How will cancer survivors use survivorship care plans?

Nicole Kinnane, Amanda Piper, Michael Jefford

2 Feb 2017

Presented by Amanda Piper on behalf of the project team: Nicole Kinnane (Project Manager) and Michael Jefford (Director, Australian Cancer Survivorship Centre)
How will cancer survivors use survivorship care plans (SCPs)?

Background

- SCPs widely endorsed
- Multi-purpose communication tool
- Not broadly implemented
- Known challenges and enablers

**Recommendation 2:** Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.
Context

• 2011-13:
  – SCP delivered in 4 clinical services
• 2013 - Evaluation:
  – Hospital staff
  – GPs
  – Survivors
• Challenges and enablers consistent with the literature

➢ What is a more sustainable approach?

Aim and Methods

• Assess survivors’ preferences:
  - Most valued elements
  - Format, delivery mode
  - Who does not want an SCP?

• Single site survey

• Targeted people generally up to 12 months post treatment

• Across 10 tumour streams:
  - Breast, Gynaecology, Urology, Bone and soft tissue, Haematology, Upper GI, Lower GI, Melanoma, Head & Neck, Lung
Survey

- Addressed following domains:
  - SCP elements
    - Treatment summary (TS)
    - Follow-up plan (FU)
    - Wellbeing (WB)
  - How SCP may be used
  - Preferred format and who would deliver
Results

- 230 surveys returned (RR 68%); n = 219 included in analysis
- Treatment status:
  - 56% 1-6 months post treatment
  - 35% between 6-12 months
  - 10% receiving ongoing treatments (e.g. multiple myeloma)
- 82% had not / could not recall receiving a SCP
- 98% wanted to receive a SCP
Information desired

• Most commonly desired n=219
  – 76% - List of symptoms to watch out for and report (TS)
  – 70% - A summary of treatment received (TS)
  – 70% - Plan for when I should have follow up (FU)
  – 69% - A list of tests I am going to have and when (FU)
  – 67% - Things I can do to look after myself (WB)

• Least preference
  – 2% - No information
  – 10% - Quitting smoking (WB)
  – 11% - Fertility information (WB)
  – 23% - Sexual health information (WB)
  – 29% - Support groups (WB)
Priority elements

- Top 5 information elements desired \( n=195 \)

  1. 51% List of symptoms to watch out for and report (TS)
  2. 46% A summary of treatment received (TS)
  3. 33% Things I can do to look after myself (WB)
  4. 32% Screening for other common cancers (WB)
  5. 31%
     - Strategies to reduce worry about cancer coming back (WB)
     - Plan for when I should have follow up (FU)
     - A list of tests I am going to have and when (FU)
## Cancer groups ‘Top 5’

<table>
<thead>
<tr>
<th>List of top 5 information requests as chosen by survivor groups</th>
<th>Cohorts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breast</td>
</tr>
<tr>
<td>Summary of treatment received</td>
<td>✓</td>
</tr>
<tr>
<td>A list of symptoms to watch out for and report</td>
<td>✓</td>
</tr>
<tr>
<td>Information about side effects of treatment</td>
<td>✓</td>
</tr>
<tr>
<td>A plan of when I should have follow up appointments</td>
<td>✓</td>
</tr>
<tr>
<td>Strategies for reducing worry about cancer coming back</td>
<td>✓</td>
</tr>
<tr>
<td>Name and contact details of who I should call if I have concerns</td>
<td></td>
</tr>
<tr>
<td>A list of tests I am going to have and when</td>
<td>✓</td>
</tr>
<tr>
<td>Things I can do to look after myself</td>
<td>✓</td>
</tr>
<tr>
<td>Screening for other common cancers</td>
<td>✓</td>
</tr>
<tr>
<td>Special instructions to follow after treatment</td>
<td>✓</td>
</tr>
<tr>
<td>Pain and symptom management</td>
<td>✓</td>
</tr>
<tr>
<td>Diet information</td>
<td>✓</td>
</tr>
<tr>
<td>Exercise information</td>
<td>✓</td>
</tr>
<tr>
<td>Support group information</td>
<td>✓</td>
</tr>
<tr>
<td>Coping after treatment is over</td>
<td>✓</td>
</tr>
</tbody>
</table>

*Some topics had equal weighting within cohorts (equally chosen) so more than five indicated for some groups*
How survivors might use care plans  n=207

- 61% ‘A record of cancer’
- 57% ‘A reminder of things to do to look after myself’
- 55% ‘Help me understand side effects of treatment’
- 55% ‘Share with family and friends’
- 52% ‘Share the information with the GP’
Format of SCPs

• What would you most prefer? n=208
  – 42% - Detailed SCP (5 pages)
  – 36% - Brief SCP (1 page)
  – 19% - General information

• How should we deliver? n=212
  – 55% - face-to-face
  – 47% - booklet
  – 44% - leaflet
  – 32% - email
  – 12% - website
  – 8% - app
Delivery of SCPs

• Who would you prefer to deliver? n=212
  – 31% - Doctor
  – 27% - Specialist nurse
  – 17% - GP
  – 22% - no preference
Discussion

• There was no group that did not want an SCP
• Survivors want treatment summary and follow-up information, however one size does not fit all
• Survivors want an SCP for personal use, and as a communication tool
• Survivors endorse generic resources
Recommendations: format

• Based on needs assessment
• Reasonable to trial brief treatment summary for some
• Supplement with:
  – general survivorship information
  – general follow-up information
Recommendations: Strategies to remain well

- Top use of SCP – *Reminder of things I can do to look after myself*
- Receptivity to healthy lifestyle messages
Recommendations: Models of care

• Preference for face-to-face consult with hospital based health professional
• Consider which staff are best placed to develop and deliver
• Evidence supports nurse led care delivery
Recommendations: engage with primary care

- 51% requested information on ‘when to contact GP’
- 52% would share information with GP
- 17% preferred to receive SCP information from GP

Photo courtesy of Australian Primary Health Care Nurses Association (APNA)
Conclusions

• Strong support for SCPs
• Reasonable to trial brief care plan documents
• Consider flexible approaches using existing resources

• Deliver in the context of a model of care
• Impress the value of sharing with GP
Next steps

• IT solutions – piloting automated treatment summary
• Engage with clinical services to develop local solutions to spread SCPs at Peter Mac
• Prepare for support through Electronic Medical Record systems

When you have exhausted all possibilities, remember this: You haven’t.

- Thomas Edison
For further information contact:

Nicole.Kinnane@petermac.org OR
Amanda.Piper@petermac.org

www.petermac.org/cancersurvivorship

Visit the Australian Cancer Survivorship Centre booth in the Exhibition Hall