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A Community Empowerment Model for the Development of Palliative Programs for Patients with Breast and Cervical Cancer

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ABSTRACT

OBJECTIVE: To examine the cancer burden and status of palliative care services and develop a community empowerment model to support palliative programs in North Maluku Province.

METHODOLOGY: A sequential exploratory mixed-methods design study was conducted from April 2025 to June 2026. Phase 1 used total sampling of 145 registered individuals (72 breast cancer patients, 10 cervical cancer patients, and 63 at-risk individuals) in Ternate City and Tidore Islands City during 2023–2025. Structured interviews on palliative care awareness and utilization were conducted. Quantitative data were analyzed using IBM SPSS 26.0. Phase 2 integrated the quantitative findings with qualitative policy analysis and stakeholder engagement through focus group discussions.

RESULTS: Most patients with breast cancer were 30–45 years old (52.8%) with senior high school education level. Among cervical cancer patients (n = 10), 7(70.0%) had a senior high school education, and city of residence was significantly associated with education level. Among the 60 interviewed participants, palliative care awareness was 16.7% and prior utilization was 7.5%, while late-stage presentation was 69.5% of the 145 registered cases. These findings formed the basis for a Palliative Companion Model with trained community cadres, standardized assessment tools (Palliative Performance Scale and Distress Thermometer), defined referral thresholds, and a dashboard for digital monitoring.

CONCLUSION: The Palliative Companion Model addresses the gap between hospital care and home-based palliative care through a systematic, community-led approach for low-resource contexts. Integration of this model into primary healthcare policy is recommended to support sustainability and scalability across similar settings.

KEYWORDS: Breast Cancer, Cervical Cancer, Palliative Care, Community Empowerment, Indonesia, Low-Resource Settings

INTRODUCTION

Cancer is a major global public health problem, with more than 10 million cancer deaths occurring annually, driven by population growth and ageing, lifestyle changes, and weaknesses in health systems in low-income settings. In Indonesia, breast cancer is the most frequently diagnosed cancer among women (42.1 per 100,000 women) and the leading cause of cancer-related mortality among women (16.6 per 100,000) as of 2020. These challenges are particularly important in low- and middle-income countries, including Indonesia, where health-system capacity and financial resources can limit access to timely cancer care[1–6].

Indonesian regions, including North Maluku, face geographic, socioeconomic, and health-infrastructure barriers to early detection and cancer management. National efforts to strengthen primary care for non-communicable diseases provide an important policy context for improving cancer-related services[7,8].

Palliative care is an essential component of comprehensive cancer care because it improves quality of life and relieves suffering among patients and families facing life-threatening illness[9]. However, palliative care services remain scarce in many low- and middle-income countries, including Indonesia, and community health center–based programs may not function effectively, resulting in patients presenting only when symptoms are advanced or disease is end-stage[10]. This pattern underscores the need for proactive and accessible community-based palliative care.

Community empowerment provides a potential pathway to extend palliative care beyond institutional settings into the communities where patients live[11]. In Indonesia, the established community health volunteer (cadre) system provides an existing platform for community-based health promotion and prevention activities[12,13].

Nevertheless, community empowerment for breast and cervical cancer palliative care remains underdeveloped in Ternate City and Tidore Islands City, North Maluku Province. Palliative care awareness is low, community-based service coverage is limited, and no systematic community empowerment model for palliative care has been developed in this context. Previous evidence from Indonesia has also highlighted gaps in the integration of palliative care into the health system.

This study therefore aimed to (1) explore the conditions and responses of communities affected by breast and cervical cancer risk factors toward palliative care and (2) formulate a community empowerment policy model for breast and cervical cancer palliative care. The model is intended to bridge hospital-based cancer treatment with home-based continuing care and to improve access to palliative care in resource-limited settings.

METHODOLOGY

Study Design

This study used a sequential exploratory mixed-methods design. It assessed the burden, risks, and palliative care needs of breast and cervical cancer at two study sites from April 2025 to June 2026. The Community Empowerment Policy Model integrated quantitative findings with policy documents, evidence from community-based palliative care models, and stakeholder feedback obtained through qualitative engagement with policymakers and healthcare providers.

Study Setting

This study was conducted in Ternate City and Tidore Islands City, North Maluku Province, Indonesia. The study sites represented urban and semi-rural healthcare contexts in eastern Indonesia, where community health center infrastructure exists but palliative care programs remain underdeveloped. Data were collected from community health centers and referral units of both cities, as well as from their respective municipal health offices.

Study Population and Sample

The study population consisted of individuals with breast and cervical cancer registered at health facilities in Ternate City and Tidore Islands City during 2023–2025, together with individuals identified in health-facility records as being at increased risk for breast or cervical cancer. The total accessible population was 145: breast cancer patients (n = 72), cervical cancer patients (n = 10), individuals at risk for breast cancer (n = 37), and individuals at risk for cervical cancer (n = 26).

Total sampling was used for the quantitative population (n = 145), meaning that all eligible registered patients and at-risk individuals were included. Eligibility required registration in the health-facility records of either city, residence in the study area, and willingness to participate; incomplete medical records were an exclusion criterion. At-risk status was based on identification in the health-facility records as being at increased risk for breast or cervical cancer; the study records did not specify a further standardized clinical risk algorithm.

of assess palliative care awareness and acceptance, 60 respondents (25 from Tidore Islands City and 35 from Ternate City) were purposively selected from patients and at-risk individuals for structured interviews. Thus, the quantitative component used total sampling (n = 145), whereas the interview component used purposive sampling (n = 60). When expected cell frequencies were below five, Fisher's exact test was used; otherwise, chi-square testing was applied ($\alpha = 0.05$).

Data Collection

Data were collected using a standardized questionnaire and interview guide through structured face-to-face interviews that were conducted by trained research assistants. The instrument covered four sections: (1) sociodemographic characteristics; (2) cancer diagnosis and stage confirmed from community health center medical records; (3) breast and cervical cancer risk factors; and (4) palliative care awareness, access, utilization, and perceived barriers. Research assistants were trained in standardized interviewing, questionnaire administration, and recording procedures before data collection. The study records identify the instrument as standardized but do not report formal psychometric validity or reliability coefficients.

Secondary data were obtained from the Ternate and Tidore Islands City Health Offices through cancer patient registries, health promotion reports, communication and promotion program reports, and palliative care policy documents from 2023–2025. These data provided an

epidemiological basis for categorizing cancer patients and at-risk populations by disease status, stage, and age group.

Variables and Measurements

Key variables included cancer type (breast vs. cervical), disease status (diagnosed patient vs. at-risk individual), education level (no school, elementary school, junior high school, senior high school, or college/university), and age group (<30, 30–45, 46–60, and >60 years). Palliative care variables included knowledge of available palliative care services (yes/no) and previous use of palliative care (yes/no).

During model development, the Palliative Performance Scale (PPS) and Distress Thermometer were incorporated into the proposed community home-visit protocol. The PPS assesses functional status from 0% to 100%, whereas the Distress Thermometer screens psychological distress on a 0–10 scale; a score ≥4 was used as a referral threshold. These tools were intended to standardize community-level assessment and referral decisions.

Data Analysis

Quantitative data were analyzed using IBM SPSS Statistics version 26.0. Sociodemographic and cancer-related variables were summarized using descriptive statistics (frequency, percentage, mean, and standard deviation). Cross-tabulations were used to assess distributions by education level and age group. The PPS and Distress Thermometer were included in the model-development protocol as standardized screening measures. They served a descriptive and operational role for referral planning rather than as independent inferential predictors.

The chi-square test was conducted to evaluate associations between categorical variables. Fisher's exact test was applied when expected cell frequencies fell below five. All statistical tests used a significance level of $\alpha = 0.05$. The model synthesis combined quantitative findings with policy-document analysis and evidence from community-based palliative care models. The final model was refined iteratively using stakeholder input from community health center and health-office personnel, as well as community health cadres.

Ethical Considerations

Ethics approval was obtained from the review board of the Ternate Health Polytechnic of the Ministry of Health, Indonesia, before data collection (Approval number: UM. 02. 03/6/500/2025). All participants provided written informed consent after receiving information about the study objectives, procedures, risks, and benefits.

RESULTS

The distribution of patients with breast cancer by education level and age group in both cities (Ternate City n=32, Tidore Islands City n=40) is shown in Table I. Education levels differed significantly between the two cities (p=0.005). In Ternate, most patients graduated from high school (75.0%), whereas in Tidore, the majority of patients had junior high school education (42.5% vs. 6.25%). Most patients in both cities were in the 30–45 years age group (52.8%), followed by 46–60 years (38.8%). The distribution of age groups did not differ significantly between the two cities (p=0.178).

Table I: Distribution of Breast Cancer Patients by Education Level and Age Group in Ternate City and Tidore Islands City

Variable	Ternate City (n=32)	Tidore Islands City (n=40)	Total (n=72)	p-value
Education Level				**0.005**[a]
Elementary School	2 (6.25%)	3 (7.5%)	5 (6.9%)	
Junior High School	2 (6.25%)	17 (42.5%)	19 (26.4%)	
Senior High School	24 (75.0%)	17 (42.5%)	41 (57.0%)	
University	4 (12.5%)	3 (7.5%)	7 (9.7%)	
Age Group				0.178[b]
<30 years	1 (3.1%)	2 (5.0%)	3 (4.2%)	
30–45 years	15 (46.9%)	23 (57.5%)	38 (52.8%)	
46–60 years	13 (40.6%)	15 (37.5%)	28 (38.8%)	
>60 years	3 (9.4%)	0 (0.0%)	3 (4.2%)	

A descriptive frequency analysis was performed. [a]Chi-square test ($\chi^2 = 12.84$; df = 3). [b]Fisher's exact test was applied due to cells with expected counts <5 ($\chi^2 = 4.91$; df = 3). The bold values indicate statistical significance ($p < 0.05$).

Data on the distribution of breast cancer-prone individuals (n=37) in Ternate City (n=26) and Tidore Islands City (n=11) by education level and age group are shown in **Table II**. Most students had a high school education (83.8%) in both cities. Regarding age, those aged 30–45 years had the highest proportion (45.9%), followed by those aged 46–60 years (37.9%). There was no statistically significant association between education level (p=0.432), age group (p=0.497), and city location as per Fisher's exact test, confirming the similarity of demographic distributions for both cities.

Table II: Distribution of Individuals at Risk of Breast Cancer by Education Level and Age Group in Ternate City and Tidore Islands City

Variable	Ternate City (n=26)	Tidore Islands City (n=11)	Total (n=37)	p-value*
Education Level				0.432
No School	0 (0.0%)	0 (0.0%)	0 (0.0%)	
Elementary School	2 (7.7%)	0 (0.0%)	2 (5.4%)	
Junior High School	2 (7.7%)	2 (18.2%)	4 (10.8%)	

Senior High School	22 (84.6%)	9 (81.8%)	31 (83.8%)	
College	0 (0.0%)	0 (0.0%)	0 (0.0%)	
Age Group				0.497
<30 years	4 (15.4%)	1 (9.1%)	5 (13.5%)	
30–45 years	10 (38.5%)	7 (63.6%)	17 (45.9%)	
46–60 years	11 (42.3%)	3 (27.3%)	14 (37.9%)	
>60 years	1 (3.8%)	0 (0.0%)	1 (2.7%)	

**Descriptive frequency analysis was performed. P-values were obtained using Fisher's exact test for the association between cities and each variable.*

The distribution of education level and age group for cervical cancer patients (n = 10) and at-risk individuals (n = 26) in Ternate and Tidore Islands is shown in **Table III**. Among cervical cancer patients, 7 of 10 (70.0%) had a senior high school education. There was a significant association between city of residence and education level among cervical cancer patients (Fisher's exact p = 0.033). In contrast, no significant associations were observed for at-risk individuals (p = 0.112), cervical cancer patient age group (p = 0.467), or at-risk age group (p = 0.089). Given the small cervical cancer sample, these findings should be interpreted cautiously.

Table III: Distribution of Cervical Cancer Patients and At-Risk Individuals by Education Level and Age Group in Ternate City and Tidore Islands City

Variables	Cervical Cancer Patients			At-Risk Individuals		
	Ternate (n=6)	Tidore (n=4)	Total (n=10)	Ternate (n=12)	Tidore (n=14)	Total (n=26)
Education Level						
No School	0	0	0	0	0	0
Elementary School	0	1	1	1	5	6
Junior High School	0	2	2	3	5	8
Senior High School	6	1	7	6	4	10
College	0	0	0	2	0	2
Fisher's exact test[a]			$p = 0.033$*			$p = 0.112$
Age Group						
<30 years	2	0	2	0	0	0
30–45 years	2	1	3	5	4	9
46–60 years	2	3	5	7	6	13
>60 years	0	0	0	0	4	4
Fisher's exact test[a]			$p = 0.467$			$p = 0.089$

[a]*Fisher's exact test was applied because of small cell sizes. The* p*-values indicate the association between the city and each respective variable.* Significant at $p^* < 0.05$.

The indicators of cancer burden and palliative care from Ternate City and Tidore Islands City are presented in **Table IV**. Of the 145 registered cases, 72 were breast cancer patients, 10 were cervical cancer patients, 37 were at risk for breast cancer, and 26 were at risk for cervical cancer. Among the 60 respondents interviewed about palliative care, awareness was 16.7% and prior utilization was 7.5%. Late-stage presentation accounted for 69.5% of the registered cancer

burden. No statistically significant differences were observed between the two cities for the palliative care indicators (all $p > 0.05$).

Table IV: Summary of Cancer Burden and Palliative Care Indicators in Ternate City and Tidore Islands City

Indicator	Ternate City	Tidore Islands City	Total	p-value
Breast cancer patients	32	40	72	—
Breast cancer at-risk	26	11	37	—
Cervical cancer patients	6	4	10	—
Cervical cancer at-risk	12	14	26	—
Total cancer burden	76	69	145	—
Palliative care awareness (%)	18.3%	15.0%	16.7%	0.621*
Prior palliative care utilization (%)	8.3%	6.7%	7.5%	0.748*
Late-stage presentation (%)	71.1%	68.2%	69.5%	0.734*

**Chi-square test for independence. Palliative care awareness and utilization data were derived from structured interviews with 60 respondents (25 from Tidore Islands City and 35 from Ternate City). Percentages for awareness and prior utilization therefore refer to the interviewed sample (n = 60); the late-stage presentation percentage refers to the registered cancer burden (n = 145).*

Community Empowerment Model

Based on the quantitative findings, policy-document analysis, and stakeholder input, a Palliative Companion Model was developed as a community empowerment framework **(Figure 1).**
The model is illustrated in three figures.

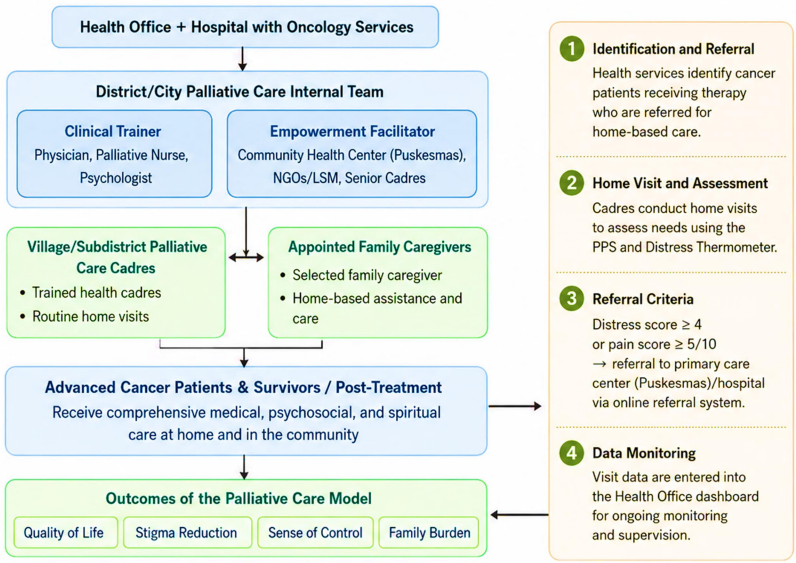

Figure 1: Framework Schema Palliative Care Model

Figure 2 shows the data collection process flow attached to the operational process. Identification of patients at referral hospitals → Referral to Core Team → Training and deployment of village cadre → Home visit using performance scale and distress thermometer (if

a distress score is ≥4 or pain score is ≥5/10, we re-refer the patient back to health facilities) → Record data on Health Office dashboard (feedback loop will be sent back to the Core Team for quality improvement).

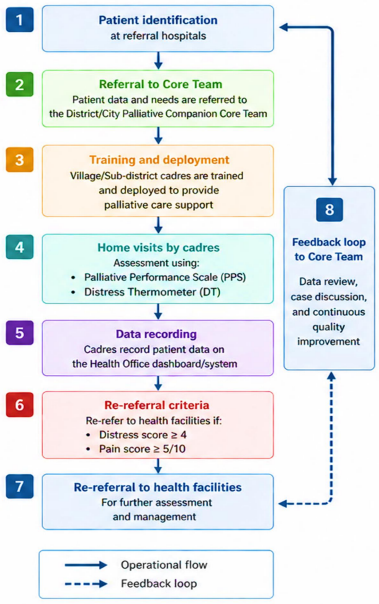

Figure 2: Operational Workflow of the Palliative Companion Model.

Figure 3 shows the expected effects in four domains: (1) patient outcomes: quality of life, pain and suffering, and medication adherence; (2) family outcomes: caregiver burden and caregiving outcomes; (3) community outcomes: palliative care stigma and awareness of palliative care with public education programs to the community; and (4) health system: control of continuity of care between providers, avoiding late-stage presentations in hospitals or emergency departments, and optimizing resource allocation.

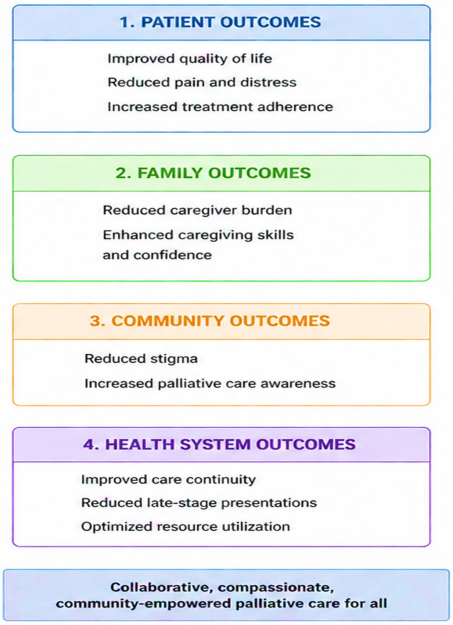

Figure 3: Expected Outcomes Framework of the Palliative Companion Model.

DISCUSSION

The results of this study indicate a high cancer burden among women in Ternate City and Tidore Islands City, with breast cancer being the most common malignancy (72 cases) compared with cervical cancer (10 cases). This pattern is consistent with global epidemiological trends in which breast cancer has surpassed cervical cancer as the most frequently diagnosed female malignancy[14]. The concentration of cases among women aged 30–60 years is consistent with evidence that breast cancer incidence is prominent during the perimenopausal and early postmenopausal periods, while cervical cancer risk increases with age in the context of persistent HPV infection[15].

Specifically, the finding that more than half of the cancer patients had a high school education (breast cancer: 56.9%, cervical cancer: 70.0%) should be interpreted with caution. While higher educational attainment is typically correlated with greater health literacy and screening participation, this distribution may reflect the demographic composition of the study population rather than a true risk gradient[16,17]. The sharper focus on high school education may reflect local population demographics, with this level of education representing a modal level in urban and semi-urban Indonesian contexts, such as Ternate and Tidore. However, the implication that 83.8% of patients at risk for breast cancer have a high school education suggests that such factors should be considered in direct health education interventions as a framework for close monitoring and well-being initiatives.

Low palliative care awareness (16.7% among 60 interviewed respondents) and prior utilization (7.5% among 60 interviewed respondents) indicate substantial access gaps. The 69.5% late-stage presentation rate among the 145 registered cases further highlights limitations in early detection, timely referral, and continuity of care. These findings suggest the need for new approaches to extend palliative care into the community[18,19].

The Palliative Companion Model is a multistep, community-based palliative care framework that aims to bridge hospital-based oncology and home-based continuity of care. The model begins with coordination through the Health Office and cancer referral hospitals to identify patients who need palliative care, consistent with other low- and middle-income country models in which referral from tertiary facilities to community services supports continuity of care[20–22]. The District/City Palliative Companion Core Team includes clinical trainers and community empowerment facilitators who coordinate cadre training and follow-up.

Village/sub-district palliative care cadres conduct home visits using the Palliative Performance Scale and Distress Thermometer, with clear referral thresholds. A distress score ≥4 or pain score ≥5/10 triggers re-referral to a health facility, while the Health Office dashboard records monitoring data. Standardized screening can improve consistency in community assessment, while training cadres and families support safe home-based care[20,23,24]. The expected benefits include improved quality of life, reduced stigma, better treatment adherence, and reduced caregiver burden, consistent with evidence from community-based palliative care interventions[25].

The Palliative Performance Scale and Distress Thermometer provide standardized assessment within the community home-visit protocol. The Palliative Performance Scale has demonstrated reliability for assessing functional status and prognostic value in palliative settings[24]. The Distress Thermometer provides rapid psychological distress screening, with a threshold of ≥4 used in this model to support referral. These thresholds are intended to maintain clinical safety by prompting referral when patient needs exceed the capacity of community health workers.

The digital dashboard addresses the need for monitoring, care coordination, and data-driven decision-making in community-based palliative care[23,26]. Digital monitoring may support symptom management and early identification of deterioration, while centralized oversight is particularly relevant in geographically dispersed island settings.
The significant differences in education level between Ternate and Tidore among breast cancer patients ($p = 0.005$) and cervical cancer patients ($p = 0.033$) suggest that local demographic characteristics should be considered when implementing the model. Cases in Ternate were predominantly among high school graduates, suggesting that health communication strategies may require adaptation to address the relatively higher educational profile of the population compared with Tidore. These findings support the principle that community empowerment models should be adapted to local contexts.

CONCLUSION

High breast cancer burden (72 cases) and cervical cancer burden (10 cases) were observed among women in Ternate City and Tidore Islands City during 2023–2025, with an additional 63 women identified as at risk. Among the 60 interviewed respondents, palliative care awareness was 16.7% and prior utilization was 7.5%, while among the 145 registered cases, late-stage presentation was 69.5%. The Palliative Companion Model provides a structured community-based framework incorporating standardized assessment tools, referral pathways, trained community health volunteers, and digital monitoring. Integration of this model into primary healthcare policy is recommended to support sustainability and scalability across similar low-resource settings.

Ethical Permission: Ternate Health Polytechnic of the Ministry of Health and Poltekkes Kemenkes Ternate, Ternate, North Maluku, Indonesia, IRB approval letter No. UM. 02. 03/6/500/2025.
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Data Sharing Statement: The corresponding author can provide the data proving the findings of this study on request. Privacy or ethical restrictions bound us from sharing the data publicly.

AUTHOR CONTRIBUTION

Pandawa RM: Conceptualization and design of the study, including the acquisition, analysis, and interpretation of data; drafting and critical revision of the manuscript; and final approval of the version submitted for publication.
Saleh FM: Conceptualization and design of the study, including the acquisition, analysis, and interpretation of data; drafting and critical revision of the manuscript; and final approval of the version submitted for publication.
Djama NT: Conceptualization and design of the study, including the acquisition, analysis, and interpretation of data; drafting and critical revision of the manuscript; and final approval of the version submitted for publication

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