Implementing Cancer Survivorship Care Plans: State of the Science

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WHEN LIFE IS SEWN BACK TOGETHER, IT HAS CHANGED
A brief history of SCPs

2005
Institute of Medicine report:
“Lost in Transition”

2011
Grunfeld et al.’s RCT of SCPs

2012
Commission on Cancer SCP program standards
Goal of SCPs
SCP Core Elements

1. Summary of the cancer type, treatment, and potential treatment-related late complications
2. Recommendations for follow-up
3. Information on secondary cancer prevention and health promotion
4. Guidance on protection of employment and insurance coverage
5. Content and local availability of psychosocial resources
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  Commission on Cancer SCP program standards
# RCTs of SCPs’ effectiveness

<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Survivor group</th>
<th>Country</th>
<th>Outcomes Assessed</th>
<th>Intervention</th>
</tr>
</thead>
</table>
| Grunfeld (2011); Boekhout (2016) | Early-stage breast cancer | Canada | 1) Cancer-related distress at 12 months  
2) Quality of life  
3) Patient satisfaction  
4) Continuity/coordination of care | SCP + RN educational session (vs. standard discharge) |
| Brothers (2013) | Gynecologic cancers, one year post treatment | United States | 1) Patient assessment of administrative, clinical, and educational health services  
2) Helpfulness of written materials  
3) Quality of care | Physician provision of SCP (vs. standard physician care) |
| Hershman (2013) | Early-stage breast cancer | United States | 1) Impact of cancer  
2) Patient satisfaction  
3) Assessment of survivor concerns | SCP + provider visit + “Facing Forward: Life After Cancer Treatment” (vs. “Facing Forward: Life After Cancer Treatment” only) |
| van de Poll-Franse (2011); Nicolaije (2015) | Endometrial and ovarian cancer | The Netherlands | 1) Patient satisfaction with information and care  
2) Illness perceptions and healthcare use  
3) Health-related QOL  
4) Prevalence, course and referral rate of survivors in distress  
5) providers’ evaluation of care | SCP generated by a Web-based EHR system (vs. standard care) |
A brief history of SCPs

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Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials

Gordon C S Smith, Jill P Pell

Abstract

Objectives To determine whether parachutes are effective in preventing major trauma related to gravitational challenge.

Design Systematic review of randomised controlled trials.

Data sources: Medline, Web of Science, Embase, and the Cochrane Library databases; appropriate internet sites and citation lists.

Study selection: Studies showing the effects of using a parachute during free fall.

Main outcome measure Death or major trauma, defined as an injury severity score > 15.

Results We were unable to identify any randomised controlled trials of parachute intervention.

Conclusions As with many interventions intended to prevent ill health, the effectiveness of parachutes has not been subjected to rigorous evaluation by using randomised controlled trials. Advocates of evidence based medicine have criticised the adoption of accepted intervention was a fabric device, secured by strings to a harness worn by the participant and released (either automatically or manually) during free fall with the purpose of limiting the rate of descent. We excluded studies that had no control group.

Definition of outcomes

The major outcomes studied were death or major trauma, defined as an injury severity score greater than 15.6

Meta-analysis

Our statistical approach was to assess outcomes in parachute and control groups by odds ratios and quantified the precision of estimates by 95% confidence intervals. We chose the Mantel-Haenszel test to assess heterogeneity, and sensitivity and subgroup analyses and fixed effects weighted regression techniques to explore causes of heterogeneity. We selected a funnel plot to assess publication bias visually and Egger’s and Begg’s tests to test it quantitatively. Stata software, version 7.0,
Using Implementation Science to Examine the Impact of Cancer Survivorship Care Plans

Rebecca Selove, Tennessee State University, Nashville, TN
Sarah A. Birken, The University of North Carolina at Chapel Hill, Chapel Hill, NC
Ted A. Skolarus, University of Michigan; Veterans Affairs Health Services Research and Development Center for Clinical Management Research; and Veterans Affairs Ann Arbor Healthcare System, Ann Arbor, MI
Erin E. Hahn, Kaiser Permanente Southern California, Pasadena, CA
Anne Sales, University of Michigan, Ann Arbor, MI
Enola K. Proctor, Washington University in St Louis, St Louis, MO

“We contend that the effectiveness of SCPs is determined, in part, by context and delivery.”
“ROGY studies omit important details regarding [SCPs’] implementation... [F]uture studies should consider how the SCP is implemented and how implementation may influence SCP effectiveness.”
Implementation

Proficiency  Consistency
None of the NCI-designated cancer centers included in the study delivered SCPs with all IOM-recommended components.

Implementation

**Consistent SCP use** involves developing and delivering SCPs to all cancer survivors and their primary care providers.

**Proficiency**

*Less than 3%* of included cancer programs developed and delivered SCPs to survivors and their primary care providers for at least 75% of their survivors.

## What influences SCP implementation?

<table>
<thead>
<tr>
<th>Study</th>
<th>Determinants identified</th>
<th>Unit of analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hewitt et al. (2007)</td>
<td>Electronic medical records, insurers’ reporting requirements, patient advocacy, survivorship training</td>
<td>Cancer program</td>
</tr>
<tr>
<td>Merport et al. (2012)</td>
<td>Lack of training, reimbursement, and templates as barriers to preparing care plans</td>
<td>Oncologist</td>
</tr>
<tr>
<td>Forsythe et al. (2013)*</td>
<td>Training in late- and long-term effects of cancer, use of electronic medical records</td>
<td>Oncologist</td>
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</table>

*Statistical tests of variables’ influence on SCP implementation were conducted; all other studies listed were descriptive*
**What influences SCP implementation?, cont.**

<table>
<thead>
<tr>
<th>Study</th>
<th>Determinants identified</th>
<th>Unit of analysis</th>
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</thead>
<tbody>
<tr>
<td>Birken, Mayer &amp; Weiner (2013a)</td>
<td>Insufficient organizational resources and systems for SCP use</td>
<td>Cancer program</td>
</tr>
<tr>
<td>Birken, Mayer &amp; Weiner (2013b)*</td>
<td>Geographic location, program type (e.g., teaching hospitals), professional organization affiliation (e.g., American Hospital Association)</td>
<td>Cancer program</td>
</tr>
<tr>
<td>Birken et al. (2014)*</td>
<td>Geographic location, initiating SCP use in response to survivors’ requests, membership in the National Cancer Institute’s National Community Cancer Centers Program</td>
<td>Cancer program</td>
</tr>
</tbody>
</table>

*Statistical tests of variables’ influence on SCP implementation were conducted; all other studies listed were descriptive*
What influences SCP implementation?, cont.

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<th>Unit of analysis</th>
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</thead>
<tbody>
<tr>
<td>Birken et al. (2014)</td>
<td>beliefs about the consequences of SCP use, motivation and goals regarding SCP use, environmental context and resources, social influences</td>
<td>Oncologist</td>
</tr>
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</table>
### What influences SCP implementation?, cont.

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<th>Determinants identified</th>
<th>Unit of analysis</th>
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<tbody>
<tr>
<td>Birken et al. (2015)</td>
<td>Quality of guidelines for SCP use</td>
<td>Oncologist</td>
</tr>
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**Guidelines for the use of survivorship care plans: a systematic quality appraisal using the AGREE II instrument**

Sarah A Birken¹*, Shellie D Ellis², Jennifer S Walker³, Lisa D DiMartino¹, Devon K Check¹, Adrian A Gerstel⁴ and Deborah K Mayer⁴
Stakeholders’ Perspectives on SCP Implementation and Outcomes (CRN)

• Setting
  • UNC (Sarah Birken, PI)
  • Kaiser Permanente Southern California (Erin Hahn, site PI)
  • Beatrice Hunter Cancer Institute (Robin Urquhart, site PI)

• Interviews (n=26 to date)
  • Cancer program administrators
  • Cancer care providers (MDs, NPs, RNs)
  • Primary care providers
  • Survivors
  • Caregivers

• Topics:
  • Implementation processes/strategies
  • SCP outcomes (realized vs. ideal)
SCP Implementation

• Wide variation in SCP content and delivery
• Workflow for SCP implementation
  • Not systematic
  • Driven by accreditation requirements, not patient-centered care
• Implementation “strategies”:
  • “Catch as catch can”
  • Reliance on one or two dedicated staff; ambiguous responsibility for developing and delivering SCPs at clinic level → inconsistent SCP implementation
SCP outcomes

• **Ideal outcomes:**
  - **Cancer care providers:** Communicate to follow-up care providers and survivors symptoms to watch for, procedures they should perform and when
  - **PCP:** tx summary = “backward glance” and “forward glance” = road map for what/when procedures are needed in surveillance/survivorship
  - **Survivors:** Assuage fear of recurrence; minimize anxiety

• **Actual outcomes:**
  - Cancer care providers lack the impetus and resources to use SCPs
  - Survivors and PCPs like SCPs but receive SCPs at suboptimal time; information gets lost in the shuffle.
Strategies for Successful SCP Implementation (NC TraCS)

• Birken (UNC)/Jacobs (RTI), co-PIs

• Interviews with Quality Oncology Practice Initiative cancer program employees:

<table>
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<tr>
<th>TS delivery</th>
<th>TS development</th>
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</thead>
<tbody>
<tr>
<td>High</td>
<td>High n=5</td>
</tr>
<tr>
<td>Low</td>
<td>Low n=5</td>
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</table>

• Qualitative Comparative Analysis (within-case analysis and logic-based cross-case analysis)
Strategies for Successful SCP Implementation (NC TraCS)

- Two basic models
  - Devoted champion
  - Person to whom task has been delegated, willing or not
- Strategies:
  - Automatic processes
  - Reflective processes
Stakeholder-centered System Design for SCP Implementation (K01)

• Industrial engineering

• Human factors engineering

• Human-centered design → SCSD: multilevel approach to designing systems that meet user needs instead of asking users to accommodate system designs
Aim 1: Design SCP implementation systems that accommodate the needs of survivors and cancer care providers.

1. **Engage stakeholders:**
   - Stakeholder assessment
   - Promotional materials
   - Participation agreements

2. **Describe existing SCP implementation system:**
   - Data collection
   - Plus/delta evaluation
   - NASA task load index
   - Smart database
   - Process summary

3. **Redesign SCP implementation system:**
   - SCP implementation drawing board
   - Roles assignment

4. **Implement redesigned system:**
   - Implementation checklist
   - Protocols

5. **Evaluate redesigned system**
   - [Describing existing SCP implementation system tools]
Aim 1: Design SCP implementation systems that accommodate the needs of survivors and cancer care providers.
Aim 2: Develop StaRS (Stakeholder Responsive Survivorship), a toolkit for designing systems that facilitate SCP implementation.

OR TO ICU HANDOVER IMPROVEMENT DIY TOOLKIT

National Center for Patient Safety

User’s Manual
Aim 3: Pilot test the implementation and effectiveness of StaRS.

• Assess the feasibility, acceptability, and cost of implementing StaRS
• Evaluate the effectiveness of StaRS in improving SCP development and delivery
Stakeholder-tailored content

- Can cancer care providers develop SCPs tailored to the divergent needs of each stakeholder group?
- An R21 to be written during K01 funding period
Hybrid study of SCP implementation and effectiveness

• Aim 1: Assess SCP implementation.
• Aim 2: Assess the influence SCPs on stakeholder-identified outcomes.
• Aim 3: Assess the influence of SCP implementation on SCP effectiveness.
Finding the forest (Parry 2013)

• SCP vs. survivorship care

• SCPs can’t be expected to do the work of what should be a comprehensive survivorship care program
  SCPs as a convenient (if not ideal) opportunity to begin to understand survivorship care and its goals

• Survivorship care as an opportunity to begin to understand coordination of care more broadly
Acknowledgements

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• Deborah Mayer, PhD
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• Cancer Research Network (CRN15014)
• North Carolina Translational & Clinical Sciences Institute