The long-term impact of cancer survivorship care plans (SCPs) on patient-reported outcomes and health care use

Lonneke van de Poll-Franse,
Professor of Cancer Epidemiology and Survivorship
Lost in Transition (2005!)

- the American Institute of Medicine’s report “From Cancer Patient to Cancer Survivor: Lost in Transition”*
- SCPs for all cancer survivors
- personalized document
  - a treatment summary
  - information on possible long-term and late effects

- Tailored information that corresponds to patients’ need is a key factor in the support for cancer survivors during follow-up!
- ‘Common sense’ approach: no scientific evidence for SCP care

*Hewitt, Greenfield & Stovall, 2005
How satisfied are you with information?

More often satisfied:
- ‘young’
- higher educated
- recently diagnosed patient
- who use the internet

Endometrial cancer survivors N=742 (77% response)*

*Nicolaije, Patient Educ Couns (2012)
Information provision

Nicolaije, Patient Educ Couns 2012

15% of endometrial cancer survivors wanted more information:

• Side effects
• Sexual Life
• Psychological support

Husson et al, Ann Oncol 2010

Information provision has a positive impact on:

• Satisfaction with care
• Disease perception (sense of control)
• Quality of life
• Anxiety and depression
van de Poll-Franse et al. Trials, 2011
• Contact information HCP’s
• Detailed diagnostic information
• Treatment summary
• Short-term effects
• Long-term effects
• Follow-up schedule
• Where to go for additional help
• Distress thermometer
Research question ROGY Care

What is the short- and long-term impact of Survivorship Care Plans on patient-reported outcomes for endometrial and ovarian cancer survivors in daily clinical practice?
Hypotheses

Compared to patients who receive usual care, patients who receive SCP Care are expected to report:

1) higher satisfaction with information provision
2) higher satisfaction with care
3) more threatening illness perceptions
4) higher health care use
Pragmatic Cluster RCT

6 Hospitals: ‘Usual Care’
- Endometrial cancer
- Ovarian cancer

6 Hospitals: ‘SCP Care’
- Endometrial cancer
- Ovarian cancer

van de Poll-Franse et al. Trials, 2011
Patient Reported Outcomes

- Satisfaction with information provision: EORTC-INFO25
- Satisfaction with care: EORTC-INPATSAT32
- Illness perceptions: B-IPQ
- Health care utilization in past 6 months:
  - Number of visits to Primary Care Provider
  - Number of visits to Medical Specialist
Response

466 patients were sent first questionnaire
N= 221 endometrial
N=245 ovarian

**SCP Care:**

- **Diagnosis**
  - 73% response
  - N= 119 endometrial
  - N= 61 ovarian

- **6 months**
  - 53% response
  - N= 85 endometrial
  - N= 44 ovarian

- **12 months**
  - 47% response
  - N= 79 endometrial
  - N= 35 ovarian

**Usual care:**

- 72% response
  - N=102 endometrial
  - N=114 ovarian

- 51% response
  - N= 73 endometrial
  - N= 80 ovarian

- 45% response
  - N= 68 endometrial
  - N= 66 ovarian

Nicolaije, JCO 2015
### Patient characteristics

<table>
<thead>
<tr>
<th></th>
<th>Endometrial</th>
<th>Ovarian</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>SCP care (N=119)</td>
<td>Usual care (N=102)</td>
<td>SCP care (N=61)</td>
</tr>
<tr>
<td>Age</td>
<td>67</td>
<td>68</td>
<td>64</td>
</tr>
<tr>
<td>SES (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>high</td>
<td>19</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>medium</td>
<td>42</td>
<td>40</td>
<td>36</td>
</tr>
<tr>
<td>low</td>
<td>39</td>
<td>34</td>
<td>34</td>
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<tr>
<td>Partner (%)</td>
<td>73</td>
<td>75</td>
<td>79</td>
</tr>
<tr>
<td>Employed (%)</td>
<td>21</td>
<td>16</td>
<td>33</td>
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<tr>
<td>Months after diagnosis</td>
<td>2.2</td>
<td>1.5</td>
<td><strong>p &lt;0.01</strong></td>
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<tr>
<td>FIGO stage (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>86</td>
<td>87</td>
<td>34</td>
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<tr>
<td>II</td>
<td>4</td>
<td>2</td>
<td>11</td>
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<td>III</td>
<td>7</td>
<td>7</td>
<td>38</td>
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<tr>
<td>IV</td>
<td>3</td>
<td>4</td>
<td>16</td>
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<tr>
<td>Chemotherapy (%)</td>
<td>5</td>
<td>12</td>
<td>72</td>
</tr>
<tr>
<td>Radiotherapy (%)</td>
<td>37</td>
<td>37</td>
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<tr>
<td>Comorbidities &gt;1 (%)</td>
<td>56</td>
<td>62</td>
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‘Did you receive an SCP?’

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Nicolaije, JCO 2015
‘Did you receive an SCP?’

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Intention to treat analyses and per protocol

Nicolaije, JCO 2015
Information provision – endometrial cancer

No effect on satisfaction with information provision

Nicolaije, JCO 2015
Information provision – ovarian cancer

No effect on satisfaction with information provision
Satisfaction with care

Graph showing satisfaction levels for different aspects of care:
- Doctor interpersonal skills
- Nurse interpersonal skills
- Exchange information caregivers
- General satisfaction with care

Legend:
- Endometrial - SCP
- Endometrial - Usual care
- Ovarian - SCP
- Ovarian - Usual care

Note: No effect on satisfaction with care
‘How much do you experience symptoms from your illness?’

Increased experienced symptoms in endometrial cancer survivors

*p<0.05

Nicolaije, JCO 2015
‘How concerned are you about your illness?’

Increased concerns in ovarian cancer survivors after diagnosis

Increased concerns in endometrial cancer survivors at all time points

Nicolaije, JCO 2015
Contact Primary Care Physician

More cancer-related contact with PCP in endometrial cancer survivors

*p<0.05

Nicolaije, JCO 2015
Contact medical specialist

Fewer visits to medical specialist in ovarian cancer survivors

Nicolaije, JCO 2015
Discussion - implementation

• ‘Only’ 74% (endometrial) and 66% (ovarian) reported to have received SCP

Secondary analyses

• Of all patients in SCP arm (n=180), SCPs were generated by the care provider for 90% of patients
• Factors related to no receipt
  - older age  
  - ovarian cancer  
  - Distressed (Type D) personality (negative affect + social inhibition)
• Are they in more or less need?

*de Rooij, J Cancer Surviv, 2016
Discussion – subgroup differences

- SCPs did not improve satisfaction with information provision
- SCPs did not improve satisfaction with care
- Subgroup effects? - secondary analyses ROGY Care trial

*Dicolaije, J Med Internet Res, 2016*
Discussion – disease perception

• SCPs affected illness perceptions:
  - increased concern (endometrial & ovarian)
  - increased symptoms experienced (endometrial)

• Harmful or perhaps even beneficial?
  -> *realistic* perceptions may empower patients to find necessary support
  -> long-term impact of SCPs on health-related quality of life, anxiety & depression
Discussion – health care use

• More cancer-related contact with primary care physician (endometrial)
• Less contact with medical specialist (ovarian)
• Self-reported health care utilization
• Patients in SCP care arm completed questionnaire later than patients in usual care arm
Discussion – literature review*

• SCP Content and delivery (14 studies); focus groups, surveys
  - Health promotion, psychosocial support (flexible and tailored)

• SCP dissemination and implementation (14 studies); surveys, interviews, focus groups:
  - Use is limited (<25% cancer program providers)

• SCP outcomes (14 studies);
  - 3 RCTs: No benefit on distress, QoL, satisfaction, concerns
  - 11 observational studies: positive outcomes on satisfaction with care, improved communication, knowledge, confidence, etc..

*Mayer, Cancer, 2015
What are the “active ingredients” of effective transitions from treatment to follow-up care?

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**Recommendations by Mayer et al.**

**TABLE 5. Recommended Areas for Future Survivorship Care Plan Research and Methodological Concerns to be Addressed**

<table>
<thead>
<tr>
<th>Content</th>
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<tbody>
<tr>
<td>1. When do survivors and providers prefer for SCP to be delivered?</td>
<td></td>
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<tr>
<td>2. How frequently do survivors and providers prefer for SCP to be delivered?</td>
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<tr>
<td>3. Which type of provider most effectively develops SCP?</td>
<td></td>
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<tr>
<td>4. Which type of provider most effectively delivers SCP?</td>
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**Dissemination and implementation**

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<table>
<thead>
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<tbody>
<tr>
<td>1. What determines whether survivors and primary care providers receive and retain SCP?</td>
<td></td>
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<tr>
<td>2. Does a limited-content SCP template minimize resources required for SCP use?</td>
<td></td>
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<td>3. Does a limited-content SCP template increase SCP use?</td>
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**Outcomes**

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**Methodological concerns to be addressed**

1. Biases associated with observational studies may be addressed by using RCT
2. Inability to infer causality may be addressed with longitudinal studies
3. Limited generalizability may be addressed with more diverse samples of cancer programs, providers, and survivors that reflect the diversity observed in practice
4. Concerns about validity and reliability may be addressed through systematic testing of data collection tools

**Abbreviations:** RCT, randomized controlled trial; SCP, survivorship care plan.

*Mayer, Cancer, 2015*
POSTCARE randomized study: Methods

• **Patient-owned Survivorship Transition Care** for Activated, Empowered survivors
• 79 survivors stage 0-IIIB breast cancer
• Intervention is framed on Chronic care model of Wagner: moving from passive recipients to engagement in self-management

• **Care transition coach**
  - Single coaching encounter using Motivational Interviewing
  - Engage patients in developing patient-owned SCP
  - Health goals and strategies (session of 75 minutes)

*Kvale, Cancer 2016*
POSTCARE randomized study: Results

• Intervention group reported significantly better
  - Self-reported health
  - Physical function
  - Emotional function
• Priority on the process rather than on document
• Results underscore importance of SCP delivery as a behavioral intervention

*Kvale, Cancer 2016*
10 years after IOM report*

- Not enough evidence to warrant large scale implementation or abandon SCP altogether

- Change focus from SCP as information delivery intervention to behavioral intervention?

- Beneficial, cost-effective on the long-term, subgroups?
- SCPs are not a purpose in itself, but merely a tool to improve quality of care

*Hewitt, Greenfield & Stovall, 2005