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## **NURSES' EXPERIENCE IN CARING FOR PALLIATIVE PATIENTS**

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### **ABSTRACT**

Reducing suffering is an important thing in health services when healing is impossible. Palliative care is a chronic and terminal disease, which often happens when palliative patients have a poor prognosis. Objective: This study aims to describe the experiences of nurses in providing nursing care to palliative patients at Tugu Rejo Regional Hospital, Semarang. Method: This research uses a qualitative research approach on 6 nurse respondents with in-depth interview method Results: the results of this research found 3 themes of palliative care experiences, namely problems that arise during palliative patient care, including physical, psychological, social and spiritual problems. The second theme is the implementation of palliative care including management of signs and symptoms, psychological, social and spiritual support, communication, education, cross-sectoral collaboration. The third theme is barriers to care, including those that come from the patient, family, social environment, and knowledge about health services. Conclusions Increasing the ability of nurses is needed to improve the quality of palliative patient care services. This capability is expected to be able to overcome barriers to care and realize the goals of palliative care.

Keywords: caring; nurse experience; palliative care

### **INTRODUCTION**

Reducing suffering is important in health services when healing is impossible. Palliative disease is a chronic and terminal disease, which often occurs when palliative patients have a poor prognosis. (Leuna, Cherley Fanesa Maria, 2018) explains that terminal disease patients cannot be cured with curative treatment, terminal treatment aims to reduce the signs and symptoms felt by the patient from the physical, social and psychological disease process. Explains several diseases that are included in palliative diseases, including cancer, degenerative diseases, chronic obstructive pulmonary disease, cystic fibrosis, stroke, Parkinson's, heart failure, genetic diseases and infectious diseases such as HIV/AIDS. (Indonesian Ministry of Health, 2023) shows that data on the increase in non-communicable chronic diseases has increased from 2013 to 2018, the number of cancer cases rose from 1.4% to 1.8%, strokes rose from 7% to 10.9%, chronic kidney disease rose from 2% to 3.8%, and diabetes mellitus rose from 6.9% to 8.5%. This description explains that the management of chronic and terminal diseases is important. As explained above, cancer is one of the palliative diseases that is often found in Indonesia. ((KPKN), 2019) explains that the incidence of cancer in Indonesia is the second highest after heart disease, namely 34.01% of all existing palliative diseases. (Prasetyo, 2020) explains that cancer sufferers often experience several problems, including the prognosis and factors related to the development of the disease process and its treatment. Several regional health services have currently developed many palliative services, one of which is Adiyatma Regional Hospital, MPH, Central Java Province.

Adiyatma Hospital, MPH Central Java Province is a Class B Educational Hospital belonging to the Central Java Provincial Government. Adiyatma Hospital Services, MPH, Central Java Province, Semarang, apart from having a number of polyclinics, HD, heart care rooms, radiology, clinical

pathology, anatomical pathology, psychology, obstetrics, orthopedic, trauma center and cancer referral units. Currently the cancer unit at the hospital has undergone development where the treatment unit now has a special clinic for cancer sufferers, chemotherapy services and classroom care for cancer patients. To support resource services, especially nurses in this unit are equipped with several training and experience in caring for cancer patients. This study aims to describe the experience of nurses in providing nursing care for palliative patients at Tugu Rejo Regional Hospital, Semarang.

## METHOD

This research is a qualitative research study of the phenomenology of nurses' experiences in caring for palliative patients in the Dahlia ward at Adiyatma Hospital, MPH, Central Java Province. The sample was selected using proportion sampling with the inclusion criteria of dahlia nurses who had 5 years of nursing experience. The research was conducted on 4 nurses. The data collection technique was carried out by means of in-depth triangulation interviews. Data collection tools during interviews are using a voice recorder, interview guide and field notes.

## RESULTS

This research was carried out in the Dahlia room on July 12 2024. From the research results, data on the characteristics of the four respondents were obtained, namely women with a working period of between 5-10 years. The highest level of education was a bachelor's degree in nursing, as many as 3 respondents.

Table 1.  
Respondent characteristics (n= 4)

Respondent characteristics	f	%
Length of work (5-10 years)	4	100
Gender	4	100
education		
D3	1	25%
S1	3	75%

The research results showed that there were 3 themes related to palliative care, including:

1. Problems that arise in palliative patients. Assessment of changes that occur related to prognosis, disease progression and treatment. The nurse explains several problems that arise in patients including physical, social, psychological and spiritual problems.

### Physical Problems

*"If it's a physical problem, it's the same, sis, if it's pain, we'll give anti-pain medication, if the patient needs suction, then we'll do it, so it's appropriate to the problem that arises in the patient, sis" R1*

*"Patients are different, if it is palliative, don't let there be pain, don't let the pain cause discomfort if the patient has an open wound in the breast" R2*

### Psychosocial Problems

*"..... first they have to be shocked, afraid, worried about what it will be like, sis, because they were diagnosed with a disease like that" R1*

*"So there are patients who come in and there's nothing wrong with psychological nausea, there are those who deal with the nausea for days and even when they go home for treatment the patient is still complaining of nausea; nauseous. "If you look at the condition, the complaint should no longer exist, so because of psychology, the complaint finally appeared" R4*

### Social problem

*"If a patient with breast cancer has an open wound and chemo and radiation treatment has no effect or*

*response, the physical complaint is that there is a feeling of imperfection that disturbs other people because of the smell of the wound" R2*

*"Yesterday there was a patient who died who couldn't go home because he didn't have the money." R4*

#### Spiritual Issues

*"Family support and the surrounding environment are needed by patients. "The best support system is the family so that patients are enthusiastic about seeking treatment" R3.*

Management or implementation of palliative care. The implementation of nursing includes several things including management of signs and symptoms, psychological, social and spiritual support, communication, education, cross-sectoral collaboration, care for the dying and bereavement.

#### Management of Signs and Symptoms

*"Same as Sis, if there's pain, we give anti-pain medication, if the patient needs suction, then we do it, so it suits the problem that arises in the patient, Sis" R1*

#### Psychological, Social and Spiritual Support

*"It's more psychosocial, ma'am, it's human, who wants an illness that can't be cured? At most, treatment is only symptomatic, not healing, so support from family and the surrounding environment is really needed by patients. ...the best support system is the family so that patients are enthusiastic about seeking treatment. ....we usually also involve clergy, ma'am, every Wednesday, but beforehand we give informed consent to the clergy's actions whether the patient wants to be visited by clergy or not." R3*

*"... Emotions are different from other patients, there are also those who are mentally and spiritually ready, the biggest influence in getting through difficulties is the family, the patient feels like he will die because of the illness he is experiencing. For example, patient a is more seriously ill but has good family support, so his condition is much better than patient b, who may not be as serious but lacks support." R2*

#### Communication & Education

*"Communication with patients and families requires more approaches and cannot be instant, it must be repeated several times." R3*

*"In communication, you can't speak in a high tone, it seems like if you speak high, the lady will be loud, so you have to be soft, slow, good to the patient or family" R4*

*".....we usually educate a healthy family...." R2*

#### Cross-Sectoral Collaboration

*"Information for health service or government facilities that can be used, for example great ambulances that can be used or private ambulances. We educate patients about government or village facilities such as village ambulances, we usually educate healthy families to look for information in the village, maybe there is transportation that can be borrowed ." R2*

*"We also informed them like the zakat house's ambulance, it could be used yesterday when a patient died who couldn't go home because there was no money, then we connected it to the zakat house and finally it was delivered." R4*

#### Dying and Bereavement Care

*"The biggest influence in going through difficulties is the family, who will die because of the illness they are experiencing." R2*

2. Barriers to Care. From the research results, it was found that barriers to care were not only obtained from the patient but also from the family, social environment, and lack of knowledge about health

facilities.

#### Patient

*"It's more traumatic, ma'am, sometimes I usually put in an IV once, but this can happen several times, low self-esteem, embarrassed because two sensitive parts were opened" R2*

*"More towards new patients because of denial, if they have been around for a long time they are usually more cooperative, if there is an action they make excuses so that the action is delayed" R3*

#### Family

*"There was a patient who was admitted to the hospital and wanted to have an IV installed even though he had not done anything but was already screaming in pain, so the family misunderstood and got angry at the nurse. "In fact, because the patient's condition is uncooperative and the family is not supportive, the patient was placed on an NGt and was suddenly released by the family, even though there had been informed consent beforehand." R4*

#### Socioeconomic Environment

*"When the patient has gone home, for example, when we have educated him, he can eat healthy food, vegetables, protein, meat for healing and the patient goes back to the hospital because his HB is low, but at home he only eats tofu and tempeh. Why, my neighbor said..."R2*

*"So, there is a patient who previously was fine, but had regular check-ups and didn't show up again for a long time, but after being traced, it got worse, one of the reasons is the economy." R2*

*"There are patients who died who couldn't go home because they didn't have the money." R4*

#### Lack of Knowledge Regarding the Use of Health Facilities

*"We usually educate healthy families to look for information in the village, maybe there is transportation that can be borrowed. Usually it's because I'm embarrassed why I'm sick and get picked up by an ambulance even though I can walk. "For example, if you use a village ambulance, you might not need to pay for car rental, just a driver and petrol." R2*

## DISCUSSION

There are 3 topics obtained by researchers including:

1. Problems that arise in palliative patients. Changes that occur are related to prognosis, disease progression and treatment. The nurse explains several problems that arise in patients including physical, social, psychological and spiritual problems. Assessment is an important aspect that a palliative nurse must have. (Sheng-Feng, 2020) explains in his article that the problems that arise in cancer tumor patients are identified through an assessment process using the Gordon approach which includes physical, social, psychological and spiritual assessments. The main problem found is chronic pain. Palliative nurses need to be sensitive to the problems experienced by palliative patients because the problems that arise from palliative patients are not only physical but also social, psychological and spiritual. (Sofia & Tahlil, 2018) explains the experience of cancer patients where it was found that problems arise from the development of cancer itself such as pain, lumps appearing, wounds, swelling. Complaints also arise from the effects of chemotherapy treatment such as nausea, vomiting, anorexia, hair loss, fatigue, bone marrow suppression such as anemia and decreased immunity. Psychological changes that arise include feelings of panic, fear and anxiety. (Leuna, Cherley Fanesa Maria, 2018) The needs of terminal patients are care that can help reduce suffering from the disease process physically, socially and psychologically . (Decree of the Minister of Health of the Republic of Indonesia, 2007) In the advanced stages, patients with chronic diseases not only experience various physical problems such as pain, shortness of breath, weight loss, activity disorders but also experience psychosocial and spiritual disorders that affect the quality of life of the

patient and his family. The explanation above provides an overview of the abilities possessed by nurses in assessing the needs of patients at an advanced stage including physical, psychological, social (environmental, family, education, knowledge, economic status) and spiritual aspects so that care management can be carried out comprehensively. The problems that occur include the patient's condition, and the surrounding environment, especially the family who provide care. (Stajduhar, 2018) long life care has an impact on the surrounding environment, especially the family. The research results show that families caring for terminal patients show symptoms of family burden, both physical, social and financial.

2. Management or implementation of palliative care. The implementation of nursing includes several things, including management of signs and symptoms, psychological, social and spiritual support, communication, education, cross-sectoral collaboration, care for the dying and bereavement. (Putranto, 2015) explains the principles of palliative care, including managing signs and symptoms, integrating psychological and spiritual aspects of patient care. offers a support system to help patients live as actively as possible until the end of their lives, using a team approach to address the needs of patients and families. (Tinggi et al., 2018) explains the description of palliative care management including nurse support for families in dealing with loss, as well as hope in palliative care (..... Indonesian Ministry of Health, 2016) The palliative team was formed to achieve the goals of the palliative program for cancer patients, namely reducing patient suffering, family burden, and achieving a better quality of life. The palliative team can consist of doctors, nurses, care givers, clergy, therapists, psychologists, volunteers. Appropriate palliative services do not just stop at one service center but are thorough and comprehensive. (Sahar & Wiarsih, 2006) identified the needs of palliative care givers, one of which is related to clear information regarding treatment, examination and treatment, and apart from that, families also need time to ask health workers to be given the information they need.
3. factors influencing Treatment. From the research results, it was found that barriers to care were not only obtained from the patient but also from the family, social environment, and lack of knowledge about health facilities. (Leuna, Cherley Fanesa Maria, 2018) explains that barriers to treatment can be obtained from patients and families where this condition occurs during the denial phase where the patient and family are in a state of rejection and do not accept their illness. Several behaviors emerge, including that families often make decisions when they are in an unstable condition so that the decisions taken often change. This certainly becomes an obstacle in the treatment process. (Fangidae & S, 2022) explains that sometimes nurses encounter where the social environment, especially cultural factors, beliefs and values held by patients sometimes conflict with the principles of care provided. (Sugiyanto, 2020) explains that economic factors and family knowledge in palliative patient care influence the success of treatment.

## CONCLUSION

The research results showed that there were 3 themes of palliative care experiences, namely problems that arise during palliative patient care, including physical, psychological, social and spiritual problems. The second theme is the implementation of palliative care including management of signs and symptoms, psychological, social and spiritual support, communication, education, cross-sectoral collaboration. The third theme is barriers to care, including those that come from the patient, family, social environment, and knowledge about health services. Increasing the ability of nurses is needed to improve the quality of palliative patient care services. The first ability is the ability to carry out assessments where the assessment ability must be holistic and comprehensive. The ability to manage palliative patients includes the ability to deal with positive signs and symptoms, the ability to provide social, psychological and spiritual support. Communication skills also need to be improved to increase

the relationship of mutual trust between patient nurses and families. Ability to develop networks and teamwork to improve services. This capability is expected to be able to overcome barriers to care and realize the goals of palliative care.

## ACKNOWLEDGMENTS

We would like to thank those who played a role in this research, especially the care respondents who provided information. Thank you to the directors of Adiyatma Hospital, MPH for providing the opportunity to carry out this research. Thank you to the Chancellor of Widya Husada University Semarang for the support provided so that this research could be carried out

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