

Experiences Of Cancer Patients With Palliative Care At The Reference Hospital In Medan City

Shandra¹, Setiawan², Rosina Tarigan²

¹Master Student, Faculty of Nursing, Universitas Sumatera Utara

^{2,3}Faculty of Nursing, Universitas Sumatera Utara

shandra2608@gmail.com

Abstract: *The increasing number of adult patients with advanced cancer emphasizes the importance of providing palliative care with standard oncology care. In Indonesia, the development of palliative care services is still slow and the availability of services is still limited. The complaints that often arise related to physical, psychological, social relations, self-concept, and spiritual aspects cannot be completely intervened with curative and this requires handling with an appropriate approach. The aim of study was to describe the experiences of cancer patients regarding their palliative care at hospital. The study used descriptive phenomenology following the approach of Giorgi. There were 15 participants who qualified using purposive sampling based on the inclusion criteria. The data were gathered using depth interviews. Analysis and interpretation used verbatim descriptions. The research data revealed six themes, namely: namely getting the fulfillment of minimal care needs, getting independent care education at home, having positive and negative attitudes in accepting sick conditions, getting motivation and family support in supporting recovery, feeling comfortable interacting with the palliative care team, and feel pessimistic about the palliative care services provided. The study revealed that the implementation of palliative care has not been optimal. Comprehensive care by an interdisciplinary palliative team is not yet holistic (bio-psycho-socio-spiritual) but still focuses on curative, thus it can be concluded that the fulfillment of palliative care needs is still minimal.*

Keywords: *Cancer patients, Palliative care, Life experiences*

1. INTRODUCTION

Cancer is the leading cause of death in the world, accounting for 8.2 million deaths from cancer in 2012. Data from the International Agency for Research on Cancer (IARC) Globocan in 2012 contained 14.1 million new cancer cases and 32.6 million people living with cancer (within 5 years of diagnosis) worldwide and 48% (15.6 million) of cancer cases generally occur in developing countries [1]. Based on Basic Health Research data [2], nationally the prevalence of cancer in the population of all ages in Indonesia in 2013 was 1.4 or an estimated 347,792 people with North Sumatera occupying the sixth position as the province with the most cancer cases in Indonesia.

The increasing number of adult patients who experienced advanced cancer emphasizes the importance of carrying out palliative care coincide with standard oncology care. One of the handling of terminal conditions in cases of patients with cancer is palliative care, which is an important part of the care of terminal patients carried out in an integrated manner [3]. In Indonesia, the development of palliative care services is still slow and the availability of services is still limited. This is because professionals have limited knowledge regarding palliative care, facilities and family/community support factors are not supportive, limited availability of oral opioids/morphine, concerns about the safety of opioid use at home, population size and geographic location are constraints regarding the number palliative care services available [4].

Furthermore, in Indonesia palliative care is a new thing. In Medan City in particular, palliative care was first introduced by Murni Teguh Hospital in 2015 as the first and only hospital to become a member of the palliative community in Medan, namely the Indonesian Palliative Society. The provision of palliative care in hospitals is still rare because it still focuses on curative, while complaints that often arise related to physical, psychological, social relations, self-concept, and spiritual aspects cannot be completely intervened with curative and this requires handling with an appropriate approach. However, the patient's initial perceptions of palliative care were related to death, hopelessness, dependence and to end-of-life care so that these perceptions triggered the patient's own fear and avoidance of palliative care.

2. METHODS

The study used a qualitative with a descriptive phenomenology approach [5]. The study was conducted from March 2019 - June 2019. Fifteen were samples who were undergoing palliative care at Murni Teguh Hospital for at least one month of treatment. Data were collected using structured interview techniques that have been tested for validity by experts, demographic data questionnaires, voice recording devices, and field notes. Data were analysed using content analysis with Giorgi approach. The content analysis process was done manually.

3. RESULTS

The majority of participants were women and married with a high school education background. Participants had various cancer diagnoses, namely lung cancer, rectum cancer, ovarian cancer, liver cancer, breast cancer, meningioma, gastric cancer, cervical cancer, vaginal cancer, and colon cancer with an average palliative treatment of one to two months. Based on the results of the study, six themes were obtained, namely getting the fulfillment of minimal care needs, getting independent care education at home, having positive and negative attitudes in accepting sick conditions, getting motivation and family support in supporting recovery, feeling comfortable interacting with the palliative care team, and feel pessimistic about the palliative care services provided. In its implementation, it was found that the implementation of palliative care was not optimal, where the care was still focused on curative and not comprehensive where the service was not touched by the whole palliative interdisciplinary team in a holistic (bio-psycho-socio-spiritual) manner.

In this case, participants stated that the needs they received during treatment were not optimal, only a few participants received independent education for home care, the participants' attitudes towards their illness were strongly influenced by the family support they received while negative things felt by the participants in response negative attitudes of pain conditions did not get much attention from palliative psychologist services, and although the participants admitted they felt comfortable interacting with the palliative team, some felt pessimistic about palliative care where participants felt palliative care was the same as regular patient care and considered palliative care as a final action waiting for death.

4. DISCUSSION

The results of interviews with 15 participants regarding the experiences of cancer patients with palliative care at referral hospitals has obtained six themes, namely:

a. Getting Fulfillment of Minimal Maintenance Needs

Palliative care obtained from the results of the study shows the fulfillment of minimal care, where there are still few participants who admit to getting it. According to Meghani [6], the total care that given to patients with palliative care is a total attention to patients who focuses on attention to physical, emotional, social and spiritual pain and suffering. Referring to this, the handling of needs that was explored from the participants was in the form of handling physical problems, handling psychological needs, spiritual needs and social needs. Based on the results of the study, the most frequently complained of handling physical problems was pain which was complained of by 14 participants. Handling pain complaints in palliative care in the form of continuous pain medication, additional pain medication doses, education on relaxation pain management techniques and massage. The various treatments carried out had an impact on the lack of pain complaints that were felt and this was expressed by 6 participants where pain complaints were reduced after being given treatment by the palliative team. Joint care with a psychologist is a holistic entity in palliative care as a comprehensive service. The results of this study found that three participants received joint care with a psychologist, where one of them received private psychiatric services from another hospital, while the other 12 participants did not receive visits or joint care with a psychologist. So it can be concluded that there is minimal interaction with a psychologist, so that a participant expresses the expectation of joint care with a psychologist.

The implementation of other needs in palliative care is spiritual needs. The results showed that there were only 7 participants who said that they were visited by spiritualist and received prayer guidance services from religious leaders, namely priests. All participants who get visits from clergy are only participants who are Christian, while participants who are Muslim have never received a visit from the spiritualist. According to Puchalski [7], spiritual support for cancer patients is important and affects the strength and motivation of participants in undergoing treatment, where cancer patients with a low spiritual level tend to be more depressive than cancer patients whose spiritual needs are met. What is needed in other total care is social needs. Where 11 participants said they enjoyed being visited by friends, neighbors and relatives. According to Tel [8] in his research, he stated that the social support obtained by cancer patients can prevent and treat depression they experience and have a positive effect on emotional adjustment for patients in accepting their condition.

b. Getting Care Education Independently at Home

Health education is one of the things that participants need for their continued care information at home, considering that palliative care is a continuous care where patients receive symptomatic and supportive care from beginning to end [9]. Therefore, patient empowerment is needed as part of health promotion for patients and their families to be independent. In the study results, 14 participants said they received health education related to their continued care. The nurse explains various kinds of education to participants and families based on the conditions of the participants. The education obtained was in the form of how to care for yourself at home such as cleaning colostomy bags, how to feed through the Naso Gastric Tube (NGT), health education related to range of motion, activities to tilt left and right tilt in bed, teaching participants to be independent, mobilization, pain management techniques, education of secretions and so on.

The information obtained by the participants was not only related to disease diagnosis and treatment at home, but also supported by health education by the nutritionists. Based on the results of the study, there were 11 participants who said that they received education regarding dietary arrangements at home and dietary restrictions and foods recommended for patients to consume. Based on the results of research conducted by [10] on seven nutritionists who treat cancer patients with palliative care, it is known that the role of nutritionists in palliative care in addition to nutritional assessment and development of nutritional care plans, must also be able to support the patient and family psychology and provide education for patient. In addition to health education provided as independent follow-up care at home, participants also need information regarding what to do in the event of an emergency at home. Based on the results of the study, there were only 7 participants who said that they received education from the palliative team regarding what to do in the event of an emergency at home, while the other 8 said they had their own initiative to decide what to do in the event of an emergency. According to Mierendorf [11], the main thing in emergency care for palliative patients is the need to find out why the patient is in an emergency condition and it is necessary to do a quick assessment of their palliative care needs, where doctors must be able to immediately make an assessment and make interventions that aim to prevent unwanted things and reduce unnecessary suffering.

c. Having a Positive and Negative Attitude in Accepting Sick Conditions

The results showed that related to the participants' attitudes towards pain, there were 12 participants who expressed positive coping as a participant's response to their illness, several things that were felt, namely the participants were sincere with their illness, were not afraid of pain, patience, enthusiasm to face the pain and believe that sickness and healing are from God. In addition to expressing positive responses, 11 participants also expressed negative responses to their sick conditions, such as feelings of anxiety, resignation, fear of pain, crying if they remember their sickness condition, stress, feeling tired with their illness, sadness, hopelessness, difficulty accepting sick conditions, annoyed with their sick conditions until they resigned themselves to facing death. The results of research conducted by Aydogan [12] on 74 cancer patients, found that the cancer treatment process is traumatic for the patient and tends to cause negative coping for the patient, and it is hoped that the health professionals will play their role in minimizing the effects of negativity by using various coping methods.

d. Get Motivation and Family Support in Supporting Healing

Palliative care provides an opportunity for the patient's family to help reconcile conflicts felt by patients, relationships with others, and provide professional support such as counseling, resilient care, financial assistance to the stage of bereavement support [6]. Based on the results of the research conducted, the family involvement experienced by the participants is related to the role of the family for the participants and the support provided by the family for the participants. The role of the family was expressed by the 14 participants where the family strived for the participants' healing, caring for the participants, as a source of motivation, and helping to care for participants during illness. The support provided by the family is in the form of motivation to recover and the family always tries everything that they can for the healing of the participants.

According to Tel [8], in the care of patients with cancer, support is needed both to patients and their families and the care of cancer patients requires a family-centered approach. This is because family is a source of support that must be used effectively by patients to prevent depression. The results of this study found that family support was almost dominantly felt by all study participants, but there was 1 participant who felt they did not get maximum family support, where the participants revealed that the participants were capable without the need for family support.

e. Feel Comfortable Interacting with the Palliative Team

The research results obtained related to the convenience of interacting with doctors and nurses, there were 8 participants who stated that they were comfortable communicating with the palliative team, were happy with the fast response, received detailed explanations related to their disease, got good two-way communication so that the participants did not feel reluctant to ask many related questions of the disease and how to treat it. According to Diefenbach [13] in care services for cancer patients, interventions in communication with cancer patients are needed for the purpose of improving cancer care. According to Allgood [14], one of the needs that patients want to be achieved in palliative care is related to patients being free from the experience of pain, a comfortable feeling, a feeling of peace free from anxiety, a good relationship with others, and a feeling of dignity and respect. Feelings of dignity and respect can be seen from the involvement of participants in making treatment decisions. Based on the results of the study, there were 8 participants who said that they have received an explanation of the treatment by doctors and were involved in making decisions. Based on these results, it can be concluded that the involvement of participants in the explanation of medical actions and decision-making by doctors or nurses can provide a sense of comfort for participants and create a sense of confidence in all actions that will be taken by the doctor or nurse.

f. Feeling Pessimistic about the Provided Palliative Care Services

Based on the results of the study, 10 participants said that they did not get physiotherapy services where 3 of them did not get service due to unfavorable conditions, but it was known that very few participants received services from physiotherapy considering that the participants' conditions, especially in terms of mobilization really needed the services of a

therapist. According to Eyigor [15] physiotherapy and rehabilitation services are urgently needed by patients with cancer, but these are often neglected by the health professionals. In this study, there were also 5 participants who stated that they did not get health education related to diet management from nutritionists. Based on the research findings, the comprehensive service from the interdisciplinary team needs to be maximally improved so that patients with cancer can receive holistic services according to their needs.

Another thing that was found in this study was related to participants who were pessimistic about palliative care, where there were two participants who expressed their disappointment with palliative care, namely participants felt that palliative care was the same as regular patient care in general and participants considered palliative care as the final act of waiting for death. In a cancer patient, it is often not death to be feared but rather the process leading to death. Patient care must touch all dimensions of life holistically, because each dimension will always interact mutually. The existing physical and psychological complaints are often interrelated and have a negative effect on the quality of life and have an important role on the welfare of patients with advanced cancer [16]. Palliative care provides benefits especially for patients with chronic diseases, in this case is cancer. This is in line with the research by Gomes [17] which states that palliative care provides benefits or advantages for patients in terms of reducing symptoms experienced by cancer patients compared to providing usual care to patients. Increasing the quality of life of cancer patients is an indicator of the success of palliative care.

The goal of palliative care is to improve the quality of life for patients and their families [18]. Sanjo [19] states that families who have family members who do palliative care have exposure to health care as a good thing by using family members who are unable to do palliative care, but the two different groups are the same as palliative care which is considered to be leading to death. This shows that palliative care in Indonesia itself is still limited. The barriers identified to providing palliative care are limited understanding of palliative care among the health care professionals, Indonesia's challenging geography, and limited access to opioid drugs [20]. However, palliative care is the recommended treatment for now where palliative care provides benefits for cancer patients in improving their quality of life, whereas palliative care aims to reduce the pain symptoms felt by cancer patients. The improvement in the quality of life felt by cancer sufferers, one of which is a reduction in symptoms such as pain, nausea, and fatigue and an improvement in physical and psychological functions [21]. The use of palliative care has also been reported to improve patient functioning in a holistic manner. Taylor [22] found that each palliative care visit during the first month of follow-up has improved the patient function.

5. CONCLUSIONS

The implementation of palliative care has not been optimal. Comprehensive care by an interdisciplinary palliative team is not yet holistic (bio-psycho-socio-spiritual) but still focuses on curative, thus it can be concluded that the fulfillment of palliative care needs is still minimal. In the results of the study, it was found that only a few participants received an explanation of self-care at home, while the other participants performed self-care based on their own initiative. The family support felt by the participants was so strong that it became a

motivation that influenced the participants' attitude towards illness. Participants also felt comfortable and happy to interact with the palliative team because doctors and nurses were quick to respond to complaints. Some participants feel pessimistic about palliative care services, participants consider palliative care as a final service waiting for death and the same as normal services.

Based on the results of the study, it was also found that the main support felt by the participants was a strong family support, which motivated the participants. This affects the attitude of the participants in accepting their sick condition, both positively and negatively. Regarding interactions with the palliative team, participants said that they felt comfortable and happy to interact with the palliative team where participants felt that doctors and nurses are quickly responded to the complaints that felt by the participants. However, regarding the palliative care services provided, some participants feel pessimistic about pessimistic services where participants feel that palliative care is the same as normal patient care in general and participants considered palliative care as a final service waiting for death.

6. REFERENCES

- [1] F. Ferlay. Cancer Incidence and Mortality Worldwide: Sources, Methods and Major Patterns in Globocan 2012. *International Journal Cancer*. (5). pp.359-86. 2015.
- [2] Kementerian Kesehatan RI. *Buletin Jendela Data dan Informasi Kesehatan: Situasi Penyakit Kanker*. 2015.
- [3] M. L. Campbell. *Nurse to Nurse: Palliative Care*. United States of America: The McGraw-Hill Companies. 2009.
- [4] E. Rochmawati, R. Wiechula and K. Cameron. Current Status of Palliative Care Services in Indonesia: A Literature Review. *Journal of International Council of Nurses*. 63(2). pp. 180-90. 2016.
- [5] H. J. Streubert and D. R. Carpenter. *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: Lippincott Williams & Wilkins. 2011.
- [6] S. H. Meghani. A Concept Analysis of Palliative Care in The United States. *Journal of Advanced Nursing*, 46 (2). pp.152-161. 2004.
- [7] C. Puchalski, B. Ferrell, R. Virani, S. Otis-Green, P. Baird, H. Chochinov. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of Palliative Medicine* 12(10). pp.1-24. 2009.
- [8] H. Tel, A. Sari and H. T. Aydin. Social Support and Depression Among the Cancer Patients. *Global Journal of Medical Research Interdisciplinary*, 13(93). pp.1-5. 2013.
- [9] I. Rasjidi. *Perawatan Paliatif Supportif dan Bebas Nyeri pada Kanker*. Jakarta: Sagung Seto. 2010.
- [10] I. F. Pinto, J. L. Pereira, C. J. Campos and J. L. Thompson. The Dietitians Role in Palliative Care: A Qualitative Study Exploring the Scope and Emerging Competencies for Dietitians in Palliative Care. *Journal of Palliative Care and Medicine*. 6(2). pp.1-8. 2016.
- [11] S. M. Mierendorf. Palliative Care in The Emergency Department. *The Permanente Journal*. 18(2). pp.77-85. 2104.

- [12] U. Aydogan, Y. C. Doganer, S. Komurcu, B. Ozturk, A. Ozet and K. Saglam. Coping Attitudes of Cancer Patients and Their Caregivers and Quality of Life of Caregivers. *Indian Journal of Palliative Care*, 2(2). pp.150-156. 20016.
- [13] M. Diefenbach, G. Turner, K. M. Carpenter, L. K. Sheldon, K. M. Mustian, M. A. Gerend. Cancer and Patient-Physician Communication. *Journal of Health Communication*, 14(1). pp.57-65. 2009.
- [14] M. R. Alligood. *Nursing Theorist and Their Works*. United States of America: Elsevier. 2018.
- [15] S. Eyigor and S. Akdeniz. Is Exercise Ignored in Palliative Cancer Patients?. *World Journal of Clinical Oncology*, 5(3). pp.554-559. 2014.
- [16] Kementerian Kesehatan RI. *Petunjuk Teknis Paliatif Kanker pada Dewasa*. 2017.
- [17] B. Gomes, N. Calanzani, V. Curiale, P. McCrone and J. I. Higginson. Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults with Advanced Illness and Their Caregivers. *Sao Paulo Medical Journal*. 2013.
- [18] C. L. Munro and R. H. Savel. Aggressive Care and Palliative Care. *American Journal of Critical Care*, 27(2). pp.84-86. 2018.
- [19] M. Sanjo, M. Miyashita, T. Morita, K. Hirai, M. Kawa, T. Ashiya. Perceptions of specialized inpatient palliative care: a population-based survey in Japan. *Journal of Pain and Symptom Management*, 35(3). pp.275-82. 2018.
- [20] E. Rochmawati, R. Wiechula and K. Cameron. Current Status of Palliative Care Services in Indonesia: A Literature Review. *Journal of International Council of Nurses*, 63(2). pp.180-90.2018.
- [21] A.P. Kassianos, M. Loannou, M. Koutsantoni and H. Charalambous. The Impact of Specialized Palliative Care on Cancer Patients' Health-Related Quality of Life: A Systematic Review and Meta-Analysis. *Support Care Cancer Journal*, 26(1). pp. 61-79. 2017.
- [22] D. H. Taylor. The effect of palliative care on patient functioning. *Journal of Palliative Medicine*, 16(10). pp.1227-1231. 2013.