

Palliative Care: an Interdisciplinary Approach for Patients with Life Threatening Illness

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Patients with life threatening illness are characterized by multi-aspect of suffering. These various aspects of suffering are interrelated and require a total comprehensive care by an interdisciplinary team. Palliative care means to address the total suffering of the patients and to maintain a rational hope when cure is absurd. Palliative care emphasizes the essential role of the family. Although the awareness about palliative care has been increasing, its development in Indonesia is still left behind compared to that of other Asian Countries. This paper discusses the definition of palliative care, total suffering, interdisciplinary approach, integration of palliative care in cancer management & barriers to Palliative Care.

Introduction

Life threatening illness such as cancer or AIDS is distinguished by multi aspect of suffering include physical, psychological, social and spiritual distresses. Although advances in cancer and AIDS research may ultimately result in universally applicable curative treatment, for many years to come most patients with cancer and AIDS will encounter total suffering and ultimately will die of their disease.² These various aspects of suffering are interrelated which means that failing to address distress relating to one aspect may cause or exacerbate other aspects of suffering. Therefore, treatment of any one suffering has to take into consideration of the consequences that suffering of each of other aspects may have. It is well documented that impossible for any one individual or profession to understand the patient's complex experience of the illness and to be able to provide an adequate care. Palliative Care is an interdisciplinary approach to perform a total comprehensive care for patients with life threatening illness. Maintaining a rational hope when cure is impossible and never saying nothing more can be done to maximize quality of remaining life is the core value of palliative care.

Definition of Palliative Care

Palliative Care has been defined by the World Health Organization (WHO), in 2002 as an approach that improves the quality of the patients and their

families facing the problems associated with life threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The determination focuses on the quality of whatever life remains for the patient (and eventually quality of death). It is human-oriented not disease-oriented, and not primarily concerned with either producing long term disease remission or life prolongation (or with life shortening). Palliative care anticipates problems that might arise and minimize the impact of the progressing illness so that maximum function and comfort can be achieved within the limit of their illness. It is a holistic approach by an interdisciplinary team, aims to address all the patient's suffering from various aspects of human life. The mission of palliative care is for any disease; however advanced it is, no matter what treatments have already been given, there is always something that can be done to improve the quality of the life remaining to the patient.⁷

Palliative care:⁶

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological, emotional, spiritual and social aspects of care for the patient, the family and close carers in a culturally sensitive manner
- Offers a support system to help patients live as

actively as possible

- Offers a support system to help the family and carers cope during the patient's illness and after the patient's death
- Uses a team approach to address the needs of patients and their caregivers
- Avoids futile interventions.

Palliative care and suffering

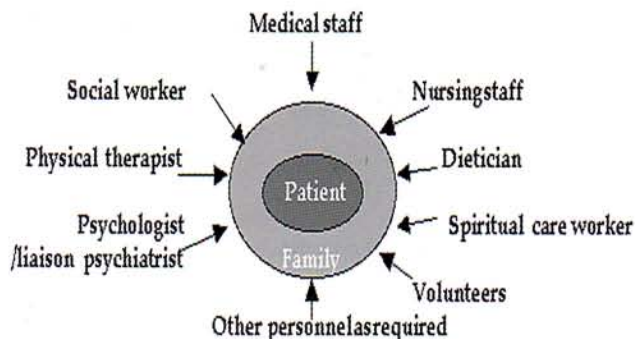
Woodruff (1999) defines suffering as the distress associated with events that threaten the intactness or wholeness of the person.⁸ The causes of suffering can be emerged from any aspect of human life- physical, psychological, social, cultural, or spiritual. For patients with advanced disease, the cause of suffering may result from any or all of the various causes and summed as total suffering. These various aspects of suffering are interdependent. For example, untreated or unrelieved pain can cause or aggravate other physical symptoms such as loss of appetite, insomnia, fatigue, etc and psychological problems, social difficulties, cultural issues as well as spiritual concerns. Conversely, pain may be exacerbated or worsened by unresolved problems relating to any other aspects of suffering. Palliative care should address the total interrelated suffering of the patient through an interdisciplinary approach

Interdisciplinary approach to palliative care

An interdisciplinary approach means involving a range of individuals from various disciplines and specialists in medical, nursing, psychological, social and spiritual domains (figure 1) who meet on a regular basis to discuss patient care and develop a unified plan of management for each patient. It distinguished from multidisciplinary team where individual work independently so may result in fragmented patient care. Interdisciplinary team underlines team identity rather than individual professional identity.^{7,4,1}

The patients are the central of the care. Besides, they are regarded as team members (although they do not personally participate in team meeting), as all treatment must have the patients' consent (if possible) and be in accordance with their wishes. The patient's families are targets of the care and also considered member of the team as they have an important role in the patient's overall care and their opinion should be included when designing plan of management.^{8,6}

Figure 1 – the interdisciplinary team



The history of cancer center interest in palliative care and the development of palliative medicine

In developed countries, during the first half of the last century, discussion about death and dying became medically and socially taboo. Dying patients were seen as medical failures. The condition was aggravated in the 1960 and 1970 with the introduction of chemotherapy for the treatment of cancer and the expectation that cancers could be cured. Unfortunately, this has not as yet been realized for many cancers. During that era, the medical profession and hospital system were criticized from lack of care and attention, commonly untreated pain and other physical symptoms, disease-orientated management to the exclusion of psychological, spiritual and social issues so that resulted in isolated physically and emotionally of dying patients, as well as biased and misleading communication. In response to these needs, a movement established, dedicated to improve the care for the terminally ill patients and support for their families. It was popularly known as "hospice movement". The first modern hospice developed in 1967 by Dr Cicely Saunders, the St Christopher's, in London for patients with advanced cancer. Inspired by the pioneering work of this hospice, the model of interdisciplinary approach to care was quickly led to be applied to the palliative care in the affluent countries around the world- Western Europe, North America, Australia and Japan. In recent years, palliative care develops widely and rapidly in Asia.³ In Indonesia, the understanding of the philosophy of palliative care and the acknowledgement of its importance is growing. However, the development of services still lags behind compare to other South-East countries.

Integration of palliative care into clinical care

In the past, palliative care had been regarded as the care applied when all avenues of the underlying disease are exhausted and further active medical treatment considered inappropriate. A modern view of palliative care, however, emphasizes the earlier initiation at such time as the patient is symptomatic of active, progressive, incurable disease and never be withheld until the terminal phases of disease. Palliative care is required for many patients early in the course of their disease, sometimes from the time of diagnosis.⁵ It is complimentary to active treatment for underlying disease.

Barriers to palliative care

Many patients with advanced disease do not receive or referred too late to palliative care

Here are some of the barriers: Poor prognostication or lacks of communication skills to address end-of-life issues result in late referral to palliative care. In many cases, physicians are reluctant to refer the patient due to lack of understanding about or do not believe in palliative care, loss of control or loss of income. On the other hand, patient believes that prognosis is better than what they are told or has unrealistic expectation of disease response. Disagreement about treatment option between patient and family may become barrier to palliative care. The health care systems, medical supplies and drugs, no reimbursement of the service as well as lack of education and trained staff are also noted as related barriers to the development of palliative care.⁷

Summary

Along with the continuum of evolving a life threatening disease, there may be a time when a patient is clinically justifiable to withdraw curative treatment. It is a time when treatments continue to the point of futility. The underlying disease is progressing and

can't be halted by the treatment. It is a moment when treatment needs to be directed to address symptoms. In clinical practice, however, many patients with life threatening illness in earlier course of the disease experience total suffering which require an interdisciplinary approach aims to maximize quality of life, comfort and function named palliative care. Integration of this service into clinical care faces some barriers that need to be solved firstly by health care professionals so that the core value of palliative care to patients with life threatening illness to keep hope for the best and prepare for the worst can be implemented.

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