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Research Article

Cancer Care in the Community Setting: A Mixed Method Study

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Abstract

Aims: This study evaluated palliative care services in Indonesia, focusing on proposing a community-based model to enhance cancer care.
Method: A mixed-method approach was employed, involving quantitative analysis of 200 patients' personal and treatment factors and qualitative insights from 21 stakeholders to FGDs and in-depth interviews.
Results: The qualitative results highlight five themes: 1) illness as a subjective and culturally influenced concept, 2) family's role in treatment decision-making, 3) perceptions of healing through multiple treatment modalities, 4) finding positive meaning in illness, and 5) hopes and aspirations for recovery. The quantitative results show that 55.5% of patients had inadequate knowledge, with 69.5% preferring modern therapy. A significant relationship was found between knowledge, perception, and treatment options, while no significant correlation was observed with self-confidence or diagnosis date.
Conclusion: An integrated community-based palliative care model tailored to Indonesia's healthcare system is proposed to improve the quality of life for cancer patients.

Keywords:
Cancer Care, Community-Based Care, Mixed Method, Palliative, Patient Care

INTRODUCTION

Healthcare systems in developing countries have not yet integrated palliative care into their services, which optimally improves patient's life quality. Therefore, a model is designed, coordinated, and managed with funds for each service carried out by interdisciplinary collaboration (doctors, nurses, pharmacists, psychologists, social workers, spiritual servants, and the public) in a professional manner (1). Currently, palliative services are mostly carried out in hospitals, however, families often prefer home treatment.

Indonesia is the largest archipelago country in the world in its development stage and has an urgent increasing burden of cancer (1.8 for every 1,000 people), with the majority of cases (70% from 240,000 incidents per year) found in the advanced stage (2). Accordingly, where the need for palliative care is not met, patients with terminal and incurable illnesses suffer total pain and burdensome costs (3). Also, in the terminal stage, patients would opt for home care for end-of-life management in consideration of cost and family ties and thus the need for good home-based palliative care in the community (4).

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In the United States, they are not only provided in hospitals, and also in the community due to the formation of Community-based Palliative Care. In European countries, such as Belgium, France, and Germany, there are specific laws regarding palliative services, due to the different history, policy, and culture. Furthermore, in Europe, palliative care regulations encompass the aspects of rights, access, policies, national funding, training, and opioid use. While in Australia, the program has become a national strategy since 1999 (5). In African countries, such as Uganda and Kenya, it is developed and integrated into the national health system, educational curriculum, health services, opioid provision and implementation (6).

In Indonesia, it has not been implemented optimally and was mostly carried out by non-government institutions. Some hospitals in Indonesia, including those in Jakarta, Yogyakarta, Surabaya, Denpasar, and Makassar, provide palliative services that are still not optimal. The constraints on its implementation include patient and family perception, socioeconomic and cultural factors, service provider attitudes, availability of trained personnel, facility distribution, consolidation, and cost guarantees (7). Meanwhile, many patients with terminal illness died in hospitals and homes without adequate support.

The global and national situation impacts cancer palliative services, especially the risks in comorbid conditions (e.g., cardiovascular disease, diabetes, and chronic respiratory infections), as well as in elderly cancer patients (8). Furthermore, the Indonesian government has made efforts to promote healthy living behavior during the pandemic, although, in practice, the implementation was not running optimally. The Indonesian government has taken steps to address palliative care through several initiatives. For instance, the Ministry of Health has integrated palliative care into its primary healthcare programs, especially for cancer patients (9). Barriers to the development of palliative care also come from healthcare professionals. Palliative care is only considered an option when active treatment is no longer continued and limited insurance coverage under BPJS. Psychological problems, social difficulties, and spiritual aspects are not considered to be part of medical services at the end of life (10).

Moreover, while efforts like promoting healthy living behavior during the pandemic were helpful, they did not adequately address the growing demand for palliative services (11). Insurance coverage for palliative care under BPJS is still limited, and there is a lack of targeted policies that ensure equitable access to services, particularly in rural areas (12).

Conversely, the community considers palliative care only for patients in terminal conditions. However, the new concept emphasizes the importance of its early integration for addressing physical, psychosocial, and spiritual problems. Palliative care is a holistic and integrated health service involving various professions based on the philosophy that every patient is entitled to the best care (13). Palliative care policy is focused on all patients (adults and children), family members, and the physical environment.

The early and holistic integration of palliative care requires systemic efforts to ensure accessibility for all patients, particularly those with cancer. Key strategies include training healthcare professionals by incorporating palliative care into medical and nursing curricula and providing continuous professional development programs (14,15). Improving healthcare infrastructure is also crucial, such as establishing dedicated palliative care units (16). Public awareness campaigns are needed to address misconceptions and promote cultural acceptance, while policies must mandate palliative care integration into primary healthcare (17). These efforts will ensure that every patient receives the best possible care.

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Creating an appropriate program should be based on definite observations. Therefore, considering management methods in different countries provides useful information for determining the most appropriate model modification options. The model and theory used to create cancer services need to be elaborated on in several step indicators in the following paragraphs. This study evaluated palliative care services in Indonesia, focusing on proposing a community-based model to enhance cancer care.

METHODS

Study Design

This study employed an Exploratory Sequential mixed-methods design, which involved collecting and analyzing quantitative data first, followed by qualitative data to provide a deeper understanding of the findings. The quantitative phase aimed to gather numerical data on the current state of palliative care, while the qualitative phase sought to explore the contextual factors, such as cultural and psychological conditions, that influence the effectiveness of palliative care services.

Sampling techniques

For the quantitative phase, a purposive sampling technique was used to select 200 patients who had received palliative care in referral hospitals. These patients were chosen based on the criteria of having a cancer diagnosis and having engaged with palliative services. In the qualitative phase, snowball sampling was applied to select 21 stakeholders, including healthcare workers, decision-makers, and policymakers involved in palliative care services. This approach allowed for the inclusion of key individuals who could provide valuable insights into the service model.

Data Collection

Qualitative data collection

Interviews with healthcare workers, policymakers, and other stakeholders were conducted to explore their perceptions of the palliative care system, and the discussions were recorded for transcription and analysis.

Quantitative data collection

1. Questionnaires were completed by patients and their families who had received palliative care, capturing their experiences, needs, and satisfaction with the services. The researchers developed the questionnaire, focusing on the domains of **patient characteristics, treatment preferences**, and **caregiver support**. The validity of the instrument was established through expert reviews. The questionnaire was administered in **approximately 40 minutes.** Participants filled out the questionnaire on-site, and completed forms were returned directly to the research team
2. Clinical observations in hospitals, community health centers (*Puskesmas*), and private clinics to assess the delivery of palliative care in real-world settings.
3. Secondary data was collected from documentation, including monitoring results from health workers' meetings and reports on palliative services.

Analysis process

Quantitative data was analyzed using bivariate analysis with the Spearman test to identify correlations between independent variables such as personal factors consisting of Knowledge, Self-Confidence, Perception, and Diagnosis Date. The dependent variable was treatment options. Qualitative data was analyzed using thematic with a grounded theory methodology analysis to identify key themes related to cancer care in the community setting (18). Integrating quantitative and qualitative findings provided a comprehensive view of the current state and potential improvements for palliative care services.

Ethical Clearance

This study obtained approval from the Committee of Conduct for Health Research, Faculty of Medicine, Universitas Padjadjaran, with Ethical No. 277/UN6.C1.3.2/KEPK/PN /2016. The primary data collection was through 1) interviews with stakeholders (health workers, policymakers), 2) filling out the questionnaire by patients and families that had received palliative care, and 3) clinical observations. Informed consent was obtained from all participants, who were fully informed about the study's purpose, voluntary participation, and their right to withdraw at any time. Verbal and written consent were obtained for interviews and Focus Group Discussions (FGDs). To ensure confidentiality, all data was anonymized, securely stored in password-protected files, and accessible only to authorized researchers. Identifying information was removed from transcripts, and data was retained only for the duration necessary for analysis before being securely destroyed.

Research on palliative services was conducted in 3 phases from 2016 to 2020, an adaptation design was created, the details were shown in Figure 1.

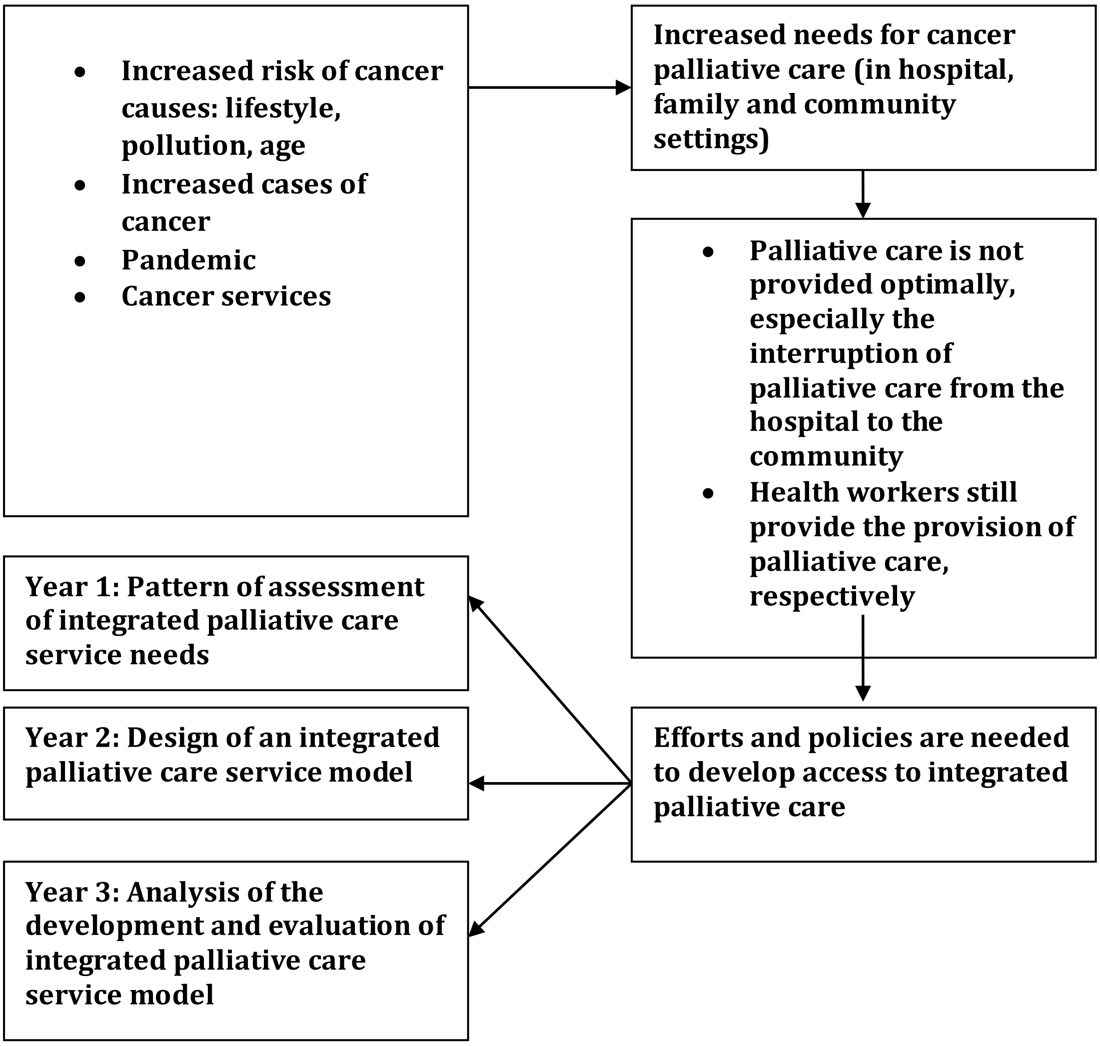

Figure 1. Framework of Research

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RESULTS

Qualitative Results

1. Illness as a Subjective and Culturally Influenced Concept

articipants often perceived illness subjectively, with many delaying acknowledgment and action due to sociocultural factors. For instance, symptoms such as small lumps were ignored for years, as they did not immediately impact daily activities.

> *"I thought the lump wasn't serious because I could still do house chores and work normally."*

The decision to seek help was often postponed out of fear or financial constraints. A participant revealed, "At that time, I couldn't afford treatment if it turned out to be something severe." Furthermore, limited knowledge about breast cancer contributed to delays, with most participants only learning about the disease through television or trusted individuals such as family or neighbors.

> *"I didn't know much about cancer except what I saw on TV or what my family told me."*

Cultural influences also played a role, as patients consulted informal leaders or religious figures for guidance.

> *"I asked my ustadz for advice before seeking treatment."*

2. Family's Role in Treatment Decision-Making

Treatment decisions were predominantly driven by the family, particularly the husband, reflecting cultural norms of collective decision-making.

> *"My husband was the one who decided what treatment I should take."*

Beyond decision-making, the family provided crucial physical and emotional support.

> *"After being diagnosed, my husband insisted I stop doing household chores and focus on resting."*

3. Perceptions of Healing Through Multiple Treatment Modalities

Participants explored a combination of conventional medical therapies and complementary or alternative medicine (CAM) to achieve healing. While chemotherapy and surgery were considered effective, they were also associated with significant challenges. One participant remarked,

Conventional Medical Therapies

The most common conventional treatments included surgery, chemotherapy, and radiation therapy. Participants were also prescribed medications such as tamoxifen (for estrogen prevention), dexamethasone (to alleviate pain), ranitidine (for stomach issues), and ondansetron (to control nausea). A few participants mentioned their cautious approach to medication during chemotherapy.

> *"Chemotherapy is the hardest. I couldn't eat or drink, felt nauseous, and my hair fell out completely."*

Several participants shared similar sentiments about the challenges of chemotherapy. One participant shared the experience of severe side effects after their first round of chemotherapy.

> *"I felt nauseous, couldn't eat, couldn't drink, I felt like I was dropping after my first chemotherapy session. The next schedule came, but I was too weak, had to be hospitalized first. I had to eat nutritious food before I could continue chemotherapy."*

Another participant emphasized the difficulties they faced with chemotherapy compared to other treatments:

> *"For me, chemotherapy is the hardest (compared to radiation and surgery). There are many complaints with each chemotherapy session: fever, mouth sores, and even eye pain."*

Physical side effects further compounded the perceptions of chemotherapy's effects.

> *"The effects of chemotherapy are worse than radiation and surgery, even losing the sense of taste in my tongue.*

> *And what I can't forget is the hair loss until I went bald."*

Complementary and Alternative Medicine (CAM)

Some participants combined hospital-prescribed treatments with CAM methods, such as consuming herbal remedies like white turmeric, yellow turmeric, temulawak, pegagan, ant nests, propolis, soursop leaves, and honey. These were consumed either as simplicia (boiled and drunk three times daily) or in capsule form to boost immunity. Others consumed vegetable and fruit juices, with or without sugar, as part of their regimen. A participant who used a special cancer-neutralizing vest developed by Prof. Warsito from Tangerang mentioned a unique form of alternative treatment.

A few participants also implemented a disciplined diet to maintain and restore their physical condition. These participants created daily menus with a variety of carbohydrates, fruits, and vegetables, often prepared as juices to facilitate absorption for those experiencing loss of appetite.

> *"Every day, I made sure to prepare six types of carbohydrates: rice, porridge, corn, cassava, sweet potato, and sago. I'd eat two spoonfuls of each. If I vomited some out, at least I knew some of it stayed in my stomach."*

4. Finding Positive Meaning in Illness

Over time, many participants began to reframe their illness as an opportunity for personal growth and reflection. They viewed the experience as a test of faith or a chance to deepen their spirituality.

> *"I see this illness as a reminder from God to focus on my faith and health."*

Some participants also used their experiences to inspire others in similar situations, finding purpose in helping others navigate their journey.

> *"Sharing my story with other patients gave me strength and made me feel useful,"*

The views on recovery varied among patients. Some believed that recovery depends on one's desire to heal.

> *"Healing depends on whether you want to get better. If you want to heal, you can. The doctor says just relax and enjoy it. You can't just cry out to Allah and expect healing, you must accept it sincerely, hoping it will be a remedy."*

Another participant reflected on how they approached their illness differently over time.

> *"The first chemo session was hard, I felt down, but now I'm not. When I feel nauseous, I just hope Allah strengthens me. Now, I just go with the flow, enjoy it. The most important thing is to get closer to Allah. Seeing other patients, if they can do it, God willing, I can too."*

Despite finding meaning and spiritual growth in their illness, some patients expressed the challenges of not being able to fulfill their household roles, which added to the burden on family members.

> *"I couldn't do my usual household tasks, which made things harder for my family."*

5. Hopes and Aspirations for Recovery

Despite the challenges, participants expressed a strong sense of hope and determination for recovery. This optimism often stemmed from their faith and the support of their families.

> *"Even though chemo was tough, I hoped it would lead to recovery."*

A common theme was the belief that recovery ultimately lies in Allah's hands. All participants expressed a deep hope for healing and continuously prayed for recovery. However, their efforts toward recovery varied widely. Some patients made significant efforts to meet nutritional needs despite a substantial decrease in appetite.

> *"Even though my appetite is reduced drastically, I try to eat enough to stay nourished, fighting the loss of appetite."*

In contrast, many patients found it challenging to meet nutritional requirements due to decreased appetit.

"Because my appetite has decreased, it's hard for me to get the proper nutrition that I need."

Participants also noted the long journey toward full recovery. A few were aware that cancer recovery is a prolonged process, even requiring medication long after five years of treatment.

> *"There are many people who have recovered, but full recovery is difficult because we still need to keep getting treatment. Even after five years, cancer patients must continue their medication."*

Quantitative Results

Table 1 shows quantitative research results regarding individual factors' identification (knowledge, beliefs, and perceptions), the diagnosis date, and the treatment options in breast cancer patients.

Table 1. Personal Factor and Identification Factor in Breast Cancer Patients (n = 200)

Factor	Frequency (*f*)	Percentage (%)
Personal Factor		
Knowledge		
Adequate	89	44,5
Inadequate	111	55,5
Confidence		
Positive	194	97,0
Negative	6	3,0
Perception		
Positive	192	99,0
Neutral	6	3,0
Negative	2	1,0
Identification Factor		
Diagnosis Date		
Less than 1 Year	98	49,0
1 to 3 Years	70	35,0
3 to 5 Years	27	13,5
More than 5 Years	5	2,5

The data on personal characteristics and identification factors in breast cancer patients showed that 111 respondents (55,5%) had inadequate knowledge regarding the disease, while 89 others (44,5%) were on the fair level. From the confidence perspective, 194 respondents (197,0%) were confident that breast cancer patients had a chance to recover (positive confidence), while six others (3,0%) stated otherwise (negative confidence).

Furthermore, the perception factor showed that 192 respondents (99,0%) highly affirmed that breast cancer was a "serious" illness, while 66 others (33,0%) being fairly affirmative, six others (3,0%) barely had the idea whether it was serious or not, and two others (1,0%) claimed otherwise.

From the diagnosis date, the research result showed that 98 respondents (49,0%) were diagnosed with cancer one year ago, while 70 respondents (35,0%) since 1 to 3 years ago, 27 respondents (13,5%) since 3 to 5 years ago, and five respondents (2,5%) more than five years ago (Table 1).

Table 2. Frequency Distribution of Treatment Options in Breast Cancer Patients (n = 200)

Treatment Options	Frequency (*f*)	Percentage (%)
Not Going for Therapy	4	2,0
Traditional Therapy	29	14,5
Modern Therapy	139	69,5
Complementary Therapy	28	14,0

The data on treatment options of breast cancer patients showed that 139 respondents (69.5%) preferred modern therapy, 29 respondents (14.5%) chose traditional medicine, 28 respondents (14.0%) chose complementary treatment, and four others (2.0%) did not select any treatment (Table 2).

Table 3. Personal Factor toward Treatment Options in Breast Cancer Patients (n = 200)

Factor	Treatment Options
Personal Factor	
Knowledge	*p* = 0,000 *r* = 0,370
Self-Confidence	*p* = 0,135 *r* = 0,106
Perception	*p* = 0,007 *r* = 0,190
Diagnosis Date	*p* = 0,161 *r* = 0,100

The correlation of personal factors with the treatment options in breast cancer patients showed a significant relationship between their knowledge regarding the disease and the therapy option with p-value = 0,000 (p < 0,05) and r value = 0,0370 (positive Spearman correlation value with moderate strength). Also, there was a significant relationship between the patient's perception and the treatment options with p-value = 0,007 (p <0,05) and r-value = 0,190 (positive Spearman correlation value with moderate strength). Meanwhile, there was no significant relationship between the patients' confidence factor toward the illness recovery and the treatment options with p-value = 0,135 (p > 0,05), as well as the diagnosis date and the treatment options with p-value = 0,161 (p > 0,05) (Table 3).

Role of Nurses, Ethical and Legal Aspects, and Palliative Care Services Management

In conducting palliative nursing care, nurses played a role as clinical executors, health educators, advocates, social workers, psychological and spiritual assistants, and service managers. The nurses had the most extended contact with the patients, therefore, understanding them, caring and assessing their conditions. Both the nurses, the patients and their families cooperated in making referrals to other disciplines and health services (19).

The requirements for selecting patients include the understanding of the meaning, purpose, and the implementation of palliative care through intensive and continuous communication between the team, patient, and family. The implementation of informed consent was carried out as stipulated in the legislation.

In palliative care, every risky action obtained informed consent from the patient, with close family member as the witness.

As patients' demand for palliative services increase, the government needs to understand the executors plans, what services were required, and how patients and families should benefit from the program. The policymakers need to understand that palliative services were part of the ongoing cancer treatment and other chronic diseases that were integrated into the health care system (WHO, 2007).

Furthermore, it was developed by the stakeholders to ensure it meet the minimum service requirements to all cancer patients, including the vulnerable groups, such as children and those with low incomes.

The public health approach were needed to integrate services at all levels of care to ensure accessibility to all targeted populations (19).

Besides, there was a referral system for health service networks, which allowed the mutual transfer of issues that arised vertically (communication between equal units) and horizontally (higher core communication to lower units) to the service facilities that were more competent, affordable, rational, and not limited by the administrative area. The referral procedure was carried out in stages and structured based on medical indications for the puskesmas to make a selection of referred cancer cases. A letter must accompany this process, while the *puskesmas* and its network had an impact on the cost control.

A national palliative care plan included the policy steps for providing various drugs needed to manage common symptoms of cancer, including pain, nausea, vomiting, delirium, agitation, insomnia, fatigue, depression, and anxiety. These drugs were included in the essential medicines' list to ensure their high demand rate, and were compiled by the multidisciplinary team.

Global, National and Local Adaptations and Palliative Services

The views of socio-cultural aspects, capable of changing the order of people's lives and palliative services in the presence of were as follows:

a. Social Perspectives
   Public understanding of social distancing initially became a very difficult, since the society considered it to reduce relationships between individuals, even though the core was to reduce transmission. This brought the change in the terminology of social to physical distancing to limit the contacts. Social relationships were then sustained through online communication media. It also changed the preference for cancer palliative care to service as government priority.
   As a first step, the government issued rules to limit mass movements with Work from Home (WFH) and Study from Home (SFH). While some agencies implemented independent quarantine for employees with risks, including those arriving from foreign country, WFH to those aged 60 years and above only, and also to all employees except the security and cleaning workers. This condition had negative impacts on palliative services both in hospitals and clinics, such as the reduction in the number of employees, transportation facilities to the place of therapy, pharmaceutical services, and those providing food for sick patients.

b. Psychological Perspectives: The research conducted by Brooks et al. (2020) reported the psychological effects of quarantine as pre-posttraumatic stress symptoms, confusion, and anger. And also the fear of infection, frustration, boredom, insufficient supplies, inadequate information, financial losses, and stigma (20).
   The fear and stigma of the COVID-19 incident had a negative impact on the disease control, both the infection and

other comorbidities, such as cancer. It eventually became a disease full of stigma with the susceptibility to the risk of virus transmission and other weaknesses. Due to this, the patient's family required extra attention. Also, an effective antistigma program was needed to break down the misperceptions, increase the knowledge, and spread positive messages.

Psychological composure affected the immune system, while the human endurance was the first and most important thing to ward off viruses entering the body. After the virus infects the host, resistance was carried out by every human's immunity. When it has finally defeated immunity, the next stage was the treatment period. During this phase, the individual's coping skills and emotions played a crucial role in increasing the confidence of returning to well-being.

In Indonesia and the world at large, the spread of the slogan that the medical team (doctors, nurses, pharmacists, and laboratory personnel) were the shield and the frontliner in eradicating the spread of Coronavirus Disease (COVID-19), gave birth to a new stigma in the community. Indirectly the public considered only the medical team was able to defeat the disease. Also, the information about the TNI and Polri ranks emerging as the frontliners, as well as several other jobs of couriers, farmers, and providers of necessities contributed to the stigma. Therefore, in dealing with a virus, it required the collaboration of the whole community.

c. Spiritual perspectives

Changes in conditions due to COVID-19 affected all walks of life, employees were 'forced' to work from home. This change had an impact on several aspects related to social activities, as well as spiritual practices. The use of public facilities in terms of worship restricted daily and certain religious moments.

The restrictions on worship meetings were also interpreted differently for all walks of life. Moreover, the government should ideally create an impacting program for all groups, even to the lower classes, such as the spiritual improvement of individuals and families in providing peace of mind during the pandemic. The religious composure factor was also one of the keys in increasing individual and the group immunity.

The spiritual intervention in increasing motivational behaviour supported the prevention of the disease by teaching healthy lifestyles in the form of regular physical activity, adequate rest, and eating nutritious food. Therefore, an excellent immune system became vital to ward off any viruses entering the body.

The personal spirituality also helped in a state of despair when facing a problem, therefore, religious enlightenment improved and strengthened individual. Therefore, there were simply three main components as the foundation and the frontline in dealing with Coronavirus Disease, namely individuals, immunity, and faith.

An individual's spiritual belief was one of the supporting factors in maintaining healthy status in cancer patients.

In the beginning, the government focused on handling rather than preventing the spread of the virus. Ideally, when there were still a few unexposed Indonesian, the government should have implemented a policy in providing information about the disease.

Palliative Cancer Care Model

In Indonesia, most cancers were found at an advanced stage, which causes a shorter life expectancy. Patients with this condition

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experienced suffering that required an integrated approach from various disciplines, for them to have a good life quality. The integration of palliative care into cancer management had long been advocated by the World Health Organization (WHO), due to the increasing number of cancer patients and deaths.

The cancer management had developed rapidly, however, the cure rate and the life expectancy of the patients were still limited, as a result, most of them eventually die of the disease. When curative medicine has not been able to provide the expected cure, as well as the primary and secondary preventive efforts, palliative care was the only pragmatic and humane service recommended.

The steps in palliative care according to the Indonesian Ministry of Health, consisted of a) determining the goals of care and patient expectations. b) Assisting patients in advanced care planning. c) The treatment of comorbidities and social aspects that arose d) Symptoms management. e) Patient care information and education. f) Psychological, cultural, and social support. g) Responding in the terminal phase by taking action according to the family decision, for example: terminating or not providing treatment that prolongs the process to death (resuscitation, ventilator, fluid, and other interventions). h) Services for patients in a terminal phase. i) The evaluations during care included the assessment of pain and other symptoms for appropriate resolution, reducing the stress of patient and family, and for improving the relationships with others (21).

Generally, palliative care was considered only for patients in terminal conditions, however, the new concept emphasized the importance of early integration of the service for physical, psychosocial, and spiritual problems to be addressed appropriately. Palliative care was a holistic and integrated health service involving various professions on the philosophic basis that every patient had the right to receive the best care.

DISCUSSION

In Indonesia, most cancers were found at an advanced stage, which causes a shorter life expectancy. Therefore, patients with this condition experienced suffering that required an integrated approach from various disciplines for them to have a good life quality. The WHO had long advocated the integration of palliative care into cancer management as the number of patients and mortality continues to increase.

Cancer management had developed rapidly, however, the cure rate and life expectancy of the patients were still limited, as a result, most of them eventually die of the disease. Furthermore, when curative treatment was not able to provide the expected recovery, as well as the primary and secondary preventive efforts, palliative care was the only pragmatic and humane response service recommended.

According to the World Health Organization’s definition, palliative nursing care is an effort to improve a patient's life quality, with respect to death as a normal process. This palliative care program performed the following processes namely 1) Not accelerating or delaying death. 2) Eliminating pain and other disturbing complaints. 3) Maintaining psychological and spiritual balance. 4) Improving the patient's life quality. 5) Assisting in overcoming the grief atmosphere in the family (22).

Palliative care aims to improve patient's life quality by preventing and alleviating suffering through early detection, assessment, and treatment of pain, symptoms, psychosocial, and spiritual issues. This palliative care was carried out holistically, encompassing the physical, psychosocial, and spiritual needs of the patient and family. It commenced when the illness was diagnosed, throughout the curative treatment, and until the patient's life time.

The palliative care was the framework of nursing practice activities that were directly provided to patients by 1) using the various methodology 2) based on the standards and professional ethics in the scope, authority, and responsibilities of nursing, 3) involving all life processes with a holistic approach and multidisciplinary and comprehensive handling. Palliative care encompasses pain management, psychological, and spiritual support for all patients (23).

To achieve the goals of cancer palliative care, which reduced patient suffering, family burdens, and improved life quality, there was a need for a team working in an integrated manner. This service team consists of doctors, nurses, social workers, psychologists, spiritual counselors, volunteers, pharmacists, other health workers, related personnel, and institutions (24). The related institutions that carried out this care were hospitals, *puskesmas*, hospice, and other health centers. The palliative care principle respected the dignity of patients and their families, and also supported the caregivers (23)

The palliative care for cancer patients also required the involvement of families and volunteers. With interdisciplinary principles (interdisciplinary coordinate in determining goals and objectives to be achieved and actions to be taken), the team periodically organizes discussions for assessments and diagnoses. And also created plans for cancer patients' palliative care, including monitoring and following up. The strong leadership and the overall program management ensured that, local managers and health service providers worked as multidisciplinary team in the health system, coordinating closely with community leaders and organizations in achieving common goals.

There were several key indicators that were consistent with the implementation of the palliative service model, as shown in the following Figure 2.

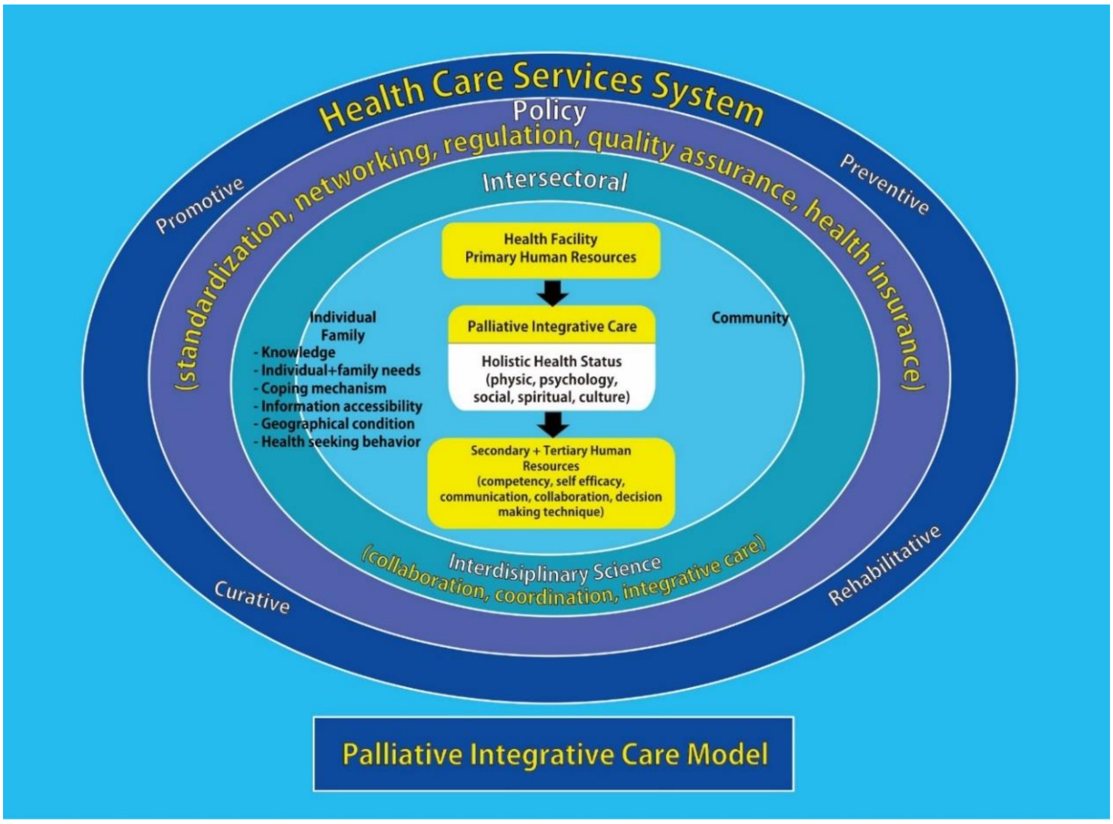

Figure 2. Integrated Palliative Care Model for Cancer Patients

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1) Health Care System: This included the facilities, resource competencies, financing (BPJS), program socialization in the community (outermost blue circle/first and second layer). Currently, the situation was not optimal, due to the decrease exposure of individual in the community.
2) In the palliative services, preventive, promotive, curative, and rehabilitative approaches were continuous (the first layer of the blue circle).
3) Intersectoral institutions and interdisciplinary sciences determined service collaboration. The service level started from the primary, the secondary, to the tertiary, or from the diagnosis stage, the case management phase, to the rehabilitation stage (third-tier circle).

The physical, psychological, social, cultural, and spiritual approach in improving life quality (inner circle/fourth layer) showed that the integrated health care services were the main focus. The integrated palliative services contained seven principles, namely 1) patient-centered. 2) Communication between patients, families, and health workers. 3) Comprehensive. 4) Interdisciplinary. 5) Continuity from diagnosis to mourning. 6) Involving the family 7) Regular assessment and treatment of patients. The service delivery was based on the fundamental ethical principles, moreover, there were many sectors serving as palliative service providers, namely 1) Hospitals. 2) Primary care services. 3) Public and non-governmental services in the form of hospice. 4) Palliative consultation. The duties of the service team included 1) identifying specific service goals, such as 2) psychological, social, spiritual evaluation, 3) understanding the treatment options, 4) managing the pains and other complaints, and 5) the transition from hospitals to primary care and homes.

The implementation of the model and its applications was carried out based on the policies, resources, facilities, family, and community participation. Besides the support given, humor therapy provided relief during the pandemic to improve patient's life quality, and stability in all aspects of holistic health, namely psychological, physical, social, and spiritual issues. It was provided through group sessions with patients and families, incorporating storytelling, jokes, and lighthearted multimedia to reduce stress and enhance emotional well-being. Healthcare providers also used empathetic and playful communication to foster positivity (25). This therapy complemented medical treatments by reducing emotional burdens and improving patient engagement. Furthermore, it was necessary to develop instruments and SOPs for the individual, family, community, organization, and policy levels.

Moreover, it was also necessary to proceed in the development of several aspects related to the palliative care, such as complementary therapy and therapeutic modalities for improving patient's life quality. The study conducted by Paterson and Zderad's (1976-2009) using a humanistic and holistic approach to care in hospice and palliative services, developed into a nursing model and culturally sensitive instruments in respect to Indonesia civilization (26). Training and education for healthcare workers should be prioritized to strengthen palliative care services, particularly in rural or underserved areas (27). These programs should focus on delivering culturally sensitive care, integrating complementary therapies, and improving communication with patients and families (28). By equipping healthcare providers with these essential skills, palliative care can be made more effective, holistic, and accessible, addressing the unique needs of diverse populations across Indonesia. However, this study has limitations because the sample may not fully represent the broader population of cancer patients across Indonesia, particularly those in rural or underserved areas, where access to palliative care services is more limited. This

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could affect the generalizability of the findings.

CONCLUSION

This study identified significant challenges in implementing palliative care services in Indonesia, including gaps in patient knowledge, limited interdisciplinary collaboration, and inadequate community engagement. The proposed community-based model addresses these issues by integrating holistic, patient-centered approaches into the existing healthcare system. Future efforts should focus on scaling this model, training healthcare workers, and ensuring sustainable funding mechanisms to optimize palliative care delivery nationwide.

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Conflict of Interest

The authors have no conflicts of interest to declare.

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