Survivorship...what does it mean?

Trish Clark RN, MN.
20\textsuperscript{th} May 2010
South Island Cancer Nurse Network
Introduction
Definition of survivorship
Literature review
Survivorship workshop
Visit to NP survivorship clinic.
Research do we need to do - more for NZ context.
Guidance for Improving Supportive Care for Adults with Cancer in New Zealand
After my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time, I wasn’t sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me.” Dr Elizabeth D. McKinley, MD, MPH, in Rowland et al, 2006.
The experience of survivorship...

- Mixed emotions leaving what became a safe haven with professional support resources and familiarity,
- Re-acquainting with your old life - not everything fits anymore
- Haunted by unresolved existential thought
- Financial stains unable to get insurance therefore loans becomes almost impossible
- Returning to our workforce can be uncomfortable the welcome mat may not be out
The experience of survivorship

- The needs and expectations of those closest to us can be at odds with our needs to take stock and assess our new perspective on life.
- Hospital check-ups take us back to where it all happened some painful memories and fears of their finding something.
- Yet also feelings of abandonment as staff don’t treat you like family as they did when you were admitted and going through treatment.
You’re considered by almost everyone to be one of the lucky ones. You lived and so should be grateful and willing to get on with it…”
Cancer survivorship nursing:

A review of the Literature.

By Dr Merian Litchfield for NZNO Cancer Nurses Section.
Definition of survivorship

- Positioned in its primary orientation.
- Differences of definition reveal whether it is sequelae or personal experience that is its primary orientation. That is whether the starting point of survival is the end of treatment, no evidence of disease or the point of diagnosis of cancer.
Definition of survivorship

- Alternatively the experience- as- primary conceptualisation that is marked by issues and needs of survivors- fully inclusive from the time of diagnosis and for the balance of life and includes family friends and care givers.

- This primary orientation to experience includes such issues as relating to living with, through and beyond a cancer diagnosis.
The Institute of Medicine defined the nurse role as

- minimizing risk and facilitating early recognition of recurrent and new cancers and other late effects;
- assessment of physiologic and psychological long term effects;
- intervention for the consequences of cancer and cancer treatment;
- and coordination among specialist and primary care givers
# Cancer Treatment Summary - Follow-up Care Plan

**Name:**

**Date of Birth:**

**Cancer Diagnosis Date:**

**Stage:**

**Date Completed Therapy:**

**Primary Care Physician:**

## History of Cancer Treatment

**Surgery/Biopsy**

**Surgeon:**

**Procedure/Date:**

## Radiation Therapy

**Radiation Oncologist:**

**Date Started:**

**Date Stopped:**

**Field:**

**Dose (cGy):**

## Chemotherapy/Medical Therapy

**Medical Oncologist:**

**Regimen/Number of cycles:**

**Dose reductions:** N/A ( ) Yes ( )

**Reasons:**

**Drug Name:**

**Bisphosphonates/idurandronate:**

( ) Aredua ( ) Zometa ( ) Other

☐ Yes ☐ No

**Schedule:**

**Growth Factors:**

Neulasta ( ) Neupogen ( ) Aranesp ( ) Procrit ( ) Other:

☐ Yes ☐ No

**Hormonal therapy:**

No ( ) Yes ( )

## Additional Information

**Clinical Trial:**

☐ No ☐ Yes

**Sponsor/Details:**

**LVEF: Baseline:** %

**Last:** %

**Transplant:**

☐ Autologous ☐ Allogeneic

**Date:**

**Transfusions:**

Red blood cells ( ) Platelets ( ) Blood type:

☐ Yes ☐ No

**Vascular Access Device:**

☐ Yes ☐ No

**Type:**

**Insertion Date:**

**Removal date:**

**Maintenance (flushing) Required:**

☐ Yes ☐ No

**Type:**

**Frequency:**

**Patient’s signature and date:**

**Clinician’s signature and date:**
### Follow-up Plan

<table>
<thead>
<tr>
<th>Cancer evaluation</th>
<th>Type</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Imaging
- Laboratory
- Physical exam

**Immunizations:**
Pneumovax once at age 65; every 5 years if immunosuppressed ( ) Influenza ( ) Other: ________________

**Complications during treatment (hospitalizations, side effects – Grade 3/4 toxicities/management, dose reductions):**
( ) Infection ( ) Peripheral neuropathy ( ) Psychological distress ( ) Thrombosis ( ) Other: ________________

### Symptoms to report

- New lumps or swelling
- Unusual bleeding
- Persistent cough
- Loss of appetite
- New pain
- Other: ________________
- Weight loss > 10 lbs
- Persistent nausea and vomiting
- Persistent fatigue
- Change in bowel habits
- Numbness
- Confusion

### Referrals

- Physical therapy
- Dietician
- Oncology Rehab
- Other: ________________
- Advanced care planning
- Nutritionist
- Genetic counseling
- Social worker

### Wellness

- Smoking cessation
- Safe sex
- Screening for and prevention of osteoporosis
- Limiting sun exposure
- Screening for and prevention of cardiovascular disease
- Physical activity
- Nutrition and healthy weight management

### Cancer Screening (frequency and type)

- Colonoscopy Frequency: ________________
- Mammogram Frequency: ________________
- PSA test and digital rectal exam Frequency: ________________
- Skin examination Frequency: ________________
- Pap smear Frequency: ________________
- Other Frequency: ________________

### Resources

- LIVESTRONG Survivorship Notebook
- NCI Facing Forward (www.journeyforward.org)

List of resources: ________________

---

Patient’s signature and date: _____________________________
Clinician’s signature and date: ___________________________
Survivorship workshop

- Identifying risks for long-term and late effects
- Late effects of cancer treatment
- Planning for Survivorship
- The role of the oncology nurse in education and treatment of late and long term effects
Late and Long Term Effects

Late effects: unrecognized toxicities that are absent or subclinical at the end of treatment and manifest months or years later

Long term effects: any side effect or complication for which the survivor must compensate
Medical Concerns

- Medical Concerns
  - Cardiovascular disease
  - Diabetes
  - Pulmonary function
  - Endocrine abnormalities
    - Thyroid, gonadal production, pituitary
- Infertility
- Premature menopause
- Sexual dysfunction
- Dental health

- Neurological problems
  - Balance, neuropathy, memory
  - Lymphedema
  - Bone health
    - Osteoporosis, osteonecrosis
  - GI
    - Motility disorders, malabsorption syndromes
    - Incontinence
  - GU
    - Renal dysfunction, incontinence
Core Psychological Aspects of Cancer

- Emotional/psychosocial journey is only partly through when treatment ends
- Has attributes of a traumatic life event (chronic extreme stressor)
- Characterized by loss and crisis
- Patients think continuously about what might happen
- Cancer is not one event, it is a process
- Cancer’s impact is individual, and familial
- Post-traumatic growth/change also occurs
Health Behaviour Referrals

- **Referrals and Educational Brochures:**
  - 100% Education on Healthy Behaviours after cancer
  - > 60%
- Exercise Program
- **30-40%**
  - Nutrition
  - Physical Therapy
  - Psychology / Psychiatry
- **20-30%**
  - Sexuality
  - Pain
  - Sleep Evaluation
  - Social Work
- **<5%**
  - Smoking
  - Alcohol abuse
  - Infertility
  - Neuropsychology
  - Rehabilitation
  - Legal
Survivorship Care Plan
- Requires commitment
- Not easy to do
- Cost concerns

Potential benefits to patients and providers
- Continuity of care
- Safety
- Quality of life
IOM asserts that survivorship care plans:
- have strong face validity
- assumed to improve care unless/until evidence to contrary

- What is best format for survivorship care plans?
- How can they be feasibly created?
- What is best setting? e.g. specialized clinics,
  - NP?
- Do all patients need it?
- Does it improve outcomes of care?
- Is it cost effective?

Earle, Craig ASCO presentation Surveillance, Disease Prevention and Health Promotion in Cancer Patients, 2006 as cited in Survivorship Navigation: the Livestrong Care Plan; N. Houlihan conference presentation
Research Question?

- Do we need to replicate?
- Use the research available for business case
- Value your input and discussion.


