Tailoring Cancer Survivorship Treatment Summaries and Care Plans in the Era of Patient-Centered Care

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Overview

• Introduction and Rationale

• Evidence

• Problems and solutions

• Our unique approach at the Wilmot Cancer Institute regarding treatment summary (TS) and survivorship care plan (SCP) development
Numbers of Cancer Survivors are increasing

Estimated Number of Cancer Survivors in the US

Changing goals of cancer care
Catalyst for Change


- Define quality health care for cancer survivors and identify strategies to achieve it.

- Improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance.
Defining and Achieving Quality Survivorship Care
Why use SCPs?

- A more systematic approach is needed (SCP’s and Transition visit)

- Improve quality and coordination of care and communication within the health care system

- Improve patient understanding of their cancer, its treatment, and the effects of that treatment

- Encourage a healthy lifestyle
By 2015 SCPs will be mandatory for ongoing accreditation

American College of Surgeons, Commission on Cancer Standard 3.3

- Pilot SCP in 10% pts by 1/1/15
- Provide SCPs to 25% pts by 1/1/16
- SCP’s to 50% eligible patients by 1/1/17
- SCP’s to 75% eligible patients by 1/1/18
- SCP’s to all eligible patient’s by 1/1/19
Treatment Summary: Essential Elements

• Names of providers of cancer care with contact information

• Essential details about the malignancy (type, stage, grade, relevant histologic details and biomarkers)

• Treatment information including type, dates, duration, complications
Care Plan: Critical Information

- Cancer type, signs and symptoms of disease recurrence and late effects specific to the treatments received
- Details about frequency of follow ups and necessary ancillary imaging tests and blood-work
- Recommendations regarding strategies to maintain health and well-being
- Available community services: psychosocial, financial
Care Plan: Critical Information

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What is the evidence?
Research Published between 2006 and 2014 on SCPs for adult cancer patients

American Cancer Society Cancer survivorship Research Conference; Abstract B-36, 2014

- 43 studies
- 9 prospective
- 4 RCTs
Evidence


- 72 Hodgkin’s disease survivors
  - Increased risk for breast cancer and cardiomyopathy
  - No mammography or echocardiography done within 2 years prior

- SCP mailed to patients and PCPs contacted

- At 6 month follow up
  - 41% reported having mammography
  - 20% reported having echocardiogram
Evaluating Survivorship Care Plans
J Clin Oncol 29:4755-4762

408 breast cancer survivors completed treatment 3 months earlier

Consenting patients allocated within 2 strata based on time from diagnosis

Discharge visit

Discharge visit plus SCP
Evaluating Survivorship Care Plans

Control
- Standard discharge visit with oncologist
- Discharge letter sent to PCP

Intervention
- Personalized treatment summary
- Patient version of Canadian follow up guideline
- Summary table of the guideline
- Resource kit with available supportive care resources

J Clin Oncol 29:4755-4762
Evaluating Survivorship Care Plans
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- Primary outcome: Cancer related distress at 12 months, assessed by Impact of Event Scale
- Secondary outcomes: quality of life, patient satisfaction, continuity/coordination of care, and health service measures
Evaluating Survivorship Care Plans
J Clin Oncol 29:4755-4762

• Conclusion: There were no differences between groups on cancer related distress or any of the patient reported secondary outcomes

• There were no differences when the 2 strata were analyzed separately
Why was there no measurable difference between the groups?

- The survey tool used may not have been sensitive enough to capture meaningful differences.
- Perhaps the outcome measures were not ideal. Consideration was given to measuring empowerment as a primary outcome but no validated tool was available for this patient population.
- Patient population: breast cancer patients are relatively well informed and may have better access to resources than patients with other types of cancer.
- The information in the standard discharge visit and letter may have been comprehensive and harder to improve upon.
Other RCTs evaluating SCPs


- Another study in breast cancer survivors (n = 126) showed no improvement in distress or concerns but did show improved cancer worry in women receiving SCPs (Breast Cancer Res Treat. 2013 Apr;138(3):795-806)

- An RCT in 121 gynecological cancer survivors revealed high ratings of care in both study arms, but no differences between women who did and did not receive SCPs (Gynecol Oncol. 2013 Jun;129(3):554-8)

- An analysis of 968 breast cancer patients reported in 2006 demonstrated no difference in recurrence rates, serious clinical events, death and distress (J Clin Oncol 24(6):848-855)

- A randomized study of SCPs provided to Dutch gynecologic oncologists has been completed and findings are forthcoming (J Cancer Surviv. 2014;8(2):248)
PATIENT CENTERED CARE IS CUSTOMIZED CARE
Our customized approach

• Considered the needs of our unique patient population of cancer survivors
• Devised an implementation strategy
• Assembled materials of a survivorship packet
• Determined who in the practice will complete TS details
• Determined when in the survivorship trajectory the transition visits occur for various malignancies
• Planned a system that would allow identification of patients needing transition visits
Table 1: Online Resources for Survivorship Care Planning

<table>
<thead>
<tr>
<th>Template</th>
<th>Description</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Society of Clinical Oncology (ASCO)</td>
<td>Care plan templates, guidelines for breast, colorectal cancer follow-up</td>
<td><a href="http://tiny.cc/Yp1yL">http://tiny.cc/Yp1yL</a></td>
</tr>
<tr>
<td>Journey Forward</td>
<td>Tool for developing care plans based on ASCO recommendations</td>
<td><a href="http://www.journeyforward.org">www.journeyforward.org</a></td>
</tr>
<tr>
<td>National Comprehensive Cancer Network (NCCN)</td>
<td>Disease-specific treatment follow-up guidelines</td>
<td><a href="http://www.nccn.org">www.nccn.org</a></td>
</tr>
<tr>
<td>LIVESTRONG Care Plan</td>
<td>Patient can develop care plan and review with healthcare team</td>
<td><a href="http://www.livestrongcareplan.org">www.livestrongcareplan.org</a></td>
</tr>
<tr>
<td>Prescription for Living</td>
<td>Downloadable care plan template</td>
<td><a href="http://tiny.cc/SFA8e">http://tiny.cc/SFA8e</a></td>
</tr>
<tr>
<td>Memorial Sloan-Kettering Cancer Center</td>
<td>Treatment Summary and Care Plan</td>
<td><a href="http://tiny.cc/rqgxq">http://tiny.cc/rqgxq</a></td>
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</table>
Judy DiMarzo Cancer Survivorship Program

Mission

To provide comprehensive and personalized care of the highest order for cancer survivors in the greater Rochester area by navigating patients through the complexities of survivorship care.
Program Components

- Treatment Summary at therapy completion
- Survivorship Care Plan at therapy completion and at transition to Primary Care
- Evidence-based
- Comprehensive Interdisciplinary Surveillance
- Services to heighten post-treatment quality of life
- Creating a support network
- Facilitate transition to primary care provider
- Identify research needs
Individualized Resources / Referrals

- Specialists to address health problems due to therapy or disease process
- Physical & Occupational Therapy / Speech Therapy
- Nutritional Support
- Exercise
- Financial Support (insurance counseling, available resources)
- Genetic Counseling
- Emotional/Mental health; Family/Relationship Counseling
- Spirituality
- Smoking Cessation
Transition to Primary Care Provider

• Care plans forwarded to PCP with letter explaining purpose of program, visit, & care plans
• Contact information provided
• Routine surveillance (mammograms, colonoscopies, etc.)
• Create early communication regarding long-term needs for patients who will be discharged from oncology care in future
• Despite the IOM report recommendations that SCPs be generated for and provided to each cancer patient.

• Despite the CoC mandating in 2011 that all accredited cancer centers to provide SCPs to all patients at the completion of treatment by 2015.

• Less than 5% of oncologists are consistently discussing survivorship recommendations and follow up care providers as well as providing SCPs to their patients on a consistent basis.
Problem


In 2012 only 43% of National Cancer Institute-designated cancer centers delivered SCPs to patients with breast or colorectal cancers.
Physician-reported Provision and Receipt of Treatment Summaries and Survivorship Care Plans

- Oncologists (always/almost always provide)
- PCPs (Always/almost always receive)

Forsythe et al, JNCI 105:1579, 2013
Why?

• What are the barriers to providing SCPs to patients?

• How can these barriers be effectively overcome?
Barriers to consistent provision of SCPs

• Insufficient time
• Insufficient staff
• Insufficient training
• Insufficient funding
• Insufficient reimbursement
Solutions

ASCO has just released a streamlined template:
- Information about the cancer diagnosis
- Potential late effects
- Key recommendations for screening
- Whom to contact for issues
- Modifiable
ASCO Streamlined Template

General Information

Patient Name: [ ]
Patient DOB: [ ]
Patient phone: [ ]
Email: [ ]

Health Care Providers (Including Names, Institution)

Primary Care Provider:
Surgeon:
Radiation Oncologist:
Medical Oncologist:
Other Providers:

Treatment Summary

Cancer Type/Location/Histology Subtype: [ ]
Diagnosis: [ ]
Diagnosis Date (year): [ ]
Stage: □ I □ II □ III □ IV □ Not applicable

Treatment

Surgery □ Yes □ No
Surgery Date(s) (year): [ ]

Surgical procedure/location/findings:

Radiation □ Yes □ No
Body area treated: [ ]
End Date (year): [ ]

Systemic Therapy (chemotherapy, hormonal therapy, other) □ Yes □ No

Names of Agents Used: [ ]
End Dates (year): [ ]

Persistent symptoms or side effects at completion of treatment: □ No □ Yes (enter type(s)):

Familial Cancer Risk Assessment

Genetic/hereditary risk factor(s) or predisposing conditions:

Genetic counseling □ Yes □ No
Genetic testing results:

Follow-up Care Plan

Need for ongoing (adjuvant) treatment for cancer □ Yes □ No
Additional treatment name
Planned duration
Possible Side effects

Schedule of clinical visits

Coordinating Provider
When/How often

Cancer surveillance or other recommended related tests

Coordinating Provider
What/When/How Often

Please continue to see your primary care provider for all general health care recommended for a man (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:
1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- Emotional and mental health
- Physical functioning
- Insurance
- School/Work
- Financial advice or assistance
- Parenting
- Fertility
- Sexual functioning
- Other

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

- Tobacco use/cessation
- Alcohol use
- Sun screen use
- Weight management (loss/gain)
- Physical activity

Resources you may be interested in:

Other comments:

Prepared by:
Delivered on:
What about the problem of training?

*J Clin Oncol* 32:1578-1585

- In a study with a nationally representative sample of 1130 oncologists:
  - Oncologists who received training about late and long-term effects of cancer were 2x more likely to provide SCPs to and discuss survivorship issues with survivors than those who did not receive such training.
  - Only 5% of oncologists reported extensive training in cancer survivorship care.
Our unique approach to SCP development at the James P. Wilmot Cancer Institute

Trainees play a key role
Please rate your confidence in assembling treatment summaries and care plans for cancer survivors. (0 = not confident; 10 = extremely confident)

<table>
<thead>
<tr>
<th>Score</th>
<th>No. of answers</th>
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<tbody>
<tr>
<td>7</td>
<td>2</td>
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<tr>
<td>8</td>
<td>5</td>
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<td>9</td>
<td>4</td>
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Mean Score 8.2 +/- 0.2
Median Score 8
Range (7-9)
N=12
The Cancer Survivorship Workshop


Scores Over Time
(Scale from 0-low/none to 10-high/extremely)

How comfortable are you discussing survivorship issues with the patients you see?
How often do you provide recommendations on survivorship care?
Please rate your knowledge of cancer survivorship care plans for the most common types of cancer.
How important do you think it is for oncologists to review survivorship care plans with their patients?
How confident are you in your ability to explain a survivorship care plan to a patient?
How often do you see oncologists using survivorship care plans in the clinics you attend?
Future Directions

- More tailored care plans
- Based on specific treatment doses or techniques used
- Based on co-morbidities
- Based on genetic mutations
- More data needed to guide this!
Summary

The provision of Cancer Treatment summaries and Survivorship Care Plans to our patients is one means of systematically optimizing patient care by:

- Providing education and information
- Improving communication between providers
- Delineating available community resources
THANK YOU FOR YOUR ATTENTION!