THE NEW ARMENIAN MEDICAL JOURNAL
Vol.16 (2022), No 2, p.113-117
DOI: https://doi.org/10.56936/18290825-2022.16.2-113

PALLIATIVE CARE: A CONCEPT ANALYSIS

Alarsan S.F.[1], Fa'ous N.[2], Alkhateeb N.A.[3]

[1] Department of Health Education, Faculty of Health Sciences, National University of Malaysia
[2] Department of Maternal and Child Health Nursing, Faculty of Nursing, Jordan University of Science and Technology, Irbid, Jordan.
[3] Medical Surgical Department, Nusseibah Almaznieh College, Irbid, Jordan

Received 12.10.2021; accepted for printing 30.05.2022

Abstract

Objective: *Palliative care is a defined medical specialty, and it is focused on helping patients and families who are facing serious illness achieve the best possible quality of life. Despite the extensive literature available about palliative care, it still has imprecise due to its involvement in different specialties and disciplines of healthcare. Therefore, it is crucial to clarify what is meant by palliative care and defines its defining attributes, antecedents and consequences.* **Method:** *This study adopted Walker and Avant's concept analysis approach for analyzing palliative care concept. A thorough literature search was performed in PubMed, CINAHL and Embase databases during the period (1970-2021). A total of 17 articles were reviewed and used to achieve the study objective.* **Result:** *After reviewing the screened articles, the study formulated a definition of palliative care as the meaningful and intentional holistic care of patients suffering from terminal illnesses caused by acknowledging and minimize symptoms that would deter the patients' quality of life while achieving patient dignity by utilizing compassion and support. The study revealed that the defining attributes of palliative care include Holistic, compassion, support, individualized, realistic care.* **Conclusion:** *Palliative care was identified as holistic, compassion, supportive and individualized realistic care provided for patients suffering serious illness in order to achieve the desired level of quality of life.*

Keywords: *Palliative care, Concept Analysis, Holistic Care, Individualized Care, Walker and Avant's concept analysis Approach*

Identifying the concept

Up until recently, palliative care has not been a topic that received much exposure. However, as nursing profession is advancing and practice is advancing, nurses need to be aware of the term palliative care [*Avati A et al., 2018*]. This includes, but is not limited to, patients with terminal illnesses, their families and support systems or patients with uncontrolled symptoms such as pain from other non-terminal illnesses [*Meier D et al., 2017*].

The goal of palliative care is simple; to promote the quality of life. According to Merriam-Webster's dictionary, the verb Palliate means to reduce the intensity or severity of a disease [*Hui D, Bruera E, 2015*]. This word has Latin roots to the term Pal, which indicates the action of cloaking or covering up oneself. It would eventually be applied to medicine and the sense of covering disease symptoms rather than being pure-based.

Purpose of concept analysis

The general purpose of the concept analysis is to explore the structure of a concept by breaking it down into many different simpler terms in order to better understand the concept. It is also used to

Cite This Article as:
Alarsan SF, Fa'ous N, Alkhateeb NA; Palliative Care: A Concept Analysis; NAMJ v.16 (2022) no.6, p. 113-117;
DOI: https://doi.org/10.56936/18290825-2022.16.2-113

Address for Correspondence:
Sami F. Alarsan. PhD
University of Science and Technology, Irbid, 22110 Jordan
E. mail: p106966@siswa.ukm.edu.my; Tel.:00962798964020

compare and contrast other alike or different concepts and allows researchers to create hypotheses that reflect the relationship between the concepts [*Berenskoetter F, 2017*].

The purpose of the concept analysis for palliative care concept is to determine the role and importance of palliative care in the nursing profession related to patient quality of life.

IDENTIFICATION OF ALL USES OF PALLIATIVE CARE CONCEPT

Care is a word with multiple definitions and categories. The world Health Organization (WHO) defined care as "the application of knowledge to the benefit of a community or individual, and continues to break down care into intermediate, primary, secondary, and tertiary categories" [*Hu R et al., 2016*].

Based on Jean Watson's theory of human caring and caring services developed between 1975 and 1979, Dr. Watson defined a caring moment to be one where people from "different backgrounds come together for an interaction that is meaningful, authentic, intentional, honoring the person and sharing human experience that expands each person's worldwide and spirit leading to new discovery of self and others and new life possibilities" [*Macario K, 2019*].

Another set of authors went on to define care as the dominant and actual, theoretical, heuristic and practice focus of nursing and no other profession is totally concerned with caring behaviors, caring processes, and caring relationships than nursing [*Trinidad M et al., 2019*].

The World Health Organization defined palliative care in 2016 as "being an approach that improves the quality of life of patients and their families facing the problem 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" [*Radbruch L et al., 2020*]. Shortly, it means identifying terminal patients, early initiating symptoms management and providing holistic care for the patient and their families.

To overcome it is possible, due to the uniting the knowledge and will of all doctors in the world

The National Hospice and Palliative Care Organization further defined palliative care as "being patient and family centered care that optimizes quality of life by anticipating, preventing and treating suffering" [*Meier D et al., 2017*].

Palliative care through "the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information, and choice" [*Fink R, 2015*]. In addition, a practicing physician in Malawi during the HIV/AIDS pandemic coined the term to be about life, quality of life and allowing people to make informed choices about the way they want to live the rest of their lives [*Altalib N, 2020*].

DETERMINING DEFINING ATTRIBUTES OF PALLIATIVE CARE

A common theme that arose within literature search was patient autonomy, caregiver relief, and the increased possibility for a patient to be allowed to die at home rather than in a hospital setting.

Based on the compilation of all literary resources, the researcher defined palliative care as the meaningful and intentional holistic care of patients suffering from terminal illnesses caused by acknowledging and minimize symptoms that would deter the patients' quality of life while achieving patient dignity by utilizing compassion and support. Therefore, the defining attributes of palliative care include Holistic, compassion, support, individualized, realistic care.

A MODEL OF PALLIATIVE CARE CONCEPT

Creating a theoretical model case of palliative care concept includes an adult individual. Although palliative care is throughout the lifespan, who has received a terminal diagnosis of pancreatic cancer. Palliative care is not initiated until the patient begins to experience symptoms that affect the individuals' daily life, such as pain that the primary care provider deems worthy of a consult.

During the patient assessment, the palliative care provider notes the location and rating of the pain and is able to assess and openly communicate with the patient support system. The provider would then be able to discuss with the pa-

tient's nurse how much pain medication is being given, what kind, and how often. Based on this discussion, the provider can call the pharmacist if they desire to discuss the patient's likelihood of pain relief from oral, IV, or even continuous pain medications.

Referring back to the family or support system, the provider can suggest supportive services, such as the chaplains, all while answering the questions regarding the patient's course of disease and expectancies. If the patient's symptoms are managed within the hospital setting and they are ready to pass at home orders can be written for hospice at discharge.

If the patient is actively dying, the provider will notice multiple changes throughout the patient's body, including gurgling in the patient's chest, otherwise known as the death rattle, periods of apnea, intermittent consciousness and possible still grimacing. If the patient isn't comfortable, more medications can be prescribed at this time and if the family feels as though, they can manage the patient's care at home, they may be discharged home with a hospice service.

Identifying borderline, related, contrary, invented and illegitimate cases

There are infinite number of ways that medical errors occur. Miscommunication is one of the top three root causes of sentinel events reported to the Joint Commission. The following palliative care case has disturbing implications in its description of aggressive medical care [*Dietz I et al., 2013*]. "A 62-year old woman was admitted to a Maryland hospital because she had infected leg ulcers. The physicians cut away dead tissue down to the bone. Physicians told the family about fourteen days later that the woman's prognosis was bleak, and that palliative care should be considered. The day after the discussion the physicians administered aggressive amounts of morphine, oxycodone, and other narcotics while stopping antibiotics. The patient became comatose and died soon thereafter. The patient claimed that the family told the physicians that they would have had to think about it. When palliative care was first suggested, the physicians however felt the family agreed to palliative care, leading to the administration of the excessive amounts of drugs. The jury awarded USD 958.000.00. The implications of this misunderstanding and miscommunication are stunning. Before the family could really process what the physicians were suggesting, their loved one was gone".

Palliative care implies dealing with symptoms in making a person comfortable, not actively terminating her life. Where were the nurses as patient advocates for this woman and her family? [*Mackriell J, Hunt J., 2008*]

Very likely they were carrying out physicians' orders.

A case study of ethical issues as following: "Mr. J has been a patient in the palliative care unit of the past four days. He is an 86-year old male World War II Veteran with a two year history of dementia and newly diagnosed small cell lung cancer, with metastasis to the femur [*Siles González J., Solano Ruiz, 2012*; *Mercadante S et al., 2018*]. His care originated in the emergency department with shortness of breath, his respiratory status became so compromised that he required intubation and was admitted to ICU. Although he is no longer on the ventilator, he has become increasingly confused and agitated. His non-verbal behaviors suggest he is in pain. His daughter, who is his power of attorney for health care, requested that the goals of care shift from a plan for chemotherapy, to "keeping him comfortable", and as a result he was transferred to palliative care".

Tom, a nurse on the floor is working his third 12-hour shift this week. In order to pay back his mounting student loan, Tom decided to pick up extra shifts for overtime. Today, the unit is down a nurse and a nursing aide. He faced an hour commute on the way to work due to a traffic accident.

The ethical issue in this palliative care here could be summarized by the following question: What about Tom and his working environment could potentially set him up for ethical distress, and how would affect Mr. J?. it seems that the personal and professional constraints can impact the nurses' ability to provide quality ethical palliative care [*De Panfilis L et al., 2019*].

Antecedents and consequences

Antecedent of palliative care typically include a terminal diagnosis. However, other antecedents could be congenital injuries, life-threatening injuries, and other types of trauma [*Lijauco C 2020*]. As mentioned previously, palliative care can be applied in situation where the patient is not terminal and requires help managing uncontrolled symp-

toms such as pain. Some defining characteristics of palliative care would be a holistic approach to caring for the patient and family [*Cheng H et al., 2015*]. It could also be seen that multiple disciplines working on one patient case such as the pharmacist, dietitians, and even chaplains. Opening an effective communication between every link is vital during this concept.

There are multiple consequences to palliative care. First, terminal patient achieved an enhanced quality of life and the family experiences a sense of peace and inclusion and medical decisions, which ultimately wards off negative emotions [*Choi S, Seo J, 2019*]. Another important consequence is obtaining an obtained human dignity by allowing the patient to choose a home death or hospital death as possible. If a home death is achieved, the patient and their family will also save financially as a further consequence.

EMPIRICAL REFERENTS

The measurement and outcomes of palliative care is not an easy thing to obtain. Typically, healthcare providers are left with family members taking surveys after the patient has passed. However, there are few scales that have been created that allowed the patient affable and their families to gauge their satisfaction and understanding of palliative care [*Bausewein C et al., 2016*].

The first scale was created in 1998 by Irene Higgenson, it was called the palliative care outcome scale, or the POS. This scale can be utilized to measure a patient's response on a variety of topics such as pain management, symptoms control, self-worth, communication and even possible questions [*Henson L et al., 2020*].

The second scale includes the FAMCARE skills. FAMCARE was created for measuring family satisfactions with advanced cancer care. It measures things such as availability of care, physical patient care, psychosocial care and information giving. Later, the FAMCARE-2 was developed to measure the palliative care services, specifically with a function, with a focus on symptoms management rather than pain management. In this version, more questions were added regarding family well-being, access to practical care assistance, and an ability to comment on how the palliative care team handled the patients' need for dignity [*Ornstein K et al., 2015*].

Any healthcare provider will more than likely at some point in time deal with a patient who has a terminal illness. This is the entryway or antecedent to palliative. Palliative care has become an important topic in the past ten years, and more studies are beginning to take place.

Nursing research is currently being done to determine effectiveness, availability and different methods to achieve the best quality of life for terminal patients. Hopefully in the future of nursing research more qualitative studies of patients and their families for us are accomplished, as advanced practice nurses to know how to handle such patients [*Lindell K et al., 2017*]. The current research also indicates that future research needs to be done while patients are still conscious and able to answer, so healthcare providers can have first-hand accounts rather than rely on the families for surveys and satisfaction scores[*Parker S et al., 2013*].

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THE NEW ARMENIAN MEDICAL JOURNAL
Vol.16 (2022). No 2

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THE NEW ARMENIAN MEDICAL JOURNAL

Vol.16 (2022). No 2

The Journal is founded by
Yerevan State Medical
University after M. Heratsi.

Address for correspondence:

Yerevan State Medical University
2 Koryun Street, Yerevan 0025,
Republic of Armenia

Phones:

(+37410) 582532 YSMU
(+37410) 580840 Editor-in-Chief

Fax: (+37410) 582532

E-mail: namj.ysmu@gmail.com, ysmiu@mail.ru

URL: http//www.ysmu.am

Our journal is registered in the databases of Scopus, EBSCO and Thomson Reuters (in the registration process)

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EBSCO

THOMSON REUTERS

Copy editor: Tatevik R. Movsisyan

Printed in "VARM" LLC
Director: Ruzanna Arakelyan
Armenia, 0018, Yerevan,
Tigran Mec 48, 43
Phone: (+374 91) 19 29 00,
E-mail: armana6@mail.ru