Caring Full Circle: New Perspectives and Practices in Palliative Care

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Scope of Palliative Care

01

Palliative care is a specialized form of medical care focused on improving the quality of life for patients with serious illnesses such as metastatic breast cancer (MBC).

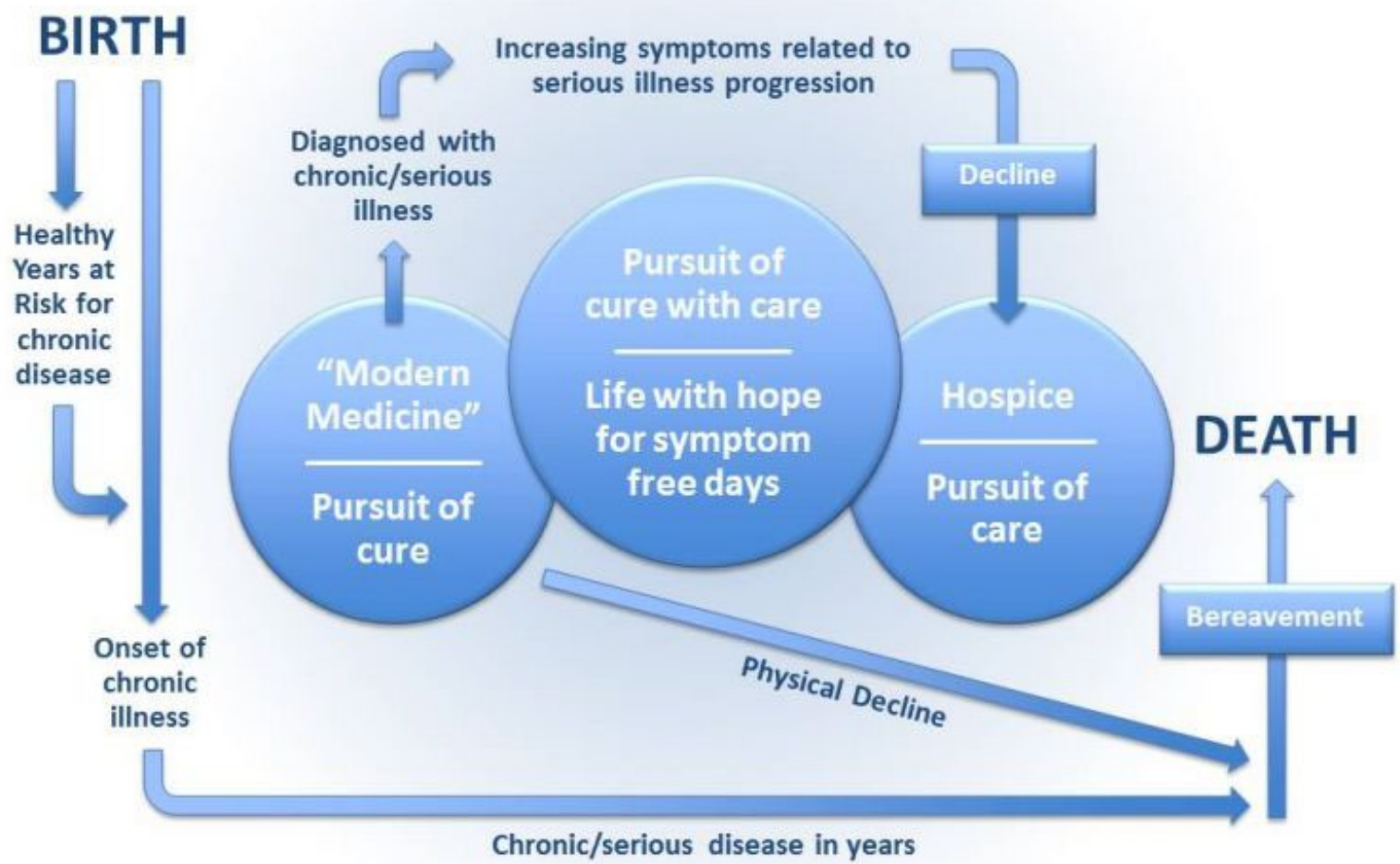
02

It addresses the physical, emotional, social, and spiritual needs of patients and their families.

03

The primary goal is symptom management and providing relief from pain, emotional distress, and other burdens associated with the disease.

SCOPE OF PALLIATIVE CARE

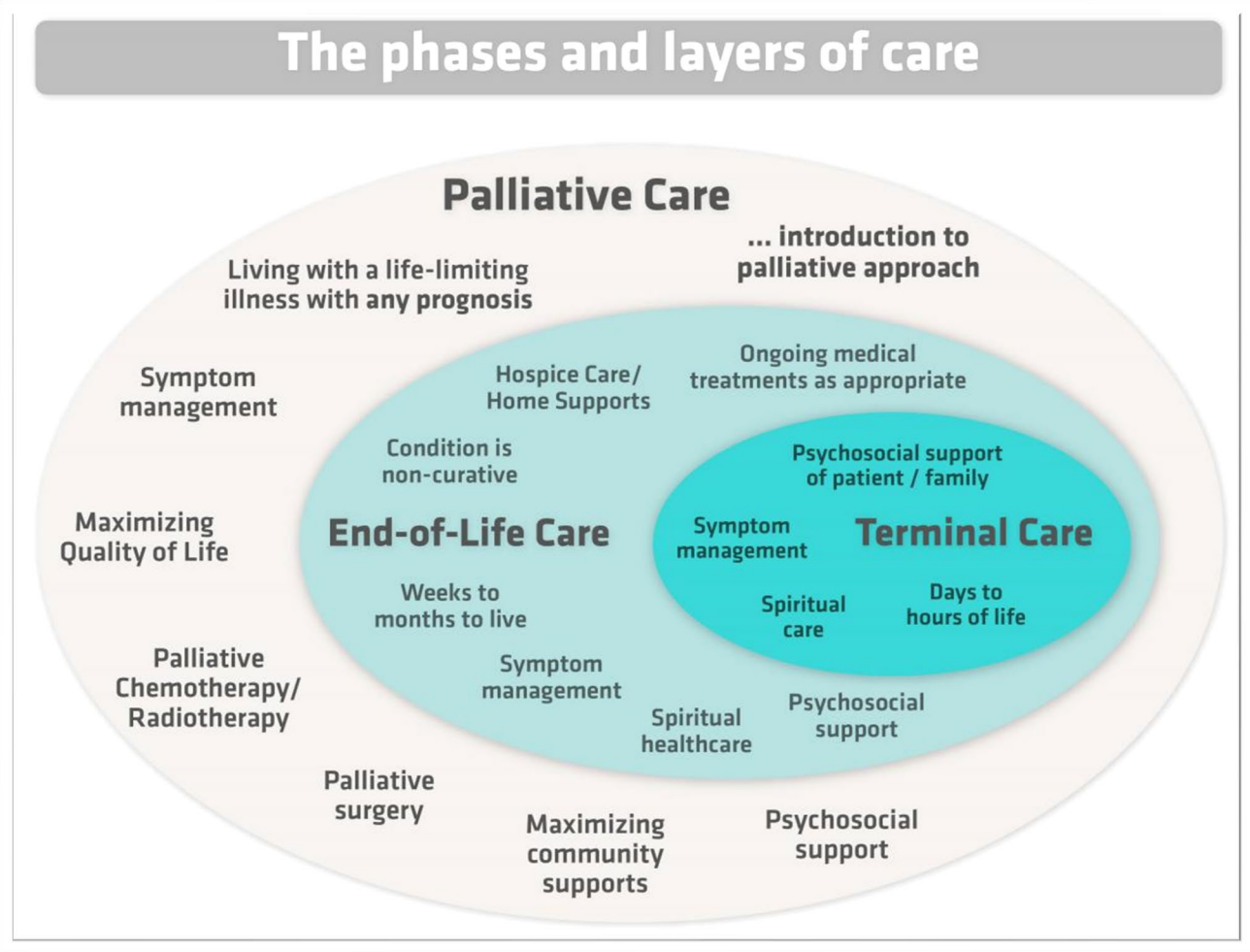


Common Language

- Supportive care is part of the larger whole of the services available to help patients and families cope with cancer

- Supportive Oncology is a vital collection of services that people with cancer may need to support them through various stages of illness

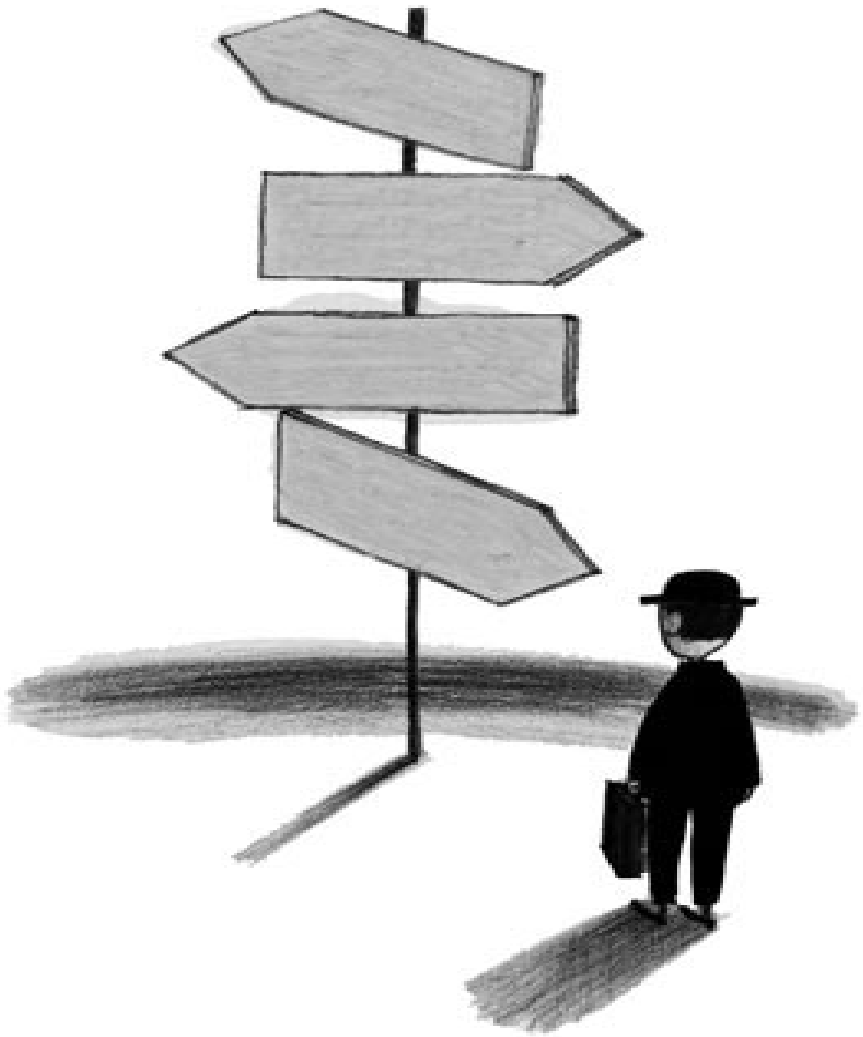
Palliative/Supportive Care



- Palliative/Supportive care in advance cancer is standard of care – ASCO Guidelines
- Palliative/Supportive care should be available to patients to maximize quality of life through all phases of illness
- Palliative/Supportive care is not equivalent to hospice care
- Hospice is the vehicle that delivers palliative care when a person is at the end of life

What is the Philosophy?

- Palliative care treats the symptoms as the primary focus
- Clarify and support patient and caregiver goals
- Work through the uncertainty together
- Evidence-based medicine fails



Where can your patients receive supportive/palliative care services?

Primary Palliative Care: palliative/supportive care provided by treating teams

Outpatient Supportive/Palliative Care Services: embedded in oncology teams or free-standing clinics provided by specialist

Hospital: consultative palliative care teams

Home based Supportive/Palliative care: provided in private homes or institutions by agencies/specialist

What do Patients with MBC and survivors need from palliative care?

Detour: No evidence of disease is one of the most ridiculous and insulting terms I have ever come across referring to patients with cancer

Focus on Emotional Support

01

MBC patients often experience emotional turmoil, including depression and anxiety. Medical trauma

02

Palliative care teams provide psychological support to help patients navigate complex emotions and improve treatment compliance.

03

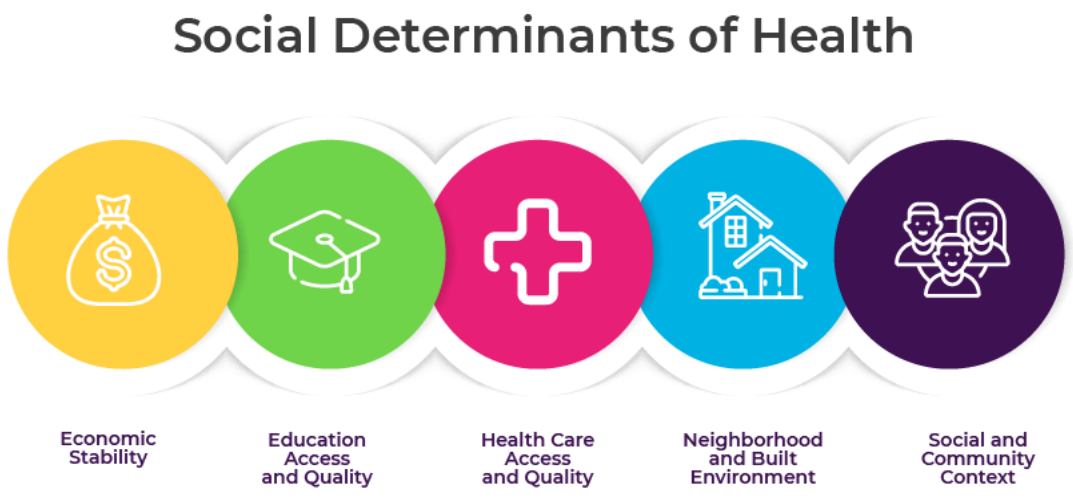
Integrating mental health professionals into palliative care teams is essential for addressing emotional well- being.

Focus on Social Determinants of Health (SDH)

Social determinants of health (SDH) such as socioeconomic status and race influence outcomes in MBC.

Disparities in palliative care utilization exist among women from different racial and ethnic backgrounds.

Palliative care must address these disparities and advocate for equitable access to comprehensive support.



Focus on Symptoms

01

Symptom management is a cornerstone of palliative care for MBC patients.

02

Common symptoms include pain, fatigue, and pyschological issues related to the disease and its treatment.

03

Effective symptom control improves quality of life and reduces hospital utilization rates.

Symptoms

Fatigue

- Cancer Related Fatigue: *"distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion* ***related*** *to* ***cancer*** *or* ***cancer*** *treatment that is not proportional to recent activity and interferes with usual functioning"*
National Comprehensive Cancer Network

https://www.nccn.org/patients/resources/life_with_cancer/managing.../fatigue.aspx

Fatigue

- CRF: prevalence in active treatment ranges from 25% to 99%
- 30–60% of patients report moderate to severe fatigue during therapy
- Fatigue typically improves in the first year following treatment completion
- In 25–30% of patients fatigue can persist for up to 5 years or greater

DSilva, Fatima, Pritanjali Singh, and Athar Javeth. "Determinants of cancer-related fatigue among cancer patients: a systematic review." *Journal of Palliative Care* 38.4 (2023): 432-455.

Fatigue

- Cancer-related fatigue is more severe, persistent, and debilitating than 'normal' fatigue simply caused by lack of sleep or overexertion

- Cancer-related fatigue is not relieved by adequate sleep or rest

- Exercise has been shown to improve CRF in appropriate candidates.

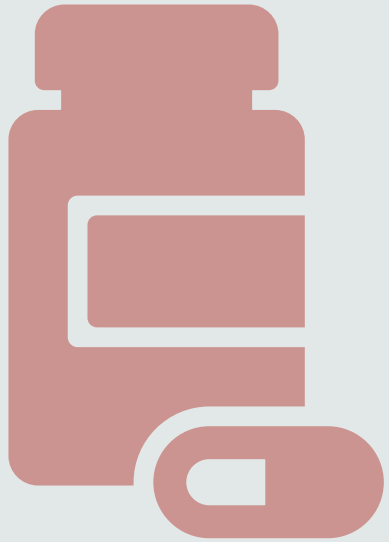
Zhang, Ya-Bin, et al. "Effectiveness of exercise interventions in the management of cancer-related fatigue: a systematic review of systematic reviews." *Supportive Care in Cancer* 31.3 (2023): 153.

Non-pharm treatment	Treatment Group	Effectiveness
Tai-Chi or Qigong	Active cancer treatment	+
Cognitive behavior Therapy	Breast cancer survivors (mod-severe)	+
Acupuncture	Cancer survivors post chemotherapy (mod-severe)	+
Mindfulness	Cancer survivor (severe)	++
Yoga	Breast cancer survivors	+
Exercise	Cancer survivor and active treatment (mod-severe)	+
Web based program	Cancer survivor (mod-severe)	+
Sleep hygiene	Cancer survivor and active tx	

Stone, Patrick, et al. "Management of fatigue in patients with advanced cancer." *Current Treatment Options in Oncology* 24.2 (2023): 93-107.

Medications and Fatigue

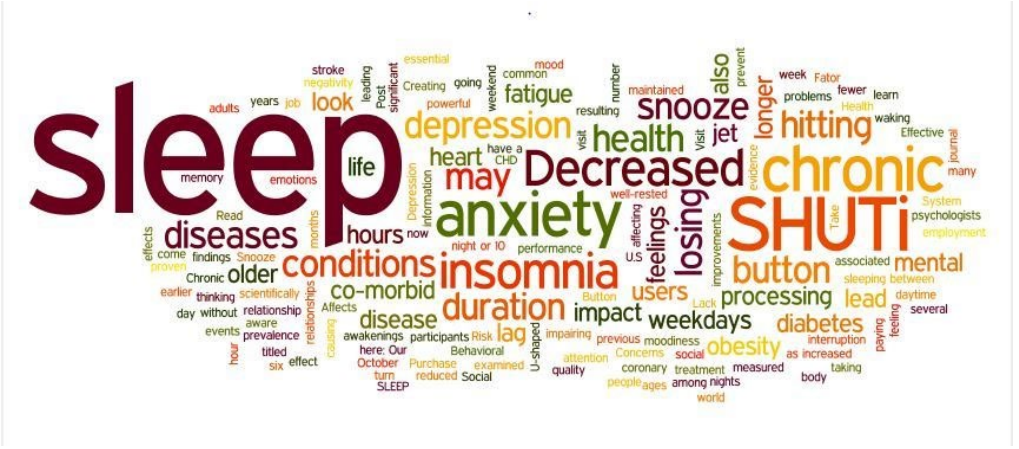
- Less evidence for medications for cancer related fatigue and per "*Management of Fatigue in Adult Survivors of Cancer: ASCO-Society for Integrative Oncology Guidelines Update" 2024*



- *Medications often offered for Fatigue*
  - *Stimulants*
  - *Wakefulness Medication*
  - *Dietary Supplements*
  - *Antidepressants*
  - *Steroids*

Insomnia

- Insomnia: impaired sleep, with difficulties in initiating or maintaining sleep, and/or experiencing sleep as nonrestorative and unrefreshing, despite having the appropriate opportunity for sleep to occur
    - prevalence of insomnia is over 60 percent in palliative care patients



Daldoul, Amira, et al. "Insomnia in breast cancer: prevalence and associated factors." *BMJ Supportive & Palliative Care* 13.e1 (2023): e51-e52.

Insomnia

- General Assessment: **Treat underlying condition**

  - **Physical**: pain, hypoxia, periodic limb movement, alter circadian rhythms
  - **Environment**: temperature, bed/pillow, noise quotation, light
  - **Psychological**: anxiety, depression, PTSD, nightmares
  - **Chemical**: stimulants, anti-depressant, caffeine, opioids, benzo, diphenhydramine (paradoxical reactions), other medications

Insomnia

- First line: behavioral therapy is first line of treatment of insomnia: sleep aides may worsen delirium at EOL
  - Sleep hygiene
  - Cognitive behavioral therapy
  - Relaxation/mindfulness mediation

Han, Jing, et al. "Efficacy of mind-body therapies for sleep disturbance in patients with early-stage cancer: A systematic review and network meta-analysis." *Psycho-Oncology* 32.9 (2023): 1315-1338.

Oral Issues

- Dry mouth: xerostomia a condition in which the salivary glands don't make enough saliva to keep the mouth moist
- Symptoms:
  - Malodorous breath
  - Altered taste
  - Feeling oral dryness or stickiness

- Difficulty chewing, dysarthria, dysphagia
- Dry or sore throat and hoarseness
- Dry or grooved tongue
- Hairy tongue
- **Tooth decay**, infections, gum disease
- Thick saliva
- Thrush

https://www.mayoclinic.org/diseases-conditions/dry-mouth/symptoms-causes/syc-20356048

Oral Issues

- Medications Contributing to Dry Mouth

Opioids	Tricyclic antidepressants	Anti-histamines
Anti inflamatories/steroids	Proton pump inhibitors	Antidepressants
Diuretics	Antipsychotics	Radiation

Oral Issues

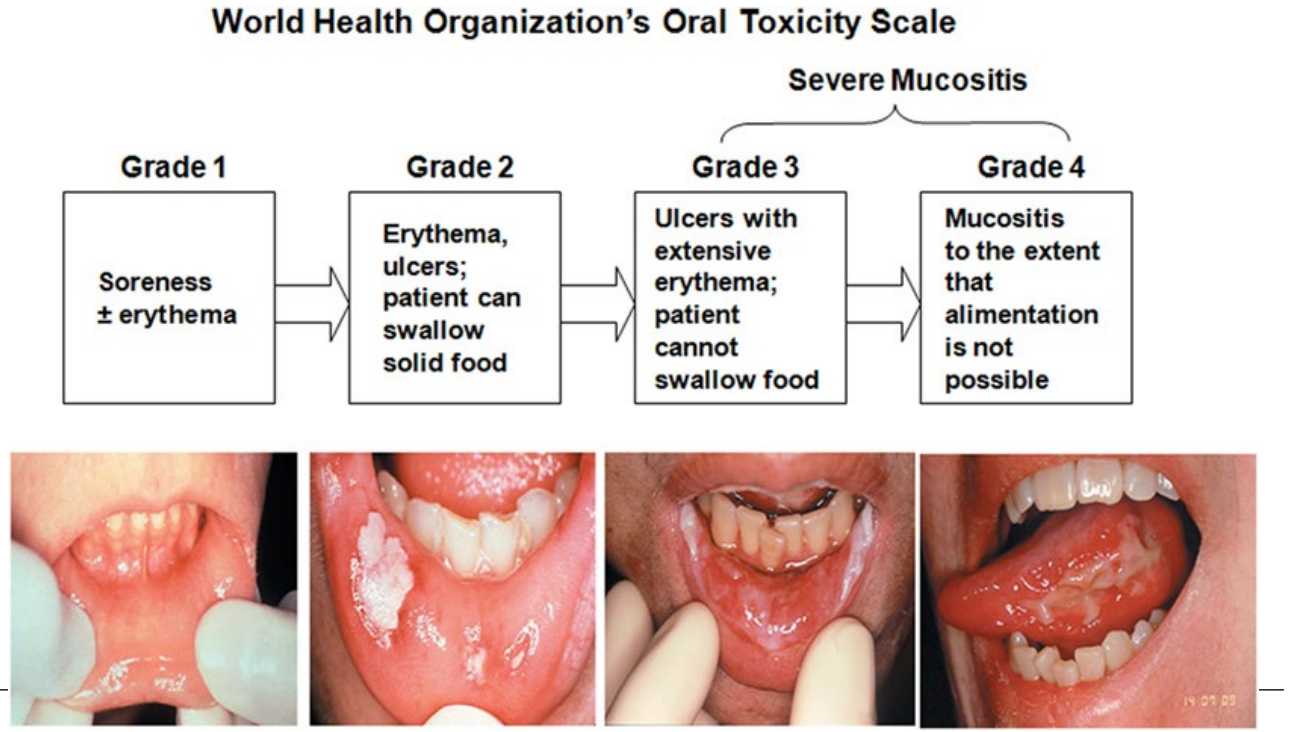
- **Xerostomia** treatment
  - Hydration
  - mucosal lubricants/saliva substitutes
  - humidifiers,
  - sugar-free chewing /candy,
  - sialogogues

BARBIERI, Tainara, Kiany Claudia da COSTA, and Letícia de Freitas Cuba GUERRA. "Current alternatives in the prevention and treatment of xerostomia in cancer therapy." *RGO-Revista Gaúcha de Odontologia* 68 (2020): e20200016.

Oral Issues

- **Mucositis**: painful inflammation and ulceration of the mucous membranes lining the digestive tract, usually as an adverse effect of chemotherapy and radiotherapy treatment for cancer

- Oral rinses
- Pain medications
- Artificial saliva
- Cryotherapy
- Diet
- Ice



Vasomotor Symptoms

Acupuncture can help reduce hot flashes and other symptoms of menopause

- Compared to no treatment: Acupuncture is more effective than no treatment for reducing hot flashes and their severity.
- Compared to sham acupuncture: There is no significant difference between acupuncture and sham acupuncture in reducing hot flashes.

Non-hormonal medications

- These include antidepressants like venlafaxine (Effexor), citalopram (Celexa), or paroxetine (Paxil), as well as gabapentin (Neurontin), clonidine, fezolinetant and oxybutynin.
- Gabapentin can reduce hot flashes in 50-60% of patient in 4 weeks
- Fezolinetat reduced hot flashes by half by week 4, another study had about 50% fewer hot flashes per day after 4 weeks vs 30% placebo

Lifestyle changes

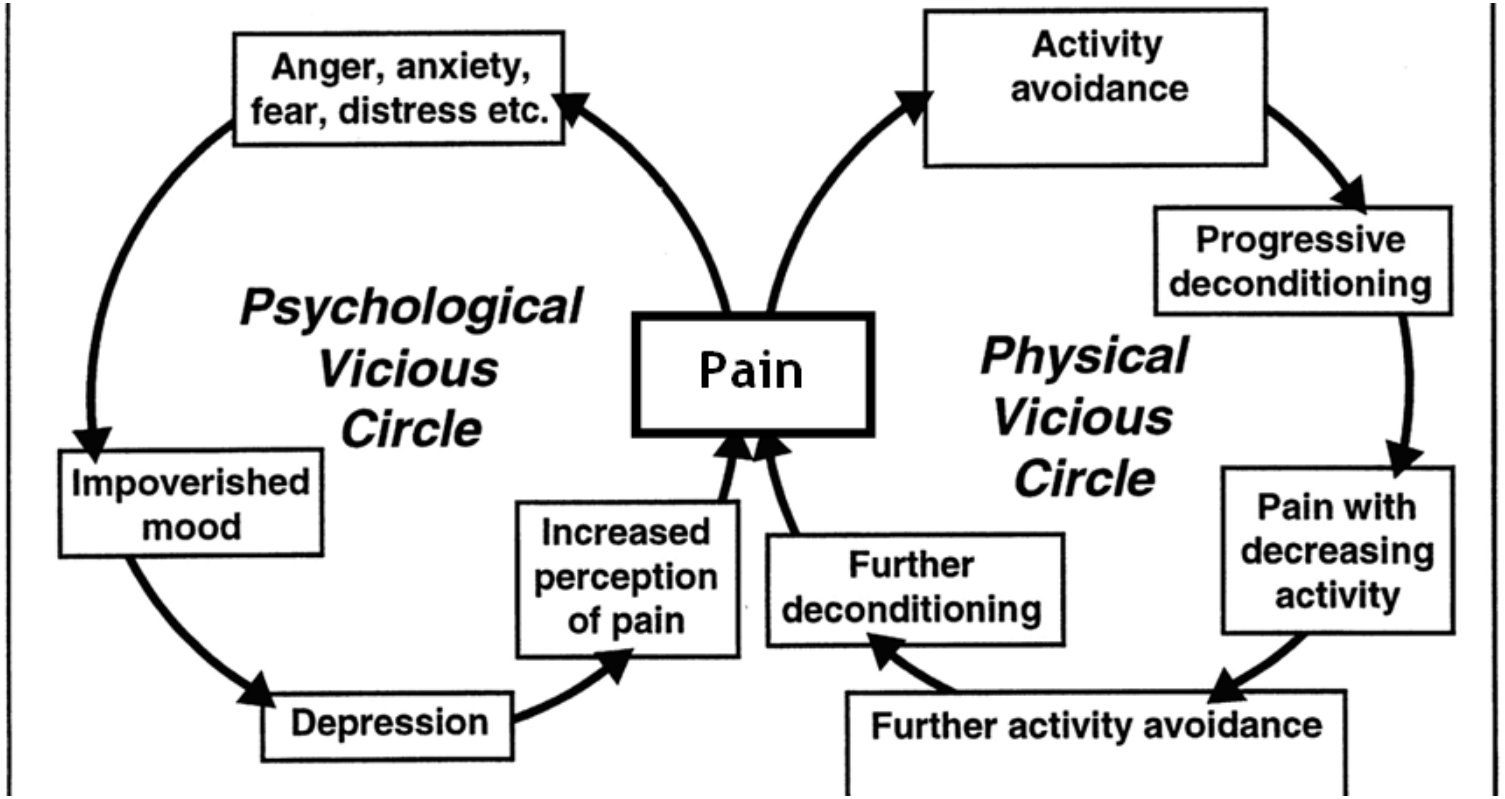
- These include dressing in layers, wearing cotton clothing and bedding, using electric fans, and carrying cold drinks. Reusable cooling bandanas can also be helpful.

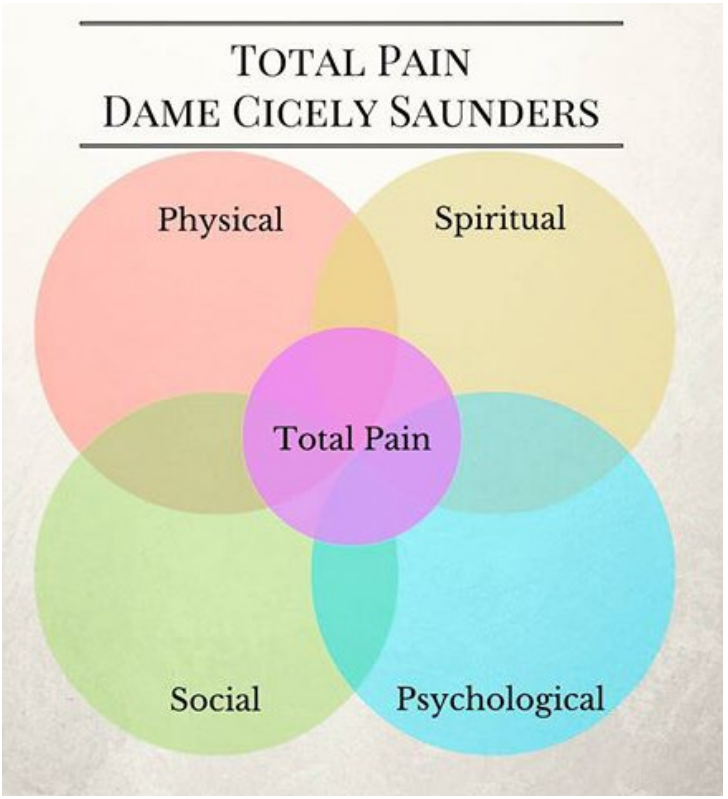
Stellate ganglian block

- This procedure involves injecting an anesthetic into a nerve cluster in the neck. It has shown promise for treating moderate to severe hot flashes, but more research is needed.

Kligman L, Younus J. Management of hot flashes in women with breast cancer. Curr Oncol. 2010 Feb;17(1):81-6. doi: 10.3747/co.v17i1.473. PMID: 20179808; PMCID: PMC2826783
Ee C, French SD, Xue CC, Pirotta M, Teede H. Acupuncture for menopausal hot flashes: clinical evidence update and its relevance to decision making. Menopause. 2017 Aug;24(8):980-987. doi: 10.1097/GME.0000000000000850. PMID: 28350757

Total Pain


Anger, anxiety, fear, distress etc.
Activity avoidance
Progressive deconditioning
Psychological Vicious Circle
Pain
Physical Vicious Circle
Impoverished mood
Increased perception of pain
Further deconditioning
Pain with decreasing activity
Depression
Further activity avoidance


TOTAL PAIN
DAME CICELY SAUNDERS
Physical
Spiritual
Total Pain
Social
Psychological

What is causing pain in patients with MBC and survivors?

Surgery: post mastectomy pain, lymphedema

Chemotherapy induced Neuropathy

Aromatase Inhibitor joint pain

Radiation: post radiation necrosis, brachial plexopathy

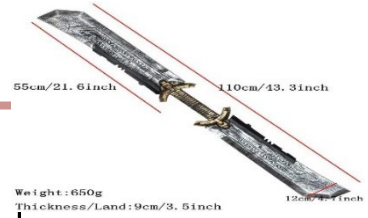
Weight gain

Cancer pain

- Research suggests that pain occurs in approximately 20% to 50% of cancer survivors
- Approximately 30% of cancer survivors do not receive pain medication proportional to their pain intensity
- Pain can negatively affect a cancer survivor's daily functional status and quality of life and can persist for years

Gallaway MS, Townsend JS, Shelby D, Puckett MC. Pain Among Cancer Survivors. Prev Chronic Dis 2020;17:190367. DOI: http://dx.doi.org/10.5888/pcd17.190367

Opioids:



- Significantly better pain relief versus placebo, opioids do not outperform other non-opioid treatment for chronic pain

- *"Opioids performed similarly to NSAIDs, tricyclic antidepressants, and anticonvulsants in improving pain and physical function scores in neuropathic, nociceptive, central sensitization, and mixed pain"*

- Risks: physical dependence, addiction/opioid misuse disorder, worsening depression, constipation, itching, cognitive dysfunction, urinary retention; dry mouth, **unintentional overdose**
  - *"Subsets of opiates also have immunosuppressive properties that may increase infection risk in those receiving concomitant immunomodulatory therapy"*

Krebs, Erin E., et al. "Effect of opioid vs nonopioid medications on pain-related function in patients with chronic back painor hip or knee osteoarthritis pain: the SPACE randomized clinical trial." *Jama* 319.9 (2018): 8
Busse, Jason W., et al. "Opioids for chronic noncancer pain: a systematic review and meta-analysis." *Jama* 320.23 (2018): 2448-2460.
Savage, Kevin T., et al. "Pain management in hidradenitis suppurativa and a proposed treatment algorithm. " *Journal of the American Academy of Dermatology* 85.1 (2021): 187-199.

Opioid Side effects you know

- Sleepiness
- Mood disorder: depression
- Neurotoxicity
- Sleep disordered breathing
- Dry Mouth
- Urinary dysfunction
- Respiratory depression
- Constipation
- Nausea/vomiting
- Itching
- Falls

Opioid Side Effects you may not know

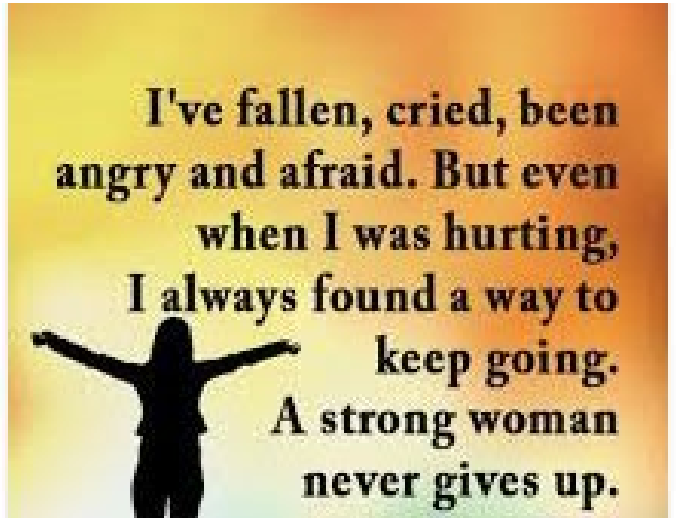
- Cardiovascular
  - Increased risk of cardiovascular death = NSAIDs
  - QTC prolongation: methadone, buprenorphine, fentanyl
- Immunosuppression
  - Morphine suppress cellular immunity and decreases resistance to infection, increase risk is vulnerable population
  - Not all opioids are immunosuppressive (buprenorphine is the least)
- Endocrine
  - reduce testosterone level: sarcopenia(muscle loss), hot flashes, fatigue, insulin resistance, sexual dysfunction
  - Increase incident of metabolic syndrome (high cholesterol, glucose intolerance)
  - Inhibit GRH – hypogonadism; , loss of menstrual cycle; breast milk production 2nd to increased prolactin
  - Estrogen deficiency
  - Osteoporosis: increase risk of bone fracture

Table I: Myths about Buprenorphine's Uses.

Buprenorphine does not control pain.
It is illegal to prescribe buprenorphine for pain without a special X-license.
Buprenorphine is less potent ("weaker") than morphine.
Buprenorphine cannot be combined with full mu agonists.
Buprenorphine is safe and cannot cause respiratory depression.
Buprenorphine/naloxone combination has minimal risk of abuse.
Naloxone in combination with buprenorphine blocks pain control.

https://www.practicalpainmanagement.com/treatments/addiction-medicine/opioid-use-disorder/buprenorphine-promising-yet-overlooked-tool; https://www.youtube.com/watch?v=4EcCIL5yETc

- What messages are your patients receiving at diagnosis and during treatment?
- What is the unintented harm?



What Does Illness threaten?

- Certainty
- Security
- Confidence
- Stability
- Wellbeing

Demoralization

- Demoralization is a syndrome that can affect cancer patients and is characterized by feelings of hopelessness, despair, and an inability to cope. It's a significant problem in oncology, with some studies reporting that 36–52% of cancer patients experience demoralization

- Demoralization is linked to negative outcomes, including: physical symptom burden, quality of life, sleep disturbance, and suicidality.

Table 1. Characteristics of demoralization syndrome and major depressive episode.

Characteristic	Demoralization Syndrome	Major Depression Episode
Mood	Mood reactive to situation	Persistent depressed mood or melancholia
Interest/pleasure	Able to experience pleasure and elevation in mood and preserved consummatory pleasure	Anhedonia – unable to experience pleasure or happiness or diminished ability to enjoy things, lack of consummatory pleasure
Psychological symptoms	Helplessness/Hopelessness Loss of Meaning and Purpose Dysphoria Disheartenment Sense of Failure	Worthlessness Inappropriate Guilt Psychomotor agitation or retardation Cognitive Impairment Anxiety Irritability
Neurovegetative symptoms	Uncommon	Disturbances in sleep, appetite are core symptoms
Suicidal behavior	Heightened risk of suicide due to wish for hastened death and death anxiety	Suicidal ideation and behavior may be present
Social behavior	Loss of control and entrapment with maladaptive coping	Social withdrawal
Treatment	CBT/WBT Meaning-centered psychotherapy Psychedelics	CBT/WBT/IPT/ACT psychotherapy Antidepressants TMS/ECT/Ketamine/Esketamine Psychedelics

Fava, Maurizio, et al. "Distinguishing and treating demoralization syndrome in cancer: A review." *General Hospital Psychiatry* (2023).

Psychological Therapy

Cognitive Behavioral Therapy	• **First-line psychosocial chronic pain treatment**
Acceptance and Commitment Therapy	• **ACT aims to eliminate the experience of suffering when pain absence is not feasible**
Cognitive Processing Therapy, Prolonged Exposure, EMDR Therapy	• **Post Traumatic Stress Disorder**

Complementary Therapies:

THERAPIES

- Physical/Occupational Therapy
- Acupuncture
- Mind-body interventions
- Manipulative and body-based methods
- Energy therapies

SUPPLEMENTS

- **Low dose naltrexone:** increase endogenous opioid, can blunt or reverse effects of opioids
- **Alpha Lipoic acid:** neuropathic pain
- **Turmeric:** anti- inflammatory
- **Cherry Juice extract/Anthocyanin**: anti - inflammatory (high sugar content)
- **Boswellia:** interferes with cell-level functions that cause both pain and inflammation
- **Ginger:** anti-inflammatory, anti- nausea
- **Devil's claw:** muscle and arthritis pain
- **THC/CBD**: pain, nausea, anxiety, appetite, insomnia

BARRIERS

Patient Concerns

Misconceptions may lead patients to hesitate in accepting palliative care, believing it means an end to curative treatment.

Educating patients on the compatibility of palliative care with active treatment is crucial.
https://getpalliativecare.org/

Provider Concerns

01

Healthcare providers may be reluctant to introduce palliative care early due to concerns about taking away hope or time constraints.

02

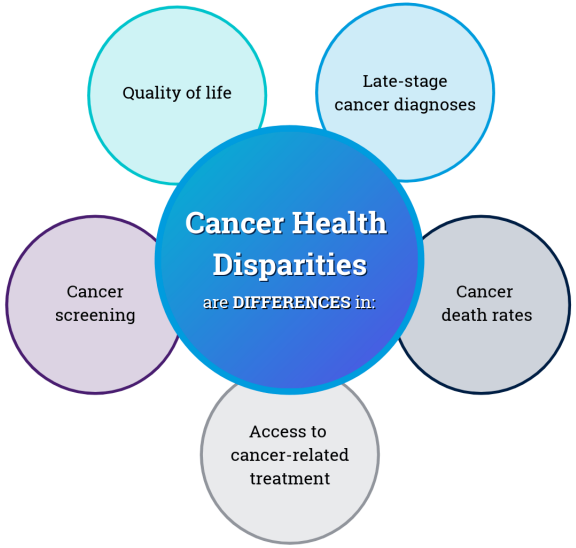
Embedding palliative care within oncology teams can address these concerns and improve communication and coordination. Decreased: hospitalizations, unnecessary health care utilization at the end of life

Rabow, M., et al. "The value of embedding: integrated palliative care for patients with metastatic breast cancer." *Breast Cancer Research and Treatment* 167 (2018): 703-708.

Access

Disparities

Significant disparities in palliative care access exist, particularly for patients from minority backgrounds or lower socioeconomic status.
Targeted culturally appropriate strategies such as community- based programs can help reduce these disparities.
Racial and ethnic minorities with MBC still receive significantly less palliative care than non-Hispanic White women.



Advocacy

Advocacy plays a critical role in ensuring equitable access to high- quality palliative care.
Collaboration between providers, policy makers, and patient groups is essential to address barriers and integrate palliative care into the MBC treatment plan. Fewer than 25% of women with MBC received palliative care between 2010 and 2017

Giap, Fantine, et al. "Palliative care utilization and racial and ethnic disparities among women with de novo metastatic breast cancer in the United States." *Breast cancer research and treatment* 200.3 (2023): 347-354.

Call To ACTION

- Access to high-quality Palliative Care delivered by an Interprofessional team for advance cancer is the standard of care.
- Primary palliative care delivered by oncology teams is essential.
- A patient asking for palliative care is not "giving up"; they are asking for the tools they need to make it through their journey.
- We as healthcare providers should fight just as hard for our patient's quality of life just as hard as we fight for access to treatment and cure.
- NED (No Evidence of Disease) is a ridiculous statement: cancer is not over when the scans are clear; a whole other journey awaits

Summary

Supportive Care is part of the larger whole of services provided by supportive oncology

Supportive/Palliative care is not hospice. Supportive/Palliative care provides symptom management and an extra layer of support for patient and families living with serious illness no matter where they are in the illness

Supportive Care is whole person care and care is directed by patient values

Oncology teams have to provide primary palliative care to improve access

Thank you

Emory Palliative Care Center

Emory Outpatient Supportive Care Clinic

Winship Cancer Institute