Cancer Survivors’ Experience of Patient-Centered Communication 2007-2012: Lost in Transition or Just Lost?

Danielle Blanch-Hartigan, PhD, MPH, Neetu Chawla, PhD, MPH, Richard P. Moser, PhD, Lila J. Finney Rutten, PhD, Bradford W. Hesse, PhD, Neeraj K. Arora, PhD
Cancer Survivors

• Large and growing population

[Bar chart showing the number of cancer survivors by year and duration since diagnosis, with legend for different time intervals: 15+ years, 10–<15 years, 5–<10 years, 1–<5 years, <1 year.]

de Moor et al., 2013
Traditional Cancer Control Continuum

Prevention  Detection  Diagnosis  Treatment  Survivorship
Cancer Control Continuum Revisited

End of life

Survivorship

Prevention

Detection

Treatment

Diagnosis

Adapted from Rowland & Bellizzi, 2008
“Lost in Transition”
Patient-Centered Care

- IOM Definition

“Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.”

Patient-Centered Care

6 Functions of Patient-Centered Communication

- Responding to Emotions
- Exchanging Information
- Managing Uncertainty
- Making Decisions
- Enabling Patient Self-Management
- Fostering Healing Relationships

Health Outcomes

Patient-Centered Communication Questions in HINTS

How often did the doctors, nurses, or other health care professionals you saw during the past 12 months do each of the following:

1. Give you the chance to ask all the health-related questions you had?
2. Give the attention you needed to your feelings and emotions?
3. Involve you in decisions about your health care as much as you wanted?
4. Make sure you understood the things you needed to do to take care of your health?
5. Help you deal with feelings of uncertainty about your health or healthcare?
6. In the past 12 months, how often did you feel you could rely on your doctors, nurses, or other health care professionals to take your of your health care needs?
Questions

1. How patient-centered is the care experience of cancer survivors?

2. Does patient-centered care vary by time since cancer diagnosis?

3. Has PCC experience changed over time?
Questions

1. How patient-centered is the care experience of cancer survivors?

2. Does patient-centered care vary by time since cancer diagnosis?

3. Has PCC experience changed over time?
Questions

1. How patient-centered is the care experience of cancer survivors?

2. Does patient-centered care vary by time since cancer diagnosis?

3. Has PCC experience changed over time?
Questions

1. How patient-centered is the care experience of cancer survivors?

2. Does patient-centered care vary by time since cancer diagnosis?

3. Has PCC experience changed over time?
Cancer Survivors in HINTS

- Merged weighted data from three administrations of HINTS
  - HINTS 3, HINTS 4 Cycle 1, HINTS 4 Cycle 2
- Limited to cancer survivors
  - Responded YES to having ever been diagnosed with cancer
- Limited to those who had seen a healthcare provider in the previous year
Cancer Survivors in HINTS

HINTS 3 (2007)
- N = 434

HINTS 4 Cycle 1 (2011)
- N = 514

HINTS 4 Cycle 2 (2012)
- N = 419

Total N = 1,367
Notes on Merged Dataset

• Choice of iterations based on question availability
  – hints.cancer.gov for information on additional items available for trend analyses

• Included only respondents from mail survey mode for HINTS 3
  – SAMPFLAG = 1
  – Address based sample (ABS) weights
  – David Cantor, Westat presentation from yesterday

• HINTS 4 cycle 1 and HINTS 4 cycle 2 were treated as separate iterations

• Stacked dataset with 150 combined replicate weights
  – Jackknife replication method
<table>
<thead>
<tr>
<th>Survivor Characteristic</th>
<th>Survey Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HINTS3 (2007-08)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43.35%</td>
</tr>
<tr>
<td>Female</td>
<td>56.65%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>18 - 34</td>
<td>2.54%</td>
</tr>
<tr>
<td>35 - 49</td>
<td>14.89%</td>
</tr>
<tr>
<td>50 - 64</td>
<td>34.10%</td>
</tr>
<tr>
<td>65 - 74</td>
<td>22.36%</td>
</tr>
<tr>
<td>75+</td>
<td>26.12%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>15.97%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>26.70%</td>
</tr>
<tr>
<td>Some College</td>
<td>28.77%</td>
</tr>
<tr>
<td>College Graduate</td>
<td>28.55%</td>
</tr>
<tr>
<td>Annual Income</td>
<td></td>
</tr>
<tr>
<td>&lt; $20K</td>
<td>21.11%</td>
</tr>
<tr>
<td>$20K to &lt;$35K</td>
<td>18.61%</td>
</tr>
<tr>
<td>$35K to &lt;$50K</td>
<td>17.31%</td>
</tr>
<tr>
<td>$50K to &lt;$75K</td>
<td>16.61%</td>
</tr>
<tr>
<td>$75K or more</td>
<td>26.36%</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>4.96%</td>
</tr>
<tr>
<td>NH White</td>
<td>84.37%</td>
</tr>
<tr>
<td>NH Black</td>
<td>8.18%</td>
</tr>
<tr>
<td>NH Asian</td>
<td>0.52%</td>
</tr>
<tr>
<td>NH Other</td>
<td>1.98%</td>
</tr>
</tbody>
</table>
# Cancer Survivors in HINTS

<table>
<thead>
<tr>
<th>Survivor Characteristic</th>
<th>Survey Year</th>
<th>Survey Year</th>
<th>Survey Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HINTS3 (2007-08)</td>
<td>HINTS4-Cycle 1 (2011-12)</td>
<td>HINTS4-Cycle 2 (2012-13)</td>
</tr>
<tr>
<td>Have health insurance?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>93.55%</td>
<td>92.74%</td>
<td>92.39%</td>
</tr>
<tr>
<td>No</td>
<td>6.45%</td>
<td>7.26%</td>
<td>7.61%</td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= 1 year</td>
<td>10.90%</td>
<td>9.88%</td>
<td>10.00%</td>
</tr>
<tr>
<td>2 to 5 years</td>
<td>26.61%</td>
<td>23.42%</td>
<td>28.42%</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>17.95%</td>
<td>20.24%</td>
<td>20.31%</td>
</tr>
<tr>
<td>11+ years</td>
<td>44.54%</td>
<td>46.46%</td>
<td>41.27%</td>
</tr>
<tr>
<td>Cancer Site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer only</td>
<td>19.52%</td>
<td>15.85%</td>
<td>18.93%</td>
</tr>
<tr>
<td>Colorectal cancer only</td>
<td>7.75%</td>
<td>7.66%</td>
<td>3.94%</td>
</tr>
<tr>
<td>Prostate cancer only</td>
<td>12.72%</td>
<td>14.46%</td>
<td>16.23%</td>
</tr>
<tr>
<td>Melanoma only</td>
<td>11.62%</td>
<td>7.56%</td>
<td>6.63%</td>
</tr>
<tr>
<td>Other Female cancers only</td>
<td>19.62%</td>
<td>19.38%</td>
<td>17.94%</td>
</tr>
<tr>
<td>Other Cancers</td>
<td>7.48%</td>
<td>8.35%</td>
<td>8.84%</td>
</tr>
<tr>
<td>Multiple Cancers</td>
<td>21.28%</td>
<td>26.75%</td>
<td>27.49%</td>
</tr>
</tbody>
</table>
Questions

1. How patient-centered is the care experience of cancer survivors?
2. Does patient-centered care vary by time since cancer diagnosis?
3. Has PCC experience changed over time?
1. How patient-centered is the care experience of cancer survivors?
2. Does PCC vary by time since cancer diagnosis?

[Graph showing PCC score (Weighted Mean) over different times since diagnosis: 
- < 1 yr: PCC Score
- 2-5 yrs: PCC Score
- 6-10 yrs: PCC Score
- 11+ yrs: PCC Score]
3. Has PCC experience changed over time?
With over 14 million cancer survivors in the US, results suggest an appreciable number of survivors are experiencing suboptimal patient-centered communication

- Managing uncertainty (2.9 million)
- Attending to emotions (2.3 million)
Discussion

- American College of Surgeons’ Commission on Cancer Mandate (2015)
  - All patients completing active treatment should be provided with a treatment summary to support the delivery of patient-centered care and facilitate transition to post-treatment survivorship care.
Future Directions

• How is patient-centered survivorship care associated with survivor experience and health outcomes?
  – Is receipt of treatment summaries associated with more patient-centered communication and higher quality of care ratings?

• How will the patient-centered survivorship care experience change with new models of care and new mandates for survivorship care planning?

• How does the patient-centered care experience of cancer survivors compare to those without a history of cancer?
Acknowledgments

- Neeraj K. Arora, PhD
- Neetu Chawla, PhD, MPH
- Bradford W. Hesse, PhD
- Richard P. Moser, PhD
- Lila J. Finney Rutten, PhD

- Cancer Prevention Fellowship Program
- Office of Cancer Survivorship
Questions?