Cancer Survivorship in the U.S.A: Models of Follow-up Care

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There were 14.1 million new cancer cases, 8.2 million cancer deaths and 32.6 million people living with cancer (within 5 years of diagnosis) in 2012 worldwide. 57% (8 million) of new cancer cases, 65% (5.3 million) of the cancer deaths and 48% (15.6 million) of the 5-year prevalent cancer cases occurred in the less developed regions.
**Long-Term or Chronic Effects of Cancer Treatment**

- **Physical/Medical** (e.g., pain, fatigue, memory problems, lymphedema, sexual impairment, amputations)

- **Psychological** (e.g., depression, anxiety, uncertainty, isolation, altered body image)

- **Social** (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to school, financial burden)

- **Existential and Spiritual Issues** (e.g., sense of purpose or meaning, appreciation of life)
Cancer Survivors at Increased Risk for Late Effects

- Disease recurrence/ new cancers
- Cardiovascular disease
- Obesity/Diabetes
- Osteoporosis
- Functional decline
- Poor quality of life
Summary of Effects

- Patients of all ages can be affected
- Some survivors have few effects, while others experience many
- Degree of risk to individual patients is often difficult to predict
- There can be long latencies in the development of some effects
- Adverse side effects contribute to burden of illness, costs, decreased length/quality of survival

*Early interventions may hold the promise of reducing adverse outcomes.*
Cancer Learning

Survivorship

This topic has been funded by the Australian Cancer Survivorship Centre, a Richard Pratt Legacy based at Peter MacCallum Cancer Centre, in collaboration with Cancer Australia, Queensland University of Technology and the University of Sydney and offers up to date, evidence based practical tools, tips, resources and an introductory package of learning modules that aim to demonstrate how you can make a positive impact improving outcomes and care for people affected by cancer.

Associate Professor Mei Krishnasamy - Peter MacCallum Cancer Centre

As a cancer nurse I have experienced the importance first hand of how the right interventions have improved the psychological wellbeing and lives of people affected by cancer. By improving our knowledge and understanding of survivorship we can make a real difference to the long-term outcomes of survivors.

I hope you find the site a useful and valuable resource that you share with your colleagues.
EU Joint Action ‘CANCON,’ which is developing a European Guide on Quality Improvement in Comprehensive Cancer Control.

9 work packages of which rehabilitation and survivorship is one!
Stresses Associated with Termination of Cancer Treatment

*Negotiating the Transition to Recovery*

- Fear that the cancer will return
- Concern about ongoing monitoring
- Loss of a supportive environment
- Diminished sense of well-being due to treatment effects
- Social demands: ‘re-entry’ problems
- *Not having a plan of action!*
Selected Recommendations from the President’s Cancer Panel & IOM Reports

• When treatment ends, all survivors should receive a summary record that includes important disease characteristics and treatments received.
• In addition, they should be provided with a follow-up care plan incorporating available evidence-based standards of care.

*Treatment summary + FU care plan = Survivorship Care Plan (SCP)*
Survivorship Care Plan Content: President’s Cancer Panel and Institute of Medicine

1. Surveillance for recurrence or new cancer
2. Assessment and treatment or referral for persistent effects (e.g., pain, fatigue, sexual dysfunction, functional impairment, depression, employment issues)
3. Evaluation of risk for and prevention of late effects (e.g., second cancers, cardiac problems, osteoporosis); health promotion
4. Coordination of care (e.g., including frequency of visits, tests and who is performing these)
Multidisciplinary Clinic
(McCabe 2013)

- Patients seen/evaluated by different providers during one clinic visit
- Oncology, endocrinology, neuropsychology, neurology, social work, etc.

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<tr>
<th>Advantages</th>
<th>Challenges</th>
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<tbody>
<tr>
<td>Common pediatric model</td>
<td>Resource intense</td>
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<tr>
<td>Easy for patients</td>
<td>Difficult to coordinate</td>
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<tr>
<td>Comprehensive</td>
<td>Not everyone needs all services</td>
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<tr>
<td>Good model for complex patient (brain tumors)</td>
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**Disease/Treatment Specific Clinic**
(McCabe 2013)

- Survivorship clinic for specific disease category (breast)
- Stem cell transplant patients frequently seen in separate clinic from general oncology
- Can be developed for psychosocial services only

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<tr>
<td>Good way to begin</td>
<td>Inequality</td>
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<tr>
<td>Focused scope of practice</td>
<td>Omit survivors with greatest needs</td>
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<tr>
<td>Easier to develop consensus guidelines for follow-up</td>
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<tr>
<td>Good model for complex patients</td>
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Integrated Care Model

(McCabe 2013)

- Survivorship visit imbedded in the oncology clinic where the patient was treated
- Survivorship Nurse Practitioner
- Ongoing care

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<td>Easy transition for patients</td>
<td>Requires busy clinical practice to justify</td>
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<tr>
<td>Access to treatment history</td>
<td>Patients may be reluctant to transition to primary care</td>
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<tr>
<td>Works well for surveillance of recurrent/new cancer as well as for late effects</td>
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Consultative Service
(McCabe 2013)

- One time consult visit to cover general survivorship issues and distribute treatment summary/care plan
- Some may see annual returns
- Referral to subspecialist, PT, nutrition, psych, etc
- Establish primary care home for survivor

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<td>Serves unrestricted survivor population, outside referrals</td>
<td>Difficult to be “expert” in long term f/u issues for all diseases</td>
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<tr>
<td>Provides core service, tx summary/care plan</td>
<td>Difficult to have consensus guidelines for f/u for all</td>
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<tr>
<td>Reinforces need for primary care f/u and transition out of cancer clinic setting</td>
<td>Buy in from multiple different oncologist for patient referral difficult</td>
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Shared-Care Model Components
(McCabe 2013)

• Care shared by two or more clinicians of different specialties
• Common understanding of expected components of care and respective roles
• Knowledge transfer
  – Clinical summary
    • Specific information on disease
    • General information about treatment
• Communication channels
  – Contact information for oncology physicians and nurses
• Active patient involvement
  – Encouraged to contact primary care physician with problems
  – Provided with the information given to the primary care physician

Tool Kit Visit
(McCabe 2013)

• Treatment summary and care plan
• Cancer screening recommendations
• Healthy living counseling
  – Smoking cessation
  – Diet
  – Exercise
• Insurance, employment and financial information
• Referral to rehabilitation and social services
Models of Care [Lead] Providers (McCabe 2013)

• **Physicians**
  – Oncologist
    • Pediatric
    • Medical
  – Primary care

• **Nurses**
  – Oncology experience
  – Non-oncology experience

• **Nurse practitioners/ physician assistants**
  – Oncology expertise
  – Primary care expertise

• **Combined MD/NP team**
Cancer Survivorship
A process for living well with and beyond a cancer diagnosis

Principles:
- How we do it
  - Survivor centred (enabling, engaging, empowering)
  - Integrated care across all service levels at every time point
  - Coordinated care

What we do:
- Promote well-being
- Prevent illness
- Manage symptoms and issues

Diagram:
- Diagnosis
- End primary treatment
- Transfer to self-monitoring
- Time of new problem

Care recommendations based on risk:
- Low Risk:
  - ↓ complexity
  - ↓ intensity
  - Surveillance & problem management (cancer related; other chronic illness)
- Moderate Risk:
  - Some moderate complexity
  - Some moderate intensity
- High Risk:
  - ↑ complexity
  - ↑ intensity
  - Specialist care required

Needs assessment:
- Risk stratification
- Treatment summary
- Relate to care plan

Education (tailored) for self-management & long-term well-being:
- Information
- Psychological support
- Behaviour change (GBT etc.)

Rehabilitation: addressing acute effects of cancer & treatment:
- Physical
- Psychological
- Social
- Spiritual
- Career/work
- Environmental

Transition period of reducing intensity of anti-cancer treatment

Supported self-management:
- Timely re-access
- Remote monitoring
- Community-led

Professionally-led follow-up:
- Specialist led (including nurses and allied health practitioners)
- Primary care led (including GPs and nurses with referral as appropriate)

Supportive care:
- Transition to end of life care

Multi-disciplinary collaborative care

The NCCN Framework™ resources are defined as:

- **Basic Resources**: Basic Resources include essential services needed to provide basic minimal standard of care.

- **Core Resources**: Core Resources include those provided in the Basic Resources Framework plus additional services that provide major improvements in disease outcomes (e.g. survival) and that are not cost prohibitive.

- **Enhanced Resources**: Enhanced Resources include those provided in the Core Resources Framework and additional services that provide lesser improvements in disease outcomes and/or services that provide major improvements in disease outcomes but are cost prohibitive in lower resource settings.

- **NCCN Guidelines**: The NCCN Guidelines are evidence-based, consensus-driven recommendations made by the NCCN Guidelines panels. They include services from the Enhanced Resources Framework and additional services that provide minor improvements in disease outcomes, interventions that are cost prohibitive in lower resource settings, and/or services that do not provide improvement in disease outcomes but are desirable services.

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ABSTRACT

Breast cancer survivors may experience long-term treatment complications, must live with the risk of cancer recurrence, and often experience psychosocial complications that require supportive care ser-
In spite of the uncertainties, there can be good quality of life after cancer!