Adult cancer survivors
Prof Michael Jefford

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Conflict of interest disclosure
Michael Jefford, MBBS, MPH, MHLthServMt, PhD, FRACP

- Travel support, Roche (January 2018)
- No other potential COI
Peter MacCallum Cancer Centre, main site, Parkville, Melbourne
Audience participation

Please rate your familiarity with / awareness / knowledge of all things cancer survivorship:

a. 0-2 / 10 (low)
b. 3-5 / 10 (moderate)
c. 6-8 / 10 (high)
d. 9-10 / 10 (very high)
Shared challenges, internationally

- Large, and growing number of survivors
- Survivors may experience a broad range of issues, concerns, needs
  - Currently poorly identified / addressed
- Limited health workforce
- Need to provide improved care within resource constraints
  - Redesign models of care
Survivors in Australia

Currently, 1.1m survivors
68% 5-year survival
1 in 22 Australians are cancer survivors

In 2040, 1.9m survivors
Majority (64%) > 5 years post diagnosis
Majority (58%) will be aged 70 or older
Survivors in the US

- 16.9m survivors in 2019
- 22.2m survivors in 2030
- Similar profile of survivors, c/w Australia

Issues experienced by cancer survivors
Issues experienced by cancer survivors

✓ Most people adjust well to life after cancer

• Varied reactions to finishing treatment
  e.g. feeling lost or abandoned

• Persisting side effects from treatment
  e.g. fatigue, pain, concerns with sleep, cognition

• Emotional, psychological issues
  e.g. fear of cancer recurrence
Issues experienced by cancer survivors

- Side effects that develop later (‘late effects’)  
  e.g. infertility, organ damage, another cancer
- Impact on relationships, family
- Vocational, financial and other practical impacts  
  e.g. difficulties resuming work or study, loss of income
- Benefit finding, growth
Unmet needs in cancer survivors

<table>
<thead>
<tr>
<th>Unmet need</th>
<th>Domain</th>
<th>No. of endorsements</th>
<th>Prevalence range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of cancer recurrence and progression</td>
<td>Psychosocial</td>
<td>14</td>
<td>14-42%</td>
</tr>
<tr>
<td>Feeling uncertain about the future</td>
<td>Psychosocial</td>
<td>9</td>
<td>12-26%</td>
</tr>
<tr>
<td>Help to reduce stress</td>
<td>Psychosocial</td>
<td>8</td>
<td>12-34%</td>
</tr>
<tr>
<td>Worry about partners, family, and friends</td>
<td>Psychosocial</td>
<td>8</td>
<td>12-26%</td>
</tr>
<tr>
<td>Information about support services</td>
<td>Supportive care</td>
<td>7</td>
<td>11-33%</td>
</tr>
<tr>
<td>Changes in sexual relationships and sexual feelings</td>
<td>Psychosocial</td>
<td>7</td>
<td>11-29%</td>
</tr>
<tr>
<td>Affordable hospital care parking</td>
<td>Supportive care</td>
<td>7</td>
<td>12-26%</td>
</tr>
<tr>
<td>Help with feeling tired/lack of energy</td>
<td>Physical</td>
<td>7</td>
<td>10-27%</td>
</tr>
<tr>
<td>Access to complementary and alternative therapy</td>
<td>Supportive care</td>
<td>6</td>
<td>17-31%</td>
</tr>
<tr>
<td>Knowing that HCPs communicate to coordinate care</td>
<td>Supportive care</td>
<td>6</td>
<td>15-31%</td>
</tr>
<tr>
<td>Not being able to do usual things</td>
<td>Physical</td>
<td>6</td>
<td>13-27%</td>
</tr>
<tr>
<td>Needing to talk to other people who have experienced cancer</td>
<td>Supportive care</td>
<td>6</td>
<td>13-26%</td>
</tr>
</tbody>
</table>
Current issues / problems relating to the care of survivors

Survivors

• are often unprepared for the post-treatment phase
• may be unaware of health risks
• don’t understand next steps
• often have symptoms and other issues that are under-recognised / under-treated
• often have too many, poorly-coordinated review appointments
  – limits the capacity for new patient appointments / waiting lists
• may travel long distances for reviews
Current issues / problems relating to the care of survivors

• Insufficient health promotion / attention to risk factors, unhealthy behaviours (secondary prevention)
• Primary care providers are not adequately engaged in the care of survivors
• Primary care providers don’t have the information and support they need
• Underuse of existing services, including rehabilitation and services provided by non-government organisations / not for profits
• Specialist-led review appointments may not represent the best use of their time
• Under-use of nurse and allied-health reviews
• Limited metrics / KPIs to describe and report on optimal survivorship care
Free PDF book
http://www.nap.edu/catalog/11468.html

Excellent 17 minute video on YouTube
BOX ES-1

Essential Components of Survivorship Care

1. **Prevention** of recurrent and new cancers, and of other late effects;
2. **Surveillance** for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. **Intervention** for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. **Coordination** between specialists and primary care providers to ensure that all of the survivor’s health needs are met.
NCSI ran from 2008 to 2013
Model of Care: Living With and Beyond Cancer

Transition from treatment to living beyond cancer:
- Complex care management
- Coping with uncertainty
- Long-term sequelae

Living beyond cancer and remain well:
- May involve surveillance and needs
- Quick access if symptoms occur

Living beyond cancer with the consequences of treatment:
- Shared care
- Self-care with support and open access

Assessment and care planning - trigger points:
- At diagnosis
- Following treatment
- If positive or negative significant event occurs
- Patient or professional trigger

Dying and transition to end of life care:
- Transition from treatment to living beyond cancer
- Coping with uncertainty
- Long-term sequelae
Priorities and performance assessment

Nine ‘must dos’ for 2017-19

11. In 2016/17 we described nine ‘must do’ priorities. These remain the priorities for 2017/18 and 2018/19. These national priorities and other local priorities will need to be delivered within the financial resources available in each year.

2017/18 and 2018/19 ‘must dos’

6. Cancer

- Working through Cancer Alliances and the National Cancer Vanguard, implement the cancer taskforce report.
- Deliver the NHS Constitution 62 day cancer standard, including by securing adequate diagnostic capacity, and the other NHS Constitution cancer standards.
- Make progress in improving one-year survival rates by delivering a year-on-year improvement in the proportion of cancers diagnosed at stage one and stage two; and reducing the proportion of cancers diagnosed following an emergency admission.
- Ensure stratified follow up pathways for breast cancer patients are rolled out and prepare to roll out for other cancer types.
- Ensure all elements of the Recovery Package are commissioned, including ensuring that:
  o all patients have a holistic needs assessment and care plan at the point of diagnosis;
  o a treatment summary is sent to the patient’s GP at the end of treatment; and
  o a cancer care review is completed by the GP within six months of a cancer diagnosis.
Stratified cancer pathways: redesigning services for those living with or beyond cancer

Provided by: NHS Improving Quality

Publication type: Quality and productivity example

Evidence summary

Savings delivered

<table>
<thead>
<tr>
<th>Estimated time to implement (months)</th>
<th>0-3</th>
<th>4-12</th>
<th>13-36</th>
<th>&gt;36</th>
</tr>
</thead>
</table>

The estimated net saving in England is £90 million over 5 years, equivalent to an annual saving of £44,592 per 100,000 population.

This document can be found online at: http://www.evidence.nhs.uk/qipp
Implementing Personalized Pathways for Cancer Follow-Up Care in the United States: Proceedings from an American Cancer Society–American Society of Clinical Oncology Summit

Catherine M. Alfano, PhD1; Deborah K. Mayer, PhD, RN, AOCN, FAAN; Smita Bhatia, MD, MPH2; Jane Maher, FRCP, FRCR; Jessica M. Scott, PhD3; Larissa Nekhlyudov, MD, MPH3; Janetto K. Morrill, MS3; Tara O. Henderson, MD, MPH1

SYMPTOMS AND SURVIVORSHIP

Building Personalized Cancer Follow-up Care Pathways in the United States: Lessons Learned From Implementation in England, Northern Ireland, and Australia

Catherine M. Alfano, PhD; Michael Jefford, MBBS, MPH, MHealthServMgt, PhD, GCertUniTeach, GAICD, FRACP; Jane Maher, FRCP, FRCR; Sarah A. Blake, PhD; and Deborah K. Mayer, PhD, RN, AOCN, FAAN


Models of care

- Recommended / most appropriate models of care will depend on factors such as
  - Type of cancer and types of treatment
  - Current symptom issues
  - Survivor-indicated concerns and needs
  - Risk of developing recurrence / other cancers / late effects
  - Comorbid illnesses
  - Personal circumstance / practical issues (e.g. availability of, distance to, and relationship with care providers)
  - Time since completing treatments
An improved model of survivorship care should involve holistic assessment of each patient and stratification to care pathways based on level of assessed needs and risk. The foundation of optimal survivorship care is support for self-management, which will likely be suitable for a large proportion of survivors, with increasing levels of intervention as needs and risks increase. “Shared care” here designates various models including primary care-led, nurse-led, or formal shared care arrangements. Bidirectional arrows indicate that patients may move between pathways if required.
Models of care

• Systematic reviews examining primary care-led follow up, shared care, nurse-led follow up

• Similar clinical outcomes, quality of life, satisfaction

• May be cheaper
Models of care

• These studies point to flexibility in follow up / models of care
• Studies have generally considered
  – Survivors of breast, prostate, colorectal cancers and melanoma
  – People at ‘low to medium risk’ (of recurrence / complications)
• These models may or may not transfer, internationally
• Studies have not necessarily considered outcomes such as
  – Symptom management, unmet needs
  – Management of comorbid illnesses
  – Return to optimal wellbeing (e.g. return to work)
Improving care delivery

• We have evidence, and we have considerable experience delivering new models of care

• Focus on implementation

• There are immediate steps we can all take to improve the care of cancer survivors
Next steps

• Prepare survivors early for the post-treatment phase
• Provide survivors with information
• Link survivors to other services and resources
• Empower patients / survivors to self manage
• Consider asking survivors about common issues and concerns
Next steps

- Health professional education
Next steps

- Assist survivors to obtain a treatment summary / survivorship care plan
Next steps

- Be aware of guidelines around follow up care
Next steps

- Liaise with primary care providers, provide PCPs with guidance

ACSC follow-up guidelines

- Follow-up of breast cancer survivors
- Follow-up of colorectal cancer survivors
- Follow-up of survivors of diffuse large B cell lymphoma (DLBCL), a non-Hodgkin lymphoma subtype
- Follow-up of survivors of Hodgkin lymphoma
- Follow-up of prostate cancer survivors
- Survivorship care in general practice: supporting patients to live well factsheet
Next steps

• Remind patients of the important role of PCPs throughout cancer care

• Consider current patterns of follow up
  – Consider opportunities to reduce review appointments / discharge patients from ongoing follow up
  – Consider most appropriate health care provider
Next steps

- Consider metrics of quality cancer survivorship care

Developing a Quality of Cancer Survivorship Care Framework:

Implications for Clinical Care, Research and Policy

Larissa Nekhlyudov,¹ Michelle A. Mollica,² Paul B. Jacobsen,² Deborah K. Mayer,³ Lawrence N. Shulman,⁴ Ann M. Geiger²

Conclusions

• Large and growing number of cancer survivors
• Survivors have significant issues, concerns and unmet needs
• We need to develop better models of care
• There is considerable experience to draw upon
• Many opportunities to improve the care of cancer survivors
Any comments or questions?

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www.petermac.org/cancersurvivorship