PSYCHOSOCIAL DIMENSIONS OF CARE

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OCN Test Blueprint

VI. Psychosocial Dimensions of Care – 10%

A. Cultural, spiritual, and religious diversity
B. Financial concerns (including available resources)
C. Altered body image
D. Learning styles and barriers to learning
E. Social relationships and family dynamics
F. Coping mechanisms and skills
OCN Test Blueprint

G. Support
   1. Patient (i.e., individual and group)
   2. Caregiver (including family)

H. Psychosocial considerations
   1. Anxiety
   2. Loss and grief
   3. Depression
   4. Loss of personal control
OCN Test Blueprint

I. Sexuality
   a. Reproductive issues (contraception and fertility)
   b. Sexual dysfunction (physical and psychological effects)
   c. Intimacy
Psychosocial Dimensions of Oncology Nursing Care

EDITED BY
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Psychosocial Dimensions of Care

- Psychological and social problems are unrecognized in 80% of patients

- Medical, psychosocial, and social factors influence the level of distress experienced by patients and family members
Psychosocial Dimensions of Care

Medical factors
- Relate to site and clinical course
- Type of treatment
- Presence of pain and suffering

Psychological factors
- Disruption of life goals
- Ability to modify life plans using coping tactics and emotional maturity

Social factors
- Availability of support from family, friends, coworkers, and healthcare workers
QOL: Conceptual Model

Quality of Life Model Applied to Cancer Survivors

Physical Well Being and Symptoms
- Functional Activities
- Strength/Fatigue
- Sleep and Rest
- Overall Physical Health
- Fertility
- Pain

Psychological Well Being
- Control
- Anxiety
- Depression
- Enjoyment/Leisure
- Fear of Recurrence
- Cognition/Attention
- Distress of Diagnosis and Control of Treatment

Social Well Being
- Family Distress
- Roles and Relationships
- Affection/Sexual Function
- Appearance
- Enjoyment
- Isolation
- Finances
- Work

Spiritual Well Being
- Meaning of Illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner Strength

Cancer Survivorship

Ferrell B., & Grant M. City of Hope
# QOL: Conceptual Model

The Psychosocial Needs of Patients with Cancer Based on Aspects of QOL

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<td>• Discomfort/pain</td>
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Psychosocial Dimensions of Care

Cultural, Spiritual, and Religious Diversity

All human beings are unique individuals, yet each of us interacts with the world around us according to values, beliefs, and social norms that are influenced by our spiritual, religious, and cultural perspective.
Most frequently reported cancer diagnoses and death by race and ethnicity

- For men, lung, prostate, and colorectal cancer are among the top 5
- Prostate most frequently diagnosed in Native American, Filipino, Japanese, non-Hispanic white, and Hispanic men
Most frequently reported cancer diagnoses and death by race and ethnicity

- Lung and bronchial cancer account for the majority of newly diagnosed cancer among men in all other racial and ethnic groups except Native Americans.
- Native American men the majority of cancer related deaths are caused by:
  - Prostate
  - Stomach
  - Liver Cancer
• Prostate and CRC rank 2\textsuperscript{nd} in mortality for men in most other racial and ethnic groups
  • The exception is that liver ca is 2\textsuperscript{nd} leading cause of ca-related death in Chinese men
• With the exception of African American, Filipino, and non-Hispanic white males, stomach cancer is in the top five diagnoses resulting in death
• Pancreatic cancer ranks in top 5 for cancer-related mortality for all groups except Alaska Natives, native Americans, and Filipinos
• For women, lung cancer is the number 1 cause of cancer-related death in most racial and ethnic groups
• For most groups, breast cancer is the 2\textsuperscript{nd} leading cause of cancer-related deaths
  • except for Filipina and Hispanic women, for whom breast cancer ranks first in cancer-related mortality
• Alaska Native women experience the highest cancer mortality from CRC
  • CRC ranks among top 5 in mortality for all groups except for Native Americans- pancreatic in top 5
Cultural Factors

- Race/ethnicity
- Gender
- Sexual orientation
- Age
- Geographic region
- Socioeconomic status
Cultural Diversity in Cancer

• Attention to cultural competence focuses on providing for the needs of patients and families with differences as well as similarities in beliefs, values, and culture

• “Cultural desire” - nurse’s motivation to become culturally aware and skillful

• Self reflection - analysis of one’s own beliefs, values, and culture
Assumptions About Culture

• Culture is learned and not genetic
• One culture is not better than another culture: they are just different
• Differences exist between, within, and among cultures
• Any person can identify with multiple cultural groups
• Culture influences one’s interpretation and response to heath care
• All people have the right to be respected for their uniqueness and cultural heritage
• **Nurses who are culturally competent will improve the care of their patients**
• Culture is a dynamic and ever-changing process
• Learning culture is an ongoing process and develops in many ways, primarily through cultural encounters
• With cultural awareness, prejudices and biases can be minimized
### Purnell’s 12 Domains

- **Overview/heritage-** country of origin, reason for emigration, economics, political affiliation, educational level, occupation
- **Communication-** dominant language, willingness to share thoughts and emotions, eye contact, touch, form of greeting, clock versus social time
- **Family roles and organizations-** gender roles, developmental tasks of children, roles of extended family members, social status, alternative lifestyles, child-rearing practices
- **Workforce issues-** autonomy, gender roles
- **Biocultural ecology-** biologic variations: skin color, physical differences, heredity, genetics, and differences in how the body metabolizes drugs
- **High-risk health behaviors-** the use of alcohol, tobacco and recreational drugs; physical inactivity; high-risk sexual practices; at–risk behaviors (e.g., non-use of seatbelts)
- **Nutrition-** having enough food, meaning of food, food choices, rituals
### Purnell’s 12 Domains

- Pregnancy and childbearing practices - fertility practices, views towards pregnancy, methods of birth control, birthing, and postpartum treatment
- Death rituals - how the culture views death, rituals, burial practices, bereavement practices
- Spirituality - religious practices, use of prayer, individual sources of strength, behaviors that give meaning to life
- Healthcare practices - focus on acute or preventative, individual responsibility for health, self-medicating practices, views about mental illness, organ donation, organ transplantation, one’s responses to pain and the sick role
- Healthcare practitioners - status of, use of, gender of practitioner may have significance
Cultural Diversity Self-Analysis

• What is the cultural identity that you most identify with?
• What values were you taught?
• How were you affected by the first encounter you had with someone from a different culture? Different race? Different sexual orientation?
• How were men and women treated differently or similarly in your cultural group?
• How do your feelings change when you find out a person abuses prescription drugs? Alcohol? Illegal drugs?
• What cultural differences in others do you find most difficult to accept? What differences do you find to be easier to accept?
• How did food affect your life within your household when you were growing up?
• How do you feel on an elevator with a person from a different race?
• Do you recall the first time you saw a person with a physical or mental disability? How did you feel?
• How old were you when you met someone with a terminal illness? How did this affect you?
Cultural Diversity in Cancer

- Care consumers in the US increasingly more diverse
- In 2010 the Hispanic population increased by 43%
- Hispanics account for 16.3% of the US population
- Asians account for 4.6%
- Native Hawaiian/Pacific islanders 0.2%
- Over 9 million in the US identify as mixed race
  - 91.7% identify 2 races
- 1/3-1/2 US population identify themselves as other than non-Hispanic white alone
  - 86.6 million in 2000 to 111.9 million in 2010
Spirituality

Spirituality within the context of a healthcare environment is defined as that aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.
Spirituality

- Spirituality expresses the reflective human quest for identity and meaning beyond a purely pragmatic approach to life.

- In defining spirituality as a broad notion of finding meaning, purpose and making sense of one’s own existence, religion might be a part of this, but that is not necessarily the case.
Spirituality

• Spiritual care aims at addressing the existential needs of patients, including questions about meaning of life and death, as well as the search for peace, spiritual resources, hope and help in overcoming fears.

• The possibility to discuss existential questions is one of the unmet needs of advanced cancer patients who are confronted with the end of life
Spiritual Distress

- A state of experiencing a disturbance in one’s belief or value system that provides strength, hope, and meaning in life

- Risk factors
  - Disease related
  - Situational
Spiritual Distress

• Hope is one of the major modes by which people anticipate the future and mobilize resources to cope with their illness

• Honest disclosure regarding diagnosis and prognosis must be balanced by realistic hope
Spiritual Distress

• Ask about beliefs, values, and sense of meaning and purpose in life since their cancer diagnoses

• Clarify language or terms patients use when they describe their spiritual beliefs
SPRING MEETING &
OCN REVIEW COURSE

NCCN Guidelines Version 2.2018
Distress Management

PSYCHOLOGICAL/PSYCHIATRIC
TREATMENT GUIDELINES

Evaluation for:
- Distress
- Problematic behaviors
- Psychiatric history/medications
- Substance use disorder
- Pain and symptom control
  - NCCN Guidelines for Adult Cancer Pain
  - NCCN Guidelines for Palliative Care
- Fatigue
  - NCCN Guidelines for Cancer-Related Fatigue
- Body image
- Sexual health
- Impaired cognitive capacity
- Safety
- Psychological/psychiatric disorder
- Medical causes
  (refer to primary oncology team)

Neurocognitive Disorders: Dementia
  (DIS-7)

Neurocognitive Disorders: Delirium (DIS-9)

Depressive Disorders (DIS-10)

Bipolar and Related Disorders (DIS-12)

Schizophrenia Spectrum and Other Psychotic Disorders (DIS-14)

Anxiety Disorders (DIS-16)

Trauma and Stressor-Related Disorders (DIS-17)

Trauma and Stressor-Related Disorders: Adjustment Disorders (DIS-18)

Obsessive Compulsive and Related Disorders (DIS-20)

Substance-Related and Addictive Disorders (DIS-21)

Personality Disorders (DIS-23)

Referral by oncology team to mental health team*

Follow-up and communication with primary oncology team, primary care physician, and family/caregivers

*Psychiatrist, psychologist, advanced practice clinicians, and/or social worker.

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.
Psychosocial Dimensions of Care

All patients, no matter what stage of disease, experience some from or level of distress related to their diagnosis and so are faced with coping challenges.

National Comprehensive Cancer Network [NCCN], 2017
Unidentified and untreated psychological distress can increase morbidity, mortality, and the duration and cost of treatment or compromise quality of life (QOL) and compliance.
Psychosocial Dimensions of Care

Coping mechanisms and skills

Distress defined as: multifactorial unpleasant emotional experiences of a psychological (cognitive, behavioral, emotional), social, and spiritual nature may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.
Psychosocial Dimensions of Care

Statement standard from the International Psycho-Oncology Society (IPOS, 2013)

*Distress considered 6th vital sign to be assessed and measured*
Psychosocial Dimensions of Care

Distress management standards or guidelines

- Support evidence-based practice
- 2015- American College of Surgeons (ACOS) require all cancer patients be routinely screened throughout the continuum of care with validated tools and have access to psychosocial services
- Screening, referrals, provision of care documented in chart
ONS & American Psychological Oncology Society
2013 Joint Recommendations

“Implementing Screening for Distress”

• Universal definition of distress needed
• Use of validated tools for screening; covering broad variety of symptoms over the continuum
• Response to screening data should be prompt, with licensed mental health professionals available
• Suicide ideation is part of all clinical evaluations
Emotional Distress

- Psychological distress and existential concerns common in patients with cancer
- Combination of psychological, social, spiritual, physical, and financial stressors that strain ability to cope
- Reflects a normative response different from psychological or psychiatric diagnoses
Emotional Distress

RISK FACTORS

Disease Type and Stage

- Highest level of distress a/w lung ca dx
- Higher level of distress in pts with advanced dx
- Impact of physical symptoms i.e. poor pain control
Emotional Distress

RISK FACTORS

Situational

• Personal meaning of diagnosis
• Resources- emotional and practical support, spiritual guidance, and financial security
• Changes in roles- occupation, within family, between friends, altered physical capacity and cognitive function
Emotional Distress

RISK FACTORS

Developmental

- Age-specific developmental life tasks disrupted by diagnosis and treatment
- Personality and coping style
NCCN Distress Thermometer for Patients

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems
- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

YES NO Physical Problems
- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

Spiritual/religious concerns

Other Problems: ____________________________

Screening for Distress
Treatment

- Psychotherapeutic
  - Individual psychotherapy, CBT, and/or group therapy
- Family psychotherapy
- Psychoeducational approaches
- Spiritual counseling
- Support groups
- Relaxation exercises i.e. meditation/guided imagry
Sequelae of Distress

- Chronic emotional distress
- Development of major psychiatric disorder
  - Anxiety, depression, adjustment disorder, suicide ideation
- PTSD
- Somatic symptoms
- Declined performance at home, school, or work
- Nonadherence or misunderstanding of health information
COPING

TYPES

1. Problem-focused
   Directed toward reducing or eliminating a stressor

2. Emotion-focused
   Directed toward changing one’s own emotional reaction

3. Meaning-focused
   Deriving meaning from the stressful experience
Post Traumatic Stress Disorder

Traumatic event or experience prompting specific clinical response

- Cognitive
  - Forgetful, distracted, cannot concentrate
- Behavioral
  - Fight or flight response, isolation
- Emotional
  - Numbing feeling, irritable, angry outbursts
- Physiologic
  - Insomnia, nightmares, agitated
Adaptation

Ability to minimize disruptions to social roles, regulate experience of emotional distress, and maintain active engagement in meaningful life activities

Ineffective coping may occur in crisis situation and may lead to suicidal ideation
Factors Influencing Coping

Cancer Diagnosis

- Perception that diagnosis of cancer is a death sentence
- Lack of knowledge of the disease process
- Physiologic effects of the disease
- Unknown prognosis or expected outcome
Factors Influencing Coping

Treatment Related

- Fear of effects of treatment
  - Chemotherapy & biotherapy
  - Radiation therapy
  - Surgery
  - Post-treatment (survivorship)
Factors Influencing Coping

Psychological

• Comorbidities
  • Psychological adjustment disorders

• Various adjustment disorders
  • Criteria based on APA DSM-5 (within 3 months stressor)
    • Symptoms/behaviors clinically significant with impairment of social/occupational functioning
Factors Influencing Coping

Social Factors

- Roles - maintaining or changing
- Health
  - routine tasks
  - family issues
  - financial management
  - living conditions
Factors Influencing Coping

Cultural Factors

• Social organization
• Communication
• Healing practices
• Beliefs
Psychosocial Dimensions of Care

Ineffective coping

Three main concerns for psycho-oncology:

• Anxiety
• Depression
• Neuro-cognitive changes
  • Including delirium
Psychosocial Dimensions of Care

Ineffective coping

Estimated that 50% of cancer patients have a normal adjustment and 50% demonstrate problems that fall in the category of psychological distress
Anxiety

Usually related to fear

• Fear is a normal response r/t unknown aspects of diagnosis and treatment
  • Fear of death, disability, pain, and suffering, and loss or disruption of relationships
Anxiety

- Often a/w cancer diagnosis
- Risk factors
  - Disease related
  - Treatment related
  - Intrapersonal related
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<th>Anxiety Types</th>
<th>Examples</th>
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<td>Generalized anxiety disorder</td>
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<td>Anxiety related to medical condition</td>
<td>Panic disorder</td>
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<tr>
<td></td>
<td>Phobias</td>
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<td>Post-traumatic stress disorder</td>
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<td>Bleeding</td>
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<td>CHF</td>
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<td>Delirium</td>
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<td>Hypocalcemia</td>
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<td>Hypoxia</td>
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<td>PE</td>
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<td>Sepsis</td>
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<td>Medications (neuroleptics/Steroids)</td>
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<td>Withdrawal</td>
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<td>(narcotics/barbituates/ETOH)</td>
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<td>Uncontrolled pain</td>
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Anxiety

Signs/symptoms

• Agitation/ restlessness/tremors
• Sleep disturbances
• Excessive autonomic activity:
  • Sweating, SOB, lightheadedness, palpitations
• Weight gain or loss
• Mood changes/irritability
Anxiety

Treatment approaches

- Aim at the cause
- Psychoeducational interventions
- Written resource material
- Self-care strategies
- Referral to supportive services
- Support groups
- Pharmacological management
Sequelae of Anxiety

- **Somatic symptoms**: N&V, HA, change in bowel habits

- **Behavioral issues**: substance abuse, altered eating, self-harm, social dysfunction

- **Cognitive effects**: difficulty concentrating/making decisions, poor attention span, impaired memory

- **Anxiety disorders**: adjustment disorder with anxious mood, generalized anxiety disorder, panic attacks, phobias, obsessive compulsive disorder, PTSD, and depression
Psychosocial Dimensions of Care

Interventions

• Referral to social work, psych, chaplaincy

• Behavioral therapies e.g. relaxation, mindfulness, CBT, guided imagery, self-hypnosis

• Medication- Benzodiazepines
Psychosocial Dimensions of Care

Depression

• A mood state of feeling sad, discouraged, hopeless, and worthless

• 25% of patients—frequently undiagnosed

• Untreated results in higher healthcare costs, decreased adherence, and decreased QOL
Ineffective coping

Depression

DSM-V criteria for diagnosis: 5 or more of the following

- Change in appetite or weight-5% or more ~ 1 month
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Decreased energy
- Feelings of worthlessness or guilt
- Difficulty concentrating or making decisions
- Recurrent thoughts of death/ suicidal ideation/ plans to attempt
Ineffective coping

Depression Risk Factors

• Personal history of depression
• Previous suicide attempt
• Family history of depression
• Comorbid medical conditions
• Sleep deprivation
• Social isolation
• Unexpected life events
• Spousal illness
Ineffective coping
Depression Risk Factors

Disease related:

• Severe active disease
• Pancreatic, lung, and CNS tumors
• Young adult cancer patients
• Poorly controlled symptoms
• Physical limitations
• Prolonged treatment/treatment failure
• Medications- biologic agents, chemotherapy, hormonal, corticosteroids, benzo’s, opioids
### Depression

#### Symptoms

- Worthlessness
- Low spirits
- Inability to sleep, early awakening
- Loss of pleasure in life
- Withdrawal

- Feelings of sadness
- Cry easily
- Oversleeping
- Negative viewing of events
- Self-blame/ self-criticism
- Death thoughts
Depression
Causes

- Poorly controlled pain
- Advanced disease
- Other life stressors
- Physical impairment or discomfort
- Pancreatic ca
- Being unmarried

- Head & neck ca
- Treatment with certain medications
- Treatment with certain chemotherapy agents
- Metabolic changes
- Endocrine abnormalities
Ineffective coping
Sequelae of Depression

- Suicide or self-harm
- Altered sleep patterns
- Inability to maintain current role-functional disability
- Poor QOL
- Social withdrawal
- Adherence issues
- Increased morbidity/ mortality
Ineffective coping
Depression

Refer patients who express thoughts of suicide or desire to hasten death for immediate psychological evaluation
Ineffective coping

Denial

Conscious or unconscious attempt to deny knowledge or meaning of an event to reduce anxiety or fear, but leading to the detriment of health

• Delays seeking health care attention
• Displaces fears of the impact of disease
• Does not perceive personal relevance of symptoms
• Uses self-treatment

*Denial not necessarily considered dysfunctional coping*
Neurocognitive Changes

- Delirium occurs in 25-40% of patients with cancer at some point during their illness
- Increases to 85% during terminal phase
- Nurses play a key role in identification and assessment of delirium
Common Behavioral Symptoms Seen in Delirium

- Disturbance in sleep-wake cycle
- Easily distracted: transient periods of disorientation
- Irritability, anger, being uncooperative
- Withdrawal, refusal to talk to staff/relatives/friends
- Perceptual disturbances
  - Illusions, misperceptions (e.g., the folds in the bed sheet may appear to be an animate object)
- Delusions, false beliefs that cannot be corrected
- Hallucinations, false perceptions, including visual, auditory, and tactile
Psychosocial Dimensions of Care

Altered body image

Response to actual or perceived change in body structure or function which may manifest as dysfunctional perceptions, cognitions, emotions, or behaviors that affect one’s daily functioning and QOL
Psychosocial Dimensions of Care

Altered body image

- Alopecia
- Weight gain or loss
- Amputation
- Infertility
- Cognitive dysfunction
Social Relationships/Family Dynamics

- Family members are challenged because many dimensions of their lives are affected.
- The burden and strain for families arises from:
  - physical strain of direct care
  - financial burdens
  - work adjustments
  - emotional adjustments and managing uncertainty
Psychosocial Dimensions of Care

Social Relationships/Family Dynamics

*Family members may experience as much, if not more, distress*

Factors that may predict high levels of stress

- Concurrent family stressors
- Conflict between family members
- Poor social support
### Family Stressors That May Interfere With Coping

**Loss of:**
- daily routine
- ability to accomplish usual tasks
- sleep, feeling tired or exhausted
- confidence in the ability to do all that is needed
- financial security, loss of employment
- intimacy
- confusion about, meaning in life

**Feeling:**
- lonely and isolated (loss of social life)
- resentment that this has happened to you and your loved ones
- guilty that you have not done enough
- medical power of attorney- help with making treatment decisions/deciding when to stop treatment
Interventions That Assist Family Members With Coping

- Help the family to understand the patient’s diagnosis/prognosis
- Teach the family to mobilize resources early
- **Encourage** family members to take time to grieve losses
- Help family members to search for meaning
- Validate behaviors that work well for the family
- Encourage the family to build in respite time (personal and recreational)
- Encourage use of coping strategies that have worked in the past (e.g., distraction, support groups, counseling)
- If the patient is terminal, educate the family about hospice/palliative care and what to expect as the patient declines
Psychosocial Dimensions of Care

Support groups

- Provide a place to share experiences and obtain knowledge from those in similar situations
  - Promotes community feeling
  - “Safe” place to share

- Shown to have a positive effect on individual’s coping during chemotherapy
Psychosocial Dimensions of Care

Support groups

- Offer inspiration
  - Witnessing courage
  - Motivation to fight
  - Exposure to role modeling

- Online and social media provide additional support
Psychosocial Dimensions of Care

Financial Concerns

\[ \frac{1}{3} \] of cancer survivors experience financial hardships as a result of their diagnosis and/or treatment.
Financial Concerns

28.7% of survivors reported at least one financial problem resulting from cancer diagnosis, treatment, or long-term side effects of treatment

- 20.9% worried about paying large medical bills
- 11.5% were unable to pay for medical visits
- 7.6% borrowed money, went into debt, or declared bankruptcy
- 8.6% said they made other financial sacrifices
Financial Concerns

• Estimated out-of-pocket expenses for people with cancer average from $1,730 to $4,727 per year depending on insurance coverage

• Survivors who have trouble paying these costs are more likely to skip or delay medical care including mental-health care, and avoid filling prescriptions

• This can put their physical and mental health at risk and increase their risk of recurrence
Financial Concerns

National service organizations

• The Cancer Financial Assistance Coalition (CFAC) is a group of national organizations that provide financial help to patients. CFAC provides a searchable database of financial resources.

• CancerCare's financial assistance programs (800-813-4673) provide limited financial assistance for people affected by cancer.

• The HealthWellFoundation (800-675-8416) is an independent, non-profit organization that helps insured patients with a chronic, life-altering disease afford their medications.

• The Leukemia & Lymphoma Society's patient financial aid program (800-955-4572) provides limited financial assistance to patients diagnosed with a blood cancer (such as leukemia, lymphoma, or multiple myeloma) with significant financial need to help defray treatment-related expenses.

• The National Foundation for Transplants (800-489-3863) provides fundraising assistance for patients needing transplants, including bone marrow and stem cell transplants.
Financial Concerns

Local service organizations

- Local service or volunteer organizations such as Catholic Charities, Jewish Social Services, the Lions Club, Lutheran Social Services, the Salvation Army, and others may offer financial assistance. Some of these organizations offer grants to help cover the cost of treatment and other expenses, while others provide assistance with specific services or products, such as travel or medications. A social worker has a list of service organizations in the community.

- The American Cancer Society (800-227-2345) and the local United Way office can also direct people to services in their community.

- Community-based groups, such as local churches, synagogues, mosques, and lodges may also provide assistance for people with cancer, sometimes even if the person is not a member of that particular organization or religion. Some hospitals also have private funds available for patients in need.

- Often, cancer advocacy and patient information groups have resources for patients.
Financial Concerns

Medication and treatment cost assistance

- Chronic Disease Fund (877-968-7233) helps underinsured patients with a chronic disease obtain medication.

- NeedyMeds.com (800-503-6897) is an information source on companies that offer patient assistance programs. These programs help those who cannot afford medications to obtain them at no or low cost through the manufacturer.

- Partnership for Prescription Assistance (888-477-2669) helps qualifying patients who lack prescription drug coverage obtain the medications they need.


- Patient Services, Inc. (800-366-7741) provides assistance with insurance premiums and co-payments for people with chronic diseases.

- RxHope.com (877-267-0517) helps patients obtain free or low-cost prescription medications.
Financial Concerns

- The American Childhood Cancer Organization maintains a list of organizations offering financial assistance.

- The Assist Fund (855-845-3663) provides financial support to chronically ill patients with high-cost medications.

- The Patient Advocate Foundation (800-532-5274) provides education, legal counseling, and referrals for people with cancer who need assistance managing insurance, financial, debt crisis, and job discrimination issues.

Financial Concerns

- Cancer Family Relief Fund is a charitable organization that encourages and facilitates grants to children whose parent or guardian is struggling with a diagnosis of cancer. These grants support the children's extracurricular activities so that they may feel some sense of normalcy as their parent focuses on treatment and recovery.

- Financial Health Matters, a booklet available from the Leukemia & Lymphoma Society, offers information and tips on money management, health insurance, and financial resources.

- The LIVESTRONG Foundation offers a section on insurance and financial assistance.
Psychosocial Dimensions of Care

Learning styles and barriers to learning
Learning Styles

Visual
- Prefers to see what they are learning; pictures and images

Auditory
- Needs to hear the message/instructions being given

Kinesthetic
- Prefers the movement of the skill or task. Demonstration and return demonstration works best
<table>
<thead>
<tr>
<th>Learning Styles</th>
<th>Teaching Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual</td>
<td>Visual material</td>
</tr>
<tr>
<td></td>
<td>Handouts—easy to read</td>
</tr>
<tr>
<td></td>
<td>Variety of technology—computers, overhead, video, TV, Internet</td>
</tr>
<tr>
<td>Auditory</td>
<td>Rephrase key points</td>
</tr>
<tr>
<td></td>
<td>Vary speed, volume, and pitch</td>
</tr>
<tr>
<td></td>
<td>Write down key points</td>
</tr>
<tr>
<td></td>
<td>Positioned to hear the message clearly</td>
</tr>
<tr>
<td></td>
<td>Use multimedia—tapes, music</td>
</tr>
<tr>
<td>Kinesthetic</td>
<td>Frequent breaks to move around</td>
</tr>
<tr>
<td></td>
<td>Learner writes own notes</td>
</tr>
<tr>
<td></td>
<td>Provide tactile activities</td>
</tr>
<tr>
<td></td>
<td>Product samples</td>
</tr>
</tbody>
</table>
Psychosocial Dimensions of Care

Barriers to learning

- Low literacy
- Language and culture
- Physical and environmental
## Communication Skills That Enhance the Psychosocial Care of Patients with Cancer

<table>
<thead>
<tr>
<th>Skill</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening with interest and empathy</td>
<td>• Use thoughtful silence to encourage the patient to talk</td>
</tr>
<tr>
<td></td>
<td>• Make and maintain eye contact</td>
</tr>
<tr>
<td>Exploring the patient’s feelings (help the patient put feelings into words)</td>
<td>• “Tell me more about feeling out of control”</td>
</tr>
<tr>
<td>Validating the patient’s feelings</td>
<td>• “It must be very difficult to manage all of this- your anger is a normal feeling”</td>
</tr>
</tbody>
</table>
Communication Skills That Enhance the Psychosocial Care of Patients with Cancer

<table>
<thead>
<tr>
<th>Skill</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Explore the patient’s response to diagnosis, treatment, and prognosis</td>
<td>• “Tell me what you understand about the seriousness of your cancer”</td>
</tr>
<tr>
<td>• Using questions and comments that encourage open communication</td>
<td>• “That sounds interesting; tell me more”</td>
</tr>
<tr>
<td>• Respecting the patient’s views/efforts</td>
<td>• “Help me understand what you mean”</td>
</tr>
<tr>
<td>• Reassure the patient with realistic hope</td>
<td>• “We can help manage your pain and distress”</td>
</tr>
<tr>
<td>• Summarizing your interactions with the patient/validating mutual understanding</td>
<td>• “Let me summarize what we just discussed”</td>
</tr>
</tbody>
</table>
Treatment Approaches

• Psychological support
• Psychotherapy
• Spiritual counseling
• Cognitive and behavioral interventions
• Occupational or recreational therapy
• Pharmacologic management
Sexuality

With the projection of 18 million cancer survivors by 2020 it is important for nurses to be aware of the long-term effects of cancer and of its treatment on sexuality

Sexuality is an important component of QOL
Sexuality

- Across all cancer types 66% of patients report that patient-provider conversations on sexual issues were important.
- With intervention 70% of patients with cancer can have their sexual function return to baseline.
- Without intervention, functioning decreases over time.
Sexuality

- Patients’ decreasing sexual functioning may increase the risk of emotional morbidity

- Not informing patients about the possible adverse effects of cancer treatment on sexual function may result in legal liability
# Sexual and Reproductive Dysfunction: High Risk Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Older than 30</td>
<td>Post-puberty</td>
</tr>
<tr>
<td><strong>Surgery</strong></td>
<td>Gynecologic A-P resection, Pelvic exenteration</td>
<td>Prostate, orchiectomy A-P resection</td>
</tr>
<tr>
<td><strong>Radiation</strong></td>
<td>Pelvic</td>
<td>Pelvic</td>
</tr>
<tr>
<td><strong>Medications</strong></td>
<td>Antidepressants, antihistamines, antihypertensives, antiemetics, antiestrogens, Narcotics, sedatives, tranquilizers, alcohol</td>
<td>Antidepressants, antihistamines, antihypertensives, antiemetics, estrogens, narcotics, sedatives, tranquilizers, alcohol</td>
</tr>
<tr>
<td><strong>Psychosocial issues</strong></td>
<td>Alterations in body image and self-esteem, decreased sense of femininity, worsening partner relationships</td>
<td>Alterations in body image and self-esteem, decreased sense of masculinity, worsening partner relationships</td>
</tr>
<tr>
<td><strong>Comorbidities</strong></td>
<td>OA, COPD, dementia, depression, diabetes, MI, spinal cord injury</td>
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</tr>
</tbody>
</table>
Assessment

History & Physical

Factors that may affect sexuality

• Age, PMH, PSH, social history (including relationship status and quality of the relationship), cultural and religious beliefs

• In men, assess desire for children, erectile dysfunction

• In women, assess for desire for children, pregnancy status, menopausal symptoms
World Health Organization (WHO)

Defines sexual health as integration of the somatic, emotional, intellectual, and social aspects of a sexual being
Sexuality

World Health Organization (WHO)

Encompasses
- Biological sex
- Gender identity and roles
- Sexual orientation
- Eroticism
- Pleasure
- Intimacy
- Reproduction

Experiences/Expressions
- Thoughts
- Fantasies
- Desires
- Beliefs
- Attitudes
- Values
- Behaviors
- Practices
- Roles
- Relationships

Influenced by
- Biology
- Psychology
- Social factors
- Economics
- Politics
- Culture
- Ethics
- Laws
- History
- Religion
- Spirituality
Sexual Health and Sexuality

- Intimacy
- Communication
- Sense of sexual self
- Body image
- Relationships
- View of oneself as sexual being

Sexual Health and Sexuality
Oncology Nursing Society (ONS)
Standards of Care for Sexuality

Assess concerns related to sexual function, sexual well-being, and fertility of patients with a past, current, or potential diagnosis of cancer, including the impact on relationships.
American Society of Clinical Oncology (ASCO)

Prior to start of chemotherapy oncologists should discuss the possibility of infertility and fertility preservation options and make appropriate referrals.
Fertility preservation assessment and discussion algorithm for patients with cancer

Assessment of risk for infertility
Communication with patient

Patient at risk for treatment-induced infertility
Patient interested in fertility preservation options*

Refer to specialist with expertise in fertility preservation methods

Eligible for proven fertility preservation methods

Investigational fertility preservation techniques
Cryopreservation of ovarian or testicular tissue
Others

Male
Sperm cryopreservation†

Female
Embryo or oocyte cryopreservation
Conservative gynecologic surgery

©2013 by American Society of Clinical Oncology

Loren A W et al. JCO 2013;31:2500-2510
Barriers to discussing and addressing patients’ sexual concerns

• Staff beliefs may prevent them from addressing patients’ sexual concerns

• When nurses do not initiate conversation about sexuality the patient may believe:
  • Not a legitimate topic to raise
  • Loss of function is a “cost” of treatment
  • No effective treatment exists, so not necessary to discuss
Beliefs that Inhibit Addressing Patients’ Sexual Concerns

• Someone else will do it
• Patients never bring up the subject
• Nurses’ personal biases regarding age, partner status, or discomfort discussing sexuality
• Patients should be grateful to be alive. Belief priority should be on treatment not on “frivolous” matters
• Patients may be offended if asked and may even sue the nurse
• Lack of knowledge or expertise, time, privacy, and administrative support
Physiologic effects of hormone therapy on sexuality in men

• Gynecomastia
• Feminization
• Erectile dysfunction
• Penile or testicular atrophy
• Decrease or loss of libido
Physiologic effects of hormone therapy on sexuality in women

- Decreased vaginal lubrication
- Vaginal atrophy
- Change in libido
- Masculinization
- Amenorrhea
- Temporary or permanent menopause with sx of mood swings, hot flashes, sleep disturbance, and dyspareunia
Physiologic effects of radiation therapy on sexuality in men

- Radiation to pelvis may result in temporary or permanent erectile dysfunction
- Amount of radiation to the bulb of penis correlates to risk due to damage to nitric oxide producing cells (erection is mediated by nitric oxide released from nerve endings close to the blood vessels in penis)
**Physiologic** effects of radiation therapy on sexuality in men

- Changes in sexual functioning significantly decline in the 1st 2 years after EBRT for prostate cancer
- Prostate brachytherapy causes erectile dysfunction in 6-61% of men
- May also cause absence or weak orgasm, painful ejaculation, decreased ejaculate volume, and decreased orgasmic quality
Physiologic effects of radiation therapy on sexuality in women

- Changes in sexual functioning after cervical cancer treatment ranges 30-90%
- Brachytherapy for cervical/uterine cancer may cause dyspareunia and vaginal stenosis
- Pelvic radiation causes decreased vaginal lubrication, hardened clitoris, dyspareunia, change in vaginal sensation, risk of infection, change in usual sexual expression, shortened vaginal vault, decreased elasticity, increased vaginal irritation, incontinence, bowel changes
**Physiologic** effects of chemotherapy on sexuality in men

Decrease or loss of libido, retarded ejaculation or inhibition of ejaculation and erectile dysfunction
Physiologic effects of chemotherapy on sexuality in women

Premature menopause, decrease or loss of libido, change in body image, decreased vaginal dispensability and capacity, lubrication, and dyspareunia
Physiologic effects of surgery on sexuality in men

- When surgery disrupts the vascular system, the sympathetic or parasympathetic nervous system, it may affect the sexual response cycle
- Prostatectomy may cause retrograde and/or erectile dysfunction, and urinary incontinence which affects body image, self-esteem
- Orchietomy (bilateral) can cause decreased libido and atrophy of the penis
Physiologic effects of surgery on sexuality in men and women

- Cystectomy causes loss of vaginal lubrication in women or ED in men because of nerve damage

- H&N surgery affects body image, change in speech, removal of spinal accessory nerve (affects ability to turn head), changes in smell and taste sensation, drooling, decreased salivation, halitosis which can affect kissing
Physiologic effects of surgery on sexuality in men and women

- Ostomy surgery in women can cause vaginal scarring changing anatomy and body image changes
- Decreased blood flow to the vagina may affect lubrication
- In men decrease blood flow may cause ED
- Appliance can stick to partner because of sweat
Physiologic effects of surgery on sexuality in men and women

- Lumpectomy or mastectomy causes numbness in the breast area affecting sexual pleasure
- Mastectomy a/w phantom nipple sensations
- May have “rubbery” sensation or occasional “electric-like” shock sensation
Other *Physiologic* effects of surgery on sexuality in men and women

- Fatigue
- Pain
- Sleep deprivation
- Stenosis
- Scarring
- Organ loss
- Constipation
- Diarrhea
- Respiratory compromise

- Alopecia
- Fistulas
- Draining wounds
- Neuropathy
- Lymphedema
- Dyspareunia
- Muscle atrophy
- Decreased blood counts
- Comorbidities
Psychological effects of cancer treatment on sexuality in men and women

- Psychological and emotional response of partner
- Physical changes resulting from treatment
  - Alopecia- “childlike” appearance
  - Ostomy- embarrassed or ashamed
  - Hysterectomy, prostatectomy, sterility from EBRT or chemo may influence view of sexuality and sense of self
Other *Psychological* effects of surgery on sexuality in men and women

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Low self-esteem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of pain</td>
<td>Feelings of isolation</td>
</tr>
<tr>
<td>Fear of premature death</td>
<td>Cultural or religious beliefs</td>
</tr>
<tr>
<td>PTSD</td>
<td>Relationship discord</td>
</tr>
<tr>
<td>Depression</td>
<td>Fear of transmitting ca</td>
</tr>
<tr>
<td>Change in affect/personality</td>
<td>Feelings of vulnerability</td>
</tr>
<tr>
<td>Grief</td>
<td>Withdrawal</td>
</tr>
<tr>
<td></td>
<td>Shame</td>
</tr>
</tbody>
</table>
Infertility

• Defined as the inability to conceive after 1 year of intercourse without conception

• Most common cancers in patients < 40yrs are breast, melanoma, cervical, NHL, and leukemia
Over 50% of cancer patients do not recall having a conversation about fertility risk when diagnosed.
Infertility Risk Factors

- Cancers of the genitourinary system
- GYN malignancies
- Exposure to radiation (diagnostic or treatment)
  - Depends on location/dosage
  - In males receiving pelvic EBRT
    - Age does not affect risk
    - Less than 4 Gy results in temporary sterility
    - More than 5 Gy results in permanent sterility
  - In females receiving pelvic EBRT
    - Age and total dose affect risk of sterility
    - <40 yrs receiving 20 Gy over 5-6 weeks
      - 95% sterility
    - >40 yrs receiving 6 Gy affect sterility
Infertility Risk Factors

Location of EBRT

Of men and women receiving radiation below the diaphragm

25% risk of sterility
Fertility Effects of Treatment-Male

Impaired sperm production
- Depletion of stem cells → potential for recovery

Impaired sperm transport
- Injury to pelvic ducts/blood vessels/nerves → erectile/ejaculatory dysfunction

Pituitary gland dysfunction
- Disruption of hypothalamic-pituitary-gonadal axis
Present sperm cryopreservation (sperm banking) as the only established fertility preservation method.

Do not recommend hormonal therapy in men; it is not successful in preserving fertility.

Inform patients that other methods (e.g. testicular tissue cryopreservation, which does not require sexual maturity, for the purpose of future reimplantation or grafting of human testicular tissue) are experimental.

Advise men of a potentially higher risk of genetic damage in sperm collected after initiation of chemotherapy.
Fertility Effects of Treatment-Female

Depletion of ovarian follicle pool (oocytes)
• Premature ovarian failure → infertility, menopause

Pituitary gland dysfunction →
• Disruption of hypothalamic-pituitary-gondal axis

Uterine damage
• Vascular changes, endometrial injury → inability to support embryo implantation
• Myometrial fibrosis → inability to accommodate a growing fetus
Present both embryo and oocyte cryopreservation as established fertility preservation methods

Discuss the option of ovarian transposition (oophoropexy) when pelvic radiation is performed as cancer treatment

Inform patients of conservative gynecologic surgery and radiation options

Inform patients that there is insufficient evidence regarding the effectiveness of ovarian suppression (GnRH analogs) as a fertility preservation method, and these agents should not be relied on to preserve fertility

Inform patients that other methods (eg, ovarian tissue cryopreservation, which does not require sexual maturity, for the purpose of future transplantation) are still experimental
Early Menopause

• Risks without treatment:
  • Early and extensive osteoporosis
  • Cardiovascular disease
  • Early dementia

• Treatment
  • No menstruation post-treatment; consider hormone replacement therapy (HRT) if appropriate
  • Pretreatment fertility counseling
Safe Sexual Practices on Treatment

- Decrease risk of infection
- Avoiding pregnancy
- Protecting partner exposure to chemo in body fluids
Contraception to Prevent Pregnancy

• Exposure to chemotherapeutic agents or radiation can cause mutagenic changes in gametes and teratogenic effects in a developing fetus

• Because of this, female patients of childbearing age and the female partners of male patients should avoid pregnancy during treatment

Klein & Okuyama, 2012
Treatment During Pregnancy

- Risk factors depend on the trimester at the time of diagnosis

- 1-4% of breast cancer patients are pregnant

- Diagnostic tests
  - Tests may present a risk to the fetus
  - Radioactive iodine contraindicated
  - Tests may be delayed due to pregnancy affecting survival
Treatment During Pregnancy

Type of agent influences the risk to fetus

- Antimetabolites, alkylating agents, and folic acid antagonists should be avoided in 1st trimester
- Radiolabeled MAB’s should be avoided
- Teratogenic potential of the agent is affected by dosage, ability to enter fetal circulation, and route of administration

1st trimester greatest risk

- Patients with high grade lymphoma should not delay therapy
- Low grade tumors may allow therapy to be delayed until 2nd trimester or after delivery
Treatment During Pregnancy

Type of agent influences the risk to fetus

Radiation therapy

- Usually delayed until after delivery
- Risk depends on dose and field of radiation
Sexual Health Communication Models

Intimacy
“If you think it’s difficult for you as a nurse to initiate the conversation, how much more difficult is it for our patients to be the first to broach the subject?”

Judy Schreiber, PhD, RN
Editor- ONS Connect
ALARM Model

- A—Activity
- L—Libido
- A—Arousal and orgasm
- R—Resolution
- M—Medical history relevant to sexuality
BETTER Model

- **B**—Bringing up the topic
- **E**—Explain that sexuality is part of QOL and nursing care
- **T**—Telling the patient about resources
- **T**—Timing the discussion to patient preference
- **E**—Educating the patient about the side effects and impact on sexuality
- **R**—Recording discussion in medical record
PLEASURE Model

- P – Partner
- L – Lovemaking
- E – Emotions
- A – Attitudes
- S – Symptoms
- U – Understanding
- R – Reproduction
- E – Energy
PLISSIT Model

P– Permission
  • Normalizing concerns

LI- Limited information
  • Increase communication, knowledge

SS- Specific suggestions
  • May need to refer to GYN

IT- Intensive therapy

80-90% of sexual problems identified by patients can be solved at 1st 3 levels