Cancer Survivorship Care Plans: Tools for Treatment Transition

Institute for Public Health and Medicine
Seminar Series
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Acknowledgements

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- Research Funding:

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Objectives

- summarize concerns / needs of post-tx cancer survivors

- describe cancer SCPs
  - tools for transition from tx → “re-entry”
  - recommendations & barriers

- discuss ways SCPs can be implemented to meet needs on a local level
  - patient populations
  - health care systems
Overview

Hx
- Rationale for SCPs
- Recommendations by professional societies & accrediting agencies have evolved

Research
- Capturing stakeholder perspectives
- Assessing feasibility / acceptability
- Preliminary evaluations of efficacy

Studies
- COMPASS
- Survivor Net
- Demonstrate need for customization @ a local level
Current Scope

- Currently **13.7 million cancer survivors** in the US
  - ≈ 4% of the population
  - 64% have survived ≥ 5 yrs

- Shift from acute \(\rightarrow\) chronic condition
- \(\rightarrow\) changes in how their health care is coordinated

Mariotto et al., J Natl Cancer Inst. 2011
Future Scope

- Improved detection & tx → # expected to climb
  - ≈ 18 million by 2020 (up >30%)

- Significant public health issue

*Parry et al. Cancer Epidemiology Biomarkers & Prevention. 2011*
Oncology Shortfalls

- 2006 ASCO study:
  - 2,550 – 4,000 by 2020 (1/4 - 1/3 of supply)


- newer indicators less bleak
  - recession → postponed retirement
  - oral medications & nonphysician practitioners → ↓ demands

- but future is uncertain
  - impact of ACA
  - impact of moves toward team-based approaches
  - new ASCO survey → results in a few months
Primary Care Shortfalls

- Shortage of PCPs expected to \( \uparrow \)
  - Association of American Medical Colleges
    - 90,000 by 2020
    - 130,000 by 2025
  - Even prior to health care reform

- PCPs w/ high pt loads \& less time / visit

- PCPs have indicated they are often under-equipped to provide f/u care to cancer survivors \& would welcome the assistance of SCPs \& other tools
Common Concerns

- Uncertainty about surveillance for recurrence & new cancers
- Fear of recurrence
- Late and long-term effects of tx
- Uncertainty about what to expect (“what is normal?”)
- Managing comorbidities & general health
  - can be neglected while under oncology care
  - fare no better than general population in executing health behavior change
  - lack of guidance from health providers (e.g., weight management)
- Uncertainty about what providers to see
- Emotional distress
- Drop in social support
- Practical concerns (e.g., return to work; job lock; insurance)
Breast Cancer Snapshot

- Long-term & late side effects

  fatigue  
deconditioning  
peripheral neuropathy  
arthralgias  
decreased range of motion  
lymphedema  
sexual dysfunction  
weight gain

  bone loss & osteoporosis  
cardiac dysfunction  
blood clots  
menopausal sxs  
infertility  
cognition problems (“chemo brain”)  
distress / depression  
insomnia

- majority of pts experience ≥ 1 (even after > 5 yrs)
- care across specialties → coordination
Brief Hx

2005: IOM Landmark Report
- survivorship = neglected phase
- reporting distress & unmet needs
- care was often not coordinated
- recommendations:
  - developing guidelines for f/u care
  - building bridges between oncology & primary care
  - SCPs delivered @ end of tx

2006 – 2009:
- SyMon-B Study: pts in active tx used computerized telephone system & wanted to continue
- Breast cancer support group
Toward Present Date

2006: IOM SCP Workshop
2011: NCI Office of Survivorship SCP Workshop
2011: LIVESTRONG Essential Elements Mtg.

- Consensus:
  SCPs as **cornerstone** of survivorship care
  Key elements of SCPs
  SCP **research** (feasibility & efficacy)

2012: ACoS CoC Program Standards

- **SCP use** = metric of quality care for accredited institutions
- **2015** – *all pts* must receive an SCP
- **2014** – *all programs* must have plan in place
  (dissemination & monitoring)
- 70% of pts w/ cancer
# Minimum Standards

## 1) Treatment Summary – Record of Care

<table>
<thead>
<tr>
<th>Dx tests &amp; results</th>
<th>Tx dates (start / end)</th>
<th>Tumor characteristics (site, stage &amp; grade, hormonal status, marker info)</th>
<th>Tx details: agents, regimens, dosage, response indicators, toxicities</th>
<th>Surgery; CTX; RT; hormonal tx; gene, bio- or other tx; transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contact information</strong> for key providers</td>
<td><strong>Supportive services</strong></td>
<td><strong>Clinical trials</strong></td>
<td><strong>IOM Cancer Survivorship Care Planning Fact Sheet. 2005</strong></td>
<td></td>
</tr>
<tr>
<td>2) Follow-up Care Plan – E-B Standards of Care</td>
<td></td>
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<td>-----------------------------------------------</td>
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<tr>
<td><strong>Likely recovery from toxicities</strong></td>
<td>Genetic counseling → further intervention (e.g., surgery, chemoprevention) &amp; inform 1st degree relatives</td>
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<tr>
<td><strong>Information on effectiveness of chemoprevention strategies for secondary prevention</strong></td>
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<tr>
<td><strong>Need for adjuvant tx</strong></td>
<td>Potential psychosocial effects &amp; referrals</td>
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<tr>
<td><strong>Possible sx$ s$ of recurrence / 2nd tumors</strong></td>
<td>Potential practical effects &amp; referrals</td>
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<tr>
<td><strong>Possible late &amp; long-term effects</strong></td>
<td>Link back to PCP</td>
<td></td>
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<tr>
<td><strong>Recommended cancer screening &amp; other tests (schedule &amp; contact)</strong></td>
<td>Referrals to specific other providers or groups</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Recommended health behaviors (e.g., exercise, nutrition, sunscreen, smoking)</strong></td>
<td>List of cancer-related resources</td>
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</tbody>
</table>
Functions Served

- Summarize key aspects of cancer care
- Make appropriate f/u care recommendations
- Do so in personalized & portable documents
  - Different versions for pts & PCPs / medical records
  - Delivered in a consultation == teachable moment
- Promote pt knowledge, engagement, health behaviors & wellbeing
- Guide pts to appropriate f/u care
- Facilitate provider communication & coordinated services → improved continuity of care
- TPs (before / during tx)
- TS (after tx)
- SCPs (f/u care)
- Word (print & complete or complete & print)
- Excel (complete w/ some drop downs)
- Breast, Colon, & Lung Cancer; Lymphoma & Generic
2006 – UCLA Ca Survivorship Center, NCCS, industry, ONS

- Based on ASCO
- SCP Builder (providers)
  - software downloaded locally NOT web-based
  - can be branded
  - drop-down menus (CTX regimens)
- My Care Plan (pts)
  - medical hx builder
  - sx assessment (0-10, Pn, A, D, FoR)
- Survivorship Library (HCP & pts)
2007 – partnering w/ U of Penn. Abramson Cancer Cntr

- SCP NOT a TP/TS
- Provides customized guidelines
  - Demographics, dx, tx
- Dedicated HCP Version
- Web based
- > 32,000 worldwide users (>5,000 HCP)
- Time to complete (M=7 min, Md=4)
- Cannot be saved before completion

Follow-up Care
Breast Cancer

After receiving treatment for breast cancer, it's important for survivors to adhere to their physician's plan for follow-up care. Guidelines developed by the National Comprehensive Cancer Network state that survivors who have had breast conserving therapy (lumpectomy) should have their first mammogram approximately 6 months after completing radiation therapy, then annually. Survivors who undergo single mastectomy should have a mammogram annually. In addition, breast MRI may be considered for survivors with the BRCA 1 or 2 genes. Those who have had double mastectomy do not need mammograms, but should examine the chest wall for swelling or a rash, and report any changes to their oncologist. However, some oncologists recommend that mammograms be performed of the reconstructed breast or breasts.

Survivors should be seen by their oncologist every 4 to 6 months for the first 5 years and then annually. Women who are taking tamoxifen and still have an intact uterus should be seen annually by a gynecologist and be sure to report any vaginal bleeding to their physician immediately, as this can be a sign of uterine cancer. Women taking an aromatase inhibitor, which results in a decrease in estrogen levels and can lead to loss of bone strength, should have their bone health evaluated by a Dexa scan at baseline and then periodically thereafter.

Routine CT scans or bone scans to look for evidence of cancer spread outside of the breast and regional lymph nodes (otherwise known as metastasis) are not recommended. This is because research has shown that if a woman develops metastatic disease, the subsequent type of treatment, response to treatment, and overall survival are equivalent regardless of when the treatment is initiated. In other words, outcomes are similar for those who are treated for metastases found on routine screening (with no symptoms present) and women who are not treated until those metastases cause symptoms. Therefore, we no longer routinely screen patients for evidence of metastatic disease unless they have developed symptoms.

Finally, research has demonstrated that leading an active lifestyle and maintaining a healthy weight, with a body mass index (BMI) of 19-25, may result in better breast cancer outcomes. Weight-bearing exercise, such as walking, yoga and dancing, can also help maintain bone strength. Talk with your healthcare team about resources to get started (or back to) a healthy lifestyle.

The National Comprehensive Cancer Network produces Clinical Practice Guidelines that can be helpful in determining the general recommendations for follow up. The recommended follow-up care for patients with breast cancer includes:
EHR Integration Initiatives

- Beta test to prepopulate SCP builder w/ registry data
  - 60% of fields
  - Breast cancer
  - Institutions using C/NET (C/NEXT) software

- Feasibility test
  - Partnering with ACS, CoC, Roswell Park Cancer Institute & UofPenn.’s Abramson Cancer Center
  - New SCP template version
  - Integrated w/ EHR & registries
SCP Research

- Qualitative studies have gathered stakeholder input
  - Survivors & PCPs have generally responded positively
  - Onc. providers supportive but concerned about feasibility
  - Time burden = #1 cited barrier

- Implementation studies
    - 43% delivered SCPs to breast & colorectal cancer survivors
  - Survey of Massachusetts providers *(Merport et al. Sup Care Ca. 2012)*
    - 56% prepared SCPs BUT only 14% of PCPs received them
  - LAF Survey of >5,000 post-tx survivors
    - 17% had SCP (21% 1 yr ; 17%1-5; 15% >5)
    - 19% had a TS
    - those w/ SCPs reported more confidence they could discuss problems w/ their doctors
1st RCT

- **Grunfeld et al., JCO, 2011**
  - 408 long-term, post-tx BrCa survivors
  - *All* pts receive oncology discharge visit & were transferred to PCPs for f/u (PCP receives discharge letter)
  - *Intervention* pts received SCP (reviewed by nurse & sent to PCP)

- **Results**
  - No significant group differences on Ca-related distress (IES), HRQL, pt satisfaction
  - Intervention pts were more aware of who was responsible for follow-up care

- **Critiques**
  - Timing of delivery
  - Hard comparison group
  - Canadian study: affordable universal health care & emphasis on care by PCPs & health promotion
  - NOT the most sensitive / useful measures (vs health behaviors & use of services)
More Trials

- **Hershman et al., Breast Cancer Res Treat, 2013**
  - 126 women with 6 wk of tx completion
    - Control Group: NCI Facing Forward
    - Intervention: NCI Facing Forward + SCP & nurse / nutritionist consultation
  - No significant group differences on pt satisfaction, IOC or depression
  - Intervention pts reported less health worry (ASC; @ 3 mo)
  - **Limitations:** measures used; single institution

- **van de Poll-Franse et al., ASCO, 2013**
  - 201 women with endometrial cancer; 12 hospitals randomized (pragmatic cluster RT) in the Netherlands
    - Control Group: standard care
    - Intervention: physicians had access to web-based SCP application
  - 69 % of Intervention pts received SCPs
  - Intervention pts who received SCPs reported ↑ satisfaction (info & care)
  - F/u measures will assess impact on HRQL & health care use
SCPs based on **common sense** & **not harmful.**

→ continue to implement while collecting further empirical evidence
Still Unknown

- How is SCP being implemented?
  - who preparing / providing, when in care, concordance of content

- What delivery & coordination models / strategies are most feasible & sustainable?

- What system & provider factors influence implementation?

- What are the correct metrics (even outcomes / constructs) to assess the impact of SCPs?
  - morbidity; self-management; adherence; health care use

- What is the impact pt-provider & inter-provider comm.?

- What is the differential cost of SCP & what value is added → do they promote cost-effectiveness long term?
<table>
<thead>
<tr>
<th>Site</th>
<th>RHLCCC</th>
<th>Mount Sinai</th>
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<tbody>
<tr>
<td>Pts</td>
<td>Women completing primary breast cancer tx.</td>
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<tr>
<td>Aim 1</td>
<td>Create a semi-automated, computerized SCP template that integrates EHR information and patient self-report data.</td>
<td>Gather stakeholder perspectives to inform development of a SCP template appropriate for a safety net hospital.</td>
</tr>
<tr>
<td>Aim 2</td>
<td>Implement the SCP intervention, evaluate feasibility / acceptability &amp; explore its impact on breast cancer survivor ((N=80, \text{per study})) outcomes over time (3-6 mo post tx).</td>
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Why Breast Cancer?

- Almost ¼ of all cancer survivors
- Survival rates improving
  - 89% @ 5 yrs post-dx
  - 77% @ 15 yrs post dx
- But recurrences occur yrs after tx → long f/u care
- 2/3 have HR+ disease → 5-10 yrs endocrine tx
  - Significantly ↓ recurrence rates
  - But ↑ tx sx → nonadherence
- Disease-specific guidelines are well-established
- Indications that needs are not being addressed adequately
Why Customize Templates?

- Provider buy-in & system fit is essential
- Pre-implementation evaluation: current procedures goals & barriers template preferences

COMPASS
- Autopopulating from EHR was key
- Integrating PROMs could further aid in individualizing SCPs

Survivor Net
- Fast completion due to limited resources was vital
- Electronic template not an option (limited computers & wireless)
**A Cautionary Tale**

- **Cancer Care Communication (C3) Study** (AHRQ; PI: Hahn)
  - RCT: LL-friendly multimedia IT pt-assmnt. & edu. system
  - Piloted a paper-based SCP template (Intervention n= 65)
    - RA to assist in creation → MDs to deliver
    - Preliminary analysis → D/C

 Patients who received SCPs (≈50%)
- Traditional hospital: 5 of 7 patients (71%)
- Large safety net: 4 of 8 patients (50%)
- Small safety net: 1 of 3 patients (33%)

 Patient comments
- “It wasn’t reviewed with me.” “Just handed it to me.”
- “Just received it.”
- “Gave a copy to my primary doctor.” “It will help me when I see other doctors.”
- “I like it.” “It’s good because I have a summary of everything.”
Do not impose SCP template on a clinic

- Clinician review is not enough
- Include clinicians in development or selection of template
- Understand clinic flow, resources & limitations
  - Available staff
  - Medical visit structure
  - EHR

Do not leave SCP delivery to clinician discretion

- Good intentions can buckle under clinic realities
- Institute real-time reminders
- Develop a manual to standardize
  - SCP completion
  - SCP review
  - SCP delivery

Align research aims / design & clinical initiatives
Breast Cancer Survivorship

- Breast Cancer (SUCCEED) Survivor Comprehensive Care Empowerment and Education Program
  - 245 pts & 308 visits

- Lynn Sage Breast Cancer Survivorship Program
  - 5/2012-present: 3 half-day clinics p/ wk
  - 150 patients seen & 208 visits
  - [http://cancer.northwestern.edu/public/why_northwestern/specialty_programs/programs/womens.cfm#note](http://cancer.northwestern.edu/public/why_northwestern/specialty_programs/programs/womens.cfm#note)

- 73 pts received a SCP
LSBCSP Visit Roadmap

**Recruitment**
- Physician Referral
- Staff Referral
- Self-referral
- Outreach

**Pre-Visit**
- Chart Abstraction
- Intake Questionnaire

**Clinical Visit**
- Hx & Physical Exam
- Lab Work / Screening Tests
- Referrals made
- Visit summary & education

**Follow-up**
- TS & SCP delivered @ f/u visit
- Additional f/u visits p.r.n.

**Preparation:**
- Mean (M) = 2 hr & 2 min
- Standard Deviation (SD) = 43 min
- Range: 60-200 min

**Pre-Visit**
- Mean (M) = 1 hr & 47 min
- Standard Deviation (SD) = 40 min
- Range: 40-240 min
SCP Informatics

System Integration Workflow

Northwestern Medicine Enterprise Data Warehouse (EDW) Data Integration & SCP Generation

Electronic Medical Record (EPIC) Clinical data
- Chart abstraction
  - Patient’s appointment is complete
    - EPIC automated progress note completed by clinical team
      - Progress Note signed and closed

ASSESSMENT CENTER (AC) Patient-reported outcomes
- Recruitment into the study by study coordinator
- Preregistration in AC by coordinator
- Coordinator emails AC link to patient (home), or presents forms on tablet (in clinic)
- Participant completes PROs (before or on day of appointment)

Study coordinator logs into EDW portal
- Study Coordinator selects patient from NOTIS study list and generates SCP

EDW pulls data from:
1) EPIC Progress Note
2) Assessment Center
3) Table with custom language and rules to create individualized survivorship recommendations

SCP is generated
- SCP is reviewed by clinical team
- Additional data entry/revision to SCP by clinical team
- SCP approved by clinical team

SCP is exported as a Word doc
- Scanned into EPIC
- Delivered to patient @ 3 mo f/u
- Filed for research (consented participants)
Developing the SCP Content

**review of literature** → >10 existing SCP templates / sources (>200 variables)

→ **selection** of those that best meet **clinic needs** & **existing guidelines**

[Logos and images related to healthcare and SCP content]
Vetting the SCP Template

1) Created **sample reports** w/ hypothetical pts
   - feasible for **clinical use** w/ real pts

2) Gathered **input from providers**
   - medical, surgical & radiation onc; IM; rehab.; psych.
   - congruent w/ **clinical practice**

3) Reviewed by **informatics** team
   - can be **programmed** as a report tailored for ind. pts
Lynn Sage Breast Cancer Survivorship Program
Survivorship Care Plan

It was a pleasure meeting you recently in the Lynn Sage Breast Cancer Survivorship Program! Our goal is to provide you with the best health care and to coordinate your health care among your team of physicians.

Now that you have completed your cancer treatment, we have created this personalized “survivorship care plan” for you. This care plan has a summary of your breast cancer diagnosis and treatment. It also has a plan to assist your survivorship care. Your survivorship care plan will become part of your electronic medical records at Northwestern Medical Faculty Foundation. We will also provide your care plan to other physicians outside our system with your written consent.

There are many medical terms listed in this survivorship care plan. Please feel free to ask any of your physicians or nurses what these medical terms mean.

We would be happy to discuss any questions or concerns you may have now or in the future. You can reach us at (312) 695-2487. Please also remember to visit our website (www.cancer.northwestern.edu) from time-to-time for a listing of workshops, events and educational updates focusing on the latest information about cancer survivorship.

We look forward to participating in your continued survivorship care.

Aubri Venneruso
Aubri S. Venneruso, MMS, PA-C
Physician Assistant, Cancer Survivorship

Date Prepared

07/24/2013

PATIENT INFORMATION

<table>
<thead>
<tr>
<th>Name</th>
<th>Alpa Ztest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth</td>
<td>08/21/1987</td>
</tr>
</tbody>
</table>
| Address       | 680 N Lakeshore Drive
                | Chicago, IL 60611 |
| Phone         | (608) 271-9000 |

The survivorship care plan is a summary document. The purpose of this document is to summarize your cancer treatment and provide you with a personalized survivorship care plan. This document does not replace information in your medical record or communicated by your physician, and it is current only as of the date of preparation. This survivorship care plan does not prescribe any particular medical treatment or care for breast cancer or any other disease. This care plan is not a substitute for the medical judgment of your treating physician. Use of the survivorship care plan is voluntary.
Autopopulation Overview

Epic → EDW → PROs (Assessment Center™)

‘business rules’ applied → create customized recommendations based upon clinical guidelines
Chronic Lymphocytic Leukemia (CLL) is a type of cancer that affects the white blood cells in the bone marrow. It is characterized by an abnormal proliferation of B cells, which are a type of white blood cell. CLL tends to develop slowly over time, and the symptoms may not be immediately apparent. The symptoms of CLL can include:

- Fatigue
- Fever
- Night sweats
- Weight loss
- Anemia
- Increased risk of infections
- Swollen lymph nodes
- Skin blemishes
- Palpitations
- Red or purple skin rash
- Itchy skin
- Changes in gallstones
- Intestinal blockage

The treatment for CLL depends on the stage of the disease and the patient's overall health. Some common treatments include:

- Chemotherapy
- Radiation therapy
- Biological therapies
- Immunotherapy
- Targeted therapies
- Stem cell transplantation

It is important for patients with CLL to work closely with their healthcare providers to determine the best treatment plan for their specific needs.
Needed to program discrete fields the EDW could query in order to populate the SCP.
Epic Discrete Fields

Date of diagnosis: *** (JA BIOPSY:17444)
Surgery: {JA TX SURG SITE:17521} {JA BREAST PROCEDURES:16928}***
Reconstructive surgery: {JA TX RECON SURG SITE:17522} {JA RECONSTRUCTIVE SURG:17459}
Pathology: {JA PATHOLOGY:17098}
Pathologic Stage: {JA STAGE:****}
Tumor TNM Stage: {JA T STAGING:16925} {JA M STAGING:16926} {JA N STAGING:16925} {JA STAGING:16926}
Tumor Grade: {JA GRADE:16936}
Sentinel node biopsy: {JA SENTINEL NODAL BIOPSY:16934}
Axillary Dissection: {JA AXILLARY DISSECTION:16933}
# positive nodes/total #: {JA # NODES 0-30:17526}
Lymphovascular invasion present: {PRESENT/Absent/Unknown:PRESENT}
In-situ Tumor Histology: {JA IN SITU HISTOLOGY:****}
ER status: {POSITIVE/NEGATIVE:10347}
PR status: {POSITIVE/NEGATIVE:10347}
HER-2/neu status: {JA HER2 +/-:17443}

Infiltrating ductal carcinoma
Infiltrating lobular carcinoma
Mixed ductal and lobular carcinoma
Invasive mammary carcinoma
Ductal carcinoma in situ
Inflammatory carcinoma
Medullary carcinoma
Mucinous carcinoma
Metaplastic carcinoma
Papillary carcinoma
Micropapillary carcinoma

Zzttest, Alpa

History of Present Illness:
 Treatment Summary: Breast Cancer
Site: right

PCP: John Smith, MD
Touchstone Nurse Navigator: Lynn Galuska-Elsyn

Method of Detection: self detected
Age at diagnosis: 49
Date of diagnosis: 10/22/12 (core biopsy, General Hospital, Nowhere)
Surgery: bilateral breasts skin-sparing mastectomy, sentinel lymph
Reconstructive surgery: bilateral expander reconstrucion (12/8/12)
Pathology: infiltrating ductal carcinoma
Pathologic Stage: IA
Tumor TNM Stage: T2 (2.5 cm) N2Mx
Tumor Grade: 3
Sentinel node biopsy: yes
Axillary Dissection: yes
# positive nodes/total #: 9/15
Lymphovascular invasion present: present
In-situ Tumor Histology: DCIS, minor component Grade 3
ER status: negative (0%)
PR status: negative (0%)
p53 status: positive (90%)
Ki-67: high (70%)
Onctype: no
Neoadjuvant treatment: no
Chemotherapy: yes; doxorubicin (Adriamycin) (60 mg/m2) every 21 days
Anthracycline used: yes; doxorubicin (Adriamycin)
Total lifetime anthracycline dose: 320 mg
Biologic therapy: no
CSF: yes pegfilgrastim (Neulasta)
Clinical Trial: yes; vaccine trial grstv
Radiation: yes; right chest wall and draining lymphatics 5040 cGy
Endocrine Therapy: no
Gene Testing: comprehensive BRCA 1 & 2 test negative and Baseline Echo: yes; and LVEF 58% (12/13)
Most recent Echo: yes; and LVEF 54% (3/25/13)
Weight at diagnosis: 65.2 lbs
Epic discrete field data is sent to EDW. EDW locates and pulls discrete data into the desired SCP fields.
Epic Data Informs Health Recommendations

Epic data is sent to EDW

EDW locates discrete data fields & applies business rules to generate tailored text in the desired SCP field
Data Source #2

Welcome to the COMPASS Breast Cancer Survivorship Assessment!

In collaboration with

the Lynn Sage Breast Cancer Survivorship Program
at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University
and Northwestern University Feinberg School of Medicine
PROs Inform SCPs

AC PRO data sent to EDW

EDW locates and uses PRO scores & applies business rules to generate tailored text in the desired SCP field
Survivorship Program

Beginning fall 2013

- APN to see post-tx survivors
- Previously, pts followed by medical oncology w/ some referral to PCPs
- Survivor Net will serve as pilot for SCP provision → other cancers

Mount Sinai Hospital

- serving Chicago’s Near West and South Sides
- designated disproportionate share hospital
- Racial/ethnic composition:
  - 53% African-American / Black
  - 36% Hispanic / Latino(a)
  - 4% White
  - 7% unknown / other
Meetings with oncology providers & administrators → learn how to synchronize study w/ new survivorship program

In-depth interviews w/ providers (N=8)

- 1 medical oncologist, 1 radiation oncologist, 1 surgeon, 1 PCP, 4 oncology nurses
- Largely unfamiliar w/ SCPs but some had created TSs
- In favor of SCPs (especially TSs) but concerned about staff time, training & reimbursement
- Believed preparation should take between 15-20 min & 1-2 hrs
- Most indicated could be prepared & delivered by oncology mid-level providers & / or medical oncologists
- Preferred more comprehensive templates BUT
  - Unsure whether they would overwhelm pts
  - Unsure how they could be completed in their setting
Conducted 2 focus groups w/ breast cancer survivors

- 8 w/in 4 months of completing tx
- 4 having completed tx in the last 2 yrs

Demographics:

Age: M=54.58 yrs (SD=9.01)

Race / Ethnicity: 75% Black / African American
- 25% Hispanic / Latino(a)
- 8% White

Household Income: 92% < 20,000

SCP template preferences

- More comprehensive
- Less medical formatting
Bad transition:

“It’s like divorce, and then my ex-husband’s family don’t speak to me anymore. So I get sick, who do I call?”

“I’m not saying we should have priority, but … If no one else will touch me it’s up to you because I’ve been under your care a whole year. So help me get into this so that I can continue….”

SCPs:

“That summary of my treatment from step one to step ten, all that was involved, you know, I need to know that.”

“…a plan… of what we’ll go through, services, maybe a guideline on how- what we should do or if this happens or in this situation, your family - how to pick up the pieces. You know, that hurricane that came through and now - bam, FEMA’s here!”
Survivor Net SCP Template

Pt-friendly intro

Brief TS

Comprehensive recommendations
# Cancer Treatment Summary

Total lymph nodes removed (total – sentinel node + dissection): Enter text.

Total lymph nodes positive: Enter text.

**Axillary dissection:**
- Yes
- No
- Date: Click here to enter a date.

**Sentinel node biopsy:**
- Yes
- No
- Date: Click here to enter a date.

**Tumor type:** Choose an item.

**T stage:** Choose an item.

**N / M Stage:** Choose an item.

**ER status:** Choose an item.

**PR status:** Choose an item.

**HER2 status:** Choose an item.

## Chemotherapy

**Chemotherapy Administered?**
- Yes
- No

**Biologic Therapy Administered?**
- Yes: Herceptin®
- No

**Treatment on Clinical Trial?**
- Yes
- No
- Date: Enter start date here.

**Neo-adjuvant Therapy Administered?**
- Yes
- No

**Anthracycline Administered?**
- Yes: Adriamycin®
- No

**Lifetime Dose:** 513mg

**Ejection Fraction**
- Pre-chemo: EF = 70%
- Most Recent: EF = 65%
- Date: 3/26/2013

**Drug Name:**
- Adriamycin
  - Dose: 60
  - Schedule: Every 2 weeks
  - Cycles: 4
  - Start Date: 4/24/2012
  - End Date: 6/5/2012

- Cytoxan
  - Dose: 600
  - Schedule: Every 2 weeks
  - Cycles: 4
  - Start Date: 4/24/2012
  - End Date: 6/5/2012

- Taxol
  - Dose: 80
  - Schedule: Weekly
  - Cycles: 12
  - Start Date: 7/9/2012
  - End Date: 9/25/2012

- Taxotere
  - Dose: 10
  - Schedule: Every 3 weeks
  - Cycles: 4
  - Start Date: 7/9/2012
  - End Date: 9/25/2012

**Comments:** Click here to enter text.

## Biotherapy Regimens

**Biotherapy Administered?**
- Yes
- No

**Drug Name:**
- Herceptin
  - Dose (mg²):
  - Schedule: Every 3 weeks
  - Cycles: 12
  - Start Date: 10/15/2012
  - End Date: N/A

**Comments:** Click here to enter text.

## Pathology

**Total lymph nodes removed (total – sentinel node + dissection):**

**Total lymph nodes positive:**

**Axillary dissection:**
- Yes
- No
- Date: Click here to enter a date.

**Sentinel node biopsy:**
- Yes
- No
- Date: Click here to enter a date.

**Tumor type:**
- Choose an item.

**T stage:**
- Infiltrating ductal
- Infiltrating lobular

**N / M Stage:**

**ER status:**
- Mixed lobular/ductal

**PR status:**

**HER2 status:**

**Comments:** Click here to enter text.
Pelvic Health and Cervical Cancer Screening

If age 21-29 with uterus/cervix intact:
Then:
• You should have a pap smear every 3 years.
• Your gynecologist or primary care physician may also recommend that you have a pap smear more often.

If age 30-65 with uterus/cervix intact:
Then:
• You should have a pap smear plus a human papilloma virus (HPV) test every 5 years (preferred) or a pap smear alone every 3 years.
• Your gynecologist or primary care physician may also recommend that you have these tests done more often.

If uterus/cervix removed (TAH):
• Discuss with your gynecologist the need for further pap smears and follow-up recommendations based upon your previous screening results.

If age >65
Then:
(clinician can delete either first or second bullets at their discretion)
• You should continue to have pap smears as recommended by your gynecologist or primary care physician.
• Now that you are 65 years old, you should discuss with your gynecologist or primary care physician the need for further pap smears.
Vetting the SCP

- Sinai oncology pt records reside in 3 EHRs
  1. MEDITECH: medical oncology visit & infusion center notes, pathology / lab reports.
  2. NextGen: used for surgical notes; medical oncology nurses have no access
  3. Aria Varian: used by radiology; oncology nurses do not have access

- Conducted mock runs of SCP completion
  - Consulted w/ medical informatics
  - 2 non-complex ‘pts’
    - \( M = 28 \) minutes for TS
    - \( 1^{st} = 35 \) min & \( 2^{nd} = 21 \) min
  - Informed creation of a manual
    - Where to find information in 3 EHRs
    - Rules on how to apply clinical practice guidelines to drop-down recs.
Aim 2

- **Implement the SCP intervention & evaluate its impact**
  - single arm longitudinal design; BL, 3 mo & 6 mo

- **Assess time & effort spent completing SCPs**
- **Examine how SCPs delivered in consultations**

Andersen. J. Health Soc. Behav. 1995
On the Horizon

- Impact of ACoS CoC guidelines & growing research

- Planning Actively for Cancer Treatment (PACT) Act introduced to Congress
  - Bipartisan sponsorship - California
  - Endorsed: ASCO, NCCN, National Coalition for Cancer Survivorship
  - Proposes establishing a new Medicare CC planning & coordination service
  - Include the development of a written CP delivered @ a visit @ dx built upon across phases of tx / survivorship
  - **service reimbursed @ rate ≈ transitional care management code (high complexity)**
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