Working with Care Teams
After Cancer Treatment

Patient-Centered Primary Care Collaborative
Webinar December 16, 2013

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Cancer Care Continuum and the Role of Primary Care

- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

- Age and gender specific screening
- Genetic testing

- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

- Systemic therapy
- Surgery
- Radiation

- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition genetics

- Implementation of advance care planning
- Hospice care
- Bereavement care

- Care planning
- Palliative care
- Psychosocial support
- Prevention and management of long term and late effects
- Family caregiver support

Acute Care
Chronic Care
End-of-Life Care
Cancer Care Continuum and the Role of Primary Care

Prevention and Risk Reduction
- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

Screening
- Age and gender specific screening
- Genetic testing

Diagnosis
- Biopsy
- Pathology reporting
- Histological assessment
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- Biomarker assessment
- Molecular profiling

Treatment
- Systemic therapy
- Surgery
- Radiation

Survivorship
- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition genetics

End-of-life Care
- Implementation of advance care planning
- Hospice care
- Bereavement care

- Care planning
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TRANSITIONS in CARE
70 yo female with **BREAST CANCER** – Invasive lobular dx 2004, stage IIB, mastectomy, chemo (taxol/AC), XRT. Hormonal tx tamoxifen, AI. Neuropathy, joint aches.

- Surveillance with mammograms, surgical oncologist, oncology, GYN, PCP!!
- Up to date with other screening and prevention
- Numerous other medical conditions managed by other specialists
- Worried about cancer!
Large population and growing

**FIGURE 1.** Estimated number of living persons ever diagnosed with cancer — United States, January 1, 1971, to January 1, 2007

13 MILLION NOW, PROJECTED TO 18 MILLION IN 2020!

FIGURE 2. Estimated number of living persons ever diagnosed with cancer, by sex and period since diagnosis — United States, January 1, 2007

Components of Cancer Survivorship Care

- **Non-Cancer Related Medical Care**
  - Disease prevention/vaccination
  - Chronic care (i.e. DM, CAD)
  - Unrelated cancer screening

- **Cancer Related Medical Care**
  - Surveillance for recurrence
  - Complications of treatment
  - Related cancer screening

- **Psychosocial Issues**
  - Quality of life, financial burden
  - Family/genetic counseling

Coordination of Care
Care for the Cancer Survivors

- Most cancer survivors are cared for in non-academic settings!
  - Oncologist only
  - Oncologist/primary care clinician
  - Primary care clinician only
  - Multiple oncology specialists +/- PCP
  - No care

- In the “real world” – cancer survivors mostly seen in primary care.
Mix of Physician Specialties Visited: Colorectal Cancer Survivors

Source: Snyder et al., JCO, 2008
Mix of Physician Specialties Visited: Breast Cancer Survivors

Source: Snyder et al., JGIM, 2009
Survivorship Care in Oncology Settings

• Oncologists get to know their patients and form a bond during time of crisis

• Oncologists expect to care for cancer survivors, particularly with respect to surveillance

• Oncologists do better in having patients participate in recommended cancer surveillance

Mariscotti 2009; Cheung 2009; Snyder 2008; Snyder 2009; Hudson 2012
Challenges for Oncology Based Survivorship Care

- Oncologists not trained to provide general medical care and manage comorbidities in growing numbers of patients.

- 7 out of 10 deaths each year are from chronic diseases.

- 1 in every 3 adults is obese.

Source: AHRQ

Source: [http://www.cdc.gov/chronicdisease/overview/index.htm](http://www.cdc.gov/chronicdisease/overview/index.htm)
Oncologist Supply ≠ Demand

Figure 2. Baseline projected supply of and demand for oncologist visits, 2005 to 2020.

WE ARE NOW 3 YEARS OUT!

Source: Erikson, J Clin Practice 2007
Survivorship in Primary Care Settings

- PCPs trained to provide comprehensive care to patients with chronic disease... such as CHF, DM, COPD
- More PCPs = better health outcomes
  - 1 PCP per 10,000 = 5.3% lower mortality
  - More PCPs = fewer hospitalizations, lower mortality
  - Data in general populations, not cancer survivors
- PCPs are willing
- PCPs focus on general medical screening and prevention
- No difference on mortality (breast cancer)

Challenges for PCP Based Survivorship Care

- Inadequate information about the previous cancer and/or its treatment
- Some cancers rarely encountered in primary care, so not enough expertise
- Lack of knowledge and confidence about survivorship care
- Patient lack of confidence in PCP knowledge
- Competing demands on their time

Duffy Land, 2006; Kadan-Lottick, 2002; Mao 2009; Del Guidice 2009; Bober, 2009; Kantsiper 2009; Potosky 2011
# Shortage of Primary Care Providers

## Doctor Gap, Pay Gap | The primary-care deficit

### Growing Shortage
Projected supply and demand for primary-care physicians in the U.S., in full-time equivalents

<table>
<thead>
<tr>
<th>Year</th>
<th>Supply</th>
<th>Demand</th>
<th>Shortage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>254,800</td>
<td>263,800</td>
<td>9,000</td>
</tr>
<tr>
<td>2015</td>
<td>263,600</td>
<td>293,400</td>
<td>29,800</td>
</tr>
<tr>
<td>2020</td>
<td>268,000</td>
<td>313,400</td>
<td>45,400</td>
</tr>
<tr>
<td>2025</td>
<td>272,000</td>
<td>337,800</td>
<td>65,800</td>
</tr>
</tbody>
</table>

### Disincentive Pay
Average starting salaries are lower in primary-care fields than in other specialties

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Pay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrics</td>
<td>$179,000</td>
</tr>
<tr>
<td>Family medicine</td>
<td>$185,000</td>
</tr>
<tr>
<td>Internal medicine</td>
<td>$208,000</td>
</tr>
<tr>
<td>Ob/gyn</td>
<td>$286,000</td>
</tr>
<tr>
<td>Emergency medicine</td>
<td>$288,000</td>
</tr>
<tr>
<td>Neurology</td>
<td>$300,000</td>
</tr>
<tr>
<td>Dermatology</td>
<td>$371,000</td>
</tr>
<tr>
<td>Urology</td>
<td>$424,000</td>
</tr>
<tr>
<td>Cardiology (invasive)</td>
<td>$451,000</td>
</tr>
<tr>
<td>Orthopedic surgery</td>
<td>$483,000</td>
</tr>
</tbody>
</table>

Note: Pay figures are for 2012-13; base salary or guaranteed income only; do not include production bonus or benefits. Higher Medicare payments under the Affordable Care Act may increase family-medicine pay roughly 2.5% and internal-medicine pay between 5% and 10%.

Sources: Association of American Medical Colleges (shortage); Merritt Hawkins (pay) based on 3,097 search assignments in the 12 months ended March 31, 2013
The Wall Street Journal
Psychosocial Care

- Patients have expressed ongoing need for emotional support.
- Patients look to both oncology and PCPs, but data suggest that neither adequately address these needs.
- Comparing PCPs versus oncology
  - Patients have reported confidence in PCP caring for their psychosocial wellbeing
Patients’ Views on PCP care?

- Survey of 300 breast cancer survivors
  - Most confident in PCPs providing
    - General care (78%)
    - Psychosocial support (73%)
    - Health promotion (73%)
  - Less confident about knowledge of
    - Cancer follow up (50%)
    - Late effects of cancer therapy (59%)
    - Treating symptoms related to cancer (41%)

Mao JCO 2009
But preferences vary...

“If there’s anything, considering anything, in reference to cancer treatment, I would see my oncologist for it. Just because that’s their specialty…I’d rather see the oncologist, someone that is familiar, who does it every day. I just wouldn’t think that a primary or my gynecologist would know, be as knowledgeable”

“You gotta have an oncologist. I would advise anyone not to go to a family doctor or a general practitioner, you gotta be an oncologist. You know, I’m a firm believer. My head hurts, I’m going to the head doctor. My foot hurts, I’m going to the foot doctor”

Hudson  Ann Fam Med 2012
But preferences vary…

“I mean, as far as being a liaison between me and that oncologist or me and the surgeon, that’s what my primary care is for, in my opinion. That’s how I used him, to be my go-between. To explain the things in the files that I didn’t understand”

“Um, maybe ob-gyn [could be involved in follow-up]…. When I go there yearly for the clinical exam, they’ll usually question about the breast cancer and stuff like that”

“[Knowing my] history is OK…, too. But they should be involved together because…primary care knows more about…me other than the cancer”
Shared Survivorship Care

- The PCP and oncologist together participate in the care of a cancer survivor.
- All seem to like this approach (Cheung 2009)
  - Patients want their oncologists and PCPs involved in surveillance for cancer recurrence and other cancer screening
  - Oncologists expect a significant role in surveillance, but also share in the screening for other cancers and general prevention with PCPs
  - PCPs prefer focus on screening, general prevention and some in surveillance
- Appears to improves all indices of care for survivors.
Challenges to Shared Care

- Often lack of clear communication between cancer specialist and primary care clinician
- Lack of supportive infrastructure within health care systems to share/transfer records (e.g., information technology, EMRs)
- In other disease states, inconclusive evidence for benefits of shared care (Cochrane 2007)
- No systematic way to delineate care and responsibilities
- Need to balance “too little” care and “too much” or duplication of care
- Is there an end to shared care???
Providers seen by cancer survivors years later....

Source: Pollack, Cancer 2009
Multiple Chronic Conditions: A Day in the Life (Audio/Video item)

"Multiple Chronic Conditions: A Day in the Life" centers around the experiences of Mae, a woman with multiple chronic conditions. Beginning at home with her family, we follow Mae as she visits one health care provider after another, struggling to keep track of the various instructions, treatments, and prescriptions she receives – all while trying to maintain a balanced life.

MCC video - Stage [2 minutes]

Challenges in Coordination and Communication across the Cancer Spectrum

TYPES OF CARE:

- Primary Prevention
- Detection
- Diagnosis
- Treatment
- Survivorship

LONG-TERM OUTCOMES
- MORTALITY
- QUALITY OF CARE

Providers:
- Provider 1
- Provider 2
- Provider 3
- Provider 4

Nurses and Staff:
- Nurses and Staff 1
- Nurses and Staff 2
- Nurses and Staff 3
- Nurses and Staff 4

Adapted from Taplin et al JNCI Monographs. 2010. [http://jncimono.oxfordjournals.org/content/2010/40.toc](http://jncimono.oxfordjournals.org/content/2010/40.toc)
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- Surveillance with mammograms, surgical oncologist, oncology, GYN, PCP!!
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Challenges in Coordination and Communication in Cancer Survivorship Care
Are there any solutions?
Institute of Medicine Panel

- Convened in 2004-2005
- Reviewed state of cancer survivorship care
- Recommendations in Report,
  - “From Cancer Patient to Cancer Survivor: Lost in Transition.”
Recommendation 2

Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third party payors of health care.
How is this going?

- Still a work in progress….
- Challenges in implementation, even in LIVESTRONG Survivorship Centers and NCI Cancer Centers
- Modifications being developed by ASCO
- SCPs soon requirement by COC

Survivorship Care Plan ≠ Survivorship Care Planning
DELIVERING HIGH-QUALITY CANCER CARE

Charting a New Course for a System in Crisis

Report published in 2013
The Crisis in Cancer Care Delivery

Cancer care is often not as patient-centered, accessible, coordinated, or evidence based as it could be.
Goals of the Recommendations

1. Provide clinical and cost information to patients.
2. End-of-life care consistent with patients’ values.
3. Coordinated, team-based cancer care.
4. Appropriate core competencies for the workforce.
5. Expand breadth of data collected in cancer research.
6. Expand depth of data collected in cancer research.
7. Develop a learning healthcare IT system for cancer.
8. A national quality reporting program for cancer care.
9. Reduce disparities in access to cancer care.
10. Improve the affordability of cancer care.
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Engaged Patients

**GOAL 1**

The cancer care team should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care.
Patient-Centered Care

- Informed, activated, participatory patient and family
- Patient-centered clinician with good communication skills
- Accessible, well-organized, responsive health care system

Improved Communication

Improved Health Outcomes
Recommendation 1

• The cancer care team should:

  • **Communicate** and **personalize** this information for their patients at key decision points along the continuum of cancer care, using decision aids when available.

  • **Collaborate with their patients** to develop a **care plan** that reflects their patients’ needs, values, and preferences, and considers palliative care needs and psychosocial support across the cancer care continuum.
Information in a Cancer Care Plan

- Patient information
- Diagnosis
- Prognosis
- Treatment goals
- Initial plan for treatment and duration
- Expected response to treatment
- Treatment benefits and harms

- Information on quality of life and a patient’s likely experience with treatment
- Who is responsible for care
- Advance care plans
- Costs of cancer treatment
- A plan for addressing psychosocial health
- Survivorship plan
Recommendation 1

• CMS and other payers should design, implement, and evaluate **innovative payment models** that incentivize the cancer care team to discuss this information with their patients and document their discussions in each patient’s care plan.

• NCI, CMS, PCORI, patient advocacy organizations, professional organizations, and other public and private stakeholders **should improve the development of this information and decision aids** and make them available through print, electronic, and social media.
Recommendation 1

• Professional educational programs for members of the cancer care team should provide comprehensive and formal training in communication.
Engaged Patients

**Goal 2**

In the setting of advanced cancer, the cancer care team should provide patients with *end-of-life care consistent with their needs, values, and preferences.*
**Recommendation 2**

- Professional educational programs for members of the cancer care team should provide comprehensive and formal training in end-of-life communication.

- The cancer care team should revisit and implement their patients’ advance care plans.

- The cancer care team should place a primary emphasis on providing cancer patients with palliative care, psychosocial support, and timely referral to hospice for end-of-life care.

- CMS and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to counsel their patients about advance care planning and timely referral to hospice care for end-of-life care.
An Adequately-Staffed, Trained, and Coordinated Workforce

**Goal 3**

Members of the cancer care team **should coordinate with each other and with primary/geriatrics and specialist care teams** to implement patients’ care plans and deliver comprehensive, efficient, and patient-centered care.
A Coordinated Workforce
A Coordinated Cancer Care Team

The Cancer Care Team

Physicians Providing Oncology Care

Clinicians Providing Psychosocial Support and Spiritual Workers

Palliative Care Clinicians (including hospice at end-of-life)

Rehabilitation Clinicians

Physician Assistants

Pharmacists

Nurses

Patient-Clinician Interactions

Patients
Recommendation 3

• Federal and state legislative and regulatory bodies should eliminate reimbursement and scope-of-practice barriers to team-based care.

• Academic institutions and professional societies should develop interprofessional education programs to train the workforce in team-based cancer care and promote coordination with primary/geriatrics and specialist care teams.

• Congress should fund the National Workforce Commission, which should take into account the aging population, the increasing incidence of cancer, and the complexity of cancer care, when planning for national workforce needs.
An Adequately-Staffed, Trained, and Coordinated Workforce

**Goal 4**

All individuals caring for cancer patients should have appropriate core competencies.
Recommendation 4

• **Professional organizations** representing clinicians who care for patients with cancer should **define cancer core competencies** for their membership.

• **Cancer care delivery organizations** should require that the members of the cancer care team have the necessary competencies to deliver high-quality cancer care, as demonstrated through **training, certification, or credentials**.

• Organizations responsible for accreditation, certification, and training of **nononcology clinicians** should promote the development of relevant core competencies across the cancer care continuum.
Goals of the Recommendations

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IOM REPORT CONCLUSIONS

- All participants and stakeholders must reevaluate their current roles and responsibilities in cancer care and work together to develop a higher quality cancer care delivery system.
- By working toward this shared goal, the cancer care community can improve the quality of life and outcomes for people facing a cancer diagnosis.
To read the report online, please visit www.nap.edu/qualitycancercare

To watch the dissemination video, please visit www.iom.edu/qualitycancervideo
Components of Cancer Survivorship Care

- **Non-Cancer Related Medical Care**
  - Disease prevention/vaccination
  - Chronic care (i.e. DM, CAD)
  - Unrelated cancer screening

- **Cancer Related Medical Care**
  - Surveillance for recurrence
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- **Psychosocial Issues**
  - Quality of life, financial burden
  - Family/genetic counseling

**Coordination of Care**
Hurdles in Caring for Cancer Survivors!

- Cancer survivors are diverse!!!
- Some cancers rarely seen in primary care, so can’t have enough expertise
- Inadequate information about the previous cancer and/or its treatment
- Lack of knowledge and confidence about survivorship care
- Patient lack of confidence in PCP knowledge
- Competing demands on PCP time
- Numerous specialists leading to gaps in communication/coordination
- Shortage!

Duffy Land, 2006; Kadan-Lottick, 2002; Mao 2009; Del Guidice 2009; Bober, 2009; Kantsiper 2009; Potosky 2011
Global Challenges in Caring for Cancer Survivors

- Lack of clear, evidence-based guidelines on proper management and limited knowledge of evolving management of co-morbidities

- Lack of effective management and transfer of information between providers needed for coordination of care
Original Contribution

Cancer Survivorship Care Plans: What Can Be Learned From Hospital Discharge Summaries?

By Larissa Neklyudov, MD, MPH, and Jeffrey L. Schnipper, MD, MPH

Harvard Medical School; Harvard Vanguard Medical Associates; Brigham and Women’s Hospital; and Partners HealthCare, Boston, MA

Abstract
The Institute of Medicine panel on cancer survivorship recommended that all patients with cancer and their primary care providers receive a written survivorship care plan that summarizes their initial treatment and provides guidance on post-treatment management. Cancer survivorship care plans aim to improve coordination of care and communication between providers as their patients transition from oncology to primary care settings. As such, survivorship care plans share similarities with hospital discharge summaries, focusing on improving the transition from inpatient to outpatient settings. In this article, we explore potential lessons that may be learned from hospital discharge summaries, which may be used to facilitate the development, implementation, and testing of survivorship care plans.

J Oncology Practice 2012
Cancer Survivorship in Primary Care is a one-stop repository where primary care providers can quickly access resources for medical information and clinical guidance.

There are close to 12 million cancer survivors in the US, and this population continues to grow.

Many survivors are living longer and most are elderly, with chronic medical conditions that also require care.

Primary care providers play an important role in caring for cancer survivors, yet research shows that their skills and comfort levels in managing issues related to cancer survivorship can be improved.

News


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QUESTIONS?

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