  | 0.410           |
| Relatives   | 0.673 (0.163–2.774)  | 0.584           | 0.368 (0.071–1.917)  | 0.235           |
| Marital status  |                      |                 |                      |                 |
| Married   | 1                    |                 | 1                    |                 |
| Single  | 0.961 (0.521–1.804)  | 0.902           | 0.334 (0.121–0.923)  | 0.035           |
| Type of Family  |                      |                 |                      |                 |
| Nuclear   | 1                    |                 |                      |                 |
| Joint   | 1.376 (0.776–2.442)  | 0.275           | 1.448 (0.740–2.834)  | 0.280           |
| Educational status                                    |                      |                 |                      |                 |
| Primary or no formal education                        | 1                    |                 | 1                    |                 |
| Secondary   | 3.216 (1.144–7.183)  | 0.004           | 3.578 (1.411–9.072)  | 0.007           |
| Higher secondary                                      | 4.501 (2.090–9.694)  | 0.001           | 5.227 (1.860–14.687) | 0.002           |
| Occupation  |                      |                 |                      |                 |
| Agriculture   | 1                    |                 | 1                    |                 |
| Business  | 1.487 (0.497–4.445)  | 0.478           | 1.112 (0.286–4.315)  | 0.878           |
| Services  | 2.298 (0.877–6.023)  | 0.090           | 1.352 (0.389–4.704)  | 0.635           |
| Labor   | 3.083 (0.898–10.586) | 0.074           | 3.503 (0.801–15.318) | 0.096           |
| Study   | 2.643 (0.942–7.415)  | 0.065           | 2.282 (0.452–11.532) | 0.318           |

(Cont'd...)

Table 2. (Continued)

| Variables                      | UOR (95% CI)        | p-value | AOR (95% CI)        | p-value |
|--------------------------------|---------------------|---------|---------------------|---------|
| Builders or construction       | 1.364 (0.445–4.185) | 0.587   | 1.842 (0.433–7.835) | 0.408   |
| Annual family income (NPR)     |                     |         |                     |         |
| <25,000                        | 1                   |         | 1                   |         |
| ≥25,000                        | 1.589 (0.870–2.902) | 0.131   | 1.113 (0.486–2.548) | 0.800   |
| Health insurance coverage      |                     |         |                     |         |
| No                             | 1                   |         | 1                   |         |
| Yes                            | 1.782 (1.001–3.172) | 0.050   | 1.242 (0.629–2.450) | 0.533   |
| Information on palliative care |                     |         |                     |         |
| No                             | 1                   |         | 1                   |         |
| Yes                            | 4.106 (1.977–8.529) | 0.001   | 3.942 (1.684–9.229) | 0.002   |

Abbreviations: AOR: Adjusted odds ratios; CI: Confidence interval; UOR: Unadjusted odds ratios.

Healthcare professionals were the main source of information on palliative care in the present study. However, the internet, social media, and friends or family were the main sources of information in India and Bangladesh-based studies.<sup>22,29</sup> Similarly, the study conducted in Northern Ireland found key sources of information on palliative care included close friend or relative, health care work setting, and newspapers and magazines.<sup>25</sup>

Education emerged as an important determinant of the extent of knowledge about palliative care in the present study. It is in line with similar studies carried out in India,<sup>22</sup> Canada,<sup>26</sup> Pakistan,<sup>30</sup> and the USA.<sup>31,32</sup> Such variables were analyzed using the socioecological framework.<sup>33</sup> The finding that most family caregivers had inadequate knowledge about palliative care highlights the need for educational interventions and better dissemination of information about palliative care services in Nepal. Such low levels of knowledge can be attributed to several issues within Nepal's health system, including inadequate integration of palliative care in hospitals and primary healthcare facilities, limited availability outside urban settings, and a culture that discourages discussing diagnoses and prognoses. The lack of knowledge, education, and training among informal caregivers could be another factor. Therefore, the health journalists can mobilize to identify, support, and report on palliative care in Nepal.<sup>34</sup> School is the best place for disseminating information on the risks of tobacco, alcohol, diets, and exercise, etc., and the importance of palliative care through teachers and students.<sup>35</sup>

Cultural issues that might affect the lack of knowledge about palliative care must be taken into account. For example, subjects like death, dying, and prognosis can be regarded as sensitive and possibly even taboo in Nepal, making people hesitant to discuss them freely. It is common practice for decisions concerning diagnoses, treatment, or

prognoses to be made at a family level, and information is provided selectively. This could reduce the information available to caregivers concerning palliative care.

Although health workers are the main source of disseminating information about palliative care, it is recommended to conduct health promotion research utilizing a socioecological framework and a multilevel approach to identify more information requirements of family caregivers.<sup>36-39</sup> This study emphasizes the need for appropriate policies to promote awareness and incorporate palliative care within the healthcare system.<sup>40</sup> Palliative care should be integrated into primary healthcare services and accessible in remote regions, along with a mass media campaign and targeted educational intervention.

#### 4.1. Strengths and limitations

This study has several strengths. First, it addresses an important gap in understanding the knowledge level of family caregivers regarding palliative care in Nepal, where there is an increasing need for such services due to the rising burden of chronic diseases, such as cancer. Second, this study used a validated PaCKS questionnaire to assess knowledge levels, which is relatively straightforward to administer. Last, bivariate and multivariate analyses provide a deeper understanding of factors associated with palliative care knowledge among family caregivers. While bivariate analysis is utilized in determining initial associations, the use of multivariate analysis ensures that adjustments are made to account for potential confounding variables.

Despite some strengths, limitations have been identified. First, this study was conducted at a single cancer hospital, which may limit the generalizability of the findings to other settings and populations. Second, the cross-sectional study design does not allow for causal

inferences about the factors associated with knowledge levels. Although associations can be identified, it is not possible to determine the direction of these relationships or establish cause-and-effect links. Third, the study relied on self-reported data, which may be subject to recall bias or social desirability bias, resulting in overreporting or underreporting. Fourth, this study did not explore the reasons behind the lack of knowledge or the specific information needs of family caregivers. Last, sensitivity analysis could not be performed because the available dataset did not include sufficient variables or subgroup sizes for additional model testing.

## 5. Conclusion

The majority of family caregivers have low knowledge regarding palliative care for cancer patients. Family caregivers who had received information about palliative care reported health workers as their main source of information. Adequate knowledge was significantly associated with marital status and prior receipt of information about palliative care. Single individuals are less likely to have high levels of knowledge than married individuals. Meanwhile, those who had received information about palliative care were likely to have high knowledge. The cross-sectional nature of this study and the reliance on a convenience sample at a single hospital limit the applicability of the findings. Therefore, future studies may benefit from employing a longitudinal design as well as utilizing multiple hospitals and diverse populations of caregivers to better understand their knowledge and needs regarding palliative care.

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## Conflict of interest

The authors declare no conflict of interest.

## Author contributions

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## Ethics approval and consent to participate

Ethical approval was obtained from the Institutional Review Committee of Nobel College before data collection (Reg no: 2021-4-70-0013) on January 23, 2023. Informed consent was obtained from study participants before the data collection. The study procedure was designed to protect participants' privacy, allowing for voluntary participation. During the consent process, it was made clear to participants that they were free to refuse participation and that if they decided not to participate, they could stop at any time. Confidentiality and privacy of participants were maintained during the analysis.

## Consent for publication

All the participants gave consent for publication in this study.

## Availability of data

All data generated or analyzed during this study are included in this published article.

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