Cancer Survivorship and the Patient-Centered Medical Home

A Few Patient Perspectives

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Cancer Survivorship Care after Active Treatment

- 14 million cancer survivors in the United States.\textsuperscript{1}
- 70\% have cancer related and non-related comorbid conditions that require comprehensive medical care follow-up.\textsuperscript{2}
- Survivors’ rates of preventive and surveillance screening are lower than optimal given their increased cancer risk.\textsuperscript{3}
- Survivors have narrow definitions of follow-up focused primarily on cancer surveillance.\textsuperscript{4}
- Survivors range in patient activation and cancer follow-up understanding from low to high which impacts care seeking.\textsuperscript{5}
- Our research focuses on patient and practice level factors that impact patient activation/self-management to promote cancer surveillance and disease prevention.

1. DeSantis et al. CA: a cancer journal for clinicians In press
Patient-Centered Medical Home

- NCQA established a core set of 6 PCMHH standards and elements, based on the founding PCMH principles
- Cancer Survivor Relevant
  - (#2) identifying and managing patient populations
  - (#3) care management
  - (#4) self-care and community support
  - (#5) tracking and coordinating care
- Activated patients are required

Sia et al, *Pediatrics.*, 2004
Nutting et al, *Health Aff.*, 2011
American Cancer Society

- Patient focused initiatives
- Provider focused initiatives
- Survivorship guidelines for primary care providers

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American Cancer Society Prostate Cancer Surviviorship Care Guidelines

Introduction

Prostate cancer survivors approach 2.8 million in number and represent 1 in 5 of all cancer survivors and over 4 in 10 male cancer survivors in the United States.1 Given that long-term survival is common after prostate cancer treatment, distinctly characterizing cancer survivorship (the phase of care after active treatment) and addressing survivor’s unique needs are critical to quality cancer care.2 Nearly a decade ago, a landmark report from the Institute of Medicine entitled From Cancer Patient to Cancer Survivor: Lost in Transition highlighted the unique issues facing all cancer survivors as well as the growing need for guidance with respect to quality survivorship care.3 With nearly 14 million cancer survivors,4 this report is relevant to these survivors, their caregivers and advocates, primary and specialty care clinicians, insurers, employers, funding agencies, and policy makers. In recognition of the increasing need for information resources to support primary care clinicians who care for prostate cancer survivors, these guidelines were developed in response to the National Cancer Survivorship Resource...
Care of survivors in community primary care settings

- More likely to report cancer screening than non-cancer patients.
- Medical record reports of cancer screening were lower than self-reports for cancer survivors and non-cancer patients.

Life After Cancer Study

Objective: To explore survivors’ understandings of follow-up and their perceptions of who delivers it.
Inclusion Criteria

- Ambulatory, early stage breast and prostate cancer survivors (stage I or II breast cancer; T1-T2a/Gleason 2-6/PSA<10ng/ml* or T2b-c/Gleason 7/PSA<20 prostate cancer).
- At least two years out of treatment (excluding hormonal therapy).
- No severe co-morbid conditions (e.g., congestive heart failure, myocardial infarction, angina) that require extensive coordination of specialist care.
- At least 30 years old.
- Must provide informed consent.
- Must be able to read and write English.
- Survivor was treated at either CINJ or FCCC or one of their community affiliates.
## Participant Selection

### Depth Interviews (N=42)

<table>
<thead>
<tr>
<th></th>
<th>Year from Tx</th>
<th>Cancer Center (CINJ/FCCC)</th>
<th>Community (CINJ/ FCCC affiliates)</th>
<th>Totals</th>
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<tbody>
<tr>
<td><strong>Breast (N=24)</strong></td>
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<td>2-5 yrs</td>
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<td>10+</td>
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<td><strong>Prostate (N=18)</strong></td>
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<tr>
<td><strong>Totals</strong></td>
<td>23</td>
<td>19</td>
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<td>42</td>
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Depth Interview

- 45-90 minute interview that probed:
  - Self rated health
  - Experiences with health care
  - Experiences with primary care
  - Cancer treatment experience
  - Cancer follow-up
  - Social support and decision making
  - Patient preferences and satisfaction with care
  - Preventive cancer screening experience
Participant Characteristics (N=33)

- 49% Women
- 67% White, 33% Black,
- 49% high school/some college, 46% college +
- 73% married or cohabiting
- 52% currently working
- 64.2 = average age (range=47-80 years)
- 63% long term survivor, (>5 years since active cancer treatment)
- 45% received treatment at NCI comprehensive cancer center
# Cancer Survivor Follow-up Care Typologies

<table>
<thead>
<tr>
<th>Limited or low patient activation</th>
<th>Little Understanding of Follow-Up Care</th>
<th>Detailed Understanding Follow-Up Care</th>
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</table>
| **Group 1:** Understanding        | - Have no frame of reference for understanding follow-up.  
- Have few skills and limited motivation to seek information and/or build skills to manage their follow-up.  
**Activation**  
- Limited skills and tools to function as decision making agent  
- Top-down relationship w/ care providers related to follow-up (rely heavily on health care team to tell them what to do).  
- Do not believe it is their responsibility to manage their care.  
- Expect that things will work out as they should. | **Group 4:** Understanding  
- Understand what to expect as part of follow-up.  
- Have access to skills and resources but little motivation to seek information and/or build skills to manage their follow-up.  
**Activation**  
- Limited skills and tools to function as decision making agent  
- Top-down relationship w/ care providers related to follow-up (rely heavily on health care team to tell them what to do).  
- Do not believe it is their responsibility to manage their care.  
- Expect that things will work out as they should. |
| High patient activation           | **Group 2:** Understanding  
- Have no frame of reference for understanding follow-up.  
- Have moderate/minimal knowledge and skills related to managing their follow-up  
**Activation**  
- Have goals and a plan to improve their health and manage their follow-up.  
- Top-down relationship w/ care providers related to follow-up (rely heavily on doctors to tell them what to do).  
- Understand they should seek care from experts so that their health care providers can tell them what to do.  
- Initially motivated to seek information and build skills and confidence necessary to manage their follow-up.  
- Can and/or have given up control for monitoring their follow-up to their health care team. | **Group 3:** Understanding  
- Understand what to expect as part of follow-up.  
- Have access to skills and resources and high motivation to seek information and/or build skills to manage their follow-up.  
**Activation**  
- Have goals and a plan to improve their health and manage their follow-up.  
- Bi-directional, shared decision making relationship w/ care providers related to follow-up.  
- Motivated to seek information and build skills and confidence necessary to manage their follow-up.  
- Believe it is their responsibility to participate in and play an active role in the management of their care.  
- Constantly check doctor’s opinion and advice on follow-up and other behavioral health care related issues. |

Group 1. Low-activated patients with modest follow-up understanding and limited resources (n=6)

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- All African American
- All community onc tx setting
- Most long-term survivors, >5 years from tx
- Annual household income <$80K
Group 1 Narratives

**Little Understanding**

“Um, I don’t know. It’s just that my urologist, he’s good. It’s just a constant, constant going back. The needles, and every time I ask him, one of the things that he always tells me, “Well I’m keeping you alive, ain’t I?” So I keep my mouth shut and drop my pants. But no, I have no real qualms about any of the follow-up care. I guess it’s been necessary. I don’t question it too much. As long as I’m feeling alright” (Interview #17).

**Limited Activation**

“What do I expect? Well, being that I don’t know anything about it, you know what I’m saying? As long as somebody was telling me that I’m good, I’m ok, and not-and nothing happened, then I’m still fine, I’m good” (Interview #44).

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**Group 2. Highly-activated patients with modest follow-up understandings and moderate resources (n=12)**

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<th>High patient activation</th>
<th>Little Understanding of Follow-Up Care</th>
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<tr>
<td></td>
<td><strong>Group 2:</strong></td>
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<tr>
<td></td>
<td><strong>Understanding</strong></td>
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- White & African American
- Mixed onc tx setting
- Most long-term survivors, >5 years from tx
- Mixed annual household income, >$80K
Group 2 Narratives

*Little Understanding*

“You know—I’m putting my faith in the doctor, and I know that he has—I feel he has the experience and the expertise” *(Interview #16)*

*High Activation*

“I did educate myself—[on] what the implications were and I worked hard ... There are certain things you have to be aware of. But as far as not being able to—losing control or anything like that, I got over that real quickly. So that kind of stuff—so they weren’t issues...luckily the surgery was successful and there wasn’t a lot of issues so—so I’m not gonna complain about follow-up when I don’t have issues. You know what I mean?” *(Interview #24).*
**Group 3. Highly-activated patients with detailed follow-up understandings and moderate-high resources (n=15)**

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- All White
- Most NCI comp ca tx setting
- Most new survivors, <5 years from tx
- Annual household income >$80K
Group 3 Narratives

**Detailed Understanding**

“[My doctor] knows I access the internet—she gave me a website where I can pull off the current—I forget the medical organization—their recommended survivor plan. [Our conversation about follow-up] was actually fairly general, as opposed to specific. She outlined the number of times that I would continue to see her, talked to me. The only specifics were really in the things that my primary care physician had said that I needed that she disagreed with” (Interview 14).

**High Activation**

“I do research online for myself but then I look at it and I think, ‘This isn’t correct,’ so a lot of the stuff you get on the internet is not correct. I’d rather get it directly from the doctor” (Interview 19).

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Summary & Implications

• Not all patients have either the knowledge and/or skills to advocate for themselves
  – Research, practice and policy should attend to the needs of moderately and non-activated patients as well as the needs of activated patients

• Different types of patients with different care models require PCMH structures that are flexible and can adapt to serve a wide range of patients and their needs

• The PCMH needs to be considered in the context of patients’ health care seeking behaviors as well as from a health care delivery system standpoint