Cancer Survivors – Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer Information?

Neeraj K. Arora, Ph.D.
National Cancer Institute, Bethesda, MD

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Acknowledgments

Collaborators:
Ellen Beckjord, Ph.D., M.P.H.
Bradford W. Hesse, Ph.D.
National Cancer Institute

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Overall Objective

• Based on data from population-based studies identify strategies for supporting the information management efforts of cancer survivors and family members
Part I: Information Needs of Cancer Survivors
Information Needs of Cancer Survivors

Review


Only 9/92 (10%) studies assessed the current needs of post-treatment cancer survivors

Abstract

Understanding what cancer patients need to know and from whom they receive information during the course of care is essential to ensuring quality care. We reviewed 112 articles published from 1980 to 2003 and developed a typology summarizing cancer patients' information needs and the sources from which they receive information. The majority of articles focused on information needs and sources
Information Needs of Survivors 2 - 5 Years Post Dx: SEER Data (N = 1,033)

(Beckjord, Arora, Hesse, McLaughlin, Oakley-Girvan, Hamilton – manuscript in preparation)
Information Seeking

- A sub sample (N = 702) of survivors were asked if they had searched for cancer-related information in the past 12 months.

- Only **28%** (195/702) had actively engaged in information seeking in the past 12 months.
Information Needs by Information Seeking Status (N = 702)

Differences for all categories except sex & fertility are statistically significant.
Part II: Information Management Approaches of Cancer Survivors

Dealing with a “Tsunami” of Information?
Focus: Role of Health Care Providers and the Internet
Data Source

• Nationally representative data from the 2005 Health Information National Trends Survey (HINTS): N = 5,586
  – 873 cancer survivors
  – 3397 family history of cancer
  – 1291 no cancer history

• Survivors grouped by years since dx
  – <= 1 year, 1+ to 5, 5+ to 10, 10+ years
% Ever Personally Searched for Cancer Information

- % Information Seeker: 63.1
- % Non Seeker: 36.9

~ 6.6 million

~ 3.9 million

~ 1/3 of non seekers had < high school education; 2/3 were 65+ years old
"Preferred" Source of Information by Information Seeking Status

P < 0.01

Wtd % "Preferred" Source

<table>
<thead>
<tr>
<th>Source</th>
<th>Information Seeker</th>
<th>Non Seeker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Care Provider</td>
<td>61.6</td>
<td>80.5</td>
</tr>
<tr>
<td>Internet</td>
<td>26.5</td>
<td>8.7</td>
</tr>
<tr>
<td>Other</td>
<td>12.0</td>
<td>10.8</td>
</tr>
</tbody>
</table>
Information Seekers
Information Seeking in the Past Year by Time Since Diagnosis

Overall, 61.9% of seekers searched in the past year (39.1% of all survivors)

P < 0.01
Trust in HCP and the Internet

- 70.9% of seekers had "a lot" of trust in HCPs as a source of information
- 23.6% had "a lot" of trust in the Internet as a source of information
- Trust in HCPs and the Internet did not vary by time since diagnosis
“First” Source of Cancer Information

Non Seeker: 36.9%

HCP: 26.4%
(41.9% of Seekers)

Internet: 22.7%
(36% of Seekers)

Other: 13.9%
(22.1% of Seekers)
Use of HCP and the Internet by Time Since Diagnosis

P < 0.01

<table>
<thead>
<tr>
<th>Time Since Diagnosis</th>
<th>Wtd % &quot;First&quot; Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;= 1 Year</td>
<td>52.5</td>
</tr>
<tr>
<td>1+ to 5 Years</td>
<td>31.3</td>
</tr>
<tr>
<td>5+ to 10 Years</td>
<td>31.9</td>
</tr>
<tr>
<td>10+ Years</td>
<td>47.6</td>
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</table>

Health Care Provider

Internet
Information Seeking Experience

- Based on the last time they searched, respondents rated four items on a strongly agree/strongly disagree scale
  - It took a lot of effort to get the information
  - You felt frustrated during your search
  - The information was too hard to understand
  - You were concerned about the quality of the information
Information Seeking Experience

~ 6.6 million survivors are seekers

~ 2 million

~ 1.5 million

~ 1.6 million

~ 2.9 million
Part III:
Information Management Approaches of Individuals with a Family History of Cancer
Information Seeking

• **39.7%** searched within the past 12 months (v/s **39.1%** of survivors)

• Levels of trust in HCPs and the Internet were similar for family members and survivors

• Family members had fewer # doctor visits compared to survivors
"First" Source of Information by Survivorship Status

- Health Care Provider
- Internet
- Other

P < 0.01

Cancer Survivor:
- Health Care Provider: 41.9%
- Internet: 36.0%
- Other: 22.1%

Family Cancer History:
- Health Care Provider: 21.6%
- Internet: 50.1%
- Other: 28.3%
Information Seeking Experiences by Survivorship Status

- Internet Info: Very Helpful
  - Cancer Survivor: 53.4%
  - Family Cancer History: 44.1%
  - P = 0.05

- Took A Lot of Effort
  - Cancer Survivor: 30.5%
  - Family Cancer History: 38.7%
  - P < 0.05
Summary

• Post-treatment cancer survivors have significant information needs.

• Cancer survivors rely on both HCPs & the Internet for cancer information.

• A quarter to almost half of cancer survivors seeking information report sub-optimal experiences.
Summary

• Survivors who do not actively seek information and individuals with a family cancer history are likely to need increased information support and warrant special attention.
Embracing the Future …

Health Care Providers & the Internet: Complementary or Alternative?? Sources of Support
Internet-based support technologies need to be integrated within the health care system resulting in a seamless environment of *unfailing, DEEP* support that cancer survivors may access 24/7.
Embracing the Future …
Embracing the Future …