

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

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Outline

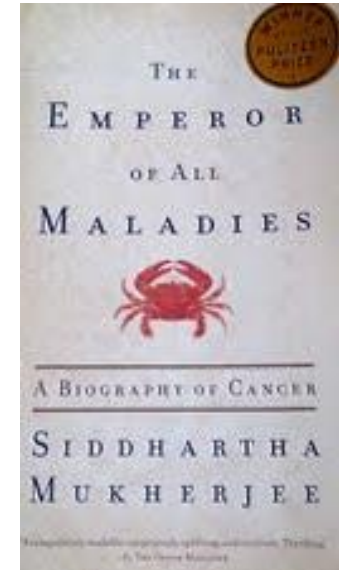
- **My personal healthcare experiences**
- **Quality of care from the survivor's lens**
- **My dream and hope for the future**



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**



A Tale of Two Cities

“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



Diagnosis Cancer!!!

- 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

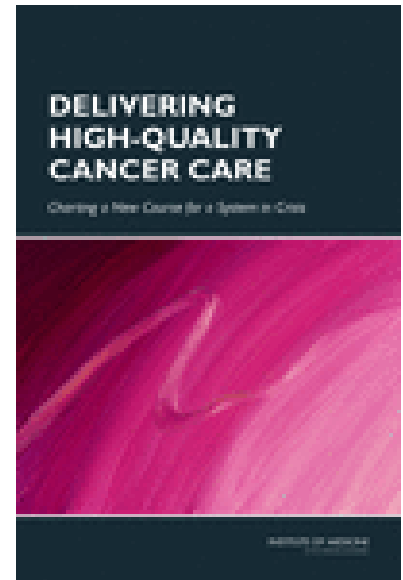
Patient needs for ongoing support:

- **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

Information Need Category	% Survivors With Need (1,197 survivors, 4-14 years post dx, Kent et al., 2012)	% Survivors With Need (1,040 survivors 2-5 years post dx, Beckjord et al., 2008)
Symptoms and Side Effects	75.8%	63.3%
Tests and Treatment	71.5%	70.8%
Health Promotion	64.5%	67.8%
Interpersonal and Emotional	60.2%	54.4%
Insurance	39.0%	42.1%
Sexual Functioning/Fertility	34.6%	30.9%



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

PATIENT

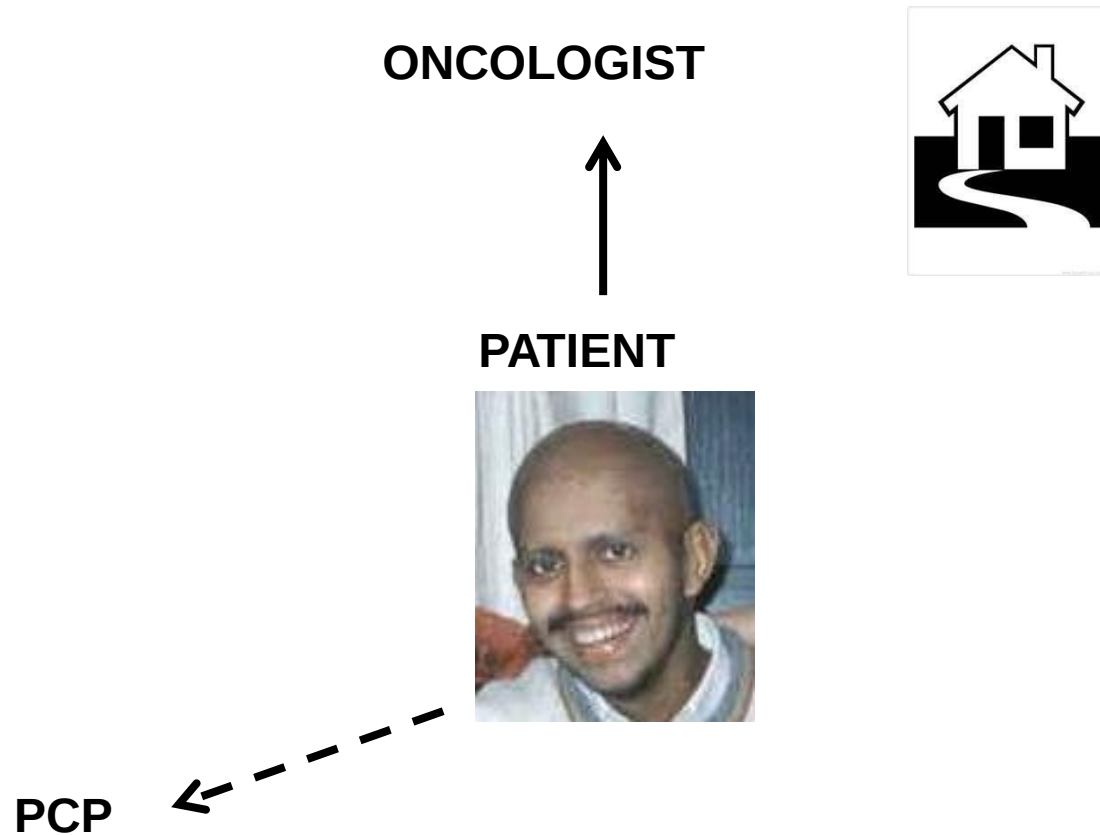


PCP



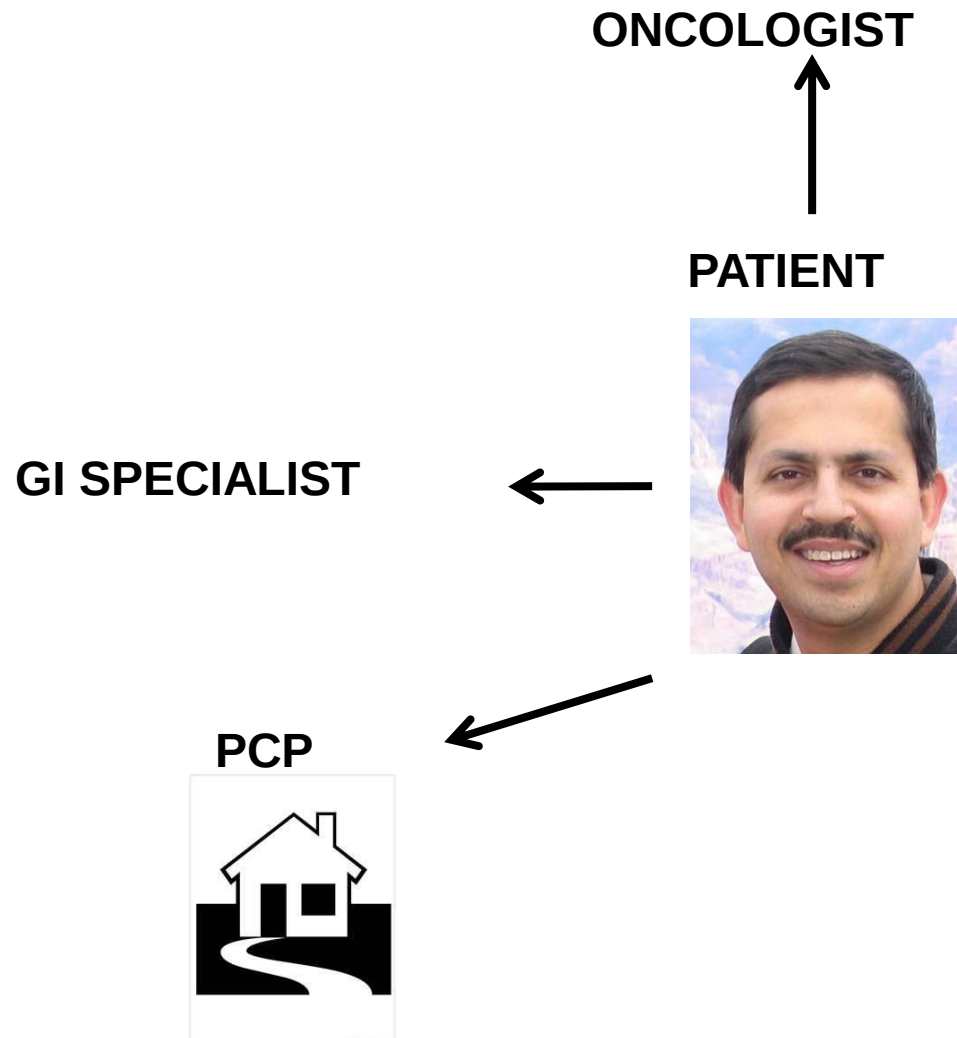
Care Coordination: A Case Study

Cancer Dx and Treatment



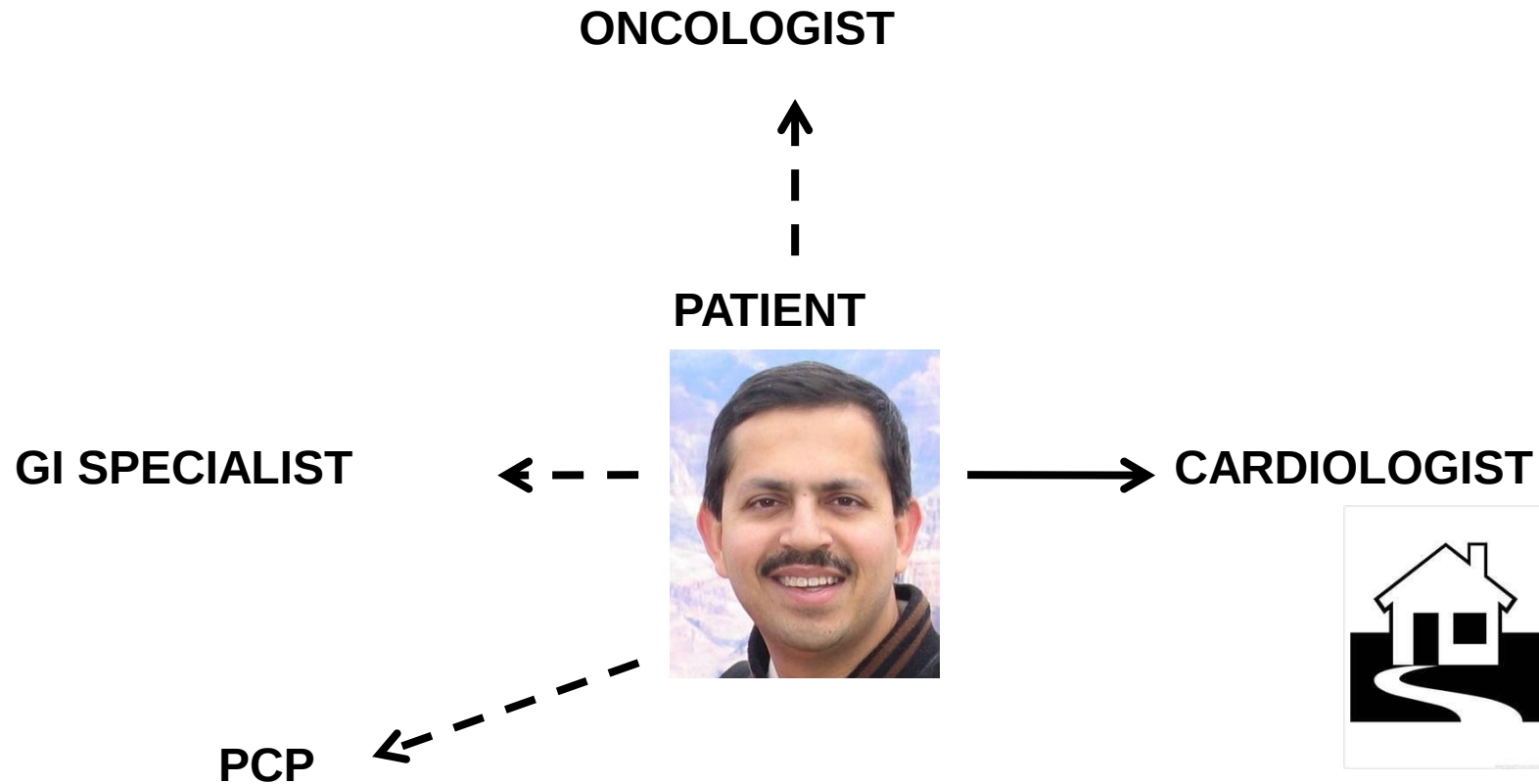
Care Coordination: A Case Study

Post-Treatment Care



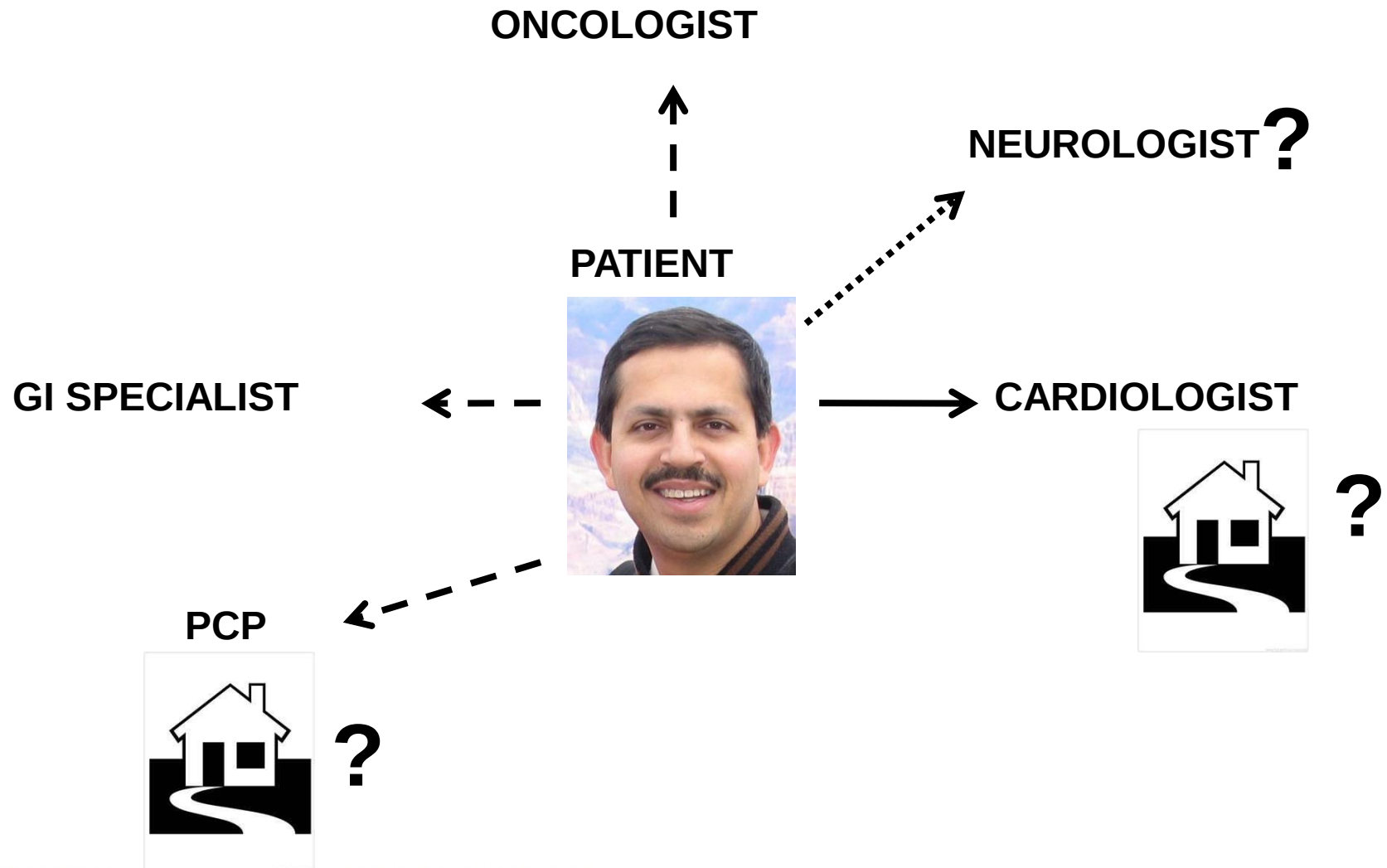
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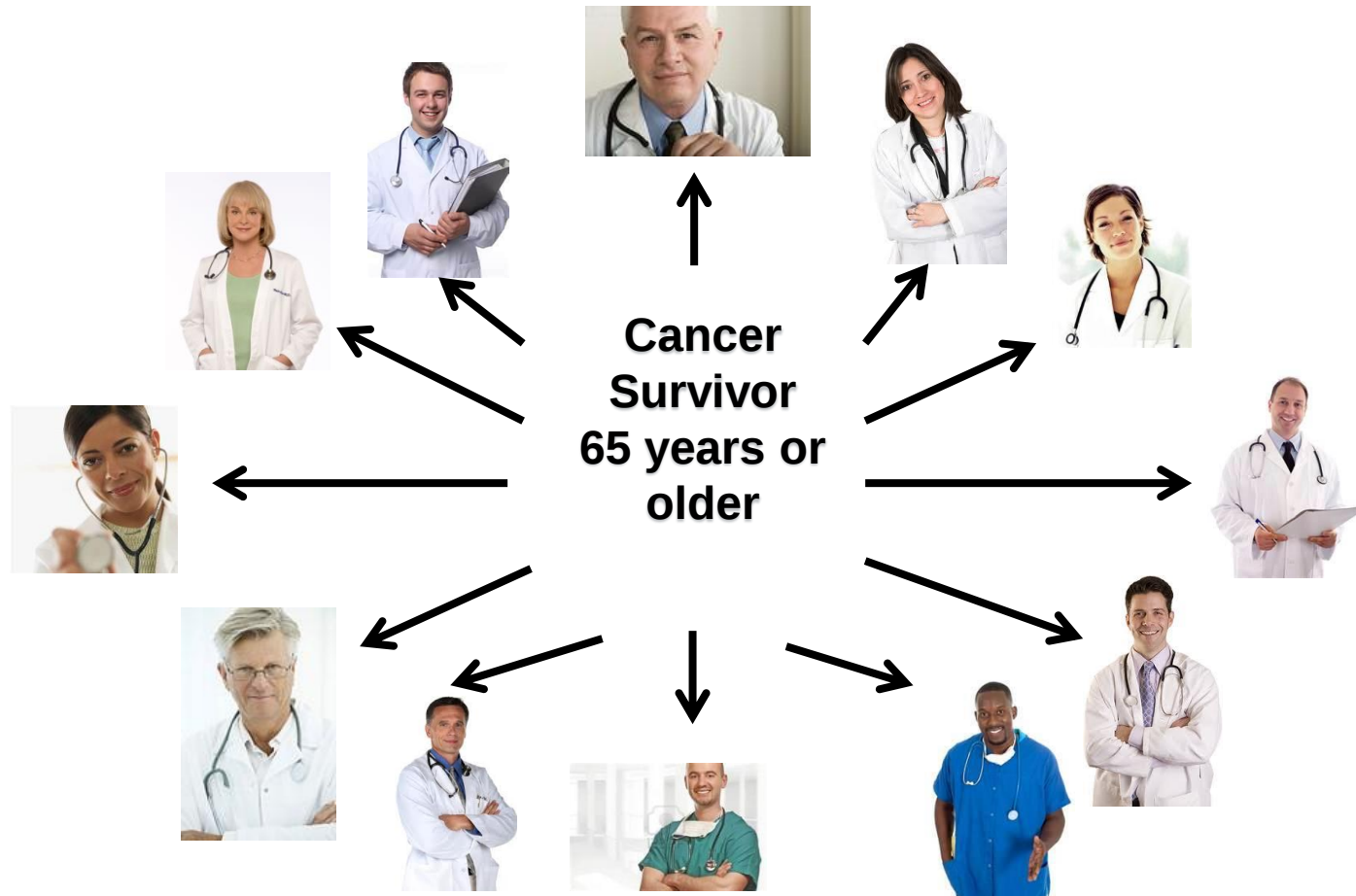
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Complexity of Cancer Care

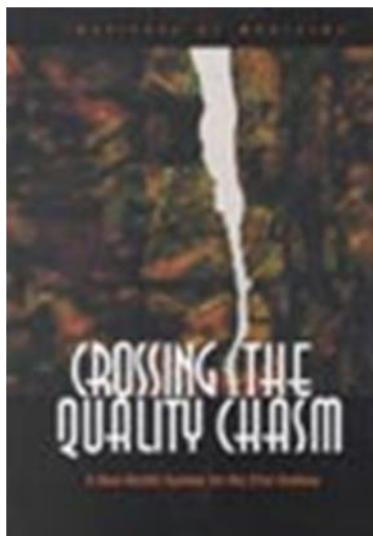
Post-Treatment Care For the Elderly Survivor



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...

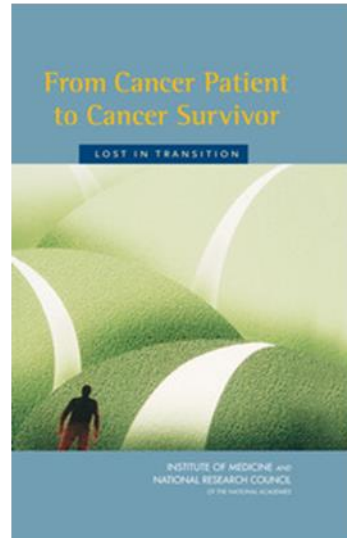
also ongoing, coordinated support from a care system that facilitates their engagement in their health and healthcare and optimizes their medical and psychosocial health outcomes during treatment and beyond



My Dream



IOM 2001



IOM 2006



IOM 2013



NAM 2030



Key to Making the Dream a Reality

Leave this workshop feeling a little more
Frustrated and a little more **Self-centered**



A photograph of a paved road with double yellow lines, curving through a forest. The trees have vibrant autumn foliage in shades of yellow, orange, and green. Sunlight filters through the canopy, creating a warm, dappled light effect. The road is bordered by fallen leaves and small shrubs.

*On the road to delivering
high quality care,
always walk in the
shoes of the patient*

--- Neeraj Arora