I Have a Dream: Patient Experiences and Perspectives on Cancer Survivorship

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Outline

• My personal healthcare experiences
• Quality of care from the survivor’s lens
• My dream and hope for the future
Why Listen to Patients’ Experiences?

“Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact...”

- June Goodfield (page 1)
I Stand on the Shoulders of Giants
My Inner Conflict

Coexistence of a cancer survivor, researcher, and funder
“It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness,… it was the spring of hope, it was the winter of despair, we had everything before us, we had nothing before us…”

National Cancer Institute
9609 Medical Center Dr,
Rockville, MD 20850

Shady Grove Adventist Hospital
9901 Medical Center Dr,
Rockville, MD 20850
Observations on Quality of Cancer Care
When diagnosed with cancer, patients are faced with two important questions...

– What is going to happen to me? (fear invoking)
– Will I get care from a healthcare system that will help me through this crisis? (support seeking)
Patient-Centered Care

Patient needs for ongoing support:

- **Informational support:** Understand information
- **Decision-making support:** Make informed decisions
- **Emotional support:** Adjust to/cope with illness
- **Appraisal support:** Deal with uncertainty
- **Instrumental support:** Navigate the health care system and coordinate care
- **Self-management support:** Take care of health outside the healthcare interaction
IOM 2013 “Cancer Crisis” Report

“The most important goal of a high-quality cancer care delivery system is meeting the needs of patients and their families”
## Information Needs Among Cancer Survivors

<table>
<thead>
<tr>
<th>Information Need Category</th>
<th>% Survivors With Need</th>
<th>% Survivors With Need</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1,197 survivors, 4-14 years post dx, Kent et al., 2012)</td>
<td>(1,040 survivors 2-5 years post dx, Beckjord et al., 2008)</td>
</tr>
<tr>
<td>Symptoms and Side Effects</td>
<td>75.8%</td>
<td>63.3%</td>
</tr>
<tr>
<td>Tests and Treatment</td>
<td>71.5%</td>
<td>70.8%</td>
</tr>
<tr>
<td>Health Promotion</td>
<td>64.5%</td>
<td>67.8%</td>
</tr>
<tr>
<td>Interpersonal and Emotional</td>
<td>60.2%</td>
<td>54.4%</td>
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<tr>
<td>Insurance</td>
<td>39.0%</td>
<td>42.1%</td>
</tr>
<tr>
<td>Sexual Functioning/Fertility</td>
<td>34.6%</td>
<td>30.9%</td>
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</tbody>
</table>
Importance of Care Coordination
Patient-Centered Medical Home

• Some of the principles of PCMH
  ─ Every patient has a personal physician who serves as the first point of contact
  ─ Team-based, whole person orientation
  ─ Care is coordinated across all specialties
  ─ Focus on quality incorporates care planning processes and shared decision-making

• PCMH – Neighbors (co-management)

• Specialty PCMH: PCMH-CVD; OPCMH
Care Coordination: A Case Study

Just Before Cancer Dx
Care Coordination: A Case Study

Cancer Dx and Treatment

ONCOLOGIST

PATIENT

PCP
Care Coordination: A Case Study

Post-Treatment Care

ONCOLOGIST

PATIENT

GI SPECIALIST

PCP
Care Coordination: A Case Study

Post-Treatment Care

ONCOLOGIST

PATIENT

GI SPECIALIST

PCP

CARDIOLOGIST
Care Coordination: A Case Study

Post-Treatment Care

ONCOLOGIST

NEUROLOGIST

GI SPECIALIST

PCP

PATIENT

CARDIOLOGIST
At least 1 in 4 survivors 65+ years old have 5+ comorbidities; Medicare beneficiaries with 5+ chronic conditions see a median of 7 to 11 (IQR range 5-16) physicians per year (IOM 2006; Pham et al., 2007)
From a Quality Chasm to a System in Crisis

IOM 2001 – There is a quality chasm that needs to be crossed

IOM 2013 – Not only have we not crossed the quality chasm, the cancer care delivery system is now in crisis
I Have a Dream

- For the 16 million cancer survivors alive today and the many more to come and their loved ones, I have a dream....

Every patient who is diagnosed with cancer will receive not only evidence-based medical interventions, but...

also ongoing, coordinated support from a care system that facilitates their engagement in their health and healthcare and optimizes their medical and psychosocial health outcomes during treatment and beyond
My Dream

IOM 2001 → IOM 2006 → IOM 2013 → CANCER CARE: A Model Of Patient-Centered Care Delivery in the U.S. → NAM 2030
Key to Making the Dream a Reality

Leave this workshop feeling a little more Frustrated and a little more Self-centered
On the road to delivering high quality care, always walk in the shoes of the patient

--- Neeraj Arora