



Palliative care: “It is OK to be not OK”

Christina Yeni Kustanti^{1,2*}

Naoko Nobe³

¹ Study Program of Nursing Science, Sekolah Tinggi Ilmu Kesehatan Bethesda Yakkum, Yogyakarta, Indonesia

² Lotus Care, Private Clinic for Wound & Palliative Care, Homecare, Yogyakarta, Indonesia

³ South Australia Medical Imaging, Royal Adelaide Hospital, Australia

***Correspondence:**

Christina Yeni Kustanti
Study Program of Nursing Science,
Sekolah Tinggi Ilmu Kesehatan
Bethesda Yakkum, Yogyakarta,
Indonesia.

Email: yeni@stikesbethesda.ac.id

ABSTRACT

Palliative care is in demand as more people are diagnosed with life-threatening illnesses. Palliative care provides primary, end-of-life, and bereavement care, considering the diversity of patients' cultural backgrounds. Various strategies have been developed and investigated to improve care access for the targeted populations. Additionally, palliative care is intended to help patients live well till death. While death is inevitable, it is nonetheless essential to life. However, some people still struggle to discuss their life-threatening conditions and accept receiving the appropriate palliative care. Notwithstanding the multitude of palliative care guidelines, the public's limited understanding or misconceptions concerning palliative care pose a significant obstacle for healthcare workers in delivering effective palliative care services. Therefore, it is critical to continue advocating for palliative care services, as each and every person deserves to experience a quality of life until their final moments. While being diagnosed with a life-threatening illness may be an unpleasant experience, it is acceptable to discuss it to allow others, including healthcare workers, the chance to offer appropriate support.

Keywords: palliative care; quality of life; healthcare workers

The incidence of life-threatening diseases is increasing with time. An estimated 56.8 million individuals require palliative care, with 25.7 million in their final year (WHO, 2020). While palliative care is widely recognized, some individuals remain reticent when confronted with a life-threatening illness, abstain from utilizing palliative care services, or only do so during the terminal phase of their condition (Hawley, 2017). Challenges, barriers, or concerns might keep those people at a distance from assistance attended by palliative care specialists. Dame Cicely Saunders, a palliative care initiative, emphasizes that acknowledging a life-threatening medical condition is a truth that must be faced (Richmond, 2005). It is not a simple topic for patients and their caregivers to discuss life-threatening illnesses such as cancer, *Human Immunodeficiency Virus* (HIV), or renal failure. Being diagnosed with a life-threatening illness is an undeniable truth that must be encountered. The emotional or psychological status of patients with life-threatening illnesses is very complicated and changing over time.

Imagine Dragons, a music band from the United States of America, composed the song “It's OK” (Hollen, 2023). The

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initial lyrics are, “*She could always hear every word they say. Everybody walks like they just know the way. Every single day, holding back the tears*”. This song explores the common sentiment of being inundated and overburdened by the difficulties and obstacles encountered in life (Hollen, 2023). “*It’s OK*” lyrics show empathy and a reminder that feeling uneasy is normal. Imagine Dragons intended to establish a safe zone where listeners may find comfort knowing they are not alone in their challenges (Hollen, 2023). Yet, many chronic illness patients report communication challenges with healthy people (Hayden, 1993). When a person is diagnosed with a life-threatening illness, many family members and associates will offer words of encouragement, such as “*Everything will be fine*” or “*You will be alright*”. Those comments are to express benevolent intentions; nevertheless, individuals afflicted with the condition may experience a sense of detachment, perceiving a lack of empathy or understanding from other; that, “*They are not wearing my shoes*”. It indicates that individuals can say this with relative ease, given that they have not been in the patients’ position of receiving a life-threatening illness diagnosis. Indeed, it is critical to recognize that embracing vulnerability and seeking assistance is equally essential amidst the challenges one faces.

The researchers call these communication issues “*miscommunication*” caused by the chronically ill’s word-meaning alterations (Hayden, 1993). The other possible barriers are a stigma on people with life-threatening illnesses, such as in the case of *Acquired Immuno-Deficiency Syndrome* (AIDS) and a wrong understanding of palliative care negatively associated with dying and death (Etkind et al., 2017; Venable et al., 2006). Some patients and their relatives might have difficulty seeking or being referred to an appropriate palliative care specialist team because their communities lack clear and informative guidance (McMaughan et al., 2020). It is crucial to resolve those issues above by spreading and promoting the appropriate notion and benefits of palliative care to the public so people with life-threatening conditions can access palliative care and discuss their own disease without hesitation.

The primary goal of palliative care interventions is to avoid and reduce suffering through early identification, accurate assessment, pain control, and other psychological, social, or spiritual issues (WHO,

2020). Palliative care emphasizes improving the quality of life of adults and children with life-threatening illnesses and their families rather than cure. Palliative care can be beneficial for many patients with incurable conditions causing suffering. The World Health Organization (WHO) reports that palliative care patients mostly have chronic conditions such as cardiovascular disease, cancer, chronic respiratory disease, AIDS, and diabetes. Other illnesses necessitating palliative care include kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological disease, dementia, congenital disabilities, and drug-resistant tuberculosis (WHO, 2020).

Primary palliative care, end-of-life care, and bereavement support are essential to person-centered palliative care. Primary palliative care is implemented in the initial stage of a life-threatening illness. When active interventions are no longer effective, and the individual faces the end of their life, end-of-life care is introduced. While the concepts of primary palliative care and end-of-life are well-understood by most people, bereavement care is unfamiliar (Kustanti et al., 2023). The termination of the relationship between the healthcare facility and the relatives of patients appears to occur upon the demise of the patient. Grief disorders represent an additional category of psychological conditions that require careful consideration (Djelantik et al., 2020; Kustanti et al., 2022; C. Y. Kustanti et al., 2022; Kustanti et al., 2023; Lunderoff et al., 2017). Bereavement care focuses on managing grief for the person with the disease and their family members, both before (anticipatory grief) and after (after-loss grief) the death (Kustanti et al., 2021).

Since improving quality of life is the fundamental goal of palliative care, primary palliative care, end-of-life care, and bereavement support all concentrate on methods to lessen physical, psychological, social, and spiritual distress experienced by the patients and their caregivers. The care management for patients’ symptoms precedes the initial stages of palliative and end-of-life care. Pain is the most common symptom experienced by those with the disease. All possible interventions should be provided to alleviate pain (Givler et al., 2020). Multi-disciplinary teams can combine medication administration, nursing care, and psychological interventions to enhance the individual’s quality of life.

A fundamental component of end-of-life palliative care is to assist patients and their caregivers with a comprehensive understanding of the nature of illness and prognosis; implementing a palliative care approach includes effective communication for a different emotional status of the individual (Rome et al., 2011). In the area of bereavement care, psychosocial interventions are utilized most frequently. Various interventions to manage grief symptoms, such as cognitive behavior therapy, bereavement support, and grief counseling, have been investigated and implemented in practice (Kustanti et al., 2021). Terminal illnesses often cause the patients to have communication difficulties, so their relatives need precise and supportive information to make decisions on behalf of their loved ones. Honest and timely communication allows patients, their caregivers, and relatives to have time to say goodbye, improving psychological outcomes and experiences of end-of-life care, which could make them feel satisfied with their lives (Anderson et al., 2019).

Many individuals have been diagnosed with a life-threatening illness, and there is an increasing demand for palliative care services. Healthcare workers often encounter the formidable task of effectively managing the symptoms associated with a life-threatening illness by implementing the three distinct domains: primary palliative care, end-of-life care, and bereavement care. Numerous palliative care strategies have been formulated and examined to enhance the accessibility and availability of palliative care services. Dame Cicely Saunders, stated, “*You matter because you are you, and you matter to the last moment of your life. We will do all that we can to help you die peacefully and live until you die*” (Richmond, 2005). The primary focus of her statement is that acknowledging a potentially fatal medical condition is an undeniable truth that must be encountered. Healthcare workers are responsible for understanding and respecting each ethnic and cultural diversity to aid chronic, life-threatening conditions sufferers.

Providing palliative care by healthcare professionals aims to support individuals in maintaining a satisfactory quality of life till the end of their lives. There is still room for improvement in palliative care, such as disease management strategies for less focused chronic conditions (Holman, 2020). Consistently advocating for palliative care services within the community will reassure individuals

afflicted with life-threatening illnesses that they are not solitary in their struggle against the illness. It is acceptable to feel unwell, given that the individual may encounter physical, psychological, social, and spiritual challenges due to the disease’s effects. Nevertheless, it is imperative that they recognise the issues, communicate their emotions or experiences, and pursue suitable healthcare attention. Presently, palliative care is included in the scope of healthcare services, which also includes preventative, curative, therapeutic, and promotional measures. Palliative care should, therefore, be encouraged at every chance, as doing so will instill optimism that although being diagnosed with a life-threatening illness may be an advanced stage of the disease, it continues to be a vital component of the present. Individuals experiencing despair will receive guidance, support, and care through palliative care services.

Declaration of Interest

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None

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