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PALLIATIVE CARE - CARING FOR THE SERIOUSLY ILL PATIENTS AND THEIR CAREGIVERS

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Palliative Care - Caring for the Seriously Ill Patients and Their Caregivers

OBJECTIVES:

1. What is palliative medicine and palliative care
2. Guidelines for Palliative Care
   Goals
   Domains and criteria
3. Supportive care for lung cancer caregivers
4. Future challenges for lung cancer caregivers

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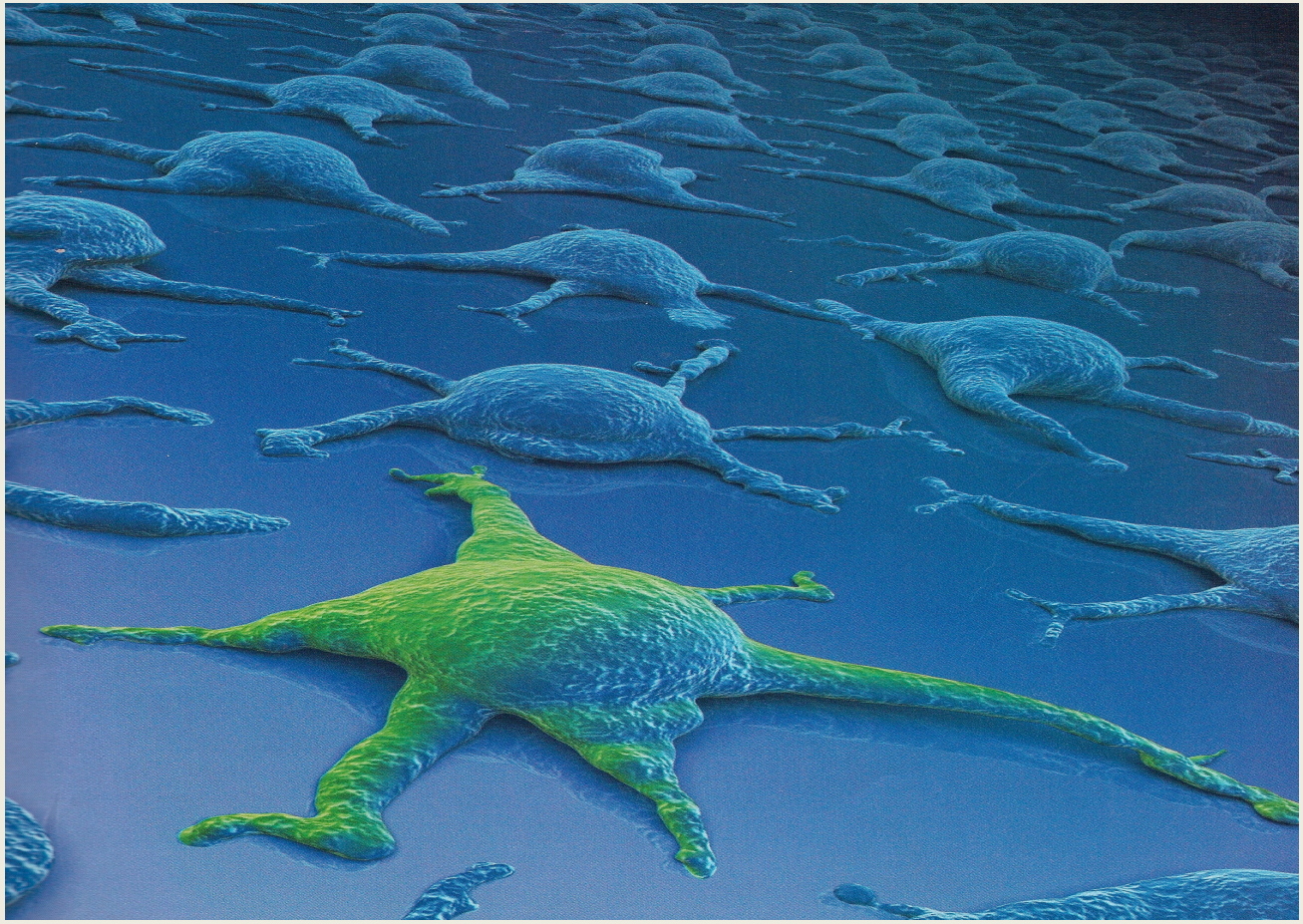
Single Cancer Stem Cell



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Cancer Stem Cells

- Cancer cells are often perceived as all having the same potential to proliferate and expand the disease, but in many types of cancer only a small subset of tumor cells have that power.
- The tumor-generating cells share key traits with stem cells (pluripotential), including an unlimited life span and the ability to generate diverse range of other cell types and are therefore considered cancer stem cells.
- These malignant progenitors are believed to spring from regulatory failures in damaged stem cells or their immediate offspring.
- Cancer treatments must target cancer stem cells in order to eradicate the cancer.
  - Clarke MF, Becker MW. Stem Cells: The Real Culprits in Cancer? Scientific American. July 2006:52-

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Hospice and Palliative Medicine

- **Historical Perspective: Symbolic Thanatology**
- Science has provided us with a very detailed process of how humans are created, even cloned; but little is known about how we die. French historian, Philippe Aries, suggested that to study the evolution of care in a short period of time is to attribute effects to the wrong causes, since fundamental changes are slow to take effect. Nonetheless, the process of dying remains a relative mystery even in today's advanced technology.
  - Aries P. *The Hour of Our Death.* Hardmonsworth:Peregrin Books, 1983:xi-xiii.
  - Oblate JMN. *Care of the dying in 18th century Spain – the non-hospice tradition.* European J Pall Care, 1999;6(1):23-

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Hospice and Palliative Medicine

- A thousand years ago, monks from the Abbey of Cluny in France provided us with prayers, music (chants), spiritual teachings to the sacred art of dying. Harpist, Therese Schroeder-Schecker has refined music thanatology as a very important therapeutic tool in addressing major domains of suffering, thus providing patients with a peaceful and comfortable journey.
  - Groves R. *The Sacred Art of Dying,* St Anthony Messenger Press, Cincinnati, Ohio

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Hospice and Palliative Medicine

- **In the early years of hospice in America, hospice services were primarily provided to patients with cancer. Many hospices in America still just provide care for patients with a terminal cancer. One reason for this practice was due to the influence by St. Christopher's Hospice, the prototype of the hospice movement worldwide started by Dame Cicely Saunders, Foundress of the Hospice Movement. A second reason could have been because in the care of cancer patients there is usually a very distinct disease trajectory; a stoichiometric point when therapeutic interventions are no longer a realistic goal and quality of life becomes the focus for patients and their family.**

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Hospice and Palliative Medicine

- End of life care is focused on relieving the four dimensions of suffering
  - Physical
  - Psychological
  - Social
  - Spiritual
    - Addressing the fragmentation of personhood - Eric Cassell, MD
    - Total Pain - Cicely Saunders
    - The challenge of meaning - Ira Byock
      - AMA: The EPEC Project

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Hospice and Palliative Medicine

- **Concepts of Hospice:**
  - **Comfort vs. Cure**
  - **Symptom Management**
  - **Home environment**
  - **Patient and Family as a Unit of Care**
  - **Interdisciplinary Team**
  - **Addressing ethical issues**
  - **Strong emphasis on social, psychological and spiritual issues**
  - **Grief support and bereavement**
    - **Peralta A. End of Life Care in the 21st Century. Texas *D.O.* May 2001;LVII(5):12-16.**

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Palliative Care Definition

- The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.
  - National Census Project for Quality Palliative Care. Executive Summary, Clinical Practice Guidelines for Quality Palliative Care, *Jour of Palliative Medicine*, 2004.

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Hospice and Palliative Medicine

- Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. Evaluation and treatment should be comprehensive and patient-centered with a focus on the central role of the family unit in decision making. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process, and death.

  - 1 National Quality Forum. A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report. 2006.
  - www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=22041.
  - 2 Centers for Medicare & Medicaid Services. Medicare and Medicaid Programs: Hospice Conditions of Participation; final rule. Federal Register. Vol 73. Washington, DC.
  - 3 National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2004.

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Hospice and Palliative Medicine

- Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining. Comprehensive palliative care services often require the expertise of various providers to adequately assess and treat the complex needs of seriously ill patients and their families. Leadership, collaboration, coordination, and communication are key elements for effective integration of these disciplines and services (NCP 2004).

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Advances in Palliative Medicine

- A Vision for Better Care at the End of Life, Last Acts - Five Principles of Palliative Care
- AMA, Institute of Ethics - Education of Physicians on End-of-Life Care (EPEC Project)
- Moyers on Dying, PBS Series - “On our Own Terms”
- Specialties in Medicine - Milbank Memorial Fund: Core Principles for End of Life Care
- National Consensus Project: Clinical Practice Guidelines for Quality Palliative Care
- National Hospice and Palliative Care Organization
- American Academy of Hospice and Palliative Medicine

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State-of-the-Art of Palliative Medicine

- Hospice and Palliative Nurses Association certification for RN, LVN, APN
- Center to Advance Palliative Care – Mount Sinai School of Medicine
- American Board of Medical Specialties – 10 Boards recognized Hospice and Palliative Medicine as a subspecialty and AOA certification in Palliative Medicine
- 41 accredited fellowships in palliative medicine
- 15 major journals devoted to palliative medicine
- Major research grants dedicated to palliative medicine.

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National Consensus Project - Clinical Practice Guidelines for Quality Palliative Care

- Goals:
- Facilitate the development and continuing improvement of clinical Palliative care programs providing care to patients and families with life-threatening and debilitating illness.
- Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency, and reliability of these services.
- Establish national goals for access to quality palliative care.
- Foster performance measurement and quality improvement initiatives in palliative care services.
- Foster continuity of palliative care across settings (home, residential care, hospital, hospice).

  - National Census Project for Quality Palliative Care. Executive Summary, Clinical Practice Guidelines for Quality Palliative Care, *Jour of Palliative Medicine*, 2004

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Domains of Quality Palliative Care

- Structure and Process of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care.
  - National Census Project for Quality Palliative Care. Executive Summary, Clinical Practice Guidelines for Quality Palliative Care, *Jour of Palliative Medicine*, 2004

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Palliative Medicine

Palliative Medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is life-limiting, life-threatening and life-altering and the focus of care is quality of life. Hospice and Palliative Medicine is a new subspecialty accredited by the American Board of Medical Specialties (2005). It is a specialty where other physicians boarded in ten (10) other subspecialties can be also boarded as Hospice and Palliative Medicine subspecialist. There are 61 accredited Universities and School of Medicine, which offer fellowship in Hospice and Palliative Medicine.

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Palliative Medicine

- Palliative Medicine specialist demonstrate their skills in pain and non-pain symptom management, collaborate with other medical specialists, develop skills to embrace different pathologies, embark on appropriate research, establish evidence base best practices, and provide supportive care to the patient and family including enhancing quality of life.

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Palliative Medicine Specialist

- Provide relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Creates a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Utilizes a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Enhances quality of life, and may also positively influence the course of illness
- Participates early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy. radiation therapy, immunotherapy, integrative medicine using traditional and Alternative and Complementary Medicine and includes those investigations needed to better understand and manage distressing clinical complications.

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Major Issues for patients and caregivers with serious illnesses:

- Pain – Symptom Management
- Loneliness – Religious and Existential Issues
- Loss of Control – Ethical Issues (our final disengagement)

- Bishop Edward Crowther, "Care versus Cure of the Terminal Illness". 1970:Unpublished Dissertation.
- Peralta, A "Ethical and Psychological Perspectives - Survival of the Mature Elite, 2013.

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Patients at Risk for Pain

- Cancer
- Non-cancer illness:
  - Dementia
  - Cardiovascular disease
  - Pulmonary disease
  - Neurological disease: stroke, ALS, MS, Muscular Dystrophy, mentally impaired
  - End Stage Organ Disease: Renal, Liver
  - AIDS
  - Osteoarthritis, RA, Vertebral Compression Fx.
  - Congenital Anomalies - Trisomy's, SMA, Leukodystrophies, Sickle Cell Disease, etc.

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Definitions of Pain

- Acute Pain - usually follows injury to the body and disappears when the injury heals. Often, but not always, associated with autonomic nervous system stimulation, i.e., tachycardia, hypertension, diaphoresis, mydriasis and pallor. It is rarely justified to defer analgesia until a diagnosis is made.
  - Pace S, Burke TF. IV morphine for early pain relief in patients with acute abdominal pain. Acad Emerg Med 1996; 3:1086-1092
- Cancer Pain - may be acute, chronic or intermittent, and usually has a definable cause, i.e., tumor progression or treatment.

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Definitions of Pain

- Chronic Pain - is rarely accompanied with signs of sympathetic stimulation. It is important to address all domains of suffering in treating chronic pain: physical, social, psychological, spiritual. Acute pain may be superimposed over chronic pain causing a crescendo/ decrescendo clinical picture. Lack of objective signs of chronic pain may cause the inexperienced clinician to discount the patient's level of pain.
  - Modified from Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain. American Pain Society 1999;4th ed.:4.
- Chronic pain may be accompanied by: anxiety, hostility, loneliness, depression, insomnia, anorexia, frustration, anger, and/or suicidal ideation.

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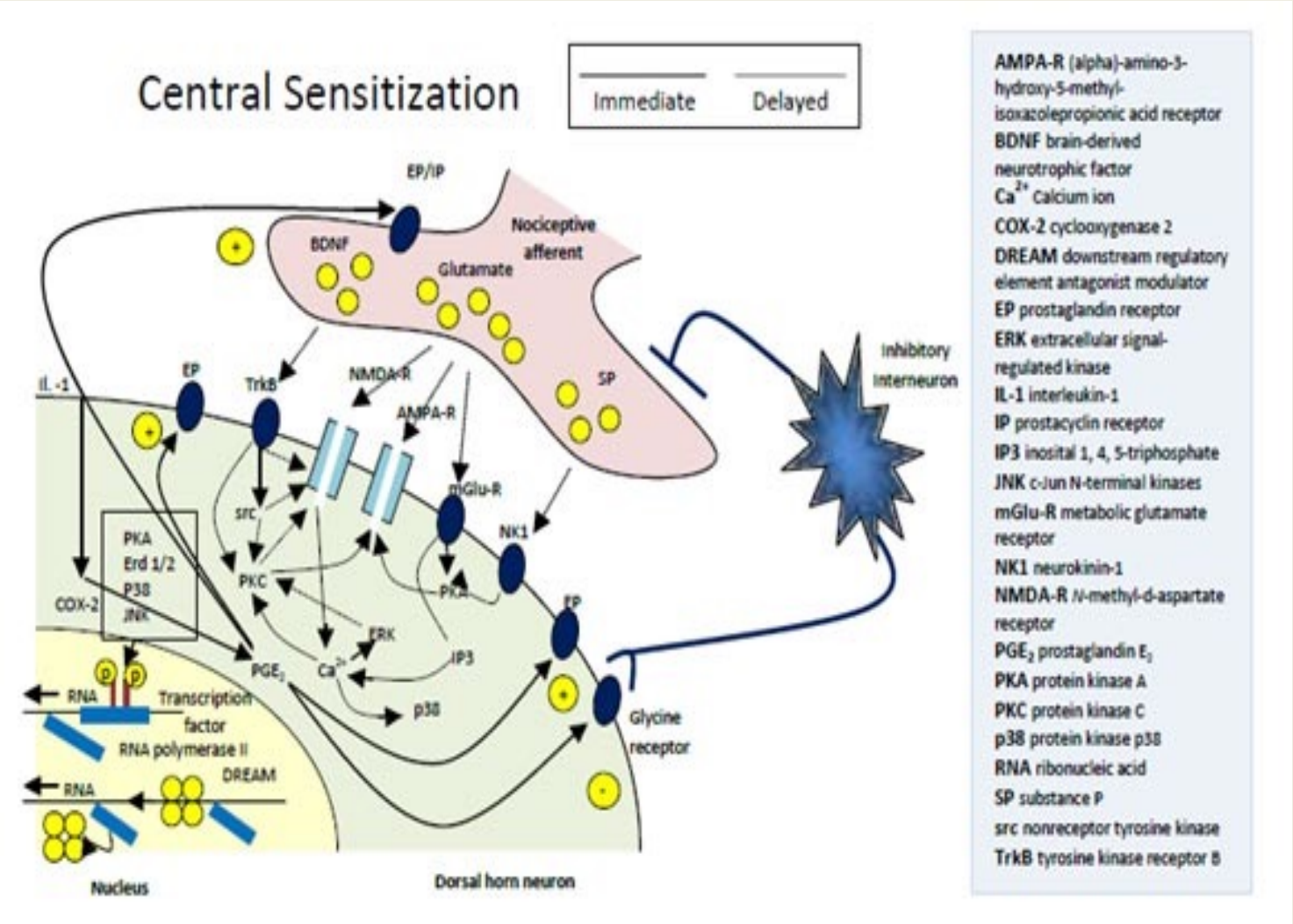

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Pain Assessment Tools

- Visual Analogue Scales:

1. Descriptive Scale: 0-10, describing no pain as zero and worst pain as ten
2. Wong-Baker Faces: 0-5, faces of no pain to severe pain
3. Numeric scale: 0-10, Zero no pain; rating of mild pain from 1-3; moderate pain from 4-7 and severe pain from 8-10
4. Pain Thermometer in the elderly: 0-10, zero is no pain; 1-2 is little pain; 3-4 is moderate pain; 5-6 is quite bad pain; 7-8 is very bad pain; 9-10 pain that is almost unbearable

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Nonspecific Behavior Observations Suggesting Pain

- Non-Verbal Behaviors:
  - Restlessness, guarding, bracing, rubbing, fidgety, striking out, recurrent agitation
- Vocalizations:
  - Crying, moaning, groaning, calling out, sighing, labored breathing
- Facial Expressions:
  - Frowning, grimacing, wincing, fearful faces, grinding of teeth
- Others:
  - Decrease in: ADL, function, appetite, sleep
  - Resisting ROM during care, abnormal gait
  - Hand grip
    - *Chronic Pain Management in the Long-Term Care Setting,* AMDA, Clinical Practice Guidelines, 1999. Modified by A. Peralta

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Barriers to Pain Management

- PATIENT
  - "Wimp"
  - Fear of adverse drug effects/events
  - Fear of addiction
  - Other illness or disease/pathology
  - Knowledge deficit
- CAREGIVER
  - Knowledge deficit
  - Fear of opioids
  - Legal pressure
  - Pain as a "symptom"
  - Fear of addiction
  - PRN

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Chronic Pain Misconceptions

- Personal weakness to acknowledge pain and conversely, strength in character to bear pain.
- Chronic pain is part of aging.
- Chronic pain is a punishment for past actions.
- Chronic pain heralds a serious disease.
- Acknowledging pain will cause painful and invasive testing and loss of autonomy.
- Cognitively impaired elders have higher thresholds and cannot be assessed for pain.
- Elders in LTCF seek attention with pain symptoms and are likely to become addicted to pain medications.
  - *Chronic Pain Management in the Long-Term Care Setting,* AMDA, Clinical Practice Guidelines, 1999.

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Ethical Imperatives to adequate pain management

- MORAL ISSUES:
  - Patients have a strong prima facie right to freedom from unnecessary pain.
  - Pain is dehumanizing.
  - Pain destroys autonomy. The Ethical Principal of Autonomy allows self-determination by patients.
  - Pain is humiliating.
  - In its extreme, pain destroys the "soul" itself and all will to live.
    - E. Cassell, MD. The Nature of Suffering. Oxford Press, 1991 and Lisson, Nurs Clin North Am. 1987; 22:654.

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The Wasting Syndrome of Cachexia and Fatigue

- Cachexia a serious but under recognized consequence of many chronic diseases. Prevalence ranges 5–15 % in end-stage chronic heart failure to 50–80 % in advanced cancer.
- A part of the terminal course of many patients with chronic Heart Failure, kidney disease, COPD and rheumatoid arthritis.
- Annual Mortality rates
  - 10–15 % - COPD
  - 20–30% - **HF** and kidney disease
  - 80 % - Cancer
    - J Cachexia, Sarcopenia and Muscle 2014, 5: 261.

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The Role of Biomarker and Inflammatory Modulators

- Inflammatory catabolic cytokines
  - Type 1:TNF-Alfa
  - Type 2: TGF-Beta, IL-4, IL -6, Il 10, IL -13
  - TNF-B , superfamily Macrophage inhibiting cytokine or MIC-1/Macrophage migration Inhibiting factor (MIF)

Cytokines are important in health and disease, specifically in host response to infection, immune responses, inflammation, trauma, sepsis and reproduction

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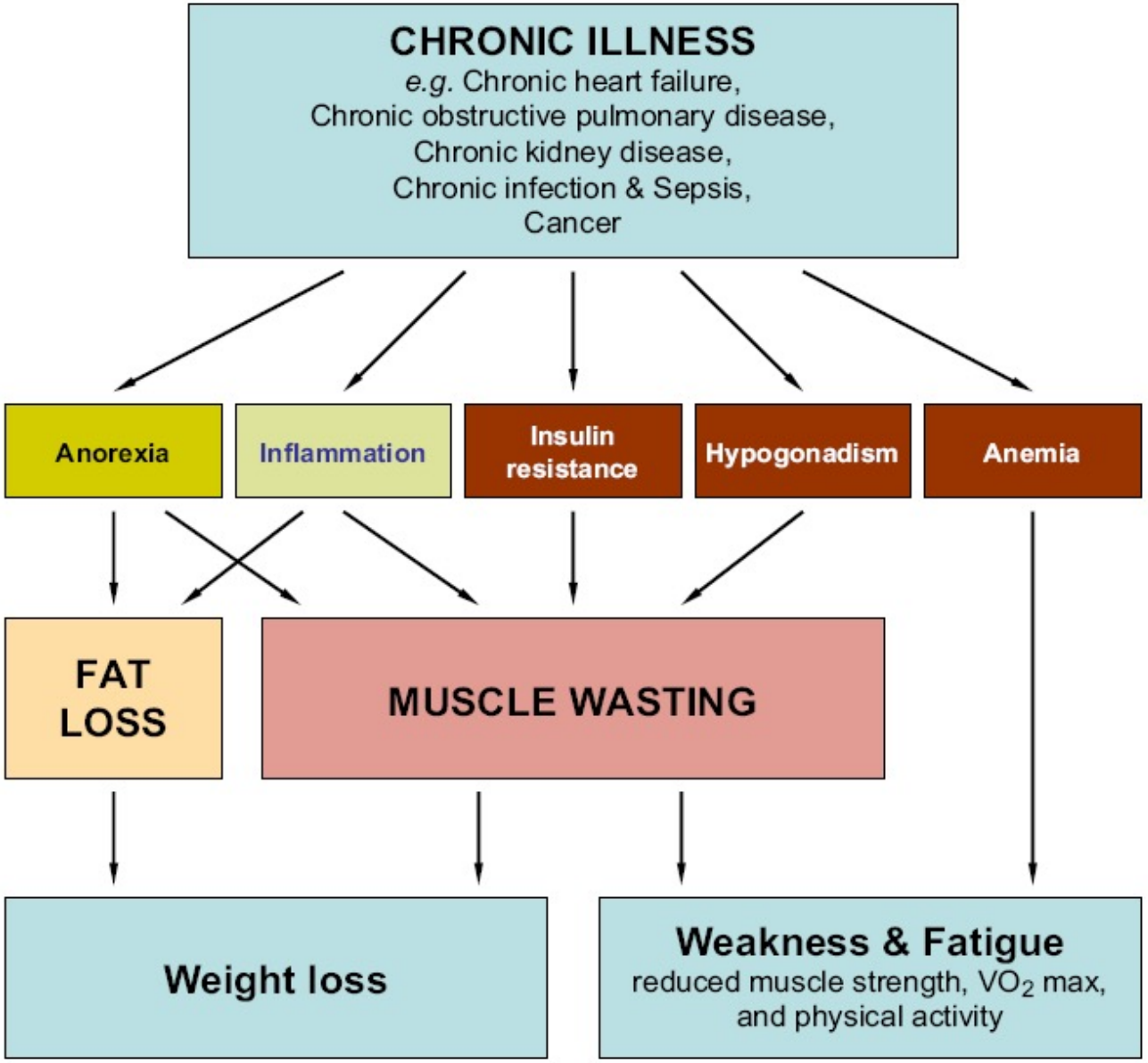

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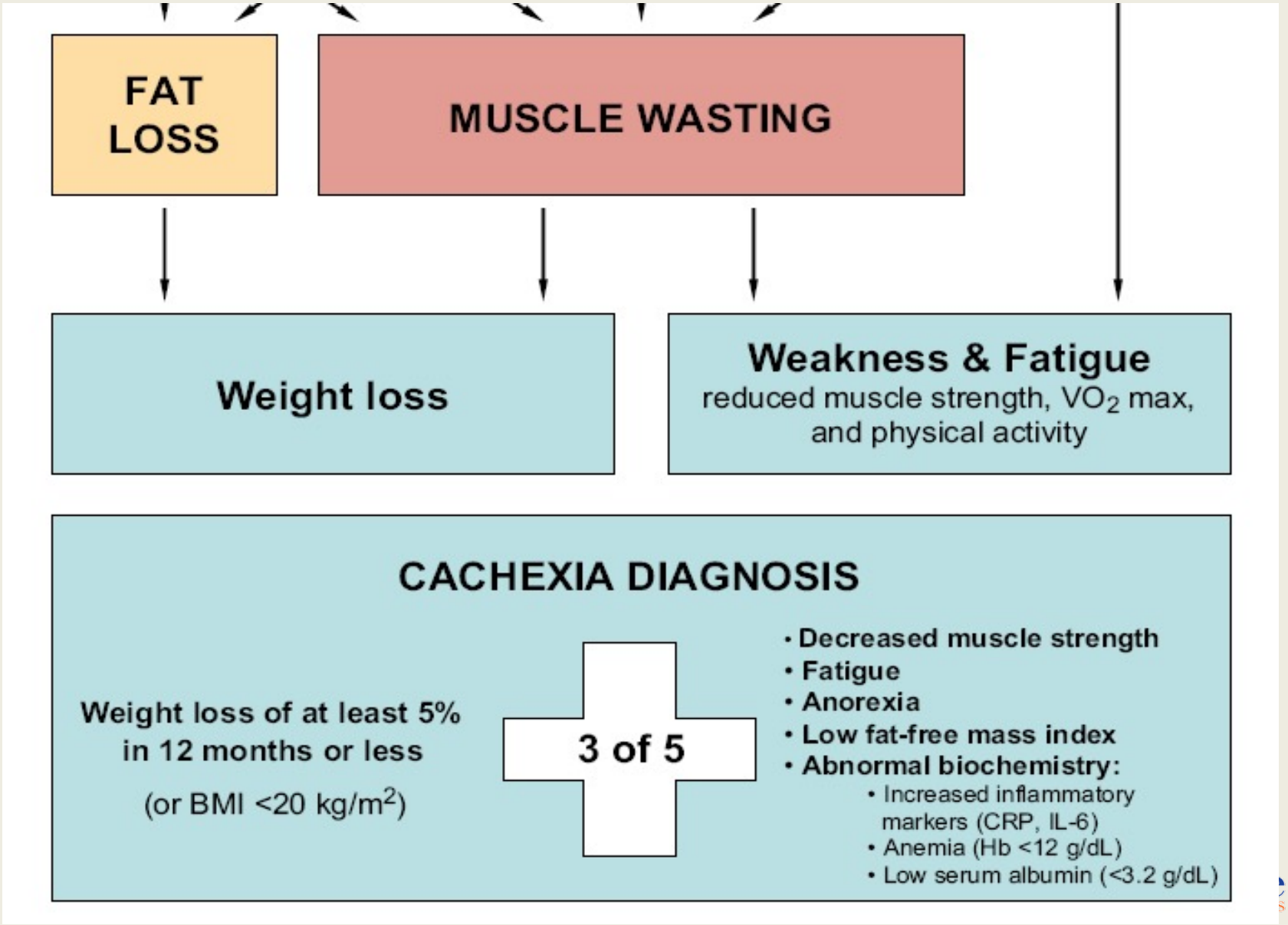
FAT LOSS
MUSCLE WASTING
Weight loss
Weakness & Fatigue
reduced muscle strength, VO_2 max, and physical activity
CACHEXIA DIAGNOSIS
Weight loss of at least 5% in 12 months or less
(or BMI <20 kg/m^2)
3 of 5
• Decreased muscle strength
• Fatigue
• Anorexia
• Low fat-free mass index
• Abnormal biochemistry:
• Increased inflammatory markers (CRP, IL-6)
• Anemia (Hb <12 g/dL)
• Low serum albumin (<3.2 g/dL)

Loneliness

AARP Article – *It there a cure for Loneliness?*

Loneliness carries a stigma that hampers efforts to help suffer.

It implies that one is a social failure.

It is clear that the pain of loneliness is real. If that is the cause could the pain of loneliness be treated.

Major metanalysis studies have shown that there is a 32% risk of early death for those living alone.

Early treatment with Cognitive Behavioral Therapy (CBT) is pivotal.

It will help the lonely person understand that their behavioral and assumptions may be working against their desire to connect with love ones.

AARP January 2020.

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Loneliness Strongly Affects Mental Health and Overall Well-Being

- Although loneliness affects a slate of health outcomes, its strongest effects appear to target mental health and overall well-being, according to a comprehensive review and meta-analysis published online in *Psychiatry Research.*
- "From a public health perspective, the adequate training of healthcare providers to perceive, detect, and respond to loneliness among patients should be prioritized," researchers advised. "Currently, loneliness is not systematically assessed and treated by clinicians; however, due to its potential adverse effects on health outcomes, the assessment and treatment of loneliness should be integrated into routine clinical care."
- To evaluate the comparative effects of loneliness on a handful of broadly defined yet distinct health outcomes (mental health, general health, well-being, physical health, sleep, and cognition), researchers reviewed and analyzed 114 studies that looked at associations between loneliness and one or more health outcomes.

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Loneliness a Common Health Threat

- The main analysis showed medium-to-large effects of loneliness on all health outcomes, with the largest effects on mental health and overall well-being. Random effects meta-analyses revealed the followed pooled effects of loneliness on specific mental health outcomes: -0.497 for depression, -0.417 for anxiety, -0.516 for suicidality, -0.489 for general mental health, and -0.476 for well-being. In contrast, effects on sleep and cognition were much smaller, with pooled correlations of -0.293 and -0.189, respectively.
  - Park C, Majeed A, Gill H, et al. The effect of loneliness on distinct health outcomes: a comprehensive review and meta-analysis. Psychiatry Research. 2020 October 19

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UCLA Three-Item Loneliness Scale

- *Questions:*
- First, how often do you feel that you lack companionship?: Hardly ever = 1, some of the time = 2 or often =3
- How often do you feel left out?: Hardly ever =1, some of the time =2, or often =3
- How often do you feel isolated from others?: Hardly ever =1, some of the time =2, or often =3?)
- NOTE: For both scales, the score is the sum of all items
- Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2394670/

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Trauma Informed Care

- Trauma informed care is an organizational culture that recognizes that everyone who interacts with an agency may have a past traumatic experience that we may or may not know about.
- A trauma-informed organization treats everyone in ways that protect trauma survivors from re-traumatization
- Trauma-Informed Approach:
  - According to the concept of a trauma-informed approach, “A program, organization, or system that is trauma-informed:
  - *Realizes* the widespread impact of trauma and understands potential paths for recovery;
  - *Recognizes* the signs and symptoms of trauma in clients, families, staff, and others involved with the system;
  - *Responds* by fully integrating knowledge about trauma into policies, procedures, and practices; and
  - Seeks to actively resist *re-traumatization*."

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Six Principles of a Trauma-Informed Approach

- A trauma-informed approach reflects adherence to six key principles rather than a prescribed set of practices or procedures. These principles may be generalizable across multiple types of settings, although terminology and application may be setting- or sector-specific:

    1. Safety
    2. Trustworthiness and Transparency
    3. Peer support
    4. Collaboration and mutuality
    5. Empowerment, voice and choice
    6. Cultural, Historical, and Gender Issues

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Moral Distress

- The idea of total Moral Injury and Trauma
  - all of us experience moral injury and trauma
  - Physical, social, psychological and spiritual injustices cause moral distress
- Transdisciplinary approach or model to create personal and team resiliency for all who are involved in providing and receiving care.
  - Covid Conversations Moral Distress and Building Moral Resilience, Marcia Glass, MD William E. Rosa, PhD, MBE, ACHPN, FAAN, Vicki A. Jackson, MD MPH FAAHPM, AAHPM 2021
- How can authenticity be part of our supportive care in all our actions and behaviors.
- To incorporate total moral trauma and injury as part of our best practices in supportive and palliative care.
  - Alexander Peralta, Jr, MD, Lungevity Hope Summit 2021

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Hope and Healing

- Hope is an expectation greater than Zero of achieving a goal
  - Robert Twycross, Pain expert and pioneer in palliative medicine.
- Hope is an orientation of the spirit, an orientation of the heart. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out.
  - Vaclav Havel-a Czechoslovakian and Czech Republic, intellectual, politician, dissent and human right activist (died December 2011).

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Dr. Carl Gustav Jung 1930 lecture

- stated that it is a tragedy in our part of the world that developmental tasks of the second half of life seem unknown to most people. We lead our lives with the erroneous apprehension that continuing with the tasks of the first half of life is all there is. As a consequence, many of us meet our death as half-developed individuals, exhibiting signs of depression, despair, fear of death, and disgust with ourselves and others, together with feeling that life has been uncompleted or wasted. Jung implies that other cultures might be better aware of the special developmental tasks of the second half of life.

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The Myth Of Life

- People say that what we're all seeking is a meaning for life. I don't think that's what we're really seeking. I think that what we're seeking is an experience of being alive, so that our life experiences on the purely physical plane will have resonance within our own innermost being and reality, so that we actually feel the rapture of being alive."
  - Joseph Campbell. The *Power of Myth,* with Bill Moyers;1988.

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Healing Assertions:

- We are people who are intrinsically spiritual.
- We are people who need to attend to the spiritual dimensions of life.
- We are people in need of reflection and spiritual nourishment.

  - **Peralta, A. Comparing NDA vs. NDE, NHPCO, Clinical Team Conference:2008.**

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Healing

- Is a state of mind when our body, mind and spirit are in harmony with our most inner self. We call this an epiphany - the oneness of self. Where deep touches deep and oneness flourishes. Where forgiveness can be extended and received, material things are put in order, broken relationships can be mended and absolute love exists.
  - Levine, Stephen "Healing into Life and Death. Doubleday Dell Publishing, 1987.
  - Magno, JB: Hospice in America, *Published Autobiography,* 2007
- It is how we philosophically orient ourselves in nostalgic and practical ways to an unseen order. Modified by Alexander Peralta MD
  - Juan Lorenzo Hinojosa, PhD, Theologian, paraphrased from *Varieties of Religious Experiences by* William James

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Post COVID-19 Pandemic Health System Science

- Post-acute COVID-19 Syndrome has caused morbidity and mortality at an unprecedented scale globally. Scientific and clinical evidence is evolving on the subacute and long-term effects of COVID-19, which can affect multiple organ systems. Reports suggest residual effects such as fatigue, dyspnea, chest pain, cognitive disturbance, coagulopathies, neurological sequelae of Guillain Barre's syndrome, severe back pain, sciatica, acute myelitis, arthralgia and overall decline in quality of life.
- It can cause cellular damage due to inflammatory cytokines and pro-coagulant state.
- The High-dimensional characterization of post-acute sequalae of COVID-19 are just being innumerated including mental health burden, GI systems and poor general wellbeing.

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Caregiver Scientists

- Describe ways contemporary culture expresses discomfort with lung cancer patients
- Learn the science of the lung cancer, treatments and CAM including herbal medicine, hypnosis, endocannabinoids – Marijuana (THC), Cannabidiol (CBD), Ketamine, Esketamine, and psychedelic assisted therapies – psilocybin
- Neuroplasticity – how the mind heals itself
- Grounding/Mindfulness therapies
- Guided imagery
- Touch therapies
- Neuropsychoanalysis
- Sand Play Therapy
- Explore the role of “antecedent losses” in shaping personal narratives
- Model Storytelling techniques

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Closing Comments

- The meaning of the experience of holistic pain determines the level of suffering.
  - Alexander Peralta
- The Four Agreements by Don Luis Ruiz
  - Be impeccable with your word – speak with integrity, say what you mean
  - Don't take anything personal – nothing others do is because of you
  - Don't make assumptions – find the courage to ask questions and to express what your really want. Your communications must be crystal to avoid misunderstanding, sadness and drama!
  - Always do your best – your best is going to change from moment to moment. It will be different when you are healthy as opposed to being sick. Avoid self-judgment, self-abuse and regret.

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The Healing Heart

- Palliative Care is intensive human caring. It is the integration of the bio-technical primary worldview of treatment of diseases with the psychosocial and spiritual secondary worldview of symptom management when cure may no longer an option. As physicians, we believe that it is privilege to learn from patients and caregivers as they narrate their life journey with a serious illness. It is where the art and science of medicine truly lives. Alexander Peralta, MD

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