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How will cancer survivors use survivorship care plans?

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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)?

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ORIGINAL ARTICLE

How will cancer survivors use survivorship care plans?

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ABSTRACT

Background: Survivorship care plans (SCPs) are internationally endorsed as an important tool to enhance post-treatment survivorship care. To support broad implementation of SCPs, we investigated survivors' preferences regarding SCPs.

Material and methods: The study was conducted at a comprehensive cancer center. Eligible patients from 10 clinical services, generally up to 12 months following end of treatment (EOT) were approached in clinics or via telephone. A purpose-designed survey assessed survivors' intended use of a SCP and preferences regarding format and content. Intended minimum sample size of 200.

Results: Two hundred and thirty surveys were returned (response rate 68%). Of the 230 participants, over 55% had completed treatment within six months, 35% between six and 12 months, and 10% were receiving ongoing treatments. Most (82%) had not received a SCP and more than one third (42%) reported receiving no information resources at EOT. Almost all (98%) desired further information. Most common information elements desired in a SCP: 'list of symptoms to watch out for and report' (76%), 'summary of treatment received' (70%) and 'things I can do to look after myself' (67%). Most common suggested uses were as: 'a record of cancer treatment' (63%), 'a reminder of things to do to look after myself' (57%) and 'to help me understand my cancer experience' (56%). Over half (52%) would share the information with their general practitioner. Most indicated preference for paper-based SCPs (91%). There was support for both brief (36%) and detailed versions (42%). Over half requested the information be delivered in a face-to-face discussion with a health professional. Regular telephone support from the treating health care team was most commonly suggested as an additional service to support survivors after EOT.

Conclusions: Although similar to international findings, results suggest alternate ways of providing the information that survivors desire. Most desired SCP elements have been defined. A flexible approach to SCP interventions is justified.

ARTICLE HISTORY

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Background

From Cancer Patient to Cancer Survivor

LOST IN TRANSITION

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

FACT SHEET • NOVEMBER 2005

From Cancer Patient to Cancer Survivor: Lost in Transition Report Recommendations

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.

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

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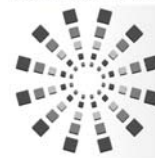
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Context

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

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The Impact of Survivorship Care Planning
on Patients, General Practitioners, and
Hospital-Based Staff

➤ *What is a more sustainable approach?*

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Nolte, L., Kinnane, N., Lai-Kwon, J., Gates, P., Shilkin, P., & Jefford, M. (2016). The Impact of Survivorship Care Planning on Patients, General Practitioners, and Hospital-Based Staff. *Cancer nursing*. Nov/Dec;39(6):E26-E35.

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

15_103L Appendix 1 Survivorship Care Plan Survey v3 dated 2015_08_14
Survey code.....

Survivorship Care Plan Survey

Section 1
Information at the end of a cancer treatment.
Please answer all of the questions.

.....

1. Below is a list of information that could be provided to patients at the end of a treatment in a Survivorship Care Plan. Please tick any of the topics you would have liked to have received at end of treatment or for ongoing treatment? You can tick as many topics as you want.

Treatment summary information

- Summary of the treatment I received
- A list of symptoms to watch out for and report to the doctor or nurse
- Information about side effects of the treatment I received
- Pain/symptom management information
- Special instructions to follow after treatment
- Name and contact details of who I should call if I have concerns
- When to contact your GP


Follow up plan information

- A plan of when I should have follow up appointments
- A list of what tests I am going to have and when

Wellbeing information

- Things I can do to look after myself after treatment
- Diet information

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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'

List of top 5 information requests as chosen by survivor groups	Cohorts									
	*Breast	Gynaecology	Haem	Head and Neck	*Lower GI	Upper GI	Melanoma	Sarcoma	*Urology	
Summary of treatment received	✓	✓	✓	✓	✓	✓		✓		
A list of symptoms to watch out for and report		✓	✓	✓		✓	✓	✓	✓	
Information about side effects of treatment	✓		✓		✓				✓	
A plan of when I should have follow up appointments	✓						✓	✓	✓	
Strategies for reducing worry about cancer coming back		✓		✓		✓		✓		
Name and contact details of who I should call if I have concerns			✓	✓					✓	
A list of tests I am going to have and when		✓			✓	✓			✓	
Things I can do to look after myself	✓				✓		✓			
Screening for other common cancers	✓	✓	✓				✓			
Special instructions to follow after treatment				✓	✓				✓	
Pain and symptom management						✓				
Diet information	✓				✓					
Exercise information	✓									
Support group information							✓			
Coping after treatment is over								✓		

*Some topics had equal waiting within cohorts (equally chosen) so more than five indicated for some groups

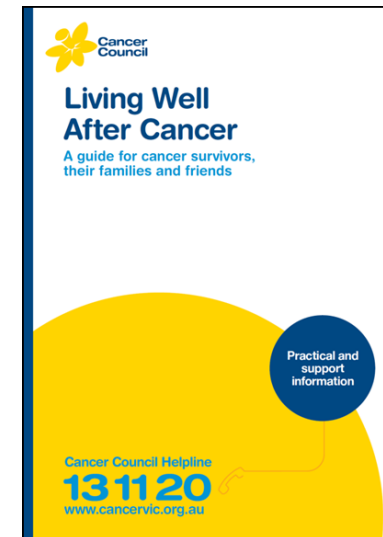
How survivors might use care plans n=207

- 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



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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



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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



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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)

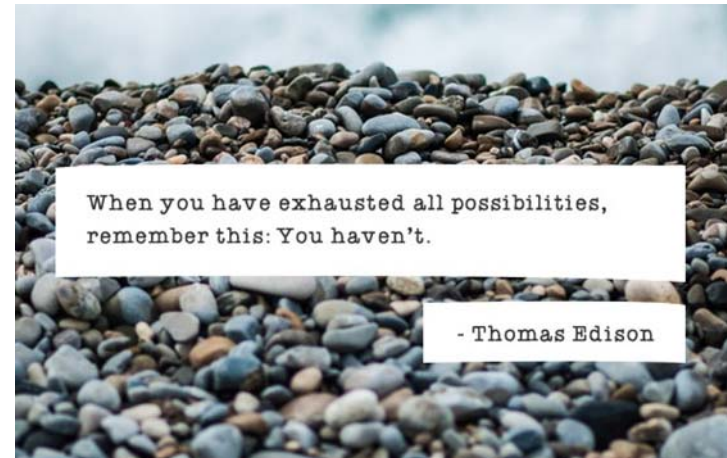
Conclusions

- 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



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*Visit the Australian Cancer
Survivorship Centre booth in the
Exhibition Hall*

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