



Lee Model of Geriatric Palliative Care

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Modelo de Cuidados Paliativos Geriátricos de Lee

RESUMEN

Palabras claves:

Dotación de personal
Enfermería
Servicios hospitalarios.

El modelo se basa en la teoría del cuidado humano escrita por el Dr. Jean Watson. Esta teoría honra la autonomía, la elección y el significado a través de la conexión humana profunda. El campo de Caritas es el "mundo interior de la práctica a nivel del corazón". El modelo tiene cuatro dominios. El primero es el más importante. La atención médica que recibe la persona (los tratamientos, la cirugía, la quimioterapia, los medicamentos) está alineada con los deseos, preferencias y valores de la persona.

Introducción

Today, I will focus on my topic of interest—geriatric palliative care.

By way of my background, I have been a nurse for 43 years. I was a nurse in intensive care for many years. I have been an advanced practice nurse for 22 years. We practice in an expanded role with full prescriptive authority in order to diagnose and manage common health problems in many settings—offices, hospitals, and homes. I am a family nurse practitioner trained to care for persons of all ages. I am also a certified hospice and palliative care nurse practitioner. We work as an interdisciplinary palliative care team – one doctor,

2 nurse practitioners, 1 social worker, and 1 chaplain—to meet the physical, emotional, social, spiritual, and existential needs of persons with serious illness. Each member of the team contributes to the well-being of the patient and family. We are a consult service and see patients who need help with pain and symptom management and goals of care discussions. We lead patient-family-clinician meetings to discuss what the right course of action is. We balance many ethical issues, as well.

I developed the first educational program in the US so that practicing nurses can gain more knowledge about palliative care. Nurses are concerned about needless suffering, futile care, aggressive end-of-life care, and feeling moral distress.

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They want to learn to be effective advocates for patients and families. The education program, called AgeWISE, was delivered at my hospital and then another 12 large hospitals in the US [Photo]. Hundreds of nurses have primary palliative care knowledge and skills. So, I come to you as a clinician and educator and theorist.

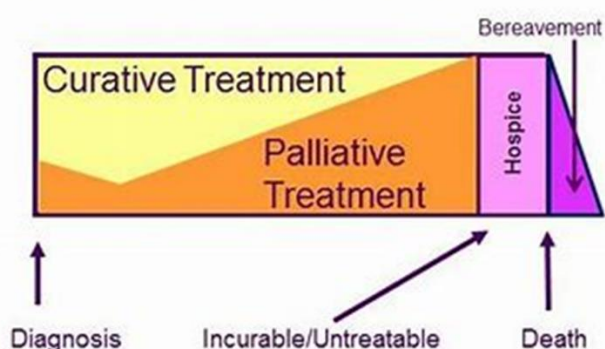
Palliative care is a philosophy of care and we are united in that philosophy here today. It is the core of who we are as nurses.

We are united in our care for humanity. We are united in our commitment to alleviate human suffering. We are united in our care for the last, the least, and the lost among us. It is our sacred covenant with society.

Women have been caring for the sick and dying for millennia. The modern hospice movement arose in England where Dame Cicely Saunders established the first hospice, Saint Christopher's Hospice, in 1948. But suffering is not limited to those who are dying. Palliative care arose from the modern hospice movement to alleviate the suffering of those with cancer. It has expanded to persons living with chronic illnesses—heart failure, kidney failure, degenerative neuromuscular diseases, Parkinson's disease, and dementia, to name a few. So, palliative care has evolved from cancer care to chronic illness care. We used to say that palliative care is for life-threatening illness. Now, the term most commonly used is serious illness. We often use the term "supportive care" instead of palliative care because many people equate palliative care with dying. Palliative care is also called an "added layer of support" for patients and families.

In the United States, hospice care is reserved for persons with 6 months or less to live, who agree to stop curative treatment, such as chemotherapy, and agree to palliative care. Hospice care is most likely provided to US citizens in their homes. There are small, inpatient hospice houses in the US but there are not enough of these. Hospice care falls under the umbrella of palliative care; hospice is palliative care for the last 6 months of life. Today's discussion of palliative care focuses on helping people to live as well as possible for as long as possible.

Palliative Care: The Integrated Model



Palliative care is critically needed throughout the world by an estimated 40 million persons (source: World Health Organization). More than 80% of the world does not have strong medicines available for pain control. Pope Francis has spoken many times in support of palliative care and supports the work of the Pontifical Academy of Life. In 2015, he said,

"...I appreciate your scientific and cultural commitment to ensuring that palliative care may reach all those who need it. I encourage professionals and students to specialize in this type of assistance which is no less valuable for the fact that it "is not life-saving". Palliative care accomplishes something equally important: it values the person" (Pope Francis, 5 Mar 2015).

In a commission of worldwide experts that the Pope himself ordered, The Pontifical Academy of Life, made several recommendations this year. One recommendation was that,

All universities engaged in formation of healthcare workers (doctors, nurses, pharmacists, social workers, chaplains, etc.) should include basic level palliative care training as mandatory undergraduate coursework.

"Todas las universidades que participan en la formación de trabajadores de la salud (médicos, enfermeras, farmacéuticos, trabajadores sociales, capellanes, etc.) deben incluir capacitación de cuidados paliativos de nivel básico como cursos obligatorios de licenciatura.

We are learning this week about palliative care upon the recommendation of the Vatican!

Palliative care started in US hospitals in the late 1990s. At Massachusetts General Hospital, the palliative care service started around 1996 with one physician and one advanced practice nurse. Massachusetts General Hospital is a Harvard teaching hospital and is one of the top 5 hospitals in the United States. In 2006, Palliative Medicine was recognized as a sub-specialty of medicine and now requires a one-year fellowship and passing certification examinations. I worked at Massachusetts General Hospital as a nurse scientist. It was during those years that palliative care became my primary interest.

There are three types of palliative care.

"Primary" palliative care or "generalist care" is the basic level of care that all nurses and doctors should be able to deliver to relieve suffering: pain and symptom management, psychological, spiritual, and existential care. Because most people do not have access to palliative care, it is very important that we all have basic knowledge.

"Secondary" palliative care is palliative care delivered by specialists who are certified in palliative care. Secondary palliative care is usually provided by interdisciplinary teams of doctors, nurse practitioners, social workers, and chaplains. Secondary palliative care began in the US hospitals but is moving now toward community palliative care.

"Tertiary" palliative care are specialty teams that focus on one type of illness or one type of pain. For example, anesthesia doctors can provide pain relief through injections or nerve blocks.

Synthesis Geropalliative Care

While we were teaching primary palliative care to nurses in the US, we conducted a literature search using terms

“geriatrics” and “palliative care” to determine how palliative care for older adults is different that for younger adults. We found 68 articles and reduced those themes to nine critical attributes of geriatric palliative care.

Critical Attributes	Brief Description
1. High risk for ineffective pain management.	Pain in older adults is under-assessed, under-reported, and under-treated especially in those with cognitive impairment.
2. Unpredictable trajectories of illness	Older adult experience less predictable trajectories of illness
3. Geriatric syndromes <ul style="list-style-type: none"> • Frailty • Falls • Polypharmacy • Dementia • Delirium • Atypical presentations 	Older adults are prone to geriatric syndromes, defined as common conditions which are associated with morbidity and mortality.
4. Chronic, comorbid conditions	Increase complexity and risk of complications
5. Shrinking social networks	Shrinking social networks due to death of spouse, siblings, peers; reduced energy; cessation of driving; distance of family members; likely resulting in less social support.
6. Insurance limitations	Out-of-pocket costs are highest for persons with chronic illness or functional impairments; At risk for omitting medications or cutting dosages.
7. Multiple settings of care	More likely to be cared for across multiple settings—hospital, rehab, long-

	term care, home; discontinuity of care.
8. Risk for ineffective communication	Due to sensory and/or cognitive impairment
9. Beneficial in the absence of disease	Older adults can benefit from palliative care by virtue of age alone, irrespective of disease

[Source: Lee, S. & Coakley, E. (2011). Geropalliative care: A concept synthesis. *Journal of Hospice and Palliative Nursing*, 13(4), 242-248.]

I will give you a case study here.

Case Study 1

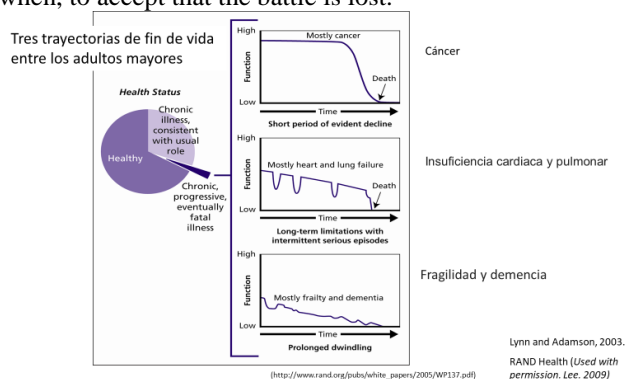
Mrs. M is an 84-year-old widow who lived independently in her own home. She was a retired nurse. Her daughters lived nearby but her husband and many of her friends and neighbors had passed away. Mrs. M. drove her car and did her own shopping and errands. About 6 months ago, she began to experience fatigue and shortness of breath with exercise, stairs, and carrying groceries. She also developed some back pain. She attributed it to old age and never said anything to her daughters. A week ago, Mrs. M developed a fever and cough and was admitted to the hospital at which time she was diagnosed with pneumonia. A lung CT scan showed that she had advanced metastatic lung cancer. The emergency department physician told her that she had pneumonia and that he also saw findings suggestive of cancer. She said, “I do not want a breathing tube.” She agreed to the plan of treating the pneumonia with intravenous antibiotics and fluids and oxygen and her condition improved on Day 2.

Further imaging, however, showed that the cancer had spread to her liver, spine, and brain. Three days later, however, she became confused and then unconscious. Her blood pressure dropped. She was diagnosed with urosepsis. Her daughters wanted everything done for their mother. She was taken to intensive care unit and intubated and mechanically ventilated. The palliative care team was consulted to discuss goals of care. The question becomes, not what you want to do, but what would your mother want done? Of course, the daughters were shocked and grieving and struggled to do the right thing. Their mother had been so healthy and took care of herself and was just driving a car 2 weeks ago. The oncologist told the daughters that, if Mrs. M survived this illness, she would only have weeks to live and would probably not return home; she would be sent to a nursing home. Mrs. M developed pulmonary edema and kidney failure. Many therapies were tried in the ICU. They were unable to stabilize her condition or wean her off the ventilator. After 10 days, Mrs. M’s daughters made the difficult decision to not escalate treatment. Two days later, the daughters agreed to allow the ICU doctor to withdraw life-sustaining treatments. The palliative care team, who visited daily, was present to ensure

effective sedation and to provide support to the family and nurses. Mrs. M died peacefully.

Uncertainty

A famous US physician and author, Dr. Atul Gawande, said, “These days, swift catastrophic illness is the exception. For most people, death comes only after a long medical struggle with an ultimately unstoppable condition—advanced cancer, dementia, Parkinson’s disease, progressive organ failure (most commonly the heart), followed in frequency by lungs, kidneys, liver), or else just the accumulating debilities of very old age. In all such cases, death is certain, but the timing isn’t. So, everyone struggles with uncertainty—with how, and when, to accept that the battle is lost.



This diagram is a very helpful when nurses teach patients’ families. Mrs. M followed the 1st trajectory of end-of-life. She had been healthy and independent (high function) until she had a sharp decline in her condition in the end. This is difficult for families to accept because they had been so healthy up until the final illness. In many ways, it is more difficult for families to let go.

The bottom trajectory shows how people slowly decline over time. People with dementia and frailty have fairly low function that dwindles. Swallowing difficulties, choking, aspiration, and pneumonia are often the reasons they die. Families have a lot of time to understand that their loved one is failing, although the long decline is heartbreaking.

The middle trajectory is associated with chronic illness, such as heart, lung, or kidney failure. People are functioning at home but do not go out much. They are frequently hospitalized. Each time they are discharged from the hospital, they never regain pre-hospitalization function. Their family members wonder, “Why cannot you fix him? Last time, he recovered well.” They also get upset and say, “If you would keep him in the hospital until he fully recovered, he would not be going back and forth from home to the hospital.” This pattern is our biggest challenge. We never know which hospitalization will end in death—but one will, eventually. So, I ask nurses to show this picture to the family and teach them, “Your mother has heart failure. This is what heart failure looks like. It is a difficult disease to manage. Many things can cause an exacerbation.” Families do find this helpful. They want to know what the future holds. Daughters want to know whether to quit their jobs to care for their mothers. Sons want to know if they should bring their mother to live with them. The family has to make many adjustments.

Referring to modern medicine, Dr. Gawande states that, “medicine has made it almost impossible to be sure who the dying even are” (Gawande, p. 157).

Medical decision-making has always taken a disease-focused approach but there is little data to guide the treatment of persons with multi-morbidity. Nurses need to understand that the science of treating multiple conditions is under-developed (Lee, 2018, p, 163). And so, we’ve moved to a new paradigm, that of goal-concordant care. Physicians can give their best opinions but they now seek the patient’s input on what matters most to the patient.

A physician says: “We can do the heart valve surgery. If successful, it will help your breathing and you will see a difference right away. But you may not recover to where you can live alone. You may need to live in a nursing home.”

Lee Model of Geriatric Palliative Care

With that background in mind, that older adults are disproportionately affected by disease and disability and that they are less likely to receive palliative care, we will consider an approach to the well-being of older persons in the last year or so of life.

This is the Lee Model of Geriatric Palliative Care. It is a situation-specific theory which will help guide the care of older persons in the last year of life.

The model is based in the theory of human caring authored by Dr. Jean Watson. This theory honors autonomy, choice, and meaning through deep human connection. The Caritas field is the “inner world of practice at the heart level” (Watson, 2008, p. 197). It is that sacred space created by the nurse through intentionality, authentic presence, deep listening. In fact, it is often said by Dr. Watson, that nurses “become the field” for healing and well-being. We sit with the patient in a private space, we establish eye contact, we listen intently, we sit in silence, we bear witness to suffering. These are caring competencies, or people skills. The nurse helps the person find meaning in illness and hope for the future.

The model has four domains. The first one is most important. Is the health care that the person is receiving—the treatments, the surgery, the chemotherapy, the medications—aligned with the person’s wishes, preferences, and values.

Case Study:

Here is a patient for whom I cared.

Mrs. A is a 90-year-old woman who has been hospitalized three times this year for bowel obstruction. She has refused surgery each time. Her goal is to remain at home and she is afraid that if she has surgery, she will either not survive, or she will have to go to a nursing home, a long-term care home for the elderly. Each time she is hospitalized, the bowel obstruction resolved with supportive care—a nasogastric tube and intravenous fluids. She is hospitalized a 4th time and supportive care was successful again. But 2 days later, she experiences abdominal pain. I was asked to see her for palliative care. I told her that she could go home again but that she would need to accept hospice care because they are the most well-trained nurses to care for her. She would have access to strong pain medications that she could receive more

quickly than taking an ambulance to the hospital. Going home was the most important thing to her. So, she accepted.

Purpose of the Model

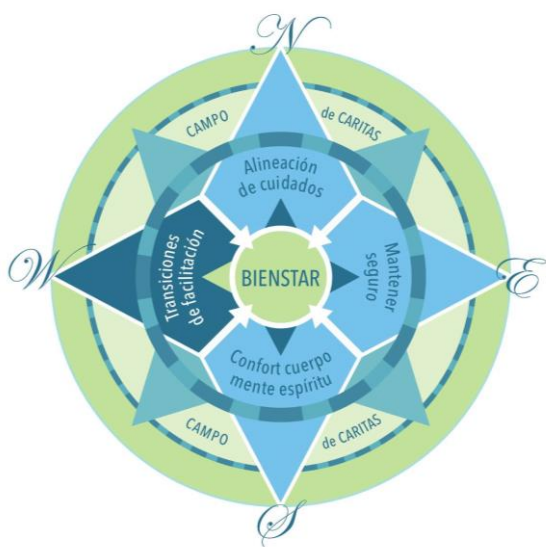


Figure. Lee Geriatric Caring Model. Copyright 2015 Susan M. Lee.

The purpose of the LGCM is to increase nurses' effectiveness in achieving well-being among older persons experiencing serious illness/frailty who are likely in the last year of life. The model aims to support caring-healing practices delivered within the Caritas field in 4 areas: 1) aligning care, 2) keeping safe, 3) comforting body/mind/spirit, and 4) facilitating transitions.

Assumptions

- 1) Well-being is attainable in end-stage disease. In fact, humans have potential for love, gratitude, joy, well-being and growth until death.
- 2) Nurses can have goals of care discussions.
- 3) Patients/families believe discussions about the future are helpful.

Well-Being as Outcome

The overarching goal of the model is well-being. I define it very broadly as one's subjective assessment of their life that leads one to judge life positively and with hope for the future. At end-of-life, people can experience well-being when they believe that their preferences for care will be met, that no harm will come to them, that their symptoms will be well managed, and that they have supportive caregivers to care for

them as their condition declines. Research shows that one of the strongest predictors of well-being are supportive relationships. We provide important support to persons. Our ability to be present, to listen, to bear witness to suffering leads to well-being.

Aligning Care

The model is a compass. True north is "aligning care" which involved intentional acts to ensure that health care is aligned with the person's values, goals, and preferences. The ethical principle that guides this domain is autonomy. We learn about others' preferences by asking questions, such as "What is your understanding of your illness?" "What is most important to you at this time?" Caring-healing nursing interventions might include: deep listening, being with, helping patients envision the future, providing patients/families information about palliative care. The outcome of these interventions is well-being—patients can tell their stories, without judgment, and receive assurance that their wishes will be honored.

Keeping Safe

These are nursing interventions that prevent harm. Older adults are extremely vulnerable in the hospital and often suffer hospital-related harms—falls, skin tears, confusion, medication side-effects, under-nourishment, etc. The nurse needs to have specialized knowledge to anticipate and prevent harms. The ethical principle that guides this domain is non-maleficence. Caring-healing, nursing interventions might include—reviewing medications for inappropriate use, assessing risk for falls and developing a nursing care plan to prevent falls, and encouraging mobility to prevent deconditioning. The outcome is well-being because of the nurses' commitment and actions to prevent harm. In this domain, we use all current geriatric knowledge.

Comforting body/mind/spirit

The third domain is comforting body/mind/spirit which is defined as caring-healing acts that minimize human suffering. The ethical principle that guides this domain is beneficence. Nurses can ask, "What is distressing to you?" "Tell me about your suffering?" In this domain, the nurse uses her/his knowledge of palliative care to alleviate physical, emotional, spiritual, and existential sources of suffering. Caring-healing nursing interventions are—offering hope to another through presence and healing energy, using standardized approaches to assess and manage symptoms, remaining present until distressing symptoms have abated, and listening to both positive and negative feelings to allow for healing (this one being a Caritas process). The outcome is well-being because the patient's distress was alleviated in a timely manner while maintaining a supportive human connection. Pope Francis recently said, "The objective of palliative care is to alleviate suffering in the final stages of illness and at the same time to ensure the patient appropriate human accompaniment." Human presence. A powerful balm to the sick.

Facilitating Transitions

The fourth domain is facilitating transitions which is defined as helping persons/families move to the next place of care, the next mind-set, a lower functional status, or a peaceful death.

The ethical principle is fidelity—keeping our promises to patients. Caring-healing nursing interventions are asking important questions, such as, “What are your goals of care at this point in your illness?” The nurse engages in deep, authentic listening, exploring sources of strength, hope, growth, love. The nurse asks, “What most concerns you?” “What are your fears?” “What are your worries?” The nurse helps the patient and/or family gently envision the future. The outcome is well-being because the patient is supported in the next phase of illness, which may entail the end of curative treatments, transfer to another setting, loss, potential for growth, or a dignified death.

These four domains will guide the nurse to take good care of an older patient who is in their last year of life. How do we know who is in their last year? Declining activity, multiple falls, low performance status, frequent illness, frequent hospitalizations, diminishing appetite, swallowing difficulties, increasing dependence. Measures of frailty are helpful. Staging a person’s dementia is helpful. The “surprise question” has been found to be a reliable indicator. This is when we ask the older person’s doctor, “Would you be surprised if Senora Gonzalez is alive in one year?” If the doctor says, “No,” it is an indication that the person is getting close to end-of-life.

Summary

- I invite you on a path of expanded practice to alleviate human suffering.
- Worldwide, 40 million people need palliative care.
- 78% in low- and middle-income countries.
- I can assure you that we need more palliative care even in the US. Even in the best hospitals, less than 5% of patients receive palliative care.
- Lack of training and awareness of palliative care among health professionals is a major barrier to improving access.
- The global need for palliative care will continue to grow as a result of the burden of noncommunicable diseases and aging populations. (World Health Organization)

Pope Francis: “All of medicine has a special role within society as a witness to the honour that we owe to the elderly person and to each human being.” Pope Francis. (5 Mar 2015). “Address of His holiness Pope Francis to participants in the plenary of the Pontifical Academy for Life.” Retrieved from

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Summary Gawande

“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way. (Gawande, p. 259).

So, we are living with a lot of medical uncertainty. Advances in surgical technology makes it possible for very old people to have surgery. Most often, however, it is their chronic medical comorbidities that cause complications—not the actual surgery. So, we discuss with older persons and their families their unique situations so that they can make decisions that are best for them. The current paradigm is heavily based on autonomy and self-determination.

There is an urgent need for palliative care that cannot be met by experts.

- Caring and compassion are not enough.
- Each of us must be knowledgeable in basic palliative care principles.
- Managing physical suffering is our covenant with society.
- But we must go beyond the physical, to comfort body/mind/spirit.
- I look forward to this conference and further dialogue.

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