Cancer Care Planning and Case Studies on Survivorship Care Planning:

Why It’s Important and Some Initial Lessons

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National Coalition for Cancer Survivorship (NCCS)

- Founded in 1986
- Mission: Advocate for Quality Cancer Care
- Survivor led: Bylaws require majority of BoD have personal diagnosis
- Established the concept of “cancer survivorship” Published Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability, leading to the establishment of the NCI Office of Cancer Survivorship in 1996
- 2006 Institute of Medicine Lost in Transition Report (Then CEO served as Vice Chair of IOM “Committee on Cancer Survivorship: Improving Care and Quality of Life”)

About NCCS

- Particular focus on skills patients and families need to be effective self advocates
  - Cancer Survival Toolbox®
  - Teaches skills: Communicating, Finding Information, Problem Solving, Negotiating, Decision Making, Standing Up for Your Rights

About me

- Health policy expert with 20 years experience including federal government and academic positions, with a particular expertise in health care coverage and health care reform;
- New to NCCS in mid-2011;
- Daughter of an ovarian cancer patient who succumbed to the disease after 5.5 years, 2 remissions, and participation in an NCI clinical trial; and
- Served as mother’s patient advocate with providers and coverage system.
What is Quality Cancer Care?

**Elements**
- Patient-centered
- Effective
- Timely
- Safe
- Efficient
- Equitable

In Practice
- Shared decision-making
- Empowered patients
- Ongoing communication
- Treatment planning and patient involvement


The Survivorship Continuum

- Pre-Treatment: Plan for treatment and management of symptoms and side effects
  - Communication
  - Follow-up care

- During Treatment: Plan for treatment and management of symptoms and side effects
  - Communication
  - Follow-up care

- Transition: Post-Treatment: Treatment summary and plan for follow-up care
  - Communication
  - Follow-up care

- Transition: End of Life: Plan for end-of-life care
  - Communication
  - Follow-up care

Advocacy Continuum

- Public interest, such as this conference, anchors one end.
- Personal, or self-advocacy, anchors the other end.
- Both necessary to bring about systemic change in delivery of cancer care.
- NCCS active in both.
Objectives of Presentation

This presentation will:

• Highlight expert views on the need for cancer care planning;

• Explain a few different examples of the implementation of survivorship care planning;

• Discuss an electronic tool developed by an innovative collaborative that brings together key leaders in healthcare, survivorship care planning, cancer advocacy, and biotechnology to develop care planning tools that address the needs of all members of the oncology community, including providers, patients and policymakers; and

• Highlight some VERY initial lessons from the implementation of this program at a number of sites.
The Need for Survivorship Care Planning

• There are a growing number of survivors within an increasingly stretched and decentralized health care system.

• There are 12 million cancer survivors—and this number will likely grow as the population ages and cancer treatment is successful in controlling, if not curing, a significant portion of patients’ diseases.

• There is a looming shortage of oncologists, and potentially other providers.


• This makes the need for efficient use of provider resources, and careful coordination, all the more important.

• In order for primary care physicians to provide adequate care to their patients post-treatment, they need the information from the plan.

• Experts have called for comprehensive care summary and treatment plans.

• The Institute of Medicine’s From Cancer Patient to Cancer Survivor: Lost in Transition identified the need for ongoing late and long-term effects monitoring.
The Need for Survivorship Care Planning

- The report found that survivors are often “lost in transition” because of lack of awareness of survivorship needs and poor coordination between oncologists and PCPs.
- Patient care is often fragmented as most patients are cared for by community providers rather than within an integrated health system.

Survivorship Care Plan (SCP)

- A SCP is a coordinated post-treatment plan shared between the Survivor’s oncology team, a primary care physician and other health care professionals.
- The oncologist creates a summary of the Survivor’s treatment and includes direction for future care.
Survivorship Care Plan (SCP)

- A typical Survivorship Care Plan includes:
  - patient diagnosis and treatment summary;
  - best schedule for follow-up tests;
  - information on late- and long-term effects of cancer treatment;
  - a list of symptoms to look for; and
  - a list of support resources.

Survivorship Care Plan (SCP)

- This comprehensive medical summary, given to the Survivor and their primary care physician, helps support better survivorship care.
- A Survivorship Care Plan also relieves a Survivor from having to recall all the details of treatment and helps to ensure that all future health care providers are working as a team for the Survivor’s care.

One Model: Journey Forward

Journey Forward (JF) is a collaboration of:
- The National Coalition for Cancer Survivorship (NCCS);
- The University of California, Los Angeles Jonsson Comprehensive Cancer Center;
- The Oncology Nursing Society;
- WellPoint; and
- Genentech.
One Model: Journey Forward

- Journey Forward is a program designed for doctors and their patients who have recently completed active treatment for cancer.
- This program was created by a unique collaboration of organizations with the common goal of improving survivorship care.

One Model: Journey Forward

- Journey Forward promotes the use of Survivorship Care Plans.
- These plans, completed by the Survivor’s oncology team, give clear steps for care after active treatment.
- A typical plan begins with a simple, yet complete, treatment summary and offers guidelines for monitoring future care.

Journey Forward’s electronic survivorship care plan builder

- Journey Forward’s Survivorship Care Plan Builder was designed to assist oncology professionals in creating custom Care Plans* for cancer patients and their physicians.
- Available at www.journeyforward.org as a free download (with free technical support)

*Adapted in part from ASCO® Chemotherapy Treatment Summary templates and Surveillance Guidelines.
Journey Forward’s online survivorship care plan builder

• This tool includes:
  – Easy-to-use forms that expedite the preparation of treatment summaries and follow-up care plans
  – Helpful, time-saving utilities such as a built-in regimen library, BSA and BMI calculators, and various checklists.

Journey Forward’s online survivorship care plan builder

– Support for breast cancer, colon cancer, lymphoma, and other types of cancer (via a generic version) in the form of common treatment regimens in “Drop-down” menus (can add other regimens as well);
– Ability to customize Survivorship Care Plans with practice logo; and
– Ability to expand post-treatment Care Plans with information on symptoms to watch for, effects of treatment, support resources, and more.

Start Screen

• To begin, the oncology professional either selects a template or chooses a recently edited care plan.
Lymphoma Template

- The lymphoma template is comprised of 5 screens, which an oncology professional fills out:
  - General Information, including contact info for the patient and his/her care team
  - Background Information, including diagnosis and other pertinent health info
  - Treatment plan, including intended chemotherapy regimen
  - Treatment summary, including actual chemotherapy schedule and dosing, results, toxicities, etc.
  - Follow-up care, including schedule of follow-up tests, other referrals, and needs concerns

General Information

- The user can add as many additional, custom contacts as they wish.
- All contact fields are auto-complete so a user can select from a list of previously entered contacts.

Background Information

- The form contains a number of drop-down lists to minimize the amount of data inputting that the user needs to do.
Treatment Plan

BSA and BMI are calculated automatically.

The lymphoma regimen selection list includes:
- CEPP
- RCHOP
- RCHOP14
- RDHAP
- REPOCH
- RESHAP
- RICE

Users can add additional regimens to the lymphoma regimen library at their discretion.

Treatment Summary

The table of chemotherapy agents is displayed automatically, based on the regimen selected.

Follow-up Care

The Coordinating Provider selection lists are based on the Care Team contact list entered on the General Information page.

Again, the user can add as many custom items as desired to any of the tables.
The Care Plan

- The oncology professional can attach documents from the Survivorship Library to the care plan at this point directed at either the PCP or the patient;
- The care plan can be printed as a hard copy or PDF, or exported to Excel or Word.
- It can be given to patient or emailed to other providers, including the primary care physician.

Survivorship Library

- The Survivorship Library includes 50+ documents relevant to survivorship care. These are searchable by cancer type and can be attached to individual care plans.

First Institutional Case Study

- Nationally recognized cancer treatment and research facility associated with the NCI Community Cancer Center Pilot Program.
- Standalone Survivorship Clinic:
  - 3-8 patients per week for total of 100-125 patients (1st yr), 200-250(2nd yr)
  - 9 oncologists
First Institutional Case Study (Cont’d)

• Survivorship Care Planning:
  – Care plan is delivered 1-3 months after completion of therapy (excluding hormone therapy or Herceptin therapy).
  – Flow for completing care plan:
    – Information is pulled from EHR system from both the center and hospital

First Institutional Case Study (Cont’d)

– Care plan is completed by the Survivorship Care Nurse with the assistance of a Lay Navigator Volunteer and reviewed by the Nurse Practitioner
– SCP is delivered to patient by nurse in paper form with optional electronic copy on encrypted flash drive.
– Instruction sheet provided to assist patients with the use of the Journey Forward SCP at home.
– Copy of SCP will be sent to PCP and housed in the EHR
– Average time to complete 30-45 minutes

First Institutional Case Study (Cont’d)

• Survivorship Care Plan Builder:
  – Implemented Journey Forward SCPB in their clinic Summer 2010 and completed approximately 60 SCPs
Second Institutional Case Study

- Community cancer clinic at hospital treating all kinds of cancer, adults only
- Hospital has 250-300 beds. The clinic has 5 oncologists and 14 treatment stations.
- They see about 30 new consults per month.

Second Institutional Case Study (Cont’d.)

- **Survivorship Care Planning:**
  - Care plan is delivered after treatment is complete (approx. 4-6 weeks after active treatment) (Sometimes the SCP is completed concurrently with treatment.)
  - Flow for completing care plan:
    - Survivorship Coordinator (who is a nurse) pulls info from EMR and completes SCP
    - The SCP is reviewed by the physician
  - The SCP is delivered to the patient by the Survivorship Coordinator. She/He generally introduces herself to the patient during treatment so they know what to expect.
Second Institutional Case Study (Cont’d)

• SCP is also provided to providers and scanned into their EMR

• Average time to complete the SCP is 1.5 to 2 hours. Implemented Journey Forward SCPB in February 2010 and have completed 38 care plans.

Third Institutional Case Study

• Community Cancer Center treating all kinds of cancer, adults only.

• New facility estimating 100 patients/year

Third Institutional Case Study (Cont’d.)

• Survivorship Care Planning:
  – Care plan is started at diagnosis, completed concurrently with treatment then delivered, depending on type of cancer, after completion of treatment.
  – Flow for completing care plan:
    – Nurse gathers info from electronic and paper sources;
    – Plan is completed by the nurse navigator;
    – Delivered by an physician to the patients; and
    – The plan is scanned into the EMR and provided to other pertinent physicians.
Third Institutional Case Study (Cont’d.)

• Average time to complete is 1-2 hours, depending on availability of information

Third Institutional Case Study (Cont’d.)

• Survivorship Care Plan Builder:
  – Nurse looked at a couple of care plan options when the clinic wanted to incorporate SCPs.
  – She liked the Journey Forward SCPB and uses Oncolink to supplement with additional information if needed.
  – Implemented Journey Forward SCPB in August 2010 and on average starts approximately 10-12 care plans per month.
  – Currently, 3 Nurse Navigators specializing in different cancer types use the SCPB along with 2 Nurses in Chemo Infusion.

Fourth Institutional Case Study

• Private Oncology Practice
• All cancer types
• Survivorship Care Plan issued during survivorship meeting about 6 weeks after end of active treatment
• Nurse practitioner gives patient SCP during meeting along with additional information
Fourth Institutional Case Study

- Takes about 15-20 minutes to complete SCP
- Patient receives SCP and hard copy is also sent to primary care physician

Preliminary Lessons from Journey Forward

Preliminary Case Study Conclusions

- Journey Forward is in the process of developing case studies at adoption sites. This is a limited number of cases, so broad conclusions cannot be drawn.

Preliminary Lessons from Journey Forward (Cont’d.)

Preliminary Case Study Conclusions

- Some of the early lessons include:
  - Need a champion for adoption to be take hold.
  - Whether it is a physician, nurse, or other provider, someone must take the program and “run with it.”
  - Adoption within a site begins with one nurse/specialty and spreads to other nurses/specialty areas.
Preliminary Journey Forward Lessons (Cont’d)

– The presence of electronic health and medical records can facilitate completion of the survivorship care plan.
– In some cases, the survivorship care plans are scanned and become part of the electronic health records.
– It takes between 30 minutes and two hours to complete the survivorship care plan, depending upon when the plan is developed and the complexity of the case.

Preliminary Journey Forward Lessons (Cont’d)

– The plans can be completed at various points in treatment.
– Some facilities complete the plans concurrently with treatment, others at the conclusion of treatment; the plans are delivered to the patients at the end of treatment.

Thank you!

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