CanCER Survivorship
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2016 OCN Test Blueprint Content Areas

<table>
<thead>
<tr>
<th>Content Area</th>
<th>Percentage of 2014 Test</th>
<th># of Scored Questions*</th>
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<tbody>
<tr>
<td>Health Promotion, Screening &amp; Early Detection</td>
<td>6%</td>
<td>9</td>
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<tr>
<td>Scientific Basis for Practice</td>
<td>9%</td>
<td>13</td>
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<tr>
<td>Treatment Modalities</td>
<td>16%</td>
<td>23</td>
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<tr>
<td>Symptom Management</td>
<td>22%</td>
<td>32</td>
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<tr>
<td>Psychosocial Dimensions of Care</td>
<td>8%</td>
<td>12</td>
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<tr>
<td>Oncologic Emergencies</td>
<td>12%</td>
<td>17</td>
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<tr>
<td>Survivorship</td>
<td>8%</td>
<td>12</td>
</tr>
<tr>
<td>Palliative &amp; End of Life Care</td>
<td>11%</td>
<td>16</td>
</tr>
<tr>
<td>Professional Performance</td>
<td>8%</td>
<td>12</td>
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</table>

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

The Cancer Control Continuum

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).
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.

2015 Cancer Statistics

Number U.S. Cancer Survivors Triples (1971)
There is no profit in curing the body, if in the process we destroy the soul.

Inscription on the Gate City of Hope National Medical Center
Duarte, California

Cancer Survivorship Institute of Medicine (IOM)

- 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?

Key Elements of a Survivorship Program

Nursing Roles and Survivorship Care

- Care provider
- Educator
- Counselor
- Advocate
- Clinical care
- Education
- Counseling
- Advocacy
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


Nursing Process for Breast Cancer Survivors: Assess, Plan, Implement, Evaluate and Educate

Survivors Need Treatment Summary & Care Plan
- Improved successful cancer therapies & increased rates of early detection result in more people surviving cancer than ever before
- 2012, were 12 million cancer survivors in 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.”
Cancer Survivorship: Institute of Medicine

Treatment Summary: Tumor & Chemotherapy Information

- Tumor characteristics
- Dates of treatment initiation and completion
- Chemotherapy agents used
- Treatment regimen, total dosage, identifying number and title of clinical trials
- Indicators of treatment response
- The likely course of recovery from treatment toxicities
- Information on possible late and long-term effects of treatment and symptoms of such effects
- Information on possible signs of recurrence and second cancers

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

Serves as an update to the original informed consent process; avoids pitfall of limited patient recall (IOM, 2005).

Figure 1. Elements of a Care Plan

Hematopoietic Stem Cell Follow-Up Guidelines: How to capture in a survivorship care plan?

Figure 2. Cancer Treatment Summary and Follow-Up Plan Template

Clinical Journal of Oncology Nursing • Volume 12, Number 3 • Implementing a Survivorship Care Plan 481

Table 1. Guidelines for Follow-Up
Hematopoietic Stem Cell Follow-Up Guidelines: How to capture in a survivorship care plan?

Journey Forward Initiative: A Survivorship Care Plan Builder

- Free, downloadable tool & CD-ROM toolkit
- Contains information on care plans, billing, and resources for MD, patients
- Templates available for breast, colon and lymphoma.
- Template begins with basic patient demographic and contact information of various HCPs participating in patient care
- 2nd page: detailed information about the tumor pathology and staging.
  - [http://journeyforward.org/](http://journeyforward.org/)

Journey Forward Initiative: A Survivorship Care Plan Builder

- 3rd page “Treatment” provides detailed information about treatment regimens, dates, dosages, and patient participation in clinical trials
- Followed by: Treatment Plan and Summary – total dosages and a record of complications
- Follow-up Care plan – detailed information about the proposed follow-up care and time and guidance about which health care provider should be giving specific follow-up at designated intervals.
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.


Survivorship Challenge: Sleep Disturbances Research Findings in Breast Cancer Survivors

- Methods: Articles published from 2003–2013 were retrieved using PubMed, Web of Science, and ScienceDirect. Key search terms included breast cancer, sleep actigraphy, and sleep disturbances. Articles assessing sleep subjectively and objectively in the post-treatment period were included.

- Findings: Twelve studies met the inclusion criteria: seven descriptive studies; one interventional study; three randomized, controlled trials; and one longitudinal study. Nighttime awakenings and wake after sleep onset were the most affected sleep variables. Association between subjective and objective sleep was significant among metastatic BCSs. Cognitive-behavioral interventions showed significant improvements in sleep quality.

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

- Background: This article elucidates the symptom experiences of breast cancer survivors after completion of their treatment. It also provides self reports of the types, frequency of use, and effectiveness of self-care measures to treat the symptoms they are experiencing.

- Objectives: The purpose of this article is to describe the self-care strategies used to alleviate symptoms reported by breast cancer survivors recruited from a secure state coalition database.


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.


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

- **Findings:** Six major themes were derived from the analysis: cognitive problems, effects on employment, emotional response, search for answers, coping mechanisms, & the providers’ role.

- The breast cancer survivors reported psychological distress about perceived cognitive problems in concentration, memory, and other cognitive functions. They sought answers about the cause and were frustrated by a lack of information from providers.

- Although treatment strategies are limited, healthcare providers should validate patients’ concerns by discussing possible cognitive limitations and should allow them to talk about the impact of cognitive problems on their lives.

Effects of Cancer Survivorship on Family Members

(Mellon, 2002)

- **Findings:** 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.
## Culture of Cancer Survivorship (Leigh 2001)

<table>
<thead>
<tr>
<th>Stages</th>
<th>Care</th>
<th>Needs</th>
<th>Culture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Acute</td>
<td>Acute-like effects of therapy</td>
<td>Acute-like effects of therapy</td>
</tr>
<tr>
<td>Late</td>
<td>Late</td>
<td>Late-like effects of therapy</td>
<td>Late-like effects of therapy</td>
</tr>
</tbody>
</table>

### Challenges:
- Psychological
- Physical
- Financial
- Spiritual
- Social

- Palliative Care
- End of life
- Rehabilitation
- Impaired Communication
- Sexual dysfunction
- Treatment Neurology

**Major organ late effects S/P chemo:** cardiac, lung, hepatic, GVHD, Chemo brain

**Major late effects S/P pelvic radiation:** stricture, fistula (rectovaginal, ureteral-vaginal)

## ONS Survivorship Initiatives

- Identify resources for nurses in all specialties who may be caring for patients who are survivors of adult cancer care
- Address gaps in survivorship care
- Develop resources to fill those gaps
- Focus on the late, long-term effects that may be identified and managed by a variety of disciplines
- Regional conferences with focus on survivorship:
  How nurses can meet the unique needs of cancer survivors across the continuum of their lives and help bridge the gaps in their health care.

## Classification of Effects

- Early – occurring during or immediately after treatment
- Late – occurring 6 months to one year after treatment

## 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: 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
- Oophorectomy - Premature menopause, infertility
- Orchiectomy - Infertility, testosterone deficiency, cardiovascular complications

Late Effects: Chemotherapy / Hormone Therapy

- Hepatic - Abnormal liver function, cirrhosis, liver failure
- Neurologic - Cognitive changes (thinking, learning, memory)
- 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 of Chemotherapy

<table>
<thead>
<tr>
<th>Agent</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actinomycin (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 ulcers</td>
</tr>
<tr>
<td>Cisplatin</td>
<td>Hearing loss, peripheral neuropathy</td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td>Progressive genital atrophy, azoospermia</td>
</tr>
<tr>
<td>Doxorubicin (Adriamycin)</td>
<td>Cardiomyopathy</td>
</tr>
<tr>
<td>Etoposide</td>
<td>Testosterone deficiency, peripheral neuropathy</td>
</tr>
<tr>
<td>Ifosfamide</td>
<td>Reduced bladder capacity, ovarian failure, azoospermia</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>Hepatic fibrosis, osteoporosis, renal failure</td>
</tr>
<tr>
<td>Nitrogen mustard</td>
<td>Azoospermia, oligospermia</td>
</tr>
<tr>
<td>Procarbazine</td>
<td>Azoospermia, oligospermia, ovarian failure</td>
</tr>
<tr>
<td>Steroids</td>
<td>Cataracts, osteonecrosis, avascular necrosis</td>
</tr>
<tr>
<td>Vinblastine</td>
<td>Regional neuropathy</td>
</tr>
</tbody>
</table>

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, scarring pericardium
- Endocrine - Sterility or low levels of testosterone or female hormones
- Gastrointestinal - Malabsorption, intestinal strictures
- Genitourinary - Bladder scarring, small bladder capacity
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>Fibrosis, 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, hypoparathyroidism, dental caries 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>Fibrosis, cirrhosis</td>
</tr>
<tr>
<td>Ovaries</td>
<td>Ovarian failure, premature menopause</td>
</tr>
<tr>
<td>Skeletal system</td>
<td>Late fractures, osteonecrosis</td>
</tr>
<tr>
<td>Skin</td>
<td>Fibrosis, necrosis, basal cell carcinoma, hyperpigmentation</td>
</tr>
<tr>
<td>Testicles</td>
<td>Dyspareunia, atrophy, telangiectasia, testosteron deficiency</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>Fibrosis, skin tumors</td>
</tr>
<tr>
<td>Vagina</td>
<td>Fibrosis, decreased vaginal secretions</td>
</tr>
</tbody>
</table>

Functional and Cosmetic Changes

- **Functional**
  - Lymphedema
  - Neuropathies
  - Fatigue
  - Decreased physical stamina

- **Cosmetic**
  - Ostomies
  - Amputations
  - Hair loss or thinning

Psychological and Spiritual 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)
Management and Follow-up

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

Survivorship References

### Table 10-4. Community Legal Rights and Advocacy Groups (Limited List)

<table>
<thead>
<tr>
<th>LAW</th>
<th>PURPOSE</th>
<th>DEETS</th>
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<tbody>
<tr>
<td>Consolidated Omnibus Budget Reconciliation Act (COBRA), 1986</td>
<td>Continues insurance</td>
<td>Must request within 60 days of leaving workplace</td>
</tr>
<tr>
<td>Health Insurance Portability and Accountability Act (HIPAA), 1996</td>
<td>Ensures insurance portability and accountability</td>
<td>Protects from denial of insurance based on preexisting health problems and sets guidelines for waiting period of coverage when changing employer group insurance</td>
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<tr>
<td>Family and Medical Leave Act (FMLA), 1993</td>
<td>Allows family and medical leave</td>
<td>Provides up to 12 weeks of job-protected leave</td>
</tr>
<tr>
<td>Americans With Disabilities Act (ADA), 1990</td>
<td>Protects Americans with disabilities</td>
<td>Helps to prevent discrimination for disabilities and provides accommodations</td>
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### ADVOCACY RESOURCES

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td>American Cancer Society</td>
<td><a href="http://www.cancer.org">www.cancer.org</a></td>
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<tr>
<td>National Coalition for Cancer Survivorship</td>
<td><a href="http://www.cancerandsurvivor.org">www.cancerandsurvivor.org</a></td>
</tr>
<tr>
<td>Patient Advocate Foundation</td>
<td><a href="http://www.patientadvocate.org">www.patientadvocate.org</a></td>
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