PAIN, SYMPTOMS, AND SIDE-EFFECT MANAGEMENT

UNDERSTANDING PANCREATIC CANCER
PANCREATIC CANCER ACTION NETWORK

PAMELA STITZLEIN DAVIES, MS, ARNP, ACHPN
SUPPORTIVE & PALLIATIVE CARE SERVICE
SEATTLE CANCER CARE ALLIANCE / UNIVERSITY OF WASHINGTON
TEACHING ASSOCIATE, UW DEPARTMENT OF MEDICINE
CLINICAL FACULTY, UW SCHOOL OF NURSING

Disclosures

- Honoraria for Invited Speaker:
  - UW Continuing Nursing Education
  - American Academy of Nurse Practitioners Annual Mtg
  - PRN Pain Resource Nurse
Off Label Discussions

- The following drugs may be discussed in a manner that does not reflect the official labeled indication from the US Food & Drug Administration (FDA):
  - Duloxetine (Cymbalta®)
  - Venlafaxine (Effexor®)
  - Gabapentin (Neurontin®)
  - Pregabalin (Lyrica®)

Content Goals for This Lecture

- Common symptoms
  - pain, weight loss, loss of appetite, nausea, vomiting, constipation, diarrhea, fatigue, anxiety.
- Management of common symptoms
- Management of treatment side effects
- Emotional and spiritual health issues
- Palliative care
- Hospice care
- Resources
Target Audience for This Lecture

- Persons impacted by pancreas cancer
  - Patients
  - Family members, friends, loved ones
  - Caregivers

- Health care providers
  - Note: This image reflects a medical focus of the slide

Pain in Pancreas Cancer

- Pain is common in those with pancreas cancer
  - 75% have pain at diagnosis
  - 90% have pain in advanced disease

- Pain location
  - Upper abdominal pain is most common
  - Diffuse abdominal pain in many
  - Back pain is associated with abdominal pain in 50% of cases; back pain alone is less common 5-30%

- Pain intensity may be mild to severe
  - Key Point: Cancer pain can be managed!

Pain Negatively Impacts Quality of Life

- Poor sleep → Increased fatigue
- Deconditioning → Increased risk of falls and injury
- Reduced activity → increased risk of pneumonia and thromboembolism (blood clots)
- Low mood, anxiety → social isolation
- Increased health care utilization
- Increased human suffering →
  - pain may have a “devastating impact”
- Possibly a shortened lifespan
- **Key Point: Cancer pain can be managed!**


Goals of Pain Management at EOL

- Reduce pain to a **tolerable** level
  - Note that “zero” pain is usually not achievable
- Reduce suffering
- Improve quality of life
- Improve function, sleep, mood
- Use the minimal effective dose of medication in order to minimize adverse effects
Consider: What is Causing the Pain?

- What is the **source** of the pain?
  - Cancer
  - Cancer treatment
  - Unrelated to cancer or cancer treatment

- Which physiological **sub-type** of pain is it?
  - Somatic pain
  - Visceral pain
  - Neuropathic pain
Sources of Pain

- **From the Cancer**
  - Abdominal and back pain from pancreas cancer
  - Right upper abdominal pain from spread of cancer to the liver
  - Upper arm pain from pathological (cancer-caused) fracture

- **From the Cancer Treatment**
  - Flank discomfort from nephrostomy (kidney) stents
  - Chemotherapy-induced painful peripheral neuropathy causing pain in the hands or feet

- **Or, Unrelated to the cancer or treatment**
  - Chronic low back pain
  - Osteoarthritis causing pain in the fingers

Pain Physiological Sub-Types

- **Somatic pain**
  - Pain arising from the bones, muscles, connective tissues
  - Quality: Aching, throbbing, bruised
  - Treat with opioids, oncological therapies, NSAIDs*, acetaminophen#

- **Visceral pain**
  - Pain originating from the organs: pancreas, gall bladder, bowel, ureter, heart
  - Quality: Cramping, colic, squeezing
  - Often “referred” to another site: gall bladder pain is felt in the shoulder
  - Tx: opioids, oncological therapies, NSAIDs, acetaminophen, celiac plexus block

- **Neuropathic pain**
  - Abnormal processing of pain signals due to damage to the nerves
  - Quality: Burning, shooting, electric shocks, abnormal skin sensitivity
  - Ex: Chemotherapy-induced peripheral neuropathy, post-surgical neuropathies
  - Responds to anticonvulsants, some antidepressants, some topical agents

* NSAIDs = non-steroidal anti-inflammatory drugs, such as ibuprofen or naproxen
**# These drugs may not be appropriate for use in all patients, check with oncologist
Why is it important to consider the Source (Cause) and Etiology of the Pain?

Because the choice of treatment depends on the pain etiology and mechanism

Pain Management in Pancreas Cancer

- Pharmacological
  - Opioids (narcotics)
    - The key therapy available for pain from pancreas cancer
  - Coanalgesics
  - Adjuvant analgesics
- Non-Pharmacological
  - Cognitive behavioral therapies
  - Alternative Therapies
  - Thermal modalities
- Interventional approaches
  - Celiac plexus block
Opioids (Narcotics)

- The best therapy available for cancer pain!
- But also the most feared ...
  - Due to side effects
  - Unnecessary fear regarding addiction
  - Various barriers to prescribing


Addiction...Know Your Definitions!

- Tolerance: a *physiological* response; increased dose needed for same effect. Presents initially as decreased *duration* of analgesia.
  - Consider progression of disease as the cause rather than tolerance
- Physiological dependence
  - Abstinence syndrome (withdrawal symptoms) occur if the drug is abruptly discontinued, or reversal agent used (naloxone)
- Addiction = *psychological* dependence
  - CRAVING the drug
  - COMPULSIVE use
  - impaired CONTROL over drug use
  - CONTINUED use despite harm
  - Use of drug for reasons other than pain control

Initiating an Opioid (Narcotic) for Pain

- Start with a immediate-release (IR) / short-acting opioid, and take as needed (“prn”)
- If requiring more than about 5 tablets /day of immediate-release opioid for adequate pain control, add a extended-release (ER) / Sustained-Release (SR) / Long-acting opioid

Selected Opioids for Pain

**Immediate-release (IR)**
- Oxycodone
- Hydromorphone (Dilaudid)
- Morphine
- Hydrocodone + acetaminophen* (Vicodin®, Norco®)

**Extended-Release/Sustained-Release/Long-Acting**
- Morphine ER (MS Contin®)
- Oxycodone SR (OxyContin®)
- Fentanyl patch (Duragesic®)
- Methadone

Not recommended:
- Codeine, Darvocet

* Dosing limited by maximum acetaminophen 2-3 grams/day
## Opioids: Adverse Effects

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<thead>
<tr>
<th>ADE that reduce over time:</th>
<th>Do not improve over time:</th>
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<tbody>
<tr>
<td>- Nausea</td>
<td>- Constipation</td>
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<td>- Pruritus</td>
<td>- Sleep disordered breathing</td>
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<td>- Sedation</td>
<td>- Obstructive sleep apnea</td>
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<td>- Dry mouth</td>
<td>- Central sleep apnea</td>
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<td>- Lightheadedness/dizziness</td>
<td>- Some cognitive effects</td>
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<td>- Cognitive changes</td>
<td>- Driving Safety!</td>
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<td>- Delirium</td>
<td>- Urinary retention</td>
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<td>- Respiratory depression</td>
<td>- Mood changes: dysphoria</td>
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<td>- Urinary retention</td>
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<td>- Mood change: euphoria</td>
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<td>- Hypotestosterone</td>
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<td>- Sexual dysfunction</td>
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## Co-Analgesics

- **NOTE:** There is a limited role for using these drugs when receiving chemotherapy -- check with your oncologist or pharmacist

- Acetaminophen (Tylenol®)
  - Mild pain, fever
  - Limit to 2000 mg/day to prevent liver damage
    - Less or none if elevated liver function tests or cancer has spread to liver
    - Often “hidden” acetaminophen in over-the-counter drugs
  - Can “mask” a neutropenic fever

- Non-steroidal anti-inflammatory drugs (NSAIDs)
  - Naprosyn (Aleve®), ibuprofen (Advil®, Motrin®)
  - For mild to moderate pain, bone pain
  - Reduces platelet effectiveness. Use only if specific permission is given by the oncologist or oncological pharmacist
  - Can cause gastric bleeding, kidney damage, fluid overload

Neuromodulating Drugs (Adjuvant Analgesics)

- **Antidepressants**
  - Neuropathic pain, depression, appetite, sleep
  - Serotonin-norepinephrine reuptake inhibitors:
    - Duloxetine (Cymbalta®); Venlafaxine (Effexor®)
  - Tricyclic antidepressants
    - Amitriptyline, nortriptyline, desipramine
    - Multiple drug interactions, used less commonly in oncology

- **Anticonvulsants**
  - Neuropathic pain, anxiety, sleep
  - Gabapentin (Neurontin®)
  - Pregabalin (Lyrica®)

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Celiac Plexus Block

- **Two approaches**
  - Endoscopic (tube down the throat, performed by GI)
  - Percutaneous (needles through the skin, performed under CT by anesthesiologist)

- Phenol or alcohol are used to destroy the nerve plexus

- **Response is variable**
  - One study showed 90% of patients reported partial or complete pain relief at 3 months
  - Pancreatic head mass has better success than body or tail mass
  - However, the tumor may impede delivery of drug to the proper area

- **Side effects:** Temporary low blood pressure, lower extremity sensory changes or diarrhea

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Nonpharmacological Strategies for Pain Management

Cognitive/behavioral therapies

- Relaxation/guided imagery
- Distraction
- Expressive arts/music
- Cognitive reframing
- Journaling
- Support groups
- Counseling
- Spiritual support / prayer


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**How to Use Imagery**

Imagery usually works best with your eyes closed. To begin, create an image in your mind. For example, you may want to think of a place or activity that makes you feel happy or at peace. Explore this place or activity. Notice how calm you feel.

If you have recent pain, you may imagine yourself in a person without pain. In your image, cut the nerve that sends pain signals from one part of your body to another. Or you may want to imagine a ball of healing energy. Others have found this exercise to be very helpful.

- Close your eyes and breathe slowly. As you breathe in, say silently and slowly to yourself, “In, one, two,” and as you breathe out, say “Out, one, two.” Do this for a few minutes.
- Imagine a ball of healing energy forming in your lungs or on your chest. Imagine it forming and taking shape.
- When it’s ready, imagine that the air you breathe in blows the ball of energy to the area where you feel pain. Once there, the ball heals and reduces the pain. You may imagine that the ball gets bigger and bigger as it takes away more of your discomfort.
- When you breathe out, imagine the air blowing the ball away from your body. As it goes, all your pain goes with it.
- Repeat the last two steps each time you breathe in and out.
- To end the imagery, count slowly to three, breathe in deeply, open your eyes, and say silently to yourself, “I feel a lot more relaxed.”
Nonpharmacological Strategies for Pain Management

**Physical Measures**

- **Hot or cold packs**
  - 10-15 minutes 4 times per day
- Massage
- Physical Therapy
- Positioning
  - Hospital bed
  - Braces

Cancer.gov/cancertopics/coping/paincontrol. 7/16/2012

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**Integrative Therapies**

- **Acupuncture/acupressure**
  - Platelets >50,000
- Reiki
- Aromatherapy

Cancer.gov/cancertopics/coping/paincontrol. 7/16/2012
Remember... Pain is

a Sensation

plus

a Reaction

WHAT IS THE MEANING OF THE PAIN?
Nausea and Vomiting: Causes

- **Chemotherapy**
  - More common in women, and those younger than 50
  - Certain agents, regimens, or schedules cause increased N/V
- **Opioids (narcotics)**
- **Constipation**
- **Emotions:** Anxiety, “Anticipatory nausea”
- **Trigger foods**
- **Treatments: Non-pharmacological**
  - Slow, deep breathing techniques
  - Relaxation techniques, hypnosis, guided imagery
  - Acupuncture, acupressure
  - Cool room, fan, cool towel to forehead
  - Small, frequent meals, avoid overeating, bland foods
  - Ginger

Nausea and Vomiting: Treatment

- **Anti-emetics**
  - **Ondansetron (Zofran®)** [5-HT receptor antagonist]
    - Causes constipation!
  - Prochlorperazine (Compazine®) or promethazine (Phenergan®) [phenothiazines]
  - Lorazepam (Ativan®) [benzodiazepines]
  - Metoclopramide (Reglan®) [dopamine 2 antagonist]
  - Dexamethasone (Decadron®) [corticosteroids]
  - Haloperidol (Haldol®) [dopaminergic D2 agent]
  - Cannabis (medical marijuana) [cannabinoid 1 & 2 receptors]
  - Aprepitant (Emend®) [substance P/Neurokinin 1 receptor antagonist]
- **Modification of chemotherapy schedule, dose, regimen**
  - Addition of steroids during and/or for a few days after chemo
  - Additional IV anti-emetics or other meds with chemotherapy
- **Additional hydration**


N & V Treatment Suggestions

- **Non-pharmacological**
  - Stay hydrated!
  - Frequent small, bland meals
  - Deep breathing, relaxation
  - Try acupuncture
- **Pharmacological**
  - Initially take meds on a scheduled basis (every 6-8 hours), then as needed
  - Ondansetron (Zofran®) and/or
  - Prochlorperazine (Compazine®)
- **Note:** Limit Lorazepam (Ativan®) to bedtime
- **If N/V is uncontrolled, contact your oncologist office**

Constipation

- **Cause:**
  - Opioids (narcotics)
  - Low food and fluid intake, lack of exercise

- **Symptoms:** Straining at stool, hard stools, “rabbit pellets”, bowel movement less often than every other day, hemorrhoids

- **Treatment**
  - Preventative – everyday bowel program
  - “Rescue” – once severe constipation has developed

Opioid Therapy Bowel Program

- **Preventative Bowel Program – Everyday Use**
  - Osmotic laxative + Stimulant
    - **MiraLax 17 gm daily to twice daily**
    - **Senna 8.6 mg or bisacodyl 5 mg 1-2 tab 1-2 times/day**
  - (Or: Docusate 250 mg twice a day [stool softener] + above stimulants)
  - Fluids, daily walking, prunes

- **“Rescue” Plan**
  - Magnesium citrate ½ - 1 bottle once daily x 2 bottles
  - Bisacodyl 10 mg suppository rectally or Fleet’s enema
    - Avoid if neutropenic or thrombocytopenic
Homemade Constipation Remedy

Yakima Fruit Paste

- 1 pound prunes + 1 pound raisins + 1 pound figs
- 2 cups of brewed senna tea
  - 4 ounces senna tea leaves (from a health food store) or 2 "Smooth Move" senna tea bags (from grocery store)
- 1 cup brown sugar
- 1 cup lemon juice

1. Prepare the senna tea in a large pot with 2 ½ cups boiling water. Allow to steep for 5 minutes. Strain. Use the remaining liquid, about 2 cups, of brewed tea.
2. Add all of the fruit to the senna tea in the large pot.
3. Boil fruit and tea for 15 - 20 minutes, until soft.
4. Remove from heat, add lemon juice and brown sugar. Allow to cool.
5. Use hand mixer, blender, or food processor to process the mixture into a paste.
6. Place in glass or plastic container and put in freezer. The paste will not freeze.
7. DOSAGE: 1 - 2 Tablespoons per day. Eat off the spoon, add to hot tea, spread on toast.


Pancreas Enzyme Deficiency

- Cause: lack of pancreas enzymes from blockage due to pancreas cancer, or after surgery (Whipple, total pancreatectomy)
  - Required for normal digestion of fats, dairy, meat, bread, dessert
  - The body secretes about 8 cups of enzymes/day!
- Symptoms:
  - Indigestion, cramping after meals, weight loss
  - Large amounts of intestinal gas, foul smelling gas or stool
  - Loose stools, light-colored yellow or orange stools
- Treatment: Pancreatic Enzymes
  - Various combinations of lipase, protease and amylase
  - Prescription forms are recommended
    - Creon®, Pancreaze®, Zenpep®, others
    - RX is costly, but OTC content is unknown
  - Take smallest dose necessary: 2-6 with meals, 1-3 with snacks

Fatigue

- Cancer related
- Treatment related
  - Chemotherapy
  - Radiation / Surgery
  - Anemia
  - Meds: opioids, benzos
- Sleep disorder
- Lack of exercise
- Pain
- Psychological
  - Depression
  - Anxiety
  - Existential

Fatigue – Management

- Realistic goals for activity levels
- “Pacing” of activities
- Daily exercise!
  - Even walking 5 minutes 1-2 times daily
- Good sleep habits
- Pain control
- Address psycho-social-spiritual distress
- Medications
  - Stimulants: caffeine
    - Methylphenidate (Ritalin®), modafinil (Provigil®)
  - Antidepressants for consistent low mood or anxiety
  - Limit or eliminate benzos (lorazepam (Ativan®))
Low Appetite / Taste Changes / Weight Loss

- These are common problems from the cancer and the cancer treatment
  - Cancer increases the metabolic needs to >5,000 kilocalories per day
  - Cancer and surgery may interfere with the ability to absorb nutrients
- Good nutrition is important to help the body heal after surgery and rebound for the effects of chemotherapy
- Eat frequent, small meals
  - “Grazing” throughout the day
- Focus on PROTEIN and CALORIE intake
  - Nutritional shakes, smoothies: add 1-2 Tbsp of protein powder
  - Chicken, fish, eggs, nuts, cottage cheese, yogurt
  - Avoid high fat foods if pancreatic insufficiency is a problem
- To boost flavor, add Tabasco sauce, soy sauce, strong seasonings
- If food tastes like metal, use plastic utensils
- See a Nutritionist for more ideas!

Common Treatment Regimens

- Single-agent gemcitabine
  - Gemzar®
- Gemcitabine + Abraxane®
  - Protein-bound paclitaxel
- FOLFIRINOX
  - FOL = folinic acid (leucovorin)
  - F = fluorouracil (5-FU)
  - IRIN = Irinotecan (Camptosar®)
  - OX = Oxaliplatin (Eloxatin®)
Common Treatment Regimens

- **Single-agent gemcitabine**
  - Usually quite well-tolerated

- **Gemcitabine + Abraxane**
  - Fatigue, nausea, nail changes, alopecia (hair loss)
  - Neutropenia (low neutrophil count)

- **FOLFIRINOX**:
  - Most toxic of the three regimens
  - Fatigue, anemia, neutropenia
  - 5-FU: hand-foot skin syndrome, oral mucositis, diarrhea
  - Irinotecan: abdominal cramps, profuse, watery diarrhea
  - Oxaliplatin: peripheral nerve dysfunction such as cold dysesthesia and chronic peripheral neuropathy

Hand-Foot Syndrome (HFS)

**Palmar-plantar erythrodynasty**

- A cutaneous toxicity of certain anti-cancer drugs
  - Both "standard" and newer "targeted" therapies
  - Causes pain, tenderness, swelling, numbness, tingling of hands or feet. Dry, cracked skin, redness, peeling, ulcerations
  - May be so severe as to interfere with activities of daily living: Dressing, bathing, eating
  - Increased risk in: women, older age, more active, continuous infusion of drug, pre-existing diabetes, peripheral arterial disease, neuropathy

- Common drugs:
  - Capecitabine (Xeloda®): 28-74%
  - 5-fluorouracil (5-FU): 13-34%
  - Sorafenib (Nexavar®); Sunitinib (Sutent®)

- Prevention and treatment
  - Protect hands and feet from injury: Gloves, shoes & socks (do not go barefoot)
  - Avoid excess friction, rubbing, very hot water, sunburn
  - Liberal use of emollients on hands and feet twice a day
    - AquaPhor, Lubriderm, Bag balm
  - Severe cases may require chemo dose reduction, steroids
  - (Pyridoxine (Vitamin B6): weak evidence)

Oral Mucositis

- Pain, sores, irritation and discomfort in the mouth
  - May involve the esophagus and gastrointestinal tract
  - A side effect of chemotherapy and radiation therapy to the head/neck
  - Occasionally it may be so severe that it is impossible to eat or drink

- Normal Saline Rinse
  - 1 teaspoon salt in 1 pint water
  - Rinse and spit every 2-4 hours

- Brush teeth with ultra soft toothbrush, non-flavored toothpaste
  - Avoid commercial mouthwashes
  - Avoid flavored or whitening toothpaste
  - Use oral flossing tool rather than dental floss

- Palifermin (human keratinocyte growth factor) or sucralfate may help, but are not superior to saline rinses

- See an oncology dentist for severe cases


Oxaliplatin Cold Dystesthesias

- Oxaliplatin cold sensitivities
  - Very common, nearly universal
  - May occur during or after oxaliplatin infusion
  - Sensitivity to cold: drinking cold fluids, holding a chilled can of pop, breathing chilled air

- Pharyngolaryngeal dysesthesia
  - A frightening sensation of being unable to breathe, with tongue swelling, difficulty talking, may include pressure in the chest
  - This will pass without treatment
  - Cup hands over face to breathe warm air
  - Sip warm water

- Prevention and treatment
  - All food and drink should be at room temperature
  - Avoid breathing in cold air from the freezer/refrigerator
  - Wear gloves or oven mitts to take items out of freezer

ASCO: cancer.net; ACS: cancer.com; NCI: cancer.gov
Chemotherapy-Induced Peripheral Neuropathy (CIPN)

- May be painful (burning, lancinating, painful tingling), or non-painful (numbness)
- "Stocking-glove" distribution: hands and feet
- Negatively impacts activities of daily living
- Associated with certain chemotherapies
  - Platinum agents (oxaliplatin), taxanes (paclitaxel), others
- Risk factors:
  - Older age, pre-existing neuropathies, nutritional deficits
  - Higher doses of neurotoxic agents, multiple neurotoxic agents
- Prevention: minimal evidence to support anything for prevention
- Treatment: duloxetine (Cymbalta®)
  - Pregabalin (Lyrica®)
  - BAK compounded topical cream: baclofen, amitriptyline, ketamine
- Precautions
  - Check hands and feet daily, avoid going barefoot
  - Use great care when driving


Diarrhea

- First, work with the oncology team to determine **what is causing the diarrhea**?
  - Chemotherapy side effect?
  - Antibiotic side effect?
  - Infectious cause? Clostridium difficile? Giardia?
  - Lactose intolerance
  - Pancreatic enzyme deficiency?
  - Constipation “overflow diarrhea”?
  - Excess constipation medicines?
  - Anxiety, stress reaction?
- Second, define what is “diarrhea”?
  - <4 watery stools over baseline
  - 4-6 loose, watery stools/day over baseline

NCI cancer.gov; Diarrhea
Treatment of
Chemotherapy-induced Diarrhea

- **Focus on staying hydrated!**
  - Frequent sips of fluids, ice chips, jello, popsicle, broth
- **Non-pharmacological**
  - Stop constipation medicines
  - Restrict possible trigger foods (lactose)
  - Ask about using probiotics (lactobacillus)
- **Loperamide (Imodium®) 2 mg tab (OTC)**
  - 2 tablets at first loose watery stool
  - Then 1 tablet with each subsequent stool
  - Max 12 mg/day
- **Lomotil® (diphenoxylate + atropine) (RX)**
  - May be added to loperamide by your oncologist for severe diarrhea

NCI: Adjustment to cancer-anxiety and distress. Cancer.gov

Mental and Spiritual Health

- Studies show that most cancer patients do not meet the diagnostic criteria for any specific mental disorder; however, many patients experience difficult emotional responses to the diagnosis
- Anxiety can significantly and negatively impact symptoms, such as nausea or pain

NCI cancer.gov; Diarrhea
Depression and Anxiety

- Major depression occurs in 15-25% of cancer patients
- Must differentiate from sadness and grief, which are normal reactions when dealing with a serious and life-limiting illness
- Symptoms:
  - Low or depressed mood most days
  - Diminished pleasure or interest in most activities
  - Significant changes in sleep patterns
  - Poor concentration
  - Recurrent thoughts of death or suicide
  - “Vegetative symptoms” are less reliable in cancer: fatigue, low appetite
- Those at risk:
  - History of depression and/or anxiety
  - Social isolation (not married, few friends)
  - Negative thinking patterns
  - Poor prognosis
  - Poorly controlled pain and symptoms
  - Certain medicines and cancer treatments
  - History of trauma

NCI; Depression; Adjustment to cancer-anxiety and distress. Cancer.gov

Treatment of Depression & Anxiety

- Non-pharmacological
  - Counseling: cognitive-behavioral therapy, psychotherapy
  - Support groups
    - Led by community groups or oncology center social worker
- Pharmacological
  - Check with oncology pharmacist for drug interactions
  - For best results, should remain on the antidepressant for 4-6 months after resolution of symptoms!
  - Antidepressants
    - SSRI drugs: citalopram, sertraline
    - SNRI drugs: duloxetine (Cymbalta®), venlafaxine (Effexor®)
    - Atypicals: mirtazapine (Remeron®), bupropion (Wellbutrin®)
  - Stimulants: methylphenidate (Ritalin®)
  - Benzodiazepines have a limited role, they lead to respiratory depression, which potentiates that from opioids

NCI; Depression; Adjustment to cancer-anxiety and distress. Cancer.gov
Existential / Spiritual Concerns

- Developing a life-limiting illness may lead to an existential crisis and uncover deep spiritual concerns
  - These issues may significantly impact a patient’s ability to cope with therapy
- Or, a serious illness may lead to stronger faith in God/Higher Power and can produce great peace and comfort
- For some, spirituality provides a refuge and a strong sense of coping for some individuals
- Your medical team is interested in supporting your spiritual and existential needs.
  - Hospital chaplains are an excellent resource!
- Concept of “post-traumatic growth”

What is Supportive & Palliative Care?

- Specialized care for those facing life-limiting illness, which focuses on
  - Improving Quality of Life
  - Pain and symptom management
  - Coping with serious illness
- Available to anyone at any point in their illness
  - Even those who are newly diagnosed with curable illness
  - Not limited to advanced disease or end-of-life
- Interestingly, involvement of Pall Care not only improves QOL, but may also prolong life!
What is Hospice

- Specialized end-of-life care for those who are expected to live for 6 months or less
- Hospice is a subset of Palliative Care
- Includes specific services as required by the Medicare Hospice Benefit:
  - Home nurse visits
  - Social work and Chaplain visits
  - Bath aide
  - 13 months of bereavement support for loved ones

Current Practice of Palliative Care and Hospice

Curative Treatment

Palliative Care (if offered at all)

Hospice

Terminal Phase Of Illness

Death
Desired Practice:
Continuum of Care

How Do I Know When to Enroll?

- Supportive & Palliative Care
  - Enroll anytime to focus on improving pain, symptoms, and quality of life
- Hospice care
  - When there are no clear benefits to receiving chemotherapy
    - Chemotherapy is no longer tolerated
    - When the burdens of treatment seem to outweigh any benefits obtained (e.g. chemotherapy seems to be making things worse)
    - When it is time for an extended “chemo break”
  - When it is more important to spend time at home, surrounded by family and loved ones, rather than spending extended time at the clinic or in the hospital
  - When someone is clearly entering the terminal phase towards death, and their desire is to die at home, not in the hospital
- Note: Earlier enrollment in Hospice does not hasten death—in fact the opposite may be true!
- Note: A patient can always “un-enroll” from Hospice if they change their mind, or their health improves.
“Paperwork” That We All Need to Do… Regardless of Age, Health Status, Diagnosis, Prognosis

- **Durable Power of Attorney for Health Care (DPOAHC)**
  - **Who** would make medical decisions for you if you could not make your own?
    - Such as if you were in a bad car accident or suffered a major stroke?
    - WA: DPOAHC; Spouse/Domestic Partner; Adult Children; Parents; Siblings

- **Advanced Directives**
  - **What kind of medical decisions** would you want made?
    - Such as, if you were seriously injured and you are ...
      - Expected to survive with some chance of good quality of life?
      - In a persistent vegetative state, and expected to live in a nursing home for the rest of your life, kept alive with feeding tubes?
      - Not expected to live, but currently in the ICU, being kept alive on a ventilator and kidney dialysis, and the doctors are asking for permission to stop ‘life-prolonging’ measures?
  - Advanced Directives give you an opportunity to express your wishes, in writing, regarding some of these situations, which will help guide your loved ones and the medical team.

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Additional Notes and Resources for Advanced Directives

- **Note:** In Washington State, you do not need a lawyer or a notary public to complete DPOAHC or Advanced Directives
  - Just Do It! 😊
- It is important to talk to your designated DPOAHC to make sure they are willing to function in this role, and understand your wishes
- Keep this paperwork handy (not in a safety deposit box!)
  - Give a copy to your oncologist, family doctor, DPOAHC, family

- **Where to get Advanced Directives/ DPOAHC forms:**
  - [Compassion and Choices of Washington State](CompassionWA.org)
  - [Five Wishes](AgingWithDignity.org/five-wishes.php)
  - Your local Cancer Resource Center
  - Oncologist’s Social Worker

DPOAHC: Durable Power of Attorney for Health Care
Resources

- **Pancreas Cancer Action Network**
  - Pancan.org

- **Cancer Lifeline**: Cancerlifeline.org
  - 24-hour telephone support: 206.297.2500; 1.800.255.5505
  - Support Groups

- **Gilda’s Club**: gildasclubseattle.org

- **NCI**: National Cancer Institute: cancer.gov
  - Guidelines on pain & symptom management

- **ACS**: American Cancer Society: cancer.org