

Care Across the Continuum: Survivorship and Psychosocial Issues

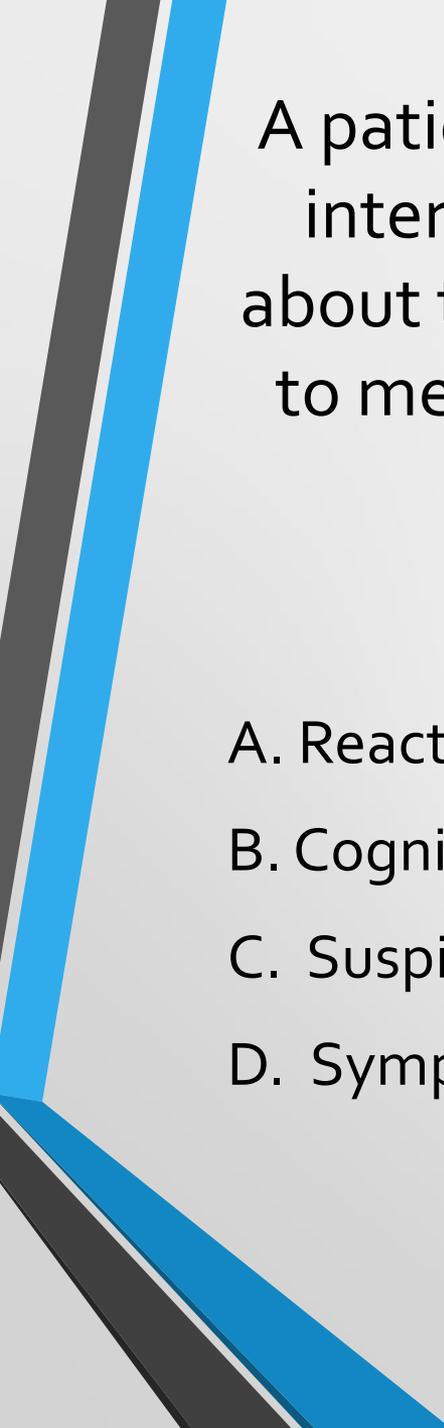
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A patient states, "I have been afraid to show my body to my spouse since the mastectomy." To promote open communication, the nurse responds:

- A. Do not worry, things will look better in a few weeks."
- B. "There are many options for prostheses and reconstruction."
- C. "I am sure your spouse loves you just the way you are."
- D. "Let's practice discussing your concerns with your spouse."

A patient with cancer receiving palliative services reports poor sleep, fatigue, and frequently feeling worried. Which medication should the nurse expect to be prescribed for the patient?

- A. Citalopram
- B. Mirtazapine
- C. Diphenhydramine
- D. Methylphenidate



A patient newly diagnosed with cancer frequently interrupts the nurse, who is providing teaching about treatment, and states, "Why did this happen to me?" The nurse recognizes this behavior most likely represents:

- A. Reactive anxiety.
- B. Cognitive impairment.
- C. Suspicion of the treatment.
- D. Symptoms of depression.

Psychosocial Dimension of Care

8%

- Cultural, spiritual and religious diversity
- Financial concerns
- Altered body image
- Patient and family support groups
- Learning styles and barriers to learning
- Social relationships
- Coping mechanisms and skills

Psychosocial Disturbances and Alterations

- Anxiety
- Loss and grief
- Depression
- Loss of personal control

Survivorship 8%

- Psychosocial, physical and cognitive alterations
- Issues
 - Financial
 - Employment
 - Insurance
 - Discrimination
 - Family and social support
 - Sexuality
- Long term effects
- Late effects
- Rehabilitation and long term follow up

Sexuality

- Risks Factors/Prevention/Education/Management
- Reproductive issues
- STD and HIV risks
- Sexual dysfunction
 - Physical
 - Intimacy
 - Psychological
- Fertility

Addressing Psychosocial Concerns in Oncology Patients

- 2007 IOM reported that the psychosocial needs of people with cancer as a vital component of comprehensive cancer care.
- 2015 the American College of Surgeons Commission on Cancer, (CoC) developed a new accreditation standard addressing the psychosocial concerns of cancer patients. During first course of treatment distress assessment with referral plan
- CoC is a consortium of 47 professional organizations, including ONS.
- Canada has required “Screening for Distress” as the sixth vital sign

Implementation of Psychosocial Standards

- American College of Surgeons Commission on Cancer, (CoC) Standard (2020) 5.2 requires cancer centers seeking accreditation to screen for distress at least once during the patients first cycle of therapy.
 - Provide resources and appropriate referrals to patient
 - Distress Assessment: Several tools
- Cancer center decide the appropriate tool and who will administer the tool
- Multiple position statements (NCCN, ONS, APOS, AOSW, ASCO)

Case Study

- Jacqui is a 49 year old single mother of 3 with stage II ovarian cancer. She underwent a TAH followed by 6 cycles of carboplatin/paclitaxel X6 cycles. She is seen for follow-up in the Women's Cancer Clinic. She completed her therapy 4 months ago.

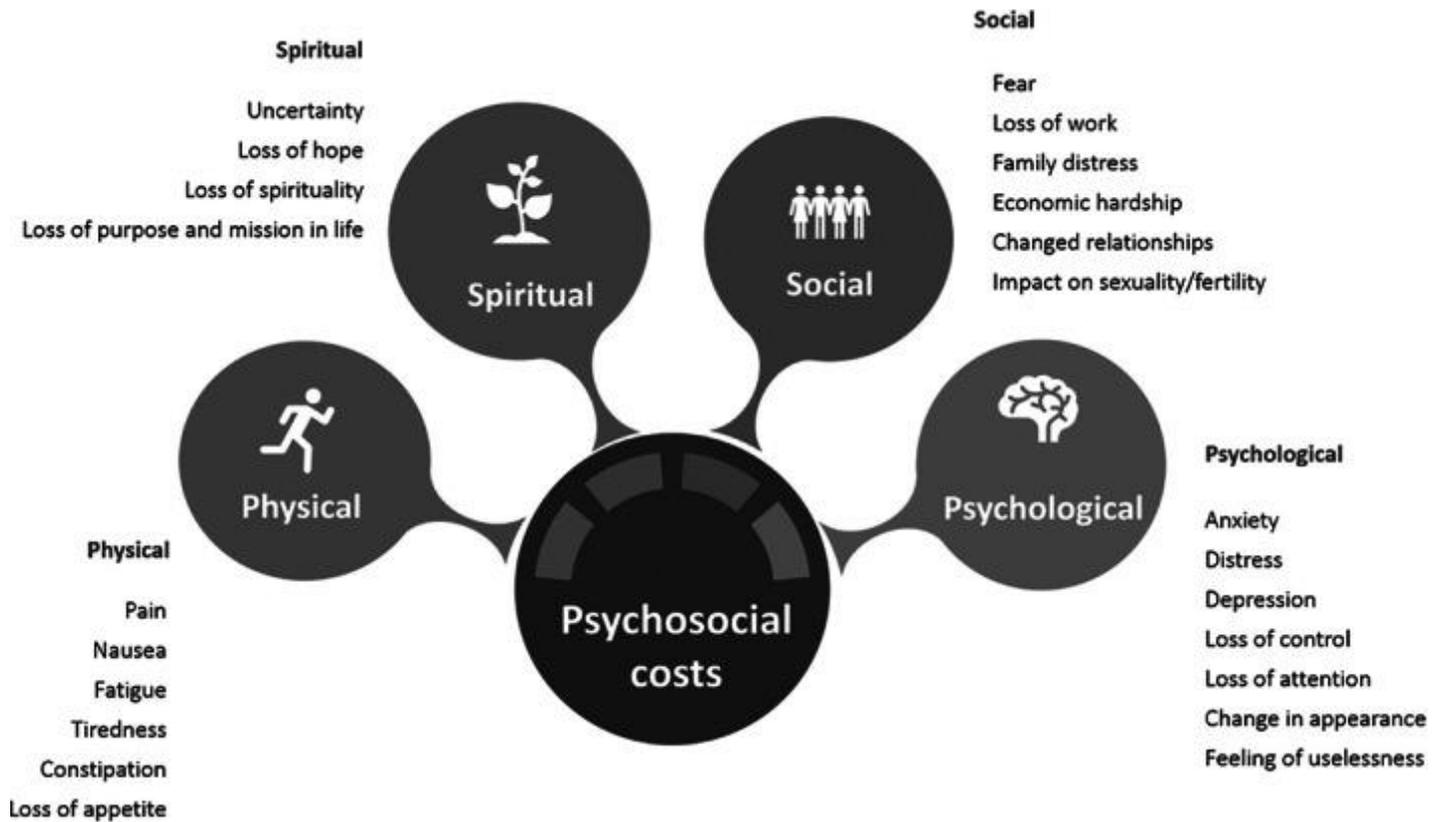
CANCER

- Distress
- Anxiety
- Depression
- Loss of personal control
- Loss and grief
- Most common psychosocial findings:
 - Depression
 - Anxiety
 - Fear of relapse
 - 30-60% diagnosed psychiatric disorder in newly diagnosed cancer patients



Psychosocial Costs

- Psychosocial Costs: Illness and disease are responsible for a wide variety of deteriorations in quality of life
- Disease may bring about personal catastrophes that are not reflected in the direct and indirect economic costs that are usually estimated for a specific disease
- Symptoms: undesired changes in life plans, anxiety, reduced self-esteem and feeling of well-being, and other emotional problems
- Psychosocial costs are a significant, and very likely quite large, component of the total burden of illness.
- To ignore them, or misrepresent them, can result in an underestimate of the impact of disease and bias the decision-making process



High Risk for Psychosocial Problems

- Younger age
- Female
- Multiple co-morbidities
- Psychiatric history
- Poverty
- Use of denial or behavior disengagement
- Pain
- Only 45% of patients surveyed reported psychosocial assessments about the psychosocial cancer concerns

Forsythe et al., 2014; Wang, et al., 2017

Factors Influencing Psychosocial Issues

- Cancer diagnosis related
- Treatment related oncology
- Psychological
- Social factors
- Cultural Factors
- Ineffective Coping
 - Anxiety
 - Depression
 - Suicidal ideation
 - Denial

Interventions

Assess for thoughts of suicide or self harm, requires immediate intervention

- Identify, Discuss and Plan (ONGOING)
 - Social services/Counseling
 - Chaplain services
 - Support groups
 - Coping skills
 - Empowerment with **knowledge** and **support**
 - Assess learning styles and barriers to learning
 - Language Skills
 - Interpersonal relationships/communication skills
 - Complimentary therapies/Mindfulness
 - Adaptive equipment

Distress

- A multifactorial unpleasant emotional experience of psychological (cognitive, behavioral, emotional) social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment side-effects (NCCN, 2020)
- Distress is described at diagnosis and throughout the continuum of the disease
- Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness and fears to problems more disabling depression, anxiety, panic, social isolation and spiritual crisis
- No one distress tool is recommended
- NCCN-validated assessment tool (Distress Thermometer), scale 1-10, list of questions about barriers

Distress

- Approximately 25-50% of cancer patient report significant distress
- Distress Risk Factors
 - Psychiatric disorder
 - Substance abuse
 - Cognitive impairment
 - Comorbidity
 - Uncontrolled symptoms
 - Communication barriers
 - Social barriers
 - Younger age, living alone, young children, prior trauma,

Negative Effects of Distress

- Treatment adherence
- QOL
- Pain
- Survival
- Associated in cancer patients is associated with poor QOL and could affect survival

Batty, et al., 2017

Riba, et al. 2019



Examples of Distress

- 29-year-old woman with breast cancer who had been doing well until she developed severe panic attacks during radiation therapy.
- 55-year-old man with colon cancer with side effect of peripheral neuropathy interfering with ADL and specifically with his piano playing. He also reports financial concerns since taking a leave from work (specifically reports paying for parking at the hospital for appts).
- Both patients may have similar scores on a distress screening instrument
- Clearly require quite different clinical and programmatic responses to their distress.

Distress: Assessment & Treatment

- **Assessment**
- Ongoing distress screening associated with less distress
- Psychosocial Screen for Cancer (PSCAN)
- NCCN Distress:

Thermometer Distress Scale :

No distress Extreme

- Screened at every visit
- Pandemic distress in the setting of cancer diagnosis and treatment

Treatment

- Treating distress is associated with a decrease in symptoms
- Psychosocial Support
- Cognitive Behavioral Therapy
- Therapy: Social Services/Counseling
- Spiritual Care
- Pharmacologic interventions
- Exercise
- Complementary/Integrative therapies
- Medications

Ehlers, S. et al. (2019).

Post-Traumatic Stress Disorder

- Traumatic event or event prompting specific clinical response and manifested by intense fear, helplessness, horror, reliving the event or experience
- Cancer therapy is associated with PTSD
- Patients feel anxious, fearful, irritable, hyper-vigilant, and also emotionally numb and occurs in 5-44% of patients
 - Cognitive
 - Behavioral
 - Emotional
 - Physiologic
 - Treatment includes same interventions used for distress

Adaptation and Resiliency

- Ability to minimize disruptions to social roles, regulate experience of emotional distress and maintain active engagement in meaningful life activities
- Research suggests that traumatic characteristics of a life-threatening illness, like cancer, and how cancer patients exhibit responses is consistent with psychological trauma
- Studies reveal that overcoming cancer and its treatment can be an opportunity for personal growth, as well as for enhanced mental and emotional well-being that could potentially be linked to better coping with disease-related demands
- Difficult to identify patient that will experience adaptation and resiliency. Nursing can play an important role in identifying strategies to reduce anxiety and distress in patients to improve QOL and resilience

Seiler, A., & Jenewein, J. (2019). Resilience in Cancer Patients. *Frontiers in psychiatry*, 10, 208. <https://doi.org/10.3389/fpsy.2019.00208>

Case Study

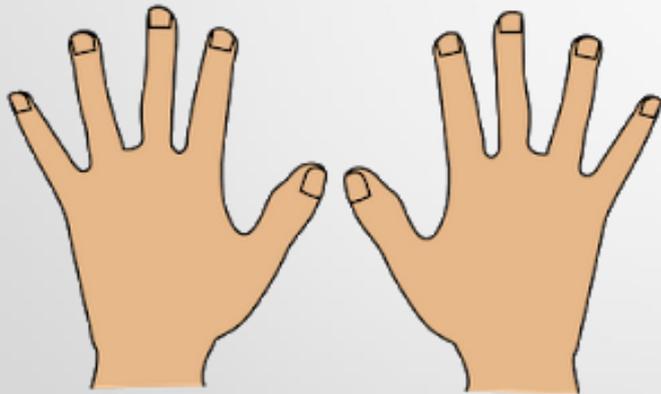
- Jacqui is a 49 year old single mother of 3 with stage II ovarian cancer. She underwent a TAH followed by 6 cycles of carboplatin/paclitaxel X6 cycles. She is seen for follow-up in the Women's Cancer Clinic. She completed her therapy 4 months ago.
- What are some of your concerns regarding Jacqui during today's appointment?

Depression and Anxiety

- Go hand in hand
- Are they one?
- It is important to differentiate
- Are you always anxious and depressed
- Is the treatment similar and should it be?



Depression and Anxiety



- Important to differentiate
- Treatment similar
- Different feelings that may be important to communicate to the patient
- Cluster symptoms

Li et al. (2019) Cancer Nursing

Case Study Scenarios: Who is Anxious and Who is Depressed?

A.

Mary has completed 6 cycles of R-CHOP for large cell lymphoma and is having difficulty focusing at work and trouble sleeping. She has an appointment next week that includes PET CT scan and lab work. She is very concerned that she will be told that she has a recurrence of her disease

B.

Gary has lost 40 lbs after completing 3 cycles of radiation and chemotherapy for head and neck cancer. He has no energy and cannot work. He is suffering from significant body image problems and sleeps most of the day.

Who is Depressed?

- A. Gary
- B. Neither Gary or Mary
- C. Both Mary and Gary
- D. Mary



Who is Anxious?

- A. Gary
- B. Neither Gary or Mary
- C. Both Mary and Gary
- D. Mary

Depression

- A mood state of feeling sad, discouraged, hopeless and worthless
- NCCN recognizes depression as a part of the continuum of distress
- Depression
 - Affects 15-25% of cancer patients
 - Associated with symptoms of worthlessness, guilt, hopelessness, loss of pleasure in activities and suicidal ideations
- Interventions
 - Referral to psychiatry or social services
 - Symptom assessment and treatment of underlying medical conditions
 - Cognitive behavioral interventions
 - Medications

Risk Factors

- History of depression
- Previous suicide attempt
- Family history of depression
- Co-morbidity
- Sleep deprivation
- Social isolation
- Spouse with illness
- Numerous losses
- Other unexpected life events

Depression

- Assessment: 4 or more to meet diagnostic criteria
 - Mood fluctuation
 - Feeling of worthlessness or guilt
 - Decrease interest in activities
 - Weight loss or gain
 - Insomnia or hypersomnia
 - Psychomotor agitation or retardation
 - Decreased energy
 - Fatigue
 - Inability to think, concentrate or make decisions
 - Thoughts of death

Depression Risk Factors

Cancer Related Risk Factors

- Depression at diagnosis
- Advanced stages of disease
- Uncontrolled pain and symptom clusters: pain, fatigue, sleep, and cognitive changes
- Increased physical impairment or discomfort
- Type of cancer associated with alterations in cellular activity
- Treatment with certain pharmacologic agents and interaction with cancer treatment regimens

Non-Cancer Related Risk Factors

- Prior history of depression; past treatment of psychological disorder
- Additional life stressors
- Family history of depression or suicide
- Lack of family support
- Previous suicide attempts
- History of alcoholism or drug abuse; concurrent illnesses

History and Physical Exam

Depression and Anxiety

- Oncologic status/progression
- Medications use, recent changes
- Presence of new or poorly controlled symptoms (pain, nausea, diarrhea)
- Co-morbidities
- History of depression or anxiety disorder
- Fatigue level
- Functional status
- Coping strategies

Depression and Anxiety Instruments

- Edmonton Symptom Assessment System (ESAS)
- Hospital and Anxiety Depression Scale (HADS)
- Brief Symptom Inventory (BSI)
- Distress Thermometer
- Becks Depression Inventory (BDI)

H & P continued

- Chemistries (electrolyte imbalance)
- Infection
- CBC (anemia)
- Endocrine
 - Thyroid disease
 - Menopause/hypogonadism, sexual dysfunction, infertility
- Cardiac
 - EKG
 - Echo
 - Stress test
- Pulmonary
 - PFT
 - Sleep study
- Neurologic (CNS imaging, neuropsychological testing)

Depression

- Interventions
 - Optimize metabolic contributors
 - Psychotherapy
 - Symptom assessment
 - Medications
- **Assess for thoughts of suicide or self harm, requires immediate intervention**

Depression Interventions

- Tricyclic antidepressants (older) nortriptyline, amitriptyline, desipramine
- SSRI (selective serotonin reuptake inhibitors)
 - fluoxetine(Prozac) fluvoxamine (Luvox)
 - sertraline (Zoloft) citalopram (Celexa)
 - paroxetine (Paxil) escitalopram (Lexapro)
- SNRI (serotonin norepinephrine reuptake inhibitors)
 - venlafaxine (Effexor)
 - duloxetine (Cymbalta)
- Psychostimulants (methylphenidate)
- Others
 - mirtazapine (Remeron) (Noradrenaline and specific serotonergic antidepressants)
 - bupropion (Wellbutrin)
 - Trazadone

Ostuzzi, et al. 2018

Anxiety and Depression Interventions

- Relaxation techniques
- Psychoeducation
- Individual psychotherapy
- Group psychotherapy
- Psychotherapeutic interventions with couples
- High level of evidence in terms of reducing anxiety and depression and improving quality of life

Anxiety

Characterized by the distress of emotional discomfort and apprehension that stimulates a physiologic adaptation to stress. Anxiety may occur at throughout the trajectory a diagnosis, treatment or restaging

- Risk Factors:
 - Medications
 - Sleep disturbances
 - Lack of knowledge & control
 - Highest anxiety is experienced after diagnosis
 - 20-30% experience anxiety after completing treatment
 - FCR is a cause of anxiety

Anxiety Interventions

- Interventions:
- Relaxation exercises, music, biofeedback, hypnosis
- Support groups
- Prayer
- Counseling
- Medication
- Compassion
- Assess learning styles

Medications

- SSRI-selective serotonin reuptake inhibitors (Paxil)
- SNRI-serotonin norepinephrine reuptake inhibitors (Cymbalta)
- Benzodiazepams
 - Lorazepam (Ativan)
 - Clonazepam (Klonopin)
 - Alprazolam (Xanax)

Anxiety and Depression: Role of Nursing

- Assessment
- Effective communication and time to talk
- Listening
- Identifying the problem
- Recognizing the role of self-efficacy (belief in one's capability to organize and execute the courses of action required to manage prospective situations) to assist patients to control negative psychological reactions and improve QOL
- Referral to appropriate discipline

Loss Associated with Cancer Diagnosis

- Loss of ability to function independently
- Loss of identity
- Changes in role definition
- Body changes (breast, limb, prostate, body altering surgery)
- Fear of death and cultural interpretations
- Provider clarification of loss is important
- Patient and families often hear different interpretation of information presented by healthcare providers

Financial Concerns

- Difficult to provide quality care to patients with cost prohibited therapies
- Individuals with low annual income are 3-7X more likely to die of cancer than those with high annual income
- Poverty not race lowers the survival rate among many ethnic groups by 10-15%
- Primary barrier is access to care
- 20-77% of family caregivers miss work or quit jobs to provide care
- In a study of 104 survivors of head and cancer (Mady, et al. 2019) described financial toxicities risks as
 - Not married
 - Younger age
 - Decrease in education level
 - Decrease in income
 - Type H & N disease (larynx/hypopharynx)

Financial Toxicity

- According to the Centers for Disease Control and Prevention, one in three Americans experiences financial burden as a result of medical care
- The burden is greater for cancer patients, who pay more out of pocket for care than those with other chronic illnesses
- 13% of nonelderly cancer patients spend at least 20% of their income on out-of-pocket expenses
- 50% of Medicare beneficiaries with cancer pay at least 10% of their income towards cancer treatment–related out-of-pocket costs

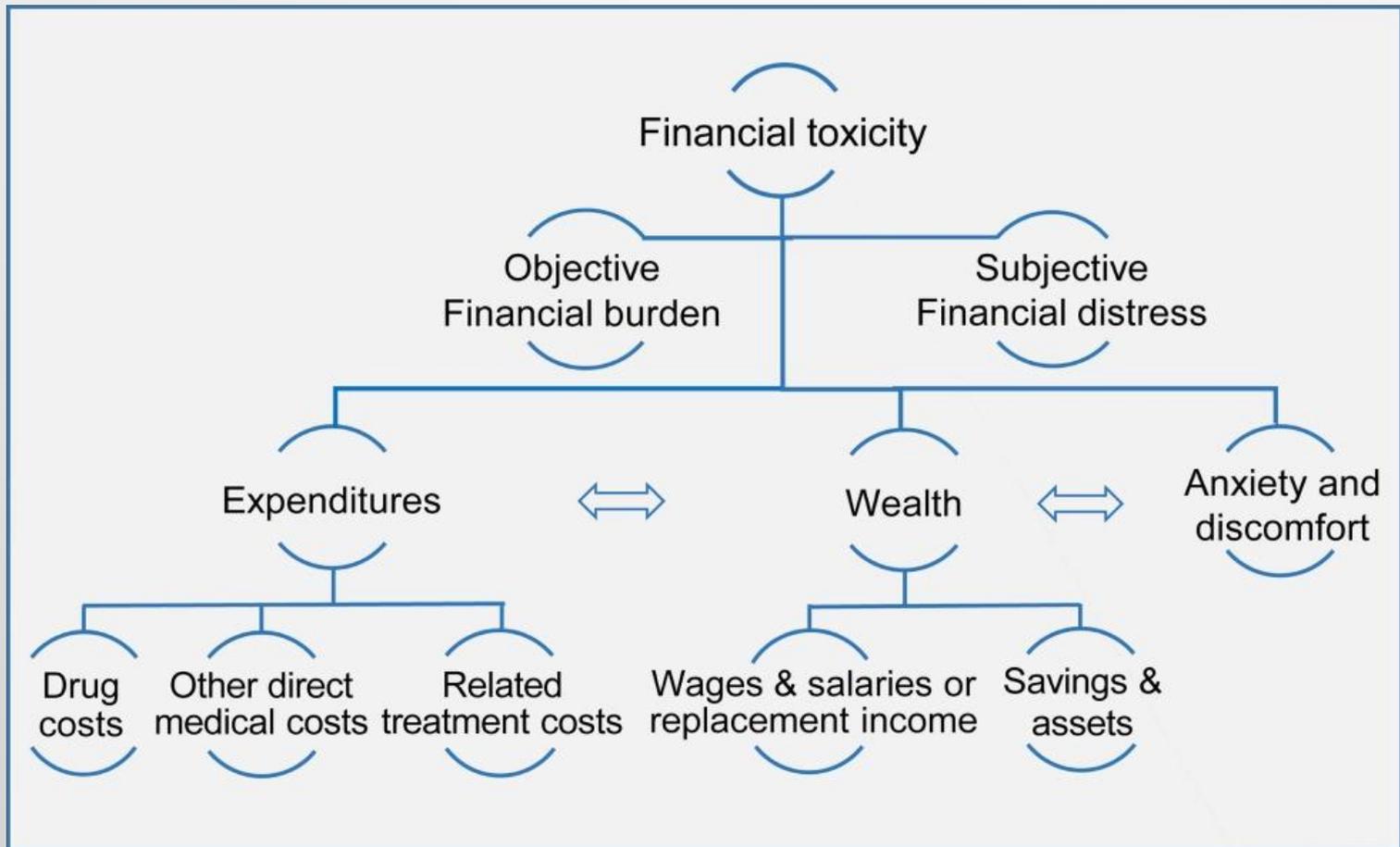
Financial Toxicities Increases Mortality

- Numerous studies have found that because of high out-of-pocket expenses cancer patients and their caregivers face considerable detriment to their subjective well-being
 - Decrease leisure activities (socialization)
 - Spending less on food and clothing
 - Work longer hours
- Financial distress might worsen survival because of its impact on health-related quality of life (HRQOL)
 - Poor physical health, poor mental health, and less satisfaction with relationships
- Higher out-of-pocket costs can harm the quality of cancer care
 - Cost related non-adherence

Carrera, et al., 2018

Financial Toxicity

Carrera et al. 2018



Financial Toxicity

Desai et al., 2020



Financial Interventions

- Identify resources; SS, hospital or clinic supports, pharmaceutical support, disability eligibility, organizational (ACS, LLS)
- Shift from hospital-based care to outpatient or home
- The American Disability Act (ADA) and Family Medical Leave Act (FMLA) apply only to employers with more than 15 and 50 employees.
- Under the ADA law employer is required to change the patient's schedule to permit chemotherapy treatment.

Social Dysfunction

- Identify family or community roles
- What is the patient's role?
- In a study by Kroenke, et al., (2017) found that breast cancer patient with social support associated with better outcomes and overall survival
- What types of relationships does patient have?
 - Negative/Stressful
 - Supportive
 - Symbiotic/Interdependent

Cultural Issues

- Cultural competence is the foundation for reducing disparities through culturally sensitive and unbiased quality care
- Care that respects diversity in the patient population and cultural factors that can affect health and health care, such as language, communication styles, beliefs, attitudes, and behaviors
- National CLAS standards (Cultural and Linguistic Appropriate Services) in the Office of HHS
- The standards cover areas such as governance, leadership, workforce; communication and language assistance; organizational engagement, continuous improvement, and accountability.
 - Language barriers
 - Lead to overwhelming patient stress
 - Medical errors
 - Home remedies vs medical treatment
 - Incorporate traditions into treatment plans
 - Cultural competence training for healthcare providers

Disparity in Cancer

- American Indians/Alaska Natives have the lowest 5-year cancer survival across all cancer types and experience elevated rates for many malignancies and major risk factors, when compared to European Americans
- Hispanics/Latinos and Asian Americans tend to have lower cancer incidence rates than other U.S. population groups.
- Asian Americans, have the lowest cancer-specific mortality
- Hispanics/Latinos, infection-related cancers are increased and are more likely to be diagnosed with late stage cancer when compared to U.S. European Americans
- African Americans disproportionately bear the cancer burden and have the highest death rates from malignancies of the breast, gastrointestinal tract, lung, and prostate, and develop multiple myeloma more commonly than other population groups
- Men of African ancestry have 2–3-times higher absolute rates of fatal prostate cancer in both the U.S. and England
- Reasons of why these specific cancer disparities exist have been extensively reviewed and require more aggressive inquiry and interventions

Minas, et al. 2018

Spiritual Distress

- Spirituality refers to that dimension of being human that prompts individuals to make sense of their universe, and to relate harmoniously with self, nature, and others.
- Issues:
 - Changes in life priorities and values
 - Search for the meaning of life
 - Enlighten

SPIRITUAL TOOLS

- **FICA**

- F = Faith or beliefs
- I = Importance and influence
- C = Community
- A = Address

- **HOPE**

- H: Source of Hope
- O: Organized Religion
- P: Personal spirituality and practices
- E: Effects on medical and end of life care

Management of Spiritual Needs

- Open and supportive dialogue
- Understanding of practices
 - Jehovah's Witness practices
 - Fasting during holy days for many faiths
- Offer support
 - Within healthcare setting
 - Community support

Fertility and Sexuality Dysfunction

- **Fertility concerns:** Consider for all pediatric and adults under the age of 40.
 - Before
 - During
 - After therapy
- **Sexual function:** Universal problem and persists during and after treatment
 - Before
 - During
 - After therapy

Fertility and Sexual Dysfunction

- Infertility: inability to conceive after 1 year of trying
- Risk factors: cancers of GU/GYN systems affect over 50% of patients and 25% of patient with other types of cancer and pelvic radiation
- 25% of women with GVHD develop vaginal scarring and vulva
- Caused by nerve and blood vessel damage
- Male sexual dysfunction is related to lack of interest and erectile dysfunction (reported in 84-95% in a Scandinavian and US study)
- Female sexual dysfunction is reported as vaginal dryness and genital changes that causes pain and lack of interest and increased in woman who have had a premature ovarian failure and ultimately are menopausal

Fertility Issues

- Chemotherapy: suppression of gonadal function, germ cell toxicity, fall in hormone levels, depletion of germinal epithelium
- Targeted therapy and robotic interventions have not had a positive impact in sexual dysfunction
- Aromatase inhibitors and chemoradiation from anal cancer associated with severe sexual morbidity
- May return as late as 4 years post therapy

Impact of Infertility and Sexual Dysfunction

- Depression
- Anxiety
- Relationship conflict
- Loss of self-esteem
- Patients remain uninformed about changes in sexual function and infertility
- Fertility preservation is underutilized
- After treatment patients have unmet needs in terms of sexual function and infertility

Schover et al. 2014

Lindau, et al. 2016

Effects of Cancer Treatment on Fertility and Sexuality

- Hormonal: Androgen Deprivation Therapy; Aromatase Inhibitors; Tamoxifen
- Radiation
- Chemotherapy: Taxanes, Alkylating agents
- Surgery
- Orchiectomy
- Cystectomy
- Head and Neck
- Ostomy surgery

Methods to Preserve Fertility

- Semen cryopreservation
- Embryo cryopreservation
- Trachelectomy (cervicetomy)
- Oophoropexy (ovarian transplantation)
- Shielding
- Oral contraception
- GnRH (Lupron) causes ovarian suppression

Chemotherapy in Pregnancy

- Risk depends on trimester of pregnancy
- Radioactive iodine contraindicated
- 1%-4% of women with breast cancer are diagnosed during pregnancy
- Chemotherapy generally considered safe (with exceptions) in 2nd and 3rd trimesters
- Radiation therapy typically delayed until after delivery

Sexuality

- Symptoms Management (N/V, mucositis, fatigue, rash, diarrhea, hair loss, menopausal, change in roles, weight change, neuropathy, vaginal dryness, erectile dysfunction, depression, fears)
- Interventions:
 - Communicating needs to partners
 - PERMISSION TO TALK WITH PROVIDERS and ASK QUESTIONS

Sexual Interventions

- Only 20% of cancer survivors seek professional care for their sexual problems
- 50% of men with a radical prostatectomy seek medication interventions for ED
- Sexuality is rated as a high priority issue by 75% of survivors
- Vaginal dryness: Lubricants, moisturizers, vaginal rings or estrogen, vaginal dilator to prevent vaginal fibrosis, avoid Irritants (douching, bubble baths)
- ED: PDE₅ inhibitors; sildenafil, vardenafil, and tadalafil
Urethral suppositories & penile self-injection agents or prosthesis

Sexual and Fertility Management

- Develop a team approach to managing sexual and fertility problems
- Involving
 - Reproductive counselors (provide information and sexual rehabilitation)
 - Nursing
 - MD
 - Therapist
 - Social services

Assessing Sexual Dysfunction

- **ALARM Model:**
 - **A**= Activity or sexual function
 - Currently involved in a sexual relationship
 - **L**= Libido or desire
 - Interest in sexual activity
 - Increased, decreased or unchanged
 - **A**= Arousal or orgasm
 - Changes in arousal or orgasms
 - **R**=Resolution or release after sexual activities
 - **M**=Medical information including medications

Five A's

- **Ask:** bring up the topic
- **Advise:** normalized symptoms and acknowledge the problem
- **Assess:** Ask about sexual functioning
- **Assist:** Provide information and resources
- **Arrange:** Provide follow-up to check in with the patient

BETTER

- **Bring** up the topic
- **Explain** about potential changes in sexuality and give the patient the opportunity to discuss concerns
- **Tell** the patient about resources
- **Time** the discussion to the patients' concerns
- **Educate** patients about side effects that may affect sexuality
- **Record** assessments and interventions

Altered Body Image

- Actual or perceived:
 - Response to actual or perceived change in body structure or function
 - Risk Factors: loss of organ, mastectomy, amputation, H&N Disease, treatment, toxicities, disfigurement, weight changes, mobility changes, long term effects, infertility cancer, colostomy/ileostomy
 - Physical signs
 - Cognitive signs
 - Psychosocial signs

Protection of Patients and Partners from Sexual Related Toxicities During Cancer Treatment

- ***Avoid becoming pregnant while on cancer therapy***
- ***ONS Guidelines:*** recommends that all patients use condoms to prevent infections and that intercourse should be avoided when counts are low
- ***HSCT Guidelines:*** more specific because of prolonged immunodeficiency and the risk of infection. Condoms should be used and barrier devices should be used during any contact of patient's mucous membranes
- ***Pelvic Radiation Patients:*** at risk of developing mucous membrane reactions such as inflammation, ulceration and bleeding. Condoms and lubricants should be used
- ***Chemotherapy:*** found in semen and vaginal secretions and condoms should be used everyday of chemotherapy and then for 1 week after

Sexually Transmitted Cancer

- HPV strains responsible for 70% of all cervical cancers, 6,11,16,18
- H & N (specifically oropharynx) increase prevalence from 17% in 2006 to 50% in 2012 publication (Granata, et al., 2012)
- Vaccine for preventing HPV and chance of developing cervical cancer, most effective prior to sexual contact
- ADM=AIDS-defining malignancies
 - Cervical, Kaposi sarcoma, NHL

Patient Resource for Additional Information on Safe Sex, Sexual Health and Fertility

- American Cancer Society: <http://bit.ly/1rTICty>; <http://bit.ly/1m5Houb>; <http://bit.ly/1qulpmS>; <http://bit.ly/1o3HZLC>
- American Congress of Obstetricians and Gynecologists: www.acog.org/patients
- Cancer.Net: <http://bit.ly/1mh7lbl>
- MyOncofertility: www.myoncofertility.org
- National Cancer Institute: www.cancer.gov/cancertopcis/pdq/supportivecare/sexuality/Patient
- Planned Parenthood: www.plannedparenthood.org
- Fertile Hope: www.fertilehope.com

Survivorship

- An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of their lives, regardless of the ultimate cause of death
- Includes family members, friends, and caregivers

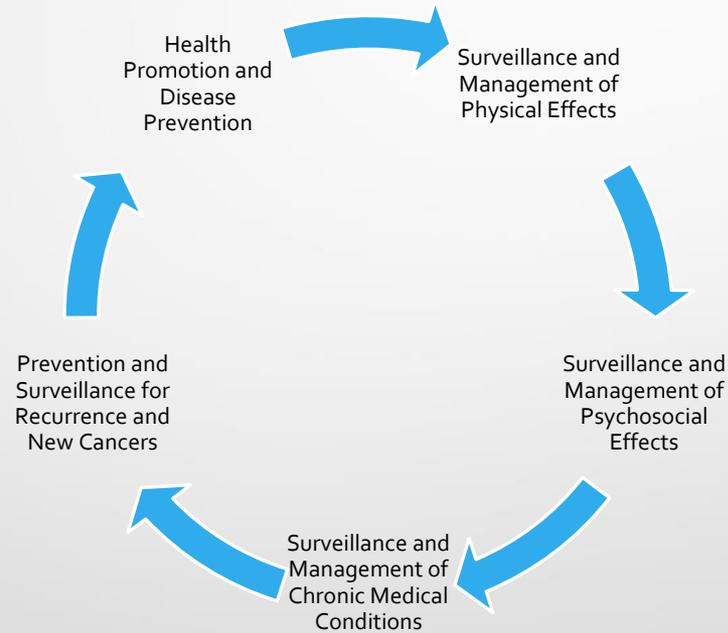
Mullan 1985, NCI; Office of Cancer Survivorship (OCS) 2012

National Coalition for Cancer Survivorship (NCCS)

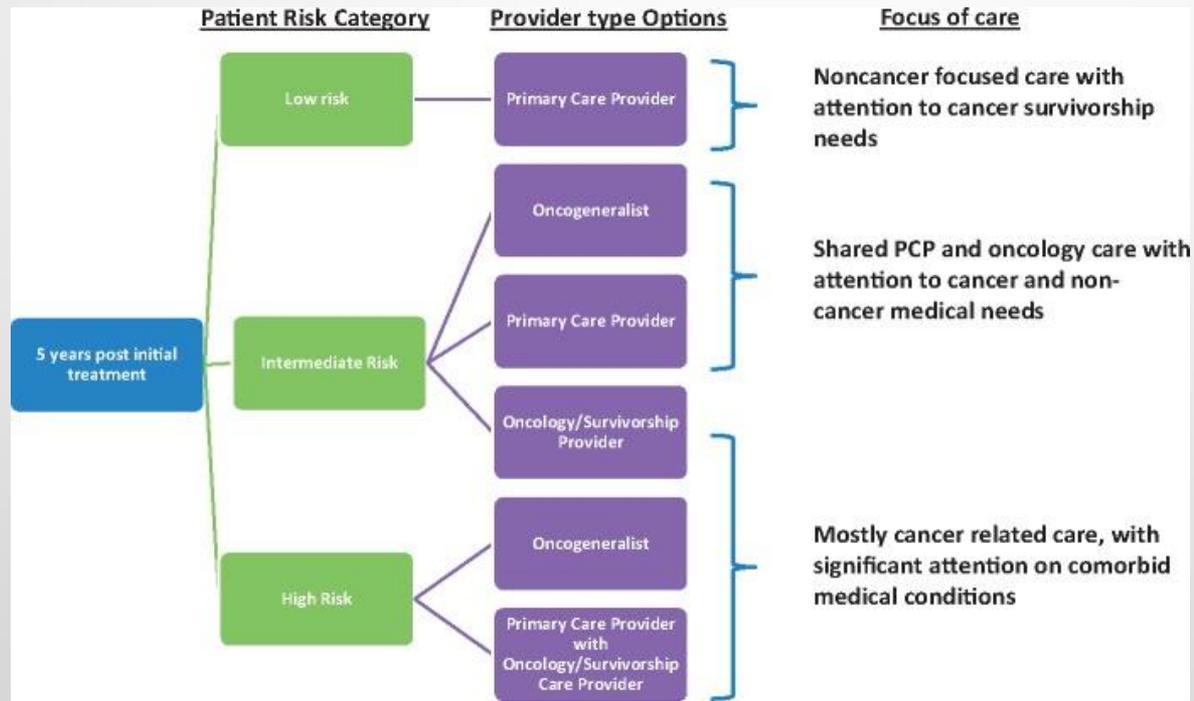
Survivorship is Ongoing

- N.A. is a 48-year-old male diagnosed with aggressive non-Hodgkin's Lymphoma at age 25 while pursuing his PhD studies and he chemotherapy for three years and radiation to the head and neck.
- In remission for 23 years. But the road through survivorship continued.
- About 13 years postdiagnosis, he developed congestive heart failure and then three years later experienced a near cardiac arrest leading to the placement of an implantable cardioverter defibrillator. Numerous other treatment-related complications ensued, each leading to a new specialist.
- Despite being an educated researcher, throughout his cancer journey, N.A. has had questions about his diagnoses and has been challenged in trying to understand complex medical information.
- He has needed help making decisions, longed for emotional support, and faced the daunting task of navigating the health care system, often by himself. He was not a patient treated in a patient-centered, primary care-based medical home, but one in several homes belonging to multiple specialists.
- Unclear if providers were communicating with one another and providing him with quality, coordinated care. Felt homeless in a world of medical homes.

Quality Cancer Survivorship Framework



Revising Existing Survivorship Care Models



Case Study

- Tom is a 57 year old gentleman who has completed 6 cycle of R-CHOP for large cell lymphoma. He is seen in clinic today for PET/CT and lab work. What are some concerns you may have regarding the care of Tom?

Case Study

- His CBC reports a hgb of 10.7/previously 13.1 g/dl with a hematocrit of 31.2%/previously 40.3%. What would be the next step?

Survivorship

- Last 30 years in US number of Cancer Survivors from 3 million to 13 million (2012)
- Expected to rise to 20.3 million by 2026
- Trends in the future Cancer survivors will be older and more ethnically diverse
- 65% of Adults and 75% of children survive beyond 10 years
- 59% of survivors are 65 years or older
 - 25% of patients >65 have 5 or more comorbid conditions
- Most common sites in survivor population: Breast (22%), prostate (20%), colorectal (9%), gynecologic (8%)
- Most powerful predictor of survival is advanced disease at diagnosis
- Estimated costs of survivorship is 57 billion dollars (2010 dollars)

Survivorship

- 60% childhood survivors have 1 or more treatment or disease related long-term effects.
- Early follow-up emphasizes surveillance and detection of disease reoccurrence
- Long-term follow-up emphasizes monitoring and managing chronic and/or late effects
 - Second malignant neoplasms (SMN)
 - Cardio-vascular disease (CVD)

Addressing Cancer Survivorship

- 2006 IOM publication: From Cancer Patient to Cancer Survivor: Lost in Transition listed 10 recommendations
- The American College of Surgeons Commission on Cancer (CoC) established a patient-centered standard requiring cancer Survivorship Care Plan (SCP) at the conclusion of their treatment. New accreditation standards were released in 2012 to be phased in beginning 2015
- Difficulty in achieving goal

Barriers to Implementing SCP

- Time consuming process for preparing SCP
- Lack of role clarity between APP, RN, oncologist, PCP, specialty
- Lack of reimbursement for preparation and development
- Lack of compatibility of existing templates with EHR in capturing important information
- Paucity of data associating SCP to positive outcomes

NCCN Survivorship Assessment

Survivorship Concerns	Assessment
Cardiac Toxicity	SOB with activity/SOB when sleeping
Anxiety, Depression, Distress, Trauma	Little interest/depressed/nervous
Cognitive Function	Difficulty multi-tasking/memory/slowed thinking
Fatigue	Persistent fatigue/effect activities/rate fatigue
Lymphedema	Swelling or heaviness on affected side
Hormone related symptoms	Night sweats/hormone side effects
Pain	Current pain/rate pain
Sexual Function	Concerns about intimacy/level of distress
Sleep disorder	Difficulty falling or staying asleep sleepiness/snoring
Healthy Lifestyle	Physical activity/weight/vitamins/healthy eating habits
Immunizations and Infections	Up to date on vaccines/infections

Long Term vs. Late Effects

- Long-term side effects begin as a complication of treatment, persist throughout treatment, and may continue after treatment is completed.
- Late effects begin after treatment is completed and may manifest years later

Long Term Effects of Treatment

Organ	Long Term Consequences
Cardiovascular	CHF, cardiomyopathy, CAD, valve disease, electrical/conductive system disease
Pulmonary	Pulmonary fibrosis, restrictive lung disease, dyspnea
GI	Malabsorption, dysphagia, GERD, hepatitis, constipation, diarrhea
Bone	Osteopenia, osteoporosis, AVN
Endocrine	Hypothyroidism, adrenal insufficiency, diabetes
GU	Chronic kidney disease, proteinuria, incontinence
Oral	Xerostomia, dental caries, ONJ
Neuro/Sensory/other	Hearing loss, visual changes, taste changes, neuropathy, lymphedema, insomnia
Reproductive	Loss of libido, body image, hormonal deficits

Long Term Effects of Cancer

- Social
 - Changes in roles and relationships
- Cognitive Impairment
 - Inability to concentrate
 - Memory loss and word finding difficulties
- Financial
 - Reduced work schedule or loss of employment
 - Difficulty obtaining insurance
 - Prescription and device costs

Late effects

- Secondary malignancies
 - Adult survivors of childhood cancers have increased incidence of 2nd malignancies
 - Women who received chest radiation as child/adolescent at increased risk of developing breast cancer at same rates as those with BRCA genetic mutations
 - Hodgkin Lymphoma survivors at risk for both recurrence and secondary malignancy r/t chemotherapy and thoracic radiation

Survivorship Interventions

- Appropriate assessment based on individual cancer diagnosis
- Patient-specific Education
- Written information about follow up plan
- Referral to appropriate specialist as needed (PT, Renal, Cardiology, etc.)
- Encourage all patients to be physically active Goal: 150 min (Moderate intensity) or 75 min (vigorous intensity) per week

Survivorship Care Plans

- Survivorship recognized as a distinct phase of the cancer trajectory, providing opportunities to promote healthy lifestyle, monitor for recurrence and identify and manage long-term and late effects.
- Provide direction and education for follow-ups
- Detail description of their treatment
- Surveillance and Prevention
- Rehabilitation

Stricker & O'Brien, CJON, 2014

Cancer Survivorship Plan

Breast	Colon	BMT
<p>Cardiac: Anthracyclines: doxorubicin Alkylating: cyclophosphamide Targeted: trastuzumab Taxanes: paclitaxel and docetaxel Hormonal Blockade: Tamoxifen</p>	<p>Surveillance: 1–2 Years Post-treatment*: H & P every 3–6 months CEA every 3–6 months Chest / abdominal / pelvic CT every 12 months (stages I–III); every 3–6 months (stage IV, NED) Colonoscopy in 1 year; if advanced adenoma, repeat in year 2 Proctoscopy (rectal cancer only) repeat every 6 months</p>	<p>Cardiovascular: CVD HF</p>
Bone Health	2nd Malignancy	Immune Dysregulation: GVHD, chronic infection
Recurrence/2 nd Malignancy	Psychosocial Issues	Psychosocial: Distress, anxiety, PTSD
Lymphedema	GI Problems Ostomy care Diarrhea/constipation	Fertility
Lifestyle assessment	Cardiovascular Cognitive Dysfunction	2 nd malignancy

Survivorship Resources

Organization	Website
National Coalition of Cancer Survivors	https://www.canceradvocacy.org/
NCI Office of Cancer Survivors	https://cancercontrol.cancer.gov/ocs/
American Cancer Society	http://www.cancer.org/index
American Society of Clinical Oncology	http://www.asco.org/practice-policy/cancer-care-initiatives/prevention-survivorship
CDC: Survivorship	https://www.cdc.gov/cancer/survivors/index.htm
NCCN: Life After Cancer	http://www.nccn.org/patients/resources/life_after_cancer
Leukemia and Lymphoma Society: Survivorship Information	https://www.lls.org/managing-your-cancer/follow-up-care-and-survivorship

Survivorship, Sexual, Psychosocial

- 16% of OCN test



- GOOD LUCK



Case Study 1

- Jacqui is a 49 year old single mother of 3 with stage II ovarian cancer. She underwent a TAH followed by 6 cycles of carboplatin/paclitaxel X6 cycles. She is seen for follow-up in the Women's Cancer Clinic. She completed her therapy 4 months ago.

What are some of your concerns regarding Jacqui during today's appointment?

- A.** Financial concerns
- B.** Depression and anxiety
- C.** Sexuality dysfunction
- D.** All of the above

Case Study 1 Continued

- Jacqui reports that she is very fatigued and sometimes sleeps 14 hours/day. She has not returned to work because of her level of fatigue.

What would be considered an appropriate first intervention

- A. Speak to PCP or primary oncology provider about her fatigue
- B. Obtain a prescription for methylphenidate
- C. Increase daily exercise
- D. None of the above

Case Study 2

- Tom is a 57 year old gentleman who has completed 6 cycle of R-CHOP for large cell lymphoma. He is seen in clinic today for PET/CT and lab work.



What are some immediate concerns you may have regarding the care of Tom?

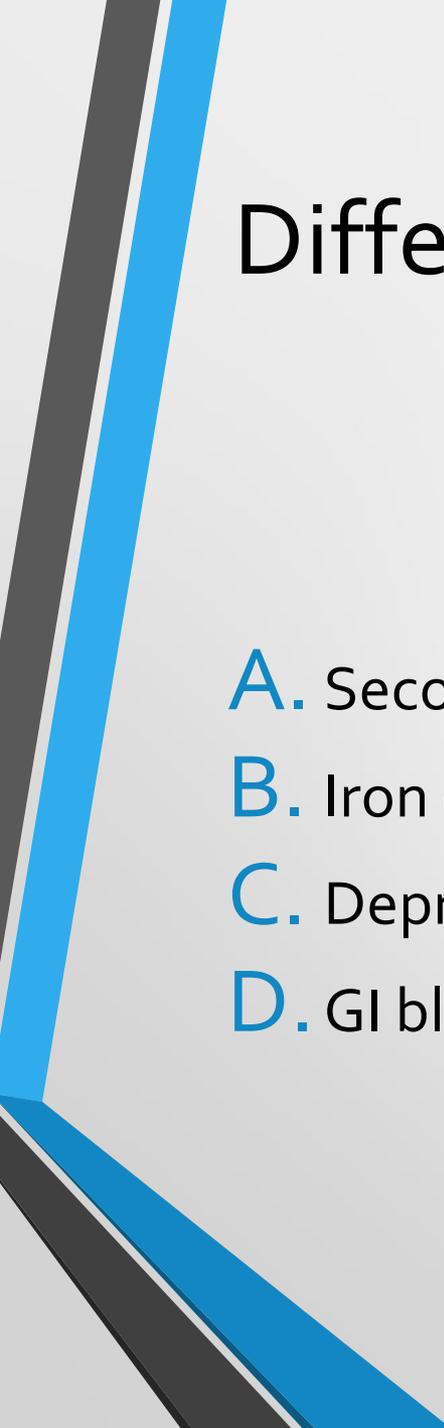
- A. Relapse
- B. Long term and late side effects
- C. Secondary malignancies
- D. All of the above

Case Study 2

His CBC reports a hgb of 10.7/previously 13.1 g/dl with a hematocrit of 31.2%/previously 40.3%. What would be the next step?

Case Study 2 continued

- Lab values: MCV/MCH/MCHC; differential/LDH,
- Assessment
 - Performance status
 - Infections
 - Physical Exam, consider colonoscopy
 - Bone marrow aspirate and biopsy



Differential diagnosis would include
all but the following?

- A. Secondary malignancy
- B. Iron deficiency anemia
- C. Depression
- D. GI bleed

A patient states, "I have been afraid to show my body to my spouse since the mastectomy." To promote open communication, the nurse responds:

- A. Do not worry, things will look better in a few weeks."
- B. "There are many options for prostheses and reconstruction."
- C. "I am sure your spouse loves you just the way you are."
- D. "Let's practice discussing your concerns with your spouse."

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A patient with cancer receiving palliative services reports poor sleep, fatigue, and frequently feeling worried. Which medication should the nurse expect to be prescribed for the patient?

- A. Citalopram
- B. Mirtazapine
- C. Diphenhydramine
- D. Methylphenidate

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A patient newly diagnosed with cancer frequently interrupts the nurse, who is providing teaching about treatment, and states, "Why did this happen to me?" The nurse recognizes this behavior most likely represents:

- A. Reactive anxiety.
- B. Cognitive impairment.
- C. Suspicion of the treatment.
- D. Symptoms of depression.

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