Palliative care for elderly People

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Abstract:

Patient health is the primary issue for any health professional. Therefore, we, as students in the nursing branch and as future nurses , want through this research work to expand our knowledge and at the same time to offer before you our experience with terminal patients who were part of palliative care. Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on relief from the symptoms and stress of a serious illness. Palliative care teams specialize in treating people suffering from the symptoms and stress of serious illnesses such as cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney disease, Alzheimer's, Parkinson's, Amyotrophic Lateral Sclerosis (ALS) and many more. Palliative care can be helpful at any stage of illness and is best provided from the point of diagnosis. In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life. Palliative care can be provided along with curative treatment and does not depend on prognosis. Our main goal is to show the role of the nurse in the care that a patient

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"PALLIATIVE CARE FOR THE ELDERLY PEOPLE"

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Contents

I.Abstract

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Keywords : Palliative care , health professional , serious illness , quality of life .

I. Abstrakt

Shëndeti i pacientit është çështja kryesore për çdo profesionist shëndetësor. Prandaj, unë, si student në degën e infermierisë dhe si infermiere e ardhshme, dua që përmes kësaj pune kërkimore të zgjeroj njohuritë e mia dhe në të njëjtën kohë të ofroj para jush përvojën tonë me pacientët terminalë që ishin pjesë e kujdesit paliativ. Kujdesi paliativ është kujdes mjekësor i specializuar për njerëzit që jetojnë me një sëmundje të rëndë. Ky lloj i kujdesit përqendrohet në lehtësimin nga simptomat dhe stresin e një sëmundjeje të rëndë. Ekipet e kujdesit paliativ specializohen në trajtimin e njerëzve që vuajnë nga simptomat dhe stresi i sëmundjeve të rënda të tilla si kanceri, dështimi kongjestiv i zemrës (CHF), sëmundja pulmonare obstruktive kronike (COPD), sëmundja e veshkave, Alzheimer, Parkinson, Skleroza Laterale Amiotrofike (ALS) dhe shumë më shumë Kujdesi paliativ mund të jetë i dobishëm në çdo fazë të sëmundjes dhe ofrohet më së miri nga pika e diagnozës. Përveç përmirësimit të cilësisë së jetës dhe ndihmës me simptomat, kujdesi paliativ mund të ndihmojë pacientët të kuptojnë zgjedhjet e tyre për trajtim mjekësor. Shërbimet e organizuara në dispozicion përmes kujdesit paliativ mund të jenë të dobishme për çdo person të moshuar që ka shumë shqetësime dhe paaftësi të përgjithshme shumë vonë në jetë. Kujdesi paliativ mund të sigurohet së bashku me trajtimin kurativ dhe nuk varet nga prognoza. Qëllimi ynë kryesor është të tregojmë rolin e infermierit në kujdesin që i duhet një pacienti nga një sëmundje e pashërueshme dhe pothuajse jeta nuk ka kuptim, që do të thotë se ne jemi një nga faktorët kryesorë në përmirësimin e cilësisë së jetës së tij / saj. Unë kam rishikuar literaturën që përmbledh të dhënat dhe informacionin e nevojshëm në lidhje me kujdesin paliativ. Punimi gjithashtu përdor metoda krahasuese, duke krahasuar kështu nivelin e zhvillimit të kujdesit paliativ në vendet e zhvilluara të botës dhe në Kosovë.

Fjalët kyçe: Kujdes paliativ, profesionist shëndetësor, sëmundje serioze, cilësi e jetës.

II. Introduction

Palliative care is 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.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[1]

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[1] World Health Organization, Palliative care

1. Palliative Care

Cancer often causes symptoms, and any treatment for cancer may cause side effects. An important part of your cancer care, regardless of diagnosis, is preventing or relieving these symptoms and side effects. Doing this helps keep you as comfortable as possible while maintaining the best possible quality of life from diagnosis through treatment and beyond. This is called palliative care. In addition to treating physical issues, such as pain, nausea, and fatigue, palliative care also focuses on supporting your emotional, spiritual, and practical needs. It also supports the needs of your family and caregivers. You can receive palliative care at any age and at any stage of illness. Receiving palliative care does not mean that you will no longer receive treatment for the disease. People often receive treatment to slow, stop, or eliminate cancer in addition to treatment to ease discomfort. In fact, research shows that people who receive both types of treatment often have less severe symptoms, a better quality of life, and report they are more satisfied with treatment.

How palliative care differs from hospice care

Although you may hear “palliative care” and “hospice care” used in similar ways, they are not the same. Palliative care is given at every step of the treatment process. It provides an extra layer of support for people with any stage of cancer. Hospice care is a specific type of palliative care. It is only provided to people with advanced cancer who are expected to live six months or less. If you have advanced disease, your doctor may suggest treatments to improve symptoms or treatments directed at the cancer. If you choose to stop treatment for cancer, such as chemotherapy, this does not mean you have stopped “fighting” the disease. It also does not 4 ASCO ANSWERS mean that your health care team has abandoned you or given up. Instead, the focus may be on relieving symptoms and allowing for additional support in all areas of your life. If a person decides to begin hospice care, a member of the palliative care team will help with the transition and address the physical and emotional issues that come with that choice.[2]

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[2] American Society of Clinical Oncology, www.cancer.net

1.1 Disease treated by palliative care

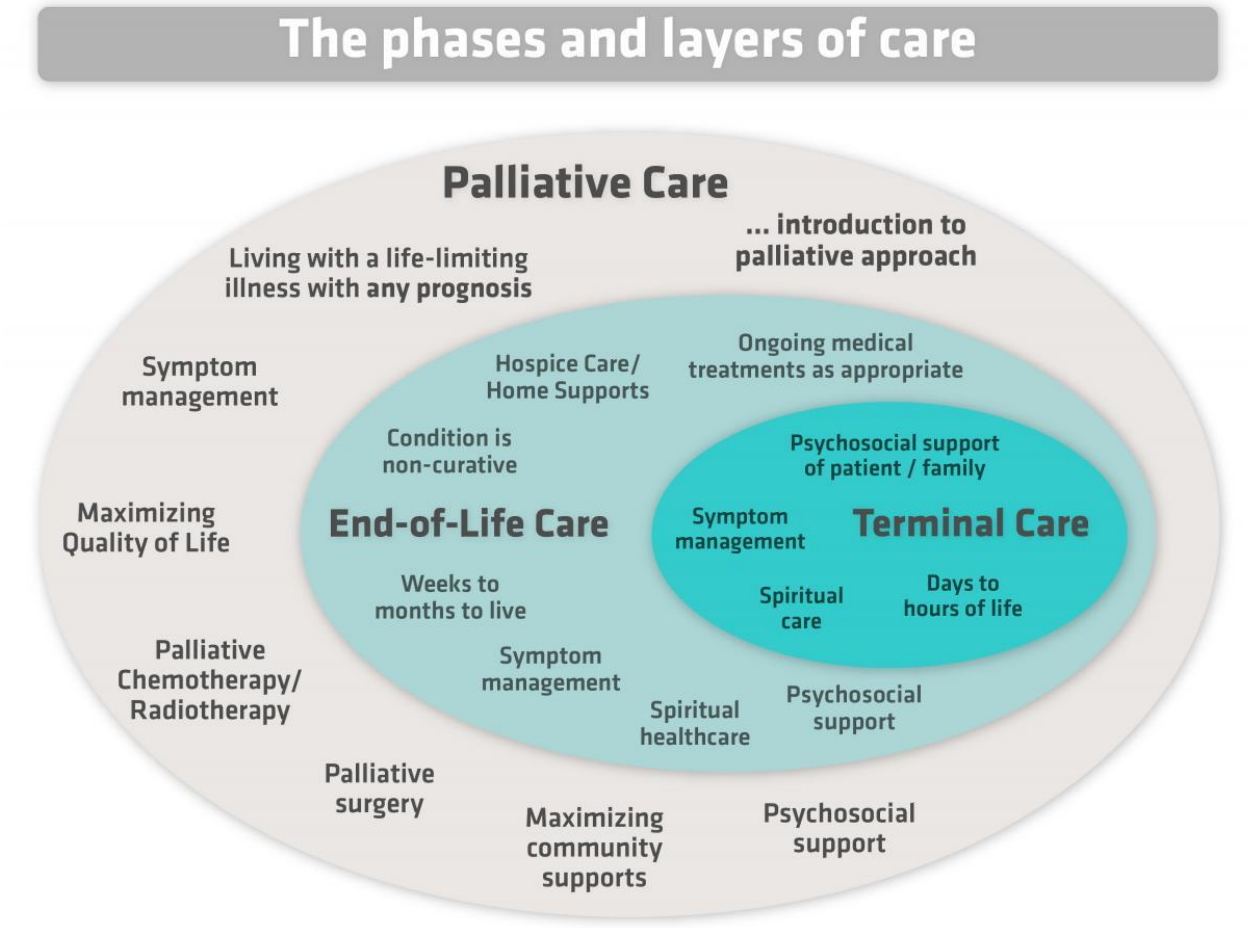
If you've been diagnosed with a serious, long-lasting disease or with a life-threatening illness, palliative care can make your life -- and the lives of those who care for you -- much easier. Palliative care can be performed along with the care you receive from your primary doctors. With palliative care, there is a focus on relieving pain and other troubling symptoms and meeting your emotional, spiritual, and practical needs. In short, this new medical specialty aims to improve your quality of life -- however you define that for yourself.

Your palliative care providers will work with you to identify and carry out your goals: symptom relief, counseling, spiritual comfort, or whatever enhances your quality of life. Palliative care can also help you to understand all of your treatment options. One of the strengths of palliative care is recognition of the human side of illness. In a 2011 survey of palliative care patients, they mentioned these particular needs: "being recognized as a person," "having a choice and being in control," "being connected to family and the world outside," "being spiritually connected," and "physical comfort."

Palliative care may also be a good option if you have a serious disease that has prompted multiple hospitalizations or emergency room visits during the previous year. Does palliative care mean that you're dying? Not necessarily. It's true that palliative care does serve many people with life-threatening or terminal illnesses. But some people are cured and no longer need palliative care. Others move in and out of palliative care, as needed. However, if you decide to stop pursuing a cure and your doctor believes that you're within the last few months of life, you can move to hospice. Palliative care does include the important component of hospice, but it's only one part of the larger field. If your family members also need help, palliative care can provide them emotional and spiritual support, educate them about your situation, and support them as caregivers. Some palliative programs offer home support and assistance with shopping, meal preparation, and respite care to give caregivers time off.

As the World Health Organization states, "All people have a right to receive high-quality care during serious illness and to a dignified death, free of overwhelming pain and in line with their spiritual and religious beliefs."

Today, patients with cancer, heart disease, chronic lung disease, AIDS, Alzheimer's, multiple sclerosis, amyotrophic lateral sclerosis (ALS), and many other serious illnesses are eligible for palliative care. One of the primary goals is symptom management. The disease itself may cause symptoms, but so can treatments. For example, chemotherapy drugs may cause nausea and vomiting. Also, narcotic drugs to control pain frequently lead to constipation.[3]



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[3] Jennifer Robinson, MD August 16, 2019, WebMd

1.2 Types of palliative care

Cancer and its treatment often cause problems called side effects. While treating the cancer is important, so is relieving side effects and symptoms. In fact, treatment of cancer and its side effects often happen at the same time. This is called palliative care or supportive care.

Palliative care works best when you start it as soon as you need it during the treatment process. People who receive palliative care along with treatment for the cancer often have less severe symptoms, better quality of life, and are more satisfied with treatment. You may have palliative care at any age and for any type and stage of cancer.

Areas where palliative care can help

Palliative treatments vary widely and often include:

- Medication
- Nutritional changes
- Relaxation techniques
- Emotional and spiritual support
- Support for children or family caregivers

Social

You might find it hard to talk with your loved ones or caregivers about how you feel or what you are going through. Or you might need a support group or a ride to and from treatment. A social worker can help with these situations. For example, they can:

- Help you plan a family meeting
- Suggest ways to organize people who want to help
- Help you find medical information, rides, or services

A social worker can also provide palliative care for family members and caregivers. For example, if they feel overwhelmed, the social worker can help them figure out what kind of help they need and find it.

Emotional

Having cancer can make you feel many different emotions, such as sadness, anxiety, or anger. It can also make you very stressed. A support group, counselor, psychologist or other specialist can help you understand and cope with these emotions.

Spiritual

Having cancer can bring up many spiritual questions. You might struggle to understand why you got cancer. Or you might want a greater purpose after surviving cancer.

If you belong to a faith community such as a church, synagogue, or other group, your spiritual leader or community members might be able to help support you spiritually. A hospital chaplain can also provide spiritual support, whether you are religious or not. Chaplains work with people of all faiths and those who do not have a specific faith.

Mental

Cancer symptoms, treatments, and medications can all affect how your mind works. For example, if you are not sleeping enough, you might feel stressed and have a hard time thinking clearly. Or you might be very anxious about whether your treatment is working.

Palliative care for mental health includes exercise, counseling, meditation, and possibly medication to help with anxiety, depression, or sleep problems. A counselor, support group leader, or psychologist might suggest that you do activities that help you reduce stress and anxiety, such as yoga, creating art, joining a group of other cancer survivors, or volunteering for a cause you find meaningful.

Financial

Cancer treatment can be expensive. This might be a cause of stress and anxiety for you and your family. In addition to treatment costs, you might find that you have other extra expenses, such as the cost of traveling to a cancer center for care.

Talk with your health care team about any financial concerns. A social worker or financial counselor can provide palliative care for these concerns. For example, they might:

- Help you talk with your health care team about the cost of care
- Explain billing and insurance, or find someone who can do this
- Help you apply for medical leave or disability payments
- Find programs that provide free or low-cost medicines

Physical

Physical side effects of cancer and its treatment depend on several factors. These include your type of cancer, its stage, the treatment, and your general health. Physical side effects can include:

- Pain
- Fatigue (being very tired)
- Nausea, vomiting, and loss of appetite
- Breathing problems, such as being short of breath
- Sleep problems

Palliative care for physical side effects might include anti-nausea medicines, physical therapy, or help with nutrition.[4]

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[4] American Society of Clinical Oncology (ASCO) 2005-2020

1.3 The Principles Of Palliative Care

Palliative care is not simply a process that a patient undergoes in hospital by themselves. It’s a philosophy that is integrated into their overall care and the care their family receives.

Palliative care:

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help patients’ families cope during the patient’s illness and in their own bereavement[5]

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[5] Hello Care Journal, 22 November 2020

1.4 Palliative care in hospital

Eight studies were identified that specifically examined the intervention of a hospital team or service . A further four studies considered interventions that included a component of hospital support or care. The interventions were very varied; for example, individual nurses with unclear training, individual doctors or multiprofessional teams. Outcomes tended to include time in hospital, total length of time in palliative care and a range of symptoms or quality of life indicators. Only one of the eight studies specifically examining a hospital team was grade II and had any comparison group (one study hops cgrade 11). This study suggested that those in the care of the hospital team spent less time in hospital, although an observational study of the same service found that quality of life deteriorated during care over time. The team consisted of one nurse with surgical and other support. The remaining studies were grade III, indicating that these were observational or retrospective studies. In some of these studies improvements in symptom management were found, although many of the potential biases and confounding variables were not accounted for. In the four studies where the hospital based components of the service had not been separated from the other elements, it is difficult to judge the degree to which the hospital based component of the service is effective. One of these studies was a randomised controlled trial, the intervention was a coordinating service, and similar to the Swedish study, it appeared to lead to reduced time in hospital. The other studies were all grade III, and improved outcomes were found in some areas. Taken together, the evidence seems to suggest that some of the palliative care teams or services can reduce time in hospital. This can be by a specialist nurse or a coordinating service, but it does not affect outcomes for the patients or carers. In one study quality of life deteriorated over time, but the multiprofessional teams appeared to improve outcomes in some instances.[6]

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[6] I. G. Finlay, I. J. Higginson, D. M. Goodwin, A. M. Cook, A. G. K. Edwards, K. Hood, H.-R. Douglas & C. E. Normand, University of Wales College of Medicine, Velindre NHS Trust, Velindre Hospital, Cardiff, UK

1.5 Palliative care at home

Do you, or someone you love, have a serious illness such as cancer, heart failure, lung disease or kidney failure? If so, you may be sick of trips to the emergency room and unwanted hospital stays to treat pain, shortness of breath or other symptoms. Palliative care can help you stay safely at home.

Palliative care is specialized medical care for people with serious illnesses. It will treat your pain and other symptoms. It will help you understand your disease and your treatment options. It will help you, and your family, cope with the everyday challenges of living with a serious illness.

There are many palliative care services to help people outside of the hospital. You may be able to get help at home, at your local doctor's office, or in your cancer center, for example. Some hospitals offer outpatient palliative care. You can get palliative care *at the same time* as treatment for your disease and at any stage of your disease.

Having this extra layer of support at home can make a big difference to your quality of life. Expert pain and symptom control will keep you, or your loved one, more comfortable. A 24-7 telephone hotline to nursing advice could help you avoid those unwanted trips to the emergency room. And you may be able to find nursing help or meal delivery services.

Your palliative care team will consist of a doctor, a nurse and a social worker. All will be specialists in palliative care. They will spend as much time as needed to understand your situation and how they can help you.[7]

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[7] Center of advice palliative care, MAR 11, 2016

1.6 Palliative care today

In today's world, palliative care is increasingly being regarded as a human right and incorporated in the United Nations' Commission on Human Rights. However, palliative care is not developed to its full extent everywhere in the world. The countries fall into one of four categories.

The categories are:

1) no identified hospice-palliative care strategy,
2) capacity building activity but no service,
3) localized palliative care provision, and
4) countries where palliative care activities are approaching integration with mainstream service providers.

Palliative services have been recognized in 115 of the world's 234 countries, encompassing 88% of the total global population. Category 1 contains 33% of the 234 countries, category 2 18%, category 3 34%, and category 4 15%. There is an indication that palliative care is a prerogative of high-income countries. However, there seems to be a stronger connection between the development of palliative care in a country and its Human Development Index than the connection to GDP. The UN's Human Development Index is based on three aspects; longevity, knowledge, and standard of living.[8]

Finland as well as almost all western European countries and North America falls into the fourth category. Countries in this category are characterized by a large number of activists, multiple providers and types of service. The health care professionals have an awareness of palliative care. Strong, pain-relieving drugs are readily available. There is a development of recognized education in palliative care and a national association exists. In many developed countries, including Finland, there is an ongoing debate regarding how to organize palliative care. Research shows that if competent and appropriate care and support would be available, the majority of terminally ill cancer patients would prefer to get their care at home.

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[8] (Wright, Wood, Lynch & Clark, 2008,469-471)

Several factors affect the possibility to receive the final care at home: access to competent care, the ability and interest of the family to help, access to beds in hospitals and nursing homes as well as the attitude of society and the health care system in general towards home-based care.[9]

There are large differences from country to country in the proportion of cancer patients dying at home. The differences are affected by social, cultural, and health care factors. The differences are illustrated by the percentages for Norway, 12.8%, England 22.1%, Belgium 27.9% and the Netherlands 45.4%. [10]

1.7 Palliative Care in Kosovo

The health sector in Kosovo is separated into three levels; primary, secondary, and tertiary. Looking at cancer specifically, screening and supportive therapies are centered at the primary and secondary levels respectively. The burden of all direct cancer treatment is focused in Pristina at the NIO. All treatments provided through the public sector are free of charge for patients. The tertiary and secondary levels are funded by the Ministry of Health (MoH), while the primary care level is funded by the Ministry of Finance through payments to municipalities. All medicines and medical equipment are procured through a central process, which differs based on the level of health care: primary care centers request medicines and equipment directly through the MoH at the municipality level, while regional hospitals and UCCK request medicines through the central pharmacy at UCCK. Only medicines on the Essential List of Medicines for Kosovo (ELMK) are available through this process in the public sector. Because of difficulties in procurement and resource constraints across the health system, many medicines on and off the ELMK must be purchased by patients out-of-pocket. Opportunities for capacity building related to the ELMK and the procurement process will be discussed further in Section 4. The responsibility of palliative care is legally placed on the primary level of health care, and all family medicine physicians receive minimal palliative care training in their residency.

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[9] (Ahlner-Elmqvist, Jordhöy, Jannert, Fayers & Kaasa, 2004, 585)

[10] Cohen, Houttelkier, Onwuteaka-Philipsen, Miccinesi, Addington-Hall, Kaasa, Blisen & Deliens, 2010).

Palliative care is specifically included in the mandate of primary care in Kosovo but is not included in the national health plan and is not prioritized or funded. There are no palliative care specialists in Kosovo. Any palliative care training doctors receive is not standardized and is often received through NGOs or through schooling and training outside of the country. Because of palliative care has not been standardized across Kosovo, there are gaps in care for many patients. In the next section we will outline the steps that have been taken to improve the quality of life and death for patients and provide a description of the current services offered and the patient populations served by the three levels of the health care system.

Palliative care has emerged as a pressing issue across Kosovo. In interviews with health care providers and administrators at all levels of the health care system, the research team found that most stakeholders recognized the need for formal palliative care services in Kosovo. Stakeholders often spoke of the burden of providing palliative care in a setting not designed to deliver this care and issues arising from lack of dedicated palliative care training. This feeling was especially strong in clinics that saw a high volume of patients in need of palliative care, most notably the NIO in Pristina. NGOs such as Smile International, Caritas Kosova, the Professional Health Association (PHA), and the Mother Teresa Society have begun to address the unmet need for palliative care. These NGOs provide palliative care and home care, hold training conferences on palliative care and pain management for doctors and nurses, and work with international groups to establish new programs. Out of these contributions, the training conferences are particularly valuable. Both Smile International and the PHA hold accredited conferences, where attendees can receive continuing education credit for the re-licensing process. These conferences give attendees between five and ten points towards the 100 points needed every five years for both doctors and nurses. These conferences are attended by doctors and nurses from around the country, and have grown rapidly, with over 2,000 attendees at a 2017 conference series put on by Smile International, according to their data. Speakers at the conferences often include international experts, including palliative care doctors from the United States and United Kingdom.

Palliative care has been on the radar of many health care providers for years, but it has only recently been incorporated into health policy planning. The NBCC has recently recognized the need for non-curative care for patients with terminal cancer cases and has identified a national palliative care system as an integral part of a comprehensive cancer control program. This officially marks palliative care as a national priority for cancer care, along with cancer screenings and curative therapies. Overall, the provision of palliative care in Kosovo has increased but still does not match the needs of the population. The following section examines the different sites of care around the country. It is crucial to note that though there are many different initiatives, care is not coordinated, and the lack of a formal system impacts access to care for many citizens in need.[11]

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[11] Io Jones, Emily Schneider, and A.J. Speigelman, Dartmouth Global Health Policy Lab, The Global Health Initiative at the Dickey Center for International Understanding, September 2018

1.8. Palliative care team

Palliative care is provided by a team of healthcare professionals with a range of skills to help you manage your life-limiting illness. Your palliative care team works together to meet your physical, psychological, social, spiritual and cultural needs and also helps your family and carers.

The members of your palliative care team may include:

- doctors
- nurses
- allied health professionals
- volunteers
- carers.

-Types of doctors in a palliative care team

If you are diagnosed with a life-limiting illness, you will probably see a range of doctors, including:

- physicians and surgeons
- general practitioners
- palliative care consultants
- psychiatrists.

Each doctor will provide a different type of medical care and the types of doctor you see will depend on the kind of illness you are diagnosed with.

Physicians and surgeons

Your physician or surgeon is a specialist in a particular area of medicine. They will diagnose you and give you information about the disease you have.

Different types of physicians or surgeons include:

- oncologists–diagnose and treat cancer
- neurologists – diagnose and treat nerve diseases
- respiratory physicians – diagnose and treat lung diseases.

General practitioners

Once you leave hospital, or after you have been diagnosed by a physician and if you can still live at home, you will need to see your general practitioner regularly.

Your doctor will manage your ongoing care while you can still live in the community.

Palliative care consultants

Palliative care consultants are medical doctors who have completed specialised training in the care of people living with a life-limiting illness. They usually deal with complex cases and work at hospitals or residential aged care homes that have dedicated palliative care units.

Psychiatrists

Psychiatrists are medical doctors who have specialist training in mental health conditions. They can provide emotional and mental health support for you while you are dealing with a life-limiting illness. Fees for psychiatrists are usually paid by Medicare. However, it is a good idea to ask about any additional costs that you may have to pay.

Palliative care nursing

Nurses manage most of your ongoing care and treatment while you receive palliative care in a hospital and they can also provide palliative care nursing services to you at home. They assess, plan and administer your daily treatment and manage your symptoms.

Every Victorian region has palliative care nurse specialists who can speak to you about what you need to manage your illness and continue living at home. Contact the palliative care service in your local area to discuss your needs.

Allied health professionals in palliative care

Allied health professionals are university-educated health practitioners who work as part of your palliative care team. They help treat symptoms, manage day-to-day tasks, offer emotional support and provide rehabilitation services.

Types of allied health professionals include:

- counsellors
- dietitians
- music therapists
- occupational therapists
- orthotists and prosthetists
- pastoral care workers
- pharmacists
- physiotherapists
- podiatrists
- psychologists
- social workers.

Palliative care volunteers

Palliative care volunteers are members of the community or family members who provide their services to people with a life-limiting illness and their families for free. They are recruited, trained and managed by local palliative care services and can offer practical help around the home, provide emotional support, and help with running errands.

Availability varies from region to region, so speak to your care provider about the options available near you.

Often, a family member who is already providing support to someone with a life-limiting illness will undertake specialist training through a volunteer program run by a local palliative care service. This ensures their loved one gets the support they need while still being cared for by a family member.

Complementary therapies and palliative care-

It is common for complementary therapy practitioners to provide treatment at the same time as conventional medical professionals to manage pain and other symptoms relating to a person's life-limiting illness. Complementary therapy is known by different terms including:

- alternative therapy
- alternative medicine
- holistic therapy
- traditional medicine.

Types of complementary therapies include:

- acupuncture
- aromatherapy
- herbal medicine
- naturopathy , yoga.[12]

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[12] Health and human services, Victoria state government , February 2017

1.9 The Difference Between Palliative Care and Hospice

If you or loved ones are facing a serious illness, you've probably been hearing a lot about treating pain. You may have heard the terms "palliative care" or "hospice." Both are meant to bring comfort and relief, but they differ in some important ways. To get the right kind of care in your situation, you need to have a good idea of what each service offers.

What Is Palliative Care?

This program aims to ease pain and help with other problems if your illness is serious but not considered to be life-threatening for now. It helps people live with the symptoms of longrunning things such as cancer, kidney disease or AIDS, or with the side effects of the treatments. Palliative medicine doesn't replace other treatments. It's an addition that helps you and your family deal with things such as nausea, nerve pain, or shortness of breath. If an illness makes it harder to work, play, get around, or causes depression, palliative care can address that, too. People have said they feel more in control of their lives as a result. Even in cases where an illness is expected to be fatal, this type of care can help you live as active a life as possible.

What Is Hospice Care?

This is for people who have learned from doctors that they are not expected to recover from their condition. It's about easing pain and helping families prepare for the end of life.

Palliative care is part of that, but it's just one part.People in hospice care generally are expected to have less than 6 months to live. They're often at home, where family members and professional caregivers look after them. But you could also choose a specialized center for hospice care. It's also offered at many nursing homes and hospitals. This kind of care can involve not only doctors and nurses, but also family members, clergy, counselors, or social workers who can address the grief of dying and emotions (such as anger, sadness, or regret) that often come with it.[13]

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[13] WebMD Medical Reference Reviewed by Kumar Shital, DO on July 20, 2020

1.10. Drug menagment in palliative care

What are the purposes of palliative medications?

Palliative medications are one component of a 'whole-person' approach to supporting people with life-limiting and terminal illnesses. Medications may be needed to treat and / or prevent symptoms associated with the palliative diagnosis. These include problems such as pain, nausea and vomiting, depression, shortness of breath, among other issues. Some specific disease modifying treatments aimed at controlling and slowing down the progress of a disease (rather than curing it), are also often called 'palliative treatments'. This may include chemotherapy, hormone treatments and radiotherapy. For more information about these go to the National Cancer Institute website, or the Cancer Council of Australia website.

What medications are we talking about?

The classes of medication most commonly used in palliative care are:

- analgesics (to treat pain)
- antiemetics (to treat and also to prevent nausea and vomiting)
- laxatives / aperients (to prevent and treat constipation)
- adjuvant medications (medications that work with analgesics to improve pain or symptom control)
- steroids (that may reduce a range of symptoms related to inflammation), and
- antidepressants (to treat depression, or sometimes pain) and other neuroleptic medications (to treat depression, anxiety, or pain delirium) and sedatives.

What is different about palliative medications?

Standard medications may be used differently in the palliative care setting, based on well established practices for which there are varying degrees of evidence. Examples include the use of antipsychotic medications to treat nausea, anticonvulsants to treat pain, and opioids to treat dyspnoea.

Where these indications are unlisted in the product information (found in the package insert or the eMIMS®) this is termed 'off-license' prescribing. Sometimes it may be difficult to access these medications for patients in the community. There are also cost implications as they are unable to be subsidised through the Pharmaceutical Benefits Scheme (PBS).

In a palliative approach to treatment, giving medications should be as simple and non-traumatic as possible, with the potential for them to be given at home. The route of administration may differ from that usually used in a hospital based acute care situation.

A frequent issue is the need to continue medications for a person who can no longer swallow, and a common alternative route of administration is a subcutaneous injection or infusion. This is less traumatic and less difficult to maintain than intravenous medication, and it can often be managed at home with nursing support. Some medications are only available by the oral route. At the time a person can no longer take solid oral preparations, other options (including dissolving the tablet in water) may need to be substituted.

Stopping unnecessary medications

When people have a number of other medical conditions that are unrelated to their palliative care diagnosis, they may be on numerous medications, many of which have a role in maintaining health and preventing the long-term consequences of diseases including, but not limited to, diabetes and hypertension. The burden in terms of cost and discomfort of taking many drugs, as well as the escalating risk of drug interactions from polypharmacy, means that long-term medications should be frequently reviewed. Decisions about which medications to stop should be made by balancing the likely prognosis from the palliative care diagnosis, with short, medium, and long-term risks associated with stopping medications to manage co-morbidities.[14]

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[14] Tait P, Morris B, To T. Core palliative medicines - Meeting the needs of non-complex community patients. Aust Fam Physician. 2014 Jan-Feb;43(1):29-32.

1.11. Euthanasia in Palliative Care

Palliative sedation, sometimes referred to as terminal sedation, is the progressive use of sedatives to achieve the desired level of comfort in terminally ill patients experiencing unrelieved suffering. Death usually follows shortly after a patient becomes sedated, making some people wonder if palliative sedation isn't just another form of euthanasia or physician-assisted suicide.

So, *Is* Palliative Sedation a Form of Euthanasia?

Palliative sedation is not euthanasia, nor is it physician-assisted suicide. Fundamental differences in each one of these things make them distinctly separate. Let's review each one and how they differ from each other.

Euthanasia

Euthanasia is defined as the act of a third party, usually a physician, ending a patient's life in response to severe pain or suffering. Euthanasia can be voluntary — meaning the physician has obtained the patient's informed consent — or involuntary, without the knowledge or consent of the patient.

For example, when an animal is euthanized, it is done so involuntarily because the animal cannot give consent. In contrast, when Dr. Jack Kevorkian, who was a strong supporter and participator in physician-assisted suicide long before any state legalized the act, gave a lethal dose of medication to Thomas Youk after Youk became unable to administer the drug to himself, it was an act of voluntary euthanasia and landed Dr. Kevorkian in prison.

Voluntary euthanasia is not legal in most parts of the world. The Netherlands and Belgium are currently the only countries who allow the practice. Involuntary euthanasia is not legal anywhere.

Physician-Assisted Suicide

Physician-assisted suicide (PAS) is the act of a physician writing a prescription for a lethal dose of medication that the patient takes himself in order to cause death. The fundamental difference here is that the patient must take the medication himself.

PAS is currently legal in the United States in several states, including Oregon and Washington, and in a handful of other countries. It is done only when a patient has a terminal diagnosis, is suffering, and wants to control when and how they die. An important piece of PAS is that the patient must take the medication himself. It is not legal for a physician, friend, family member, or anyone else to give the medication as that would be, by definition, euthanasia.

Palliative Sedation

In contrast to euthanasia and physician-assisted suicide, the intent of palliative sedation is not to cause death, but to relieve suffering. Palliative sedation is only given to relieve severe, unrelieved suffering, and it is only utilized when a patient is already close to death.

Palliative sedation may be tried for a short time with the goal of letting the sedation wear off so as to assess the patient's comfort, or it may be used in order to maintain a desired level of sedation until death. Either the patient or his healthcare decision-maker makes the decision as to how heavily and how long the patient should be sedated.

Death may occur some time after inducing sedation, but it's often unclear if the terminal illness or the sedative medication actually caused it. Because causing or hastening death isn't the intent of palliative sedation, it cannot be equated with either euthanasia or PAS.

Palliative sedation always requires the consent of the patient, or of his healthcare decision-maker if the patient can no longer make decisions himself. The medication is usually given by an infusion or suppository and often causes prompt sedation, making it impossible for the patient to give the correct dose himself. Therefore, the sedatives can be given by a physician, nurse, or the patient's primary caregiver.[15]

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[15] Angela Morrow, RN , Jenny A. Dhingra, MD on November 21, 2019

1.12. Role of nurse in palliative care

Palliative care is a key component of quality care. Oncology nurses have many of the skill sets for providing generalist quality care and are poised to play a major role in advocating and transforming palliative care for patients with cancer.

Palliative Care Nurses can play a role in end-of-life care. To accomplish this, nurses collaborate in a cultural assessment of the patient and family and provide culturally sensitive care. Although the majority of Palliative Care Nurses are "generalists," some elect to sub-specialize in areas of oncology, pediatrics, or geriatrics and pursue advanced practice credentialing. Certification for nurses practicing in palliative care as a *Certified Hospice and Palliative Nurse* (CHPN) has been available since 1999, following the initial development of the *Certified Nurse Hospice* (CRNH) in 1994. There is a distinct body of knowledge with direct application to the practice of palliative care nursing. This includes:

- Pain and symptom management
- End-stage disease processes
- Psychosocial
- Spiritual and culturally sensitive care of patients and their families
- Interdisciplinary collaborative practice
- Loss and grief issues
- Patient education and advocacy
- Bereavement care
- Ethical and legal considerations
- Communication skills
- Awareness of community resources

Palliative Care Nurses are registered nurses prepared at the associate-degree, bachelor-degree, and/or master's-degree level.

1.13. Stress on the Palliative Care Nurse

In general, nursing is recognized as an occupation that is associated with stress on both professional and personal levels. Because of the nature of their patient's advanced needs, Palliative Care Nurses may experience stressful situations related to death and dying—though they do not experience it as often as Hospice Care Nurses. However, the nursing literature suggests that stress and its effects can be moderated in these nurses through personal coping strategies and social support.

In general, it has been found that the levels of stress and distress experienced by Palliative Care Nurses were no greater than those experienced by nurses from other specialties. Palliative Care Nurses who are well-trained and experienced may be at less risk of psychological distress and burnout than other nurses, because they may better utilize self-care strategies to reduce work-related stress which they have also taught to their patients and their families. Because of the advanced training and experience required for Palliative Care Nursing, both clinical nursing skills and relationships with patients were seen as important, and these relationships has been found to reduce nurses' experiences of stress. Given the breadth of skills required to perform in this role, well-prepared Palliative Care Nurses may have ways of coping with the stress of their work environment that mitigate their stress levels. One of the most common stress-reduction strategies used by Palliative Care Nurses includes informal gatherings of staff and weekly meetings that featured reflective discussions to help nurses in their professional development, allowing for both interaction of what they are dealing with and someone who understands can listen, advise, and console.[16]

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[16] https://www.nurseregistry.com/blog/palliative-care-nursing/ , 04.2.2020

III.Purpose and objectives

The purpose of this research paper is to get acquainted with palliative care, diseases treated by palliative care, type of palliative care, principles of palliative care, palliative care in hospital and at home, palliative care today in world, palliative care in Kosovo, palliative care team, diference between palliative care and hospice, drug menagment in palliative care euthanasia, role of nurse and stress on the palliative care nurse.

Also, the purpose of this paper is to highlight the role of the nurse in the admission, evaluation, diagnosis and treatment of patients with incurable diseases that are in the terminal stages of their lives. This paper also clearly explains the development and policies of palliative care in the world and in Kosovo.

IV. Material and methodology of work

This paper is based on data obtained from statistics and data extracted in other research by various authors around the world regarding palliative care for the elderly.

I have reviewed the literature summarizing the necessary data and information regarding palliative care. The paper also uses comparative methods, thus comparing the level of development of palliative care in the developed countries of the world and in Kosovo.

V. Discussions

Palliative care is 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. This type of care is focused on relief from the symptoms and stress of a serious illness.

Palliative care teams specialize in treating people suffering from the symptoms and stress of serious illnesses such as cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney disease, Alzheimer’s, Parkinson’s, Amyotrophic Lateral Sclerosis (ALS) and many more. Palliative care is provided by a team of healthcare professionals with a range of skills to help you manage your life-limiting illness. Your palliative care team works together to meet your physical, psychological, social, spiritual and cultural needs and also helps your family and carers. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life. Palliative care can be provided along with curative treatment and does not depend on prognosis.

Our main goal is to show the role of the nurse in the care that a patient needs from an incurable disease and almost life does not make sense, meaning that we are one of the key factors in improving the quality of his/her life .

VI. Recommendations

Health care delivery organizations should take the following steps to provide comprehensive care:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community).
- Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed (including geriatricians). Depending on local resources, access to this team may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise.
- The full range of care that is delivered should be characterized by transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care. The committee believes that informed individual choices should be honored, including the right to decline medical or social services.
- all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management;
- educational institutions and professional societies should provide training in palliative care domains throughout the professional's career;
- accrediting organizations, such as the Accreditation Council on Graduate Medical Education, should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness (including primary care clinicians);
- certifying bodies, such as the medical, nursing, and social work specialty boards, and health systems, should require knowledge, skills, and competency in palliative care; • state regulatory agencies should include education and training in palliative care in licensure requirements for physicians, nurses, chaplains, social workers, and others who provide health care to those nearing the end of life;

- entities that certify specialty-level health care providers should create pathways to certification that increase the number of health care professionals who pursue specialty-level palliative care training; and
- entities such as health care delivery organizations, academic medical centers, and teaching hospitals that sponsor specialty-level training positions should commit institutional resources to increasing the number of available training positions for specialty-level palliative care

VII.Summary

Palliative care is 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.

The purpose of this research paper is to get acquainted with palliative care, diseases treated by palliative care, type of palliative care, principles of palliative care, palliative care in hospital and at home, palliative care today in world, palliative care in Kosovo, palliative care team, diference between palliative care and hospice, drug menagment in palliative care euthanasia, role of nurse and stress on the palliative care nurse. Also, the purpose of this paper is to highlight the role of the nurse in the admission, evaluation, diagnosis and treatment of patients with incurable diseases that are in the terminal stages of their lives. This paper also clearly explains the development and policies of palliative care in the world and in Kosovo.

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References

1.World Health Organization, Palliative care

2. American Society of Clinical Oncology, www.cancer.net

3. Jennifer Robinson, MD August 16, 2019, WebMd

4. American Society of Clinical Oncology (ASCO) 2005-2020

5. Hello Care Journal, 22 November 2020

6. I. G. Finlay, I. J. Higginson, D. M. Goodwin, A. M. Cook, A. G. K. Edwards, K. Hood, H.-R. Douglas & C. E. Normand, University of Wales College of Medicine, Velindre NHS Trust, Velindre Hospital, Cardiff, UK

7. Center of advice palliative care, MAR 11, 2016

8. (Wright, Wood, Lynch & Clark, 2008,469-471)

9. Ahlner-Elmqvist, Jordhöy, Jannert, Fayers & Kaasa, 2004, 585)

10. Cohen, Houttelkier, Onwuteaka-Philipsen, Miccinesi, Addington-Hall, Kaasa, Blisen & Deliens, 2010).

11. Io Jones, Emily Schneider, and A.J. Speigelman, Dartmouth Global Health Policy Lab, The Global Health Initiative at the Dickey Center for International Understanding, September 2018

12. WebMD Medical Reference Reviewed by Kumar Shital, DO on July 20, 2020

13. Tait P, Morris B, To T. Core palliative medicines - Meeting the needs of non-complex community patients. Aust Fam Physician. 2014 Jan-Feb;43(1):29-32.

14. Angela Morrow, RN , Jenny A. Dhingra, MD on November 21, 2019

15. https://www.nurseregistry.com/blog/palliative-care-nursing/ , 04.2.2020