

Families Experience and Deal With Palliative Care Provided To Their Family Members

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Abstract. *This study aims to explore the experiences of families who have members undergoing palliative care. Using a phenomenological approach, we conducted in-depth interviews with six families involved in home palliative care. Data were analyzed using Colaizzi analysis to identify the main themes that emerged from the family's experiences. The study results show that families' experiences with palliative care patients are complex and emotionally charged. The main themes that emerged included: 1) Family emotional feelings, 2) Family obstacles in facing the treatment process and 3) Family support. This study provides in-depth insight into families' experiences with palliative care patients, highlighting the complexities, challenges, and needs involved in caring for an ill family member. Clinical implications of these findings include the importance of supporting families with appropriate resources and services, improving family communication and engagement in care, and recognizing the importance of emotional and social support in strengthening family well-being throughout the palliative care journey.*

Keywords: *Experience, Family, Palliative Care.*

1. INTRODUCTION

Palliative care is a holistic approach aimed at improving the quality of life for patients facing life-threatening illnesses, as well as their families. This involves early identification, thorough assessment, and treatment of physical, psychosocial, and spiritual problems that may arise as a result of the disease (WHO, 2020). Every year it is estimated that 40 million people worldwide need palliative care services, but 86% of them have not received palliative care services. In 2015, The Economist Intelligence Unit (EIU) stated that Indonesia's Quality of Death Index was ranked 53rd in the world for palliative care services.

Palliative care can be provided to individuals suffering from a variety of life-threatening illnesses, such as: 1) Cancer: Palliative care is often provided to cancer patients who have reached an advanced stage or are not responding to curative treatments. 2) Heart disease: Patients with heart failure, coronary heart disease, or other heart diseases that have a poor prognosis may also benefit from palliative care. 3) Lung disease: Including chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, or lung cancer, where palliative care can help manage symptoms and improve quality of life. 4) Neurological diseases: Such as Alzheimer's disease, Parkinson's, or multiple sclerosis, where palliative care can help manage the associated physical and psychosocial symptoms. 5) Liver disease: Including liver cirrhosis or liver cancer, where palliative care can help manage the complications and

symptoms that arise. 6) Other chronic illnesses: Such as chronic kidney failure, liver failure, or AIDS, where palliative care can help patients and families deal with the problems that arise as the disease progresses.

Palliative care is not only for adult patients, but can also be provided to children suffering from serious or life-threatening illnesses. The palliative care approach is designed to tailor care to individual needs and provide comprehensive support to patients and their families. This research aims to understand in depth and holistically how families experience and deal with palliative care provided to their family members who are facing life-threatening illnesses.

2. THEORETICAL STUDY

One important aspect of palliative care is reducing uncontrolled pain that has a negative impact on the patient's quality of life. Additionally, family support plays a very important role in palliative care. Strong, positively involved families can provide emotional, physical, and practical support to patients, helping them better cope with their illness. Family support can help patients feel supported, appreciated, and loved, which can have a positive impact on their psychological and emotional well-being (Tarigan, 2020).

Families do play an important role in providing motivation to patients, especially in the context of palliative care. Palliative care places a focus on the comfort and quality of life of patients suffering from serious or terminal illnesses. In many cases, the family is the main pillar in providing physical, emotional and spiritual support to their patients (Mallon et al., 2021). Palliative care is also known for its holistic approach to patients, which means recognizing their physical, psychological, social, and spiritual needs. Families often have a deep understanding of these needs and can provide invaluable support.

Good collaboration between families, patients, health workers, and palliative cadres is very important to ensure optimal care for patients who need palliative care, regardless of where the care is provided, be it in a tertiary health center, community center, or at home (Macrae et al, 2020).

3. RESEARCH METHODS

The method in this research is a qualitative research design with a phenomenological approach model with data collection techniques in depth interviews with six participants. Purposive sampling data collection method. The data analysis technique uses Colaizzi

analysis. This research was conducted in February 2024. Participants were families who had family members undergoing palliative care who were undergoing outpatient treatment with an age range of 35-60 years and the patient's treatment period was 1 to 10 years and lived in the North Sumatra region.

4. RESULTS AND DISCUSSIONS

Participant characteristics include 2 male participants and 4 female participants. The research results explored the experiences of families undergoing palliative care with the following 3 themes: Family emotional feelings, family obstacles in facing the treatment process and family support.

1. Family Emotional Feelings

Theme 1 shows emotional feelings that participants feel sad seeing their family experiencing palliative illness and feel afraid of losing their family members. It's a pity because you have to limit your food, limit your use of ingredients and are tired of dealing with your mood.

“Maybe it's a little sad and we accept it anyway. What is it called, the disease that our family has suffered from. Feelings of fear, so humans must have a fear of losing someone”

“It's really sad and pitiful because eating must be limited, the use of ingredients must be limited”

“I feel tired more than dealing with the mood”

Families of palliative patients also need support in dealing with intensive and often emotionally challenging care. Support from the health care team in the form of education, training, and family counseling can help families cope with stress and strengthen their caring abilities. However, palliative patient care is often time and effort intensive, and can cause great stress and emotional burden for the family. Therefore, support from the health care team is essential to help families overcome these challenges. Here are some ways in which support from the health care team can help families of palliative care patients: Education about Care, Care Skills Training, Emotional and Psychological Support, Arrangement of Additional Support, Care Coordination.

Holistic and coordinated support to families of palliative patients, health care teams can help families feel supported, helped and better able to care for their patients at home. This not only improves the quality of care for patients, but also helps maintain the well-being and

emotional stability of families during this difficult time. Knowledge of palliative care is essential for caregivers caring for patients with cancer. Palliative care not only aims to relieve physical symptoms that the patient may experience, but also to provide emotional support to the patient and his family (Hendricks, et.al, 2019).

2. Family obstacles in facing the treatment process

Theme 2 obstacles in facing the treatment process. Patients and families have obstacles in the treatment or care process, both internal and external.

“Our obstacle, lack of funds to go to a better hospital to cure the disease may be such an obstacle”

“The obstacles are like the vehicle and the hospital being far away, so that's a pity”

“Once my mother suddenly fainted, she was immediately taken to the hospital but she didn't want to be given treatment and was tired of taking medicine”

Economic barriers can be a significant challenge for families navigating the treatment process, especially when dealing with serious medical conditions. The results of a study in Singapore regarding the benefits of health services in hospitals decreased because patients chose to receive palliative care at home. Palliative care at home has a positive impact, especially for patients who face financial constraints in terms of medical costs (Zhuang, Q., et.al. 2022).

Practical obstacles that patients and families can face in home-based palliative care, especially if they live far from a hospital or have limited access to transportation. To overcome these obstacles, it is important for patients and their families to seek out available resources and supports. This may include support programs in hospitals or in the local community, medical transportation services, or financial assistance for transportation costs. In some cases, hospitals or healthcare providers may also offer home-based palliative care services or remote support to help overcome accessibility and mobility barriers.

Patients refuse to undergo palliative care or treatment, this can be a complex and challenging situation. According to Xu et al., (2021), Patient knowledge or attitudes as well as lack of patient-provider interaction time, lack of coordination across multilevel health systems, lack of affordability due to high overall costs, and inadequate insurance policies can all contribute to difficulties in patient care and adherence to treatment, including palliative care.

Striving for patient compliance with treatment recommendations is a serious challenge, but building a strong partnership between patients, families, and healthcare professionals can help overcome this without coercing or intimidating patients.

3. Family support

Theme 3 family support, patients in palliative care or treatment really need support to provide motivation to improve the patient's quality of life.

“Take care as best as possible, provide love and family support”

“Maintain a diet that can cause symptoms or severity of disease, stay enthusiastic, don't forget to seek treatment, I always say that to parents”

Family support is attitude, action and acceptance family towards sick family members. Attention from the family is very helpful in choosing the health of the family. Family support plays a very important role in palliative care or treatment. Palliative care focuses on improving the quality of life of patients facing serious or terminal illnesses, taking into account their physical, emotional, social, and spiritual comfort. In this context, support from the family can provide great benefits for the patient.

Palliative care requires the role of the patient's environment, including family, friends, and society, in providing psychological, social, and spiritual support to cancer patients. The support provided by the patient's environment can help patients to accept their current condition better, and utilize the remaining time to live more meaningfully and productively, (Hasrima, dkk. 2022).

The family is often considered the most comfortable place for patients experiencing chronic illnesses such as cancer. Family members play a very important role in providing palliative care to patients, and emotional and spiritual support is an integral part of their role (Siregar, C.T., dkk. 2020).

Support from the patient's family and environment can have a significant impact in increasing patient compliance in carrying out control and treatment, encouraging hope, and reducing the psychological burden experienced by patients (Yaner, N.R., dkk. 2019). Support from family can provide great benefits for sufferers in dealing with the problems they face, feeling loved, and being able to share emotional burdens.

5. CONCLUSIONS AND SUGGESTIONS

Each family has a unique experience with palliative care, and it is important to listen to and understand the individual needs and experiences of each family involved. By providing appropriate and adequate support, healthcare providers and advocates can help families overcome challenges and find ways to support each other throughout the palliative care journey.

Through support, open communication, maintaining personal health, increasing knowledge about the disease and its treatment, spending time together and proper planning, families can help each other overcome challenges and navigate the palliative care journey better. Further research can provide deeper and more comprehensive insight into various aspects that influence family experiences during the palliative care process, such as aspects of the influence of cultural factors. The limitations of family experience research are that it is subjective and can be influenced by many individual and contextual factors. This means that the results of the study may not be fully applicable generally and may vary between families.

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