CANCER SURVIVORSHIP

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Oncology Clinical Nurse Specialist
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2018 OCN Test Content Outline

<table>
<thead>
<tr>
<th>Content Area</th>
<th>Percentage of 2018 Exam</th>
<th># of Scored Test Questions*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Continuum</td>
<td>19%</td>
<td>28</td>
</tr>
<tr>
<td>Oncology Nursing Practice</td>
<td>17%</td>
<td>25</td>
</tr>
<tr>
<td>Treatment Modalities</td>
<td>19%</td>
<td>28</td>
</tr>
<tr>
<td>Symptom Management &amp; Palliative Care</td>
<td>23%</td>
<td>33</td>
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<tr>
<td>Oncologic Emergencies</td>
<td>12%</td>
<td>17</td>
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<tr>
<td>Psychosocial Dimensions of Care</td>
<td>10%</td>
<td>15</td>
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</table>

*To determine the number of scored items from each subject area, multiple the percentage by 145


Care Continuum – 19% (28 Questions)

A. Health promotion & disease prevention (e.g. high-risk behaviors; preventive health practices)
   1. Rehabilitation
   2. Recurrence concerns
   3. Financial concerns
   4. Employment concerns
   5. Insurance concerns
   6. Family & social support concerns
   7. Sexuality concerns

B. Screening and early detection
C. Navigation
D. Advanced care planning (e.g. advance directives)
E. Epidemiology
   1. Modifiable risk factors (e.g. smoking, diet, exercise, occupation)
   2. Non-modifiable risk factors (e.g. age, gender, genetics)
F. Survivorship
   1. Rehabilitation
   2. Recurrence concerns
   3. Financial concerns
   4. Employment concerns
   5. Insurance concerns
   6. Family & social support concerns
   7. Sexuality concerns

The Cancer Control Continuum
Sample Practice Question
A survivor of breast cancer tearfully states, “I knew lymphedema could happen but I never thought it would happen to me”. The nurse’s priority intervention is to:

A. Allow the patient to express her feelings
B. Assure the patient that the lymphedema will resolve quickly
C. Take a recent history to identify the cause of the lymphedema
D. Teach the patient ways to reduce the risk of recurrence of the lymphedema

Sample Practice Question
A patient in remission complains of dysthymic behaviors for the past several weeks. The nurse knows to assess for:

A. Recurrence of disease
B. Cognitive learning
C. Bowel habits
D. Depression

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Sample Practice Question

A 21 year old patient recently withdrew from college classes secondary to cancer recurrence. His parents report that the patient is moody and is no longer seeing friends and classmates. The nurse initiates strategies aimed at achieving which of the following patient outcomes?

A. Participation in a clinical trial
B. Maintenance of open communication
C. Re-enrollment in college courses
D. Recognition of destructive behaviors

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Survivorship Definitions

- Cancer survivorship begins when a person receiving a cancer diagnosis hears what was told & reaches out for information, treatment plan & hope

- The National Coalition for Cancer Survivorship (2004) defines a cancer survivor as any individual that has been diagnosed with cancer, from the time of discovery & for balance of life.

- An estimated 9.6 million survivors of cancer in U.S. were alive in January 2000; overall five-year survival rate 64% (ACS, 2005).

- From 1971 to 2003, the rate of new survivors has tripled.

Trends and Progress Against Cancer

- Growth in U.S. cancer survivors: Today, 15 million Americans—nearly one in 20—are survivors of cancer, and experts estimate that there will be 26 million survivors in the U.S. by 2040.
- Long-term survival increasing: About 64% of U.S. patients diagnosed with cancer in 2005 have lived 10 years beyond diagnosis, compared to 35% of those diagnosed in 1975.
- Pace of cancer research accelerating: The number of medical journal articles with the word “cancer” in the title quadrupled in the last decade, from about 38,000 in 2007 to 120,000 in 2017.
- More treatments available to patients: In the span of just 1 year, the FDA approved 18 new therapies and 13 new uses for more than 16 types of cancer. (During the same timeframe in the previous year, eight new cancer therapies and 13 new uses were approved.)
Need for Survivorship Care

- NCCS has expanded its “definition of survivor to include family, friends and caregivers”

- There are an estimated 14 and a half million Americans alive today, who were previously diagnosed with cancer

- ACS (2009) predicted that the population of cancer survivors in the United States will be 20 million by 2020.

- Survival rate varies by the site, size, cell type, stage of cancer, and time interval from detection to the start of treatment.

There is no profit in curing the body, if in the process we destroy the soul.

Inscription on the Golter Gate, City of Hope National Medical Center
Duarte, California
The IOM published a report on the state of cancer survivorship

They published the document entitled, “From Cancer Patient to Cancer Survivor: Lost in Transition” in 2006

The recommendation in this report specific to treatment includes:
- “Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan”

Institute of Medicine Report Summary

- Establish survivorship as a distinct phase of care
- Implement survivorship care plans
- Build bridges between oncology and primary care
- Develop and test models of care
- Develop and evaluate clinical practice guidelines
- Institute quality of survivorship measures
- Strengthen professional education
- Expand use psychosocial & community support services
- Invest in survivorship research – Fund via Moonshot initiative?

Executive Summary From Cancer Patient to Cancer Survivor: Lost in Transition.

Key Elements of a Survivorship Program

Sample Practice Question

When considering general principles of rehabilitation in a patient with cancer, the nurse should:

A. Focus on disabilities
B. Develop group goals
C. Emphasize capabilities
D. Encourage more frequent rest periods
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Listening to Survivors

53% reported secondary health problems:
- Chronic pain
- Sexual dysfunction
- Relationship difficulties
- Fertility issues
- Fear of recurrence
- Depression
- Financial & job related concerns

49% reported:
- Non-medical cancer related needs not met


Survivor Treatment Summary and Care Plans
Survivors Need Treatment Summary & Care Plan

- Improved successful cancer therapies & increased rates of early detection result in more people surviving cancer than ever before
- In 2012, there were 12 million cancer survivors in the U.S.; needs aren’t met
- A survivorship treatment summary and care plan address patient safety issues, e.g., chemotherapy medication reconciliation, prior treatment, and discharge summary with hand-off instructions. Historical patient reports often incomplete.
- “When I was discharged after being in the hospital for 5 weeks after an allogeneic stem cell transplant, I did not want to leave the protection of the unit. I had 24-hour nursing care delivered by experts in their field and I felt safe; now they want me to go home and figure out what should be done on my own.”

Journey Forward: Survivorship Care Plan Builder

- Contains care plan information, billing, resources (MD, patient)
- Templates available for breast, colon, and lymphoma.
- 1st page: Template begins with basic patient demographics & contact info for various HCPs participating in pt. care
- 2nd page: Detailed information about tumor pathology, staging
- 3rd page: Treatment provides detailed info. about treatment regimens, dates, dosages, clinical trial participation

Followed by: Treatment Plan and Summary – total dosages and a record of complications

F/U Care plan: Detailed info about proposed follow-up care, time and guidance about which HCP should be giving specific follow-up at designated intervals.
Advantages of a Survivorship Care Plan

- Surveillance for disease recurrence
- Monitor for late effects of treatment
- Teach healthful lifestyles
- Educate on minimizing late effects

### Survivorship Care Plan

Late effects may be exacerbated by:

- Drugs administered
- Length of treatment
- Total amount of drug received
- Age
- Radiation (worse when given concurrently with chemotherapy, e.g. esophageal cancer)

### Treatment Plan & Summary for Breast Cancer

**Source:** Journey Forward Tool-Kit

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<thead>
<tr>
<th>Therapeutic agents</th>
<th>No. cycles</th>
<th>% dose reduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doxorubicin</td>
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<tr>
<td>Cyclophosphamide</td>
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<tr>
<td>Paclitaxel</td>
<td>7-12</td>
<td>0%</td>
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<tr>
<td>Doxorubicin + Paclitaxel</td>
<td>6</td>
<td>0%</td>
</tr>
</tbody>
</table>

### Survivorship Care Plan (IOM, NCCN, ASCO, ONS & NCCS)

Serves as update to the original informed consent process; avoids problem of limited patient recall (IOM, 2005).
Nursing Process for Breast Cancer Survivors: Assess, Plan, Implement, Evaluate and Educate
Survivorship Challenge: Sleep Disturbances Research Findings in Breast Cancer Survivors

- Sleep disturbances are recognized as a side effect of cancer treatment, affecting physiological and psychological functioning. Sleep disturbances can persist through treatment and survivorship, and are increasingly prevalent among breast cancer survivors (BCSs).

- The purpose of this review was to summarize current research on subjective and objective measures of sleep disturbances, the association between subjective and objective measures, and interventions used to manage sleep disturbances among BCSs after the completion of treatment.


Sample Practice Question

Sleeping disturbances can be problematic long after treatment ends. Research into the incidence of sleep disturbances indicates that sleeping difficulty is reported by approximately what percentage of patients with cancer?

A. 50%
B. 40%
C. 30%
D. 20%

Symptom Alleviation & Self-Care Among Breast Cancer Survivors After Treatment Completion

- **Methods**: The Therapy-Related Symptom Checklist (TRSC) was used to identify the occurrence and severity of ongoing symptoms in breast cancer survivors who were six months or more post-treatment.

- Two groups were identified to further explore self-care: those with low scores on the TRSC (n = 26) & those with high scores on the TRSC (n = 25). Participants also completed the Symptom Alleviation: Self-Care Methods tool.

- **Findings**: The self-care method category most commonly reported was diet / nutrition / lifestyle and the least common category was herbs / vitamins / complementary therapy. With few exceptions, the reported methods were perceived as effective.

When do I get my brain back? Breast Cancer Survivors’ Experiences of Cognitive Problems

- **Background:** Many survivors report troubling cognitive problems that can persist long after active treatment and seriously affect their quality of life, particularly in terms of employment.

- **Objectives:** The purpose of this study was to explore survivors’ perceptions of their cognitive functioning.

- **Methods:** Ten female breast cancer survivors receiving treatment in a community oncology setting participated in interviews or a focus group.


Effects of Cancer Survivorship on Family Members (Mellon, 2002)

- Finding positive meaning during survivorship helped to increase quality of life for survivors and families.

- Fear of recurrence became a chronic stressor but was lessened with genetic histories, early detection by monitoring exams, and expedient symptom management. Sadly, recurrence & second primary site malignancies are common, especially when treated with alkylating agents in high doses, e.g. CTX, IFOS, CDDP.

- Findings suggest existing strengths & family communication styles could alter negative meaning & enhance quality of life.

- Nursing assessment in identification of these effects was critical to intervention for the process of survivorship.

ONS Survivorship Initiatives

- Identify resources for nurses in all specialties who may be caring for patients who are survivors of adult cancer care

- Address survivorship care gap and develop resources to fill gap

- Focus on the late, long-term effects that may be identified and managed by a variety of disciplines

- Regional conferences with survivorship focus, e.g. how may nurses meet the unique needs of cancer survivors across the continuum of their lives and help bridge gaps in their health care.
Late Effects

- Can be subtle physically or determined by lab tests (such as thyroid studies, DEXA scan)
- Can be difficult to distinguish between cancer-related changes, normal aging, or comorbidities
- Important: cancer is a chronic disease
- Lack of evidence for adults from longitudinal studies that examine specific therapies over time

Late Effects: Chemotherapy / Hormone Therapy

- Hepatic - Abnormal liver function, cirrhosis, liver failure
- Neurologic - Cognitive changes (thinking, learning), paralysis, seizure
- Ophthalmologic - Cataracts
- Pulmonary - Lung scarring, inflammation
- Renal - Impaired kidney function, renal failure
- Secondary malignancies - Leukemia, lymphoma, thyroid, bladder
- Skeletal - Bone destruction, osteoporosis
- Cardiac - Cardiomyopathy, heart inflammation
- Endocrine - Diabetes, osteoporosis
- Gastrointestinal - Motility disorders
- Genitourinary - Hemorrhagic cystitis

Late Effects: Radiation Therapy

- Hepatic - Abnormal liver function, liver failure
- Lymphatic - Tissue injury
- Neurologic - Cognitive changes (thinking, learning, memory)
- Ophthalmologic - Cataracts, dry eyes, visual impairment
- Pulmonary - Lung scarring, decreased lung function
- Renal - Renal hypertension, impaired kidney function
- Secondary malignancies - Leukemia, lymphoma, myelodysplastic syndrome, breast, lung, sarcomas, thyroid, bone/soft tissue, gastrointestinal tract or skin
- Cardiac - Scarring or inflammation of heart (left chest), coronary artery disease, scarred pericardium
- Endocrine - Sterility or low levels of testosterone or female hormones
- Gastrointestinal - Malabsorption, intestinal strictures
- Genitourinary - Bladder scarring, small bladder capacity

Functional and Cosmetic Late Effects

- Functional
  - Lymphedema
  - Neuropathies
  - Fatigue
  - Decreased physical stamina
- Cosmetic
  - Ostomies
  - Amputations
  - Hair loss or thinning
Psychological and Spiritual Late Effects

- **Psychological**
  - Fear of recurrence: Number one concern
  - Heightened sense of vulnerability
  - Anxiety with routine check ups and anniversaries
  - Ambivalence about follow up care and check ups

- **Spiritual**
  - Changes in life priorities
  - Deepening sense of spirituality
  - Increased self-acceptance
  - Increased passion for life
  - Ambivalent feelings
  - Survivor’s guilt

Social and Financial Issues

- **Social**
  - Social stigma
  - Transition from sick to previous roles
  - Perceptions of state of health

- **Employment, health and life insurance issues**
  - American Disabilities Act (ADA)
  - Consolidated Omnibus Budget Reconciliation Act (COBRA)
  - Federal Rehabilitation Act
  - Health Insurance and Portability Act (HIPAA)

Nurse Role in Management and Follow-up

- Coordinate follow-up visits
- Identify problems
- Develop plan of care
- Coordinate consultation or referrals
- Educate patient and family
- Utilize resources

SAMPLE PRACTICE QUESTION

Which statement best characterizes someone in the permanent or long-term stage of survival?

A. The survivor is cancer free
B. The survivor is guaranteed a cure
C. The survivor’s cancer status has gradually evolved to where the probability for disease recurrence is minimal
D. The survivor has not responded to multiple course of therapy and is preparing to die
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Sample Practice Question
Your new position in a cancer clinic gives you the opportunity to counsel cancer survivors. You are aware that an adult cancer survivor’s ability to achieve optimal physical, social, and psychologic function can be significantly affected by all of the following except:
A. Socioeconomic considerations
B. Disease trajectory considerations
C. Physical function and cosmesis
D. Older age at diagnosis

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Sample Practice Question
The overall goal of rehabilitation for a person with cancer is to:
A. Return to baseline performance before the cancer
B. Anticipate and prepare physically for future debilitating effects of cancer
C. Achieve optimal functioning within the limits of cancer
D. Maintain an active, busy life
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Questions?
Addendum II: Reports - Survivorship Care Recommendations

Addendum III: The Culture of Cancer Survivorship (Leigh, 2001)

Challenges:
- Psychological
- Physical
- Financial
- Spiritual
- Social
- Palliative Care
- End of life
- Rehabilitation
- Impaired
- Communication
- Sexual dysfunction
- Treatment Neuropathy
- Major organ late effects S/P chemo: cardiac, lung, renal, hepatic, GVHD, Chemo brain
- Major late effects S/P pelvic radiation: stricture, fistula (rectovaginal, ureteral-vaginal)

Addendum IV: Survivorship Resources

Addendum V: Community Economic Rehabilitation Resource
Addendum VI: Community Legal Rights & Advocacy Groups

Addendum VII: Late Effects of Surgery

- Neurologic structures (brain or spinal cord) - cognitive, motor, or sensory function
- Head and neck - Communication, swallowing, breathing, disfigurement
- Removal of lymph nodes - Lymphedema
- Abdominal / ostomy - Obstructions, bowel / bladder changes, body image
- Pelvic - Sexual dysfunction, incontinence
- Amputations - Functional changes, psychosocial impact, pain
- Lung resections - Fatigue, difficulty breathing
- Prostatectomy - Incontinence, sexual dysfunction
- Oopherectomy - Premature menopause, infertility
- Orchectomy - Infertility, testosterone deficiency, cardiovascular complications

Addendum VIII: Late Effects of Chemotherapy

<table>
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<tr>
<th>Agent</th>
<th>Effect</th>
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<tbody>
<tr>
<td>Actinomycin D (Dactinomycin)</td>
<td>Hepatic fibrosis, cirrhosis</td>
</tr>
<tr>
<td>BCNU (Carmustine)</td>
<td>Pulmonary fibrosis, ovarian failure, azoospermia</td>
</tr>
<tr>
<td>Bleomycin</td>
<td>Pulmonary fibrosis, hyperpigmentation, digital cutaneous ulceration</td>
</tr>
<tr>
<td>Chlorambucil</td>
<td>Progressive genral aplasia, azoospermia</td>
</tr>
<tr>
<td>Cisplatin</td>
<td>Hearing loss, peripheral neuropathy</td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td>Progressive genral aplasia, azoospermia, ovarian failure, chronic hemorrhagic cystitis</td>
</tr>
<tr>
<td>Doxorubicin (Adriamycin)</td>
<td>Cardiomyopathy</td>
</tr>
<tr>
<td>Etoposide</td>
<td>Testosterone deficiency, peripheral neuropathy</td>
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<tr>
<td>5-fluorouracil</td>
<td>Reduced bladder capacity, bulbar dysfunction, chronic hemorrhagic cystitis, ovarian failure</td>
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<tr>
<td>Methotrexate</td>
<td>Hepatic fibrosis, cholestasis, leukoencephalopathy, renal failure</td>
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<tr>
<td>Nitrogen mustard</td>
<td>Azoospermia, oligospermia</td>
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<tr>
<td>Mitomycin</td>
<td>Azoospermia, oligospermia, ovarian failure</td>
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<tr>
<td>Radiomimetic</td>
<td>Ovarian failure, premature menopause</td>
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<tr>
<td>Vincristine</td>
<td>Peripheral neuropathy</td>
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Addendum IX: Late Effects of Radiation

<table>
<thead>
<tr>
<th>Site</th>
<th>Effect</th>
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</thead>
<tbody>
<tr>
<td>Abdomen/intestines</td>
<td>Adhesions, fibrosis</td>
</tr>
<tr>
<td>Bladder</td>
<td>Bladder, hypoplasia</td>
</tr>
<tr>
<td>Central nervous system</td>
<td>Stroke, blindness, myelitis, focal necrosis, peripheral neuropathy, leukoencephalopathy, neurocognitive deficits</td>
</tr>
<tr>
<td>Chest</td>
<td>Breast cancer, soft tissue sarcomas, difficulty swallowing, pulmonary fibrosis</td>
</tr>
<tr>
<td>Head and neck</td>
<td>Hypothyroidism, hyperthyroidism, ossaeonerosis of mandible, increased dental caries, alopecia, chronic otitis, hearing loss, xerostomia, hoarseness</td>
</tr>
<tr>
<td>Heart</td>
<td>Pericarditis, coronary artery disease, cardiomyopathy, pericardial effusions, myocardial infarction</td>
</tr>
<tr>
<td>Liver</td>
<td>Biliary, cholestasis</td>
</tr>
<tr>
<td>Ovaries</td>
<td>Ovarian failure, premature menopause</td>
</tr>
<tr>
<td>Skeletal system</td>
<td>Late fractures, osteonecrosis</td>
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<tr>
<td>Stomach</td>
<td>Stomach, pancreas, basal cell carcinoma, hyperpigmentation</td>
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<td>Testes</td>
<td>Oligospermia, azoospermia, testosterone deficiency</td>
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<tr>
<td>Urinary tract</td>
<td>Bladder, skinflakes</td>
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<td>Vagina</td>
<td>Perineal, decreased vaginal secretions</td>
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