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An EMR-Driven Approach to Survivorship Care Plans

In order to minimize the challenges of time and resource allocation, Oncology Specialists, SC, set out to create a survivorship care plan (SCP) using its electronic medical record (EMR) as a tool to ease the clinician's workload and time commitment, while still delivering patient-centered care at the end of treatment. We modeled our care plan after the IOM format in an effort to remain true to its varied components. Due to the range in health literacy among end-users (from patients and families to PCPs), we use language that is generic but still informative. Our original plan was to supply a comprehensive SCP to all patients completing therapy (including adjuvant and curative intent, as well as advanced and stage IV disease completing one-line of therapy) by January 2015. However, we have revised our efforts and are currently limiting this process to patients completing neo-adjuvant therapy only following the recent revision in the CoC standards (see page 46).

From EMR to SCP

Our EMR facilitates SCP creation through the ability to:

1. Auto populate appropriate data points, including diagnosis, stage, treatment regimen, and associated physicians.
2. Easily "copy and paste" patient-specific individualized information that does not lend itself to auto population—thus minimizing time spent free-filling the form. Examples of this category include freely-texted MD or RN documentation located in other parts of the EMR chart.
3. Format in such a way that patient-specific data only needs to be marked as present if applicable to that patient. If unmarked, it does not apply to the patient. A significant amount of generic language was added explaining the common trajectory of any cancer patient following the completion of adjuvant therapy and addressing fears and common concerns associated with diagnosis and treatment of cancer (i.e., toxicities, effects on relatives, genetic testing, effects of financial and insurance future, available local resources, among many others). Non-applicable information can be easily deleted. Throughout the SCP, text is carefully selected to address the reader using 6th grade reading level language to assure best possible patient comprehension.

> The documents, coupled with a dedicated care plan delivery meeting, provide a detailed summary of the care provided and contain a personalized road map for each patient for the next five years and beyond.
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Our SCP Components

Our SCP has four components: a treatment summary (Figure 1, page 54), a surveillance section, a health maintenance section (Figure 2, page 55), and a five-year follow-up plan (Figure 3, page 56).

Treatment Summary (IOM: Record of Care). This section indicates the patient's diagnosis, date of diagnosis, whether or not there was recurrence or metastasis and, if so, when and to which anatomic location(s). It lists hormonal, genetic, or molecular results, as well as relevant prognostic markers. The next portion of the treatment summary lists all modalities of treatment.

The chemotherapy section provides the regimen and individual drug names, in addition to specific delineation of chemotherapy

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Figure 1. Your Survivorship Care Plan

Your survivorship care plan is a summary of your recent cancer treatment and our recommendations for follow-up care. It provides you with some information about what to expect and where you can find answers.

TREATMENT SUMMARY

The Treatment Summary is a brief record of major aspects of your recent cancer treatment. It includes some information about your diagnosis, treatments used to treat your disease, and side effects that you have encountered.

New diagnosis date: _____ **Recurrence date:** _____

Diagnosis:

<All Primary Diagnoses with Stage> [^Primary – 174.4 – Malignant neoplasm of upper-outer quadrant of female breast, Diagnosed Apr 2014 (Active) Stage IIB, T2, N1, M0, G3^]

Hormone/genetic/molecular results and other prognostic markers (e.g., *BRAF*, *KRAS*) (must be manually entered)

Location of metastasis or recurrence (if applicable): _____

Cancer Therapies

1. **Surgery:** ☐ No ☐ Yes Type: _____
2. **Radiation:** ☐ No ☐ Yes Where: _____
3. **Chemotherapy:** Clinical Trial: ☐ No ☐ Yes Trial: _____

Chemotherapy Intent: ☐ Curative/Adjuvant ☐ Neo-Adjuvant ☐ Disease/Symptom Control

Regimen Given: ☐ First Line ☐ Other, specify: _____

Dose Sense-AC-P

Drugs: _____ Dose: _____ Frequency: _____

Dose Reductions: ☐ No ☐ Yes Reason: _____

Performance Status at the End of Treatment: [<Performance Status> [^0 – Fully active, able to carry on all pre-disease activities without restrictions. (ECOG)^]

Reason for Ending Chemotherapy: ☐ Completed ☐ Progression ☐ Toxicity

Response to Chemotherapy: ☐ Complete ☐ Partial ☐ Stable disease ☐ Progression ☐ Not measurable

Major Side Effects from Chemotherapy (Grade 3-4 Toxicities):

☐ Hair Loss ☐ Nausea/vomiting ☐ Diarrhea ☐ Neuropathy ☐ Low blood counts ☐ Fatigue ☐ Pain

☐ Menopause symptoms ☐ Mucositis ☐ Cognitive impairment ☐ Cardiac ☐ Weight changes ☐ Other: (Specify)

_____

4. **Hormone Therapy:** ☐ No ☐ Yes

Line of Therapy: _____

Intent: ☐ Curative/adjuvant ☐ Disease/Symptom control

Drug/dose: _____

Referrals Provided during Treatment

Physicians: _____

☐ No "Referrals to" exist for this patient

☐ Nutritionist ☐ Psychologist ☐ Physical Therapist ☐ Geneticist ☐ Survivorship Center

☐ Other (Please Identify): _____

Figure 2. Your Follow-up Plan

With any cancer diagnosis, there is a possibility your cancer could return. The chance of this happening depends on the stage and grade of the original tumor. A recurrence could occur locally, which means that the tumor may come back in or near the same area where it was originally located. There is also a chance that the cancer cells from the original tumor could travel to sites farther away from the original tumor, including organs like the lungs, liver, or bones. Part of your follow-up care may include specific exams, blood work, and scans to check for presence of recurrence of your cancer.

5-YEAR POST-TREATMENT PLAN FOR CANCER FOLLOW-UP (medications [e.g., hormones], scans, labs, exams)

Immediate Plan: _____

_____

1- to 5-Year Plan: _____

_____

Treatment for ongoing or long-term side effects (list ongoing side effects and treatment, including PT/medications, etc.):

Many of the side effects from your treatment occur during and a short time after you receive your treatment. Most of these side effects eventually resolve over days or in a few cases months after you complete your treatment. Sometimes, there may be long-lasting side effects that do not completely resolve. You will be closely monitored for long-lasting side effects, and we will discuss additional interventions with you if your recovery is slower than expected.

☐ Side effects have resolved ☐ Side effects persist and are listed below (please describe)

_____

_____

Many cancer treatments have a small risk of causing long-term problems. Some treatments can affect your kidneys, heart, or lungs. They may also cause lifelong numbness or tingling, hearing loss, brittle bones (osteoporosis), thyroid problems, swelling in an arm or leg, diabetes, and other cancers. Some people may have trouble getting pregnant or be unable to get pregnant. You will be followed closely by your doctors for possible long-term effects from your cancer treatment. We want you to discuss any changes in your usual state of health with your healthcare provider team. Many of these problems would be found as part of your routine follow-up and surveillance, but some would require specific testing.

List any known long-term effects that should be monitored based on agents given:

_____

_____

Other Possible Life Effects from Your Cancer Diagnosis:

A cancer diagnosis is always life changing. Along with the physical effects of treatment, your cancer diagnosis and your treatment may have other effects (for example):

- *It may affect your body image, your physical relationships, and your sexual function.*
- *It may impact your personal relationships or you may feel more stressed at work or with your family.*
- *It may impact on your ability to obtain life insurance and may influence your employment.*
- *But, there is help and support available at our Cancer Survivorship Center* [phone number] *or talk to your healthcare provider about your concerns.*

Concerns for Your First-Degree Relatives (children, sisters, brothers, parents):

Most cancers are not related to a genetic predisposition. But, some cancers can occur in families and may be associated with a known genetic mutation. Your genetic risk was assessed by your oncologist and a genetic referral was found to be:

☐ Indicated ☐ Not Indicated

Your Genetic Mutation is:

Your diagnosis of cancer may have implications on your family members even if a genetic mutation is not found. Please tell your first-degree relatives to inform their healthcare providers of your diagnosis and to undergo screening tests for [Fill in the type of cancer].

_____

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intent (curative, adjuvant, neo-adjuvant, or palliative). Reasons for ending chemotherapy (completion, progression, or toxicity) are listed, as well as the patient's response to chemotherapy (complete, partial, stable disease, progression, or not measurable). Common grade 3-4 toxicities from chemotherapy are listed and can be selected and explained as applicable to the patient.

Additional supportive therapies used are detailed in the referrals portion included, along with a listing of additional physicians and healthcare providers that the patient was referred to (nutritionists, psychologists, physical therapists, geneticists, etc.).

Surveillance Section (IOM: Standards of Care). This section contains generic language addressing: the short- and long-term toxicities commonly encountered with cytotoxic therapy; how the patient will be monitored for these toxicities; and what to expect in terms of recovery from any current and listed toxicities. Additionally, risk for disease recurrence and monitoring for disease recurrence is addressed here. We also discuss the risk of the patient's malignancy to affect his or her blood-related relatives and include screening recommendations for them, as applicable. Lastly, we address the need for genetic counseling and testing and document whether these options were recommended and/or performed and whether these options should or should not be pursued at this time.

Health Maintenance. This section aims to promote survivorship through identification of resources that the patient can use to incorporate healthy behaviors. The first part of this section is a reference to a separate document, the Health Maintenance Form, which outlines early prevention and standard cancer screening recommendations. The SCP contains a field to ensure that the Health Maintenance Form is explained and delivered to the patient. This explanation is followed by specific recommendations from the oncologist regarding healthy behaviors, such as smoking cessation, exercise, diet and weight loss, stress and psychosocial support, and financial counseling. Any ongoing chronic medical conditions that require follow-up with the PCP are also outlined, as these auto-populate from the medical problems/diagnoses list captured in the EMR.

Figure 3. Your Health Maintenance

With the completion of this treatment, it is a good time to re-establish your relationship with your primary care physician for general health follow up. Health maintenance is very important and a form has been provided to you for a reference. Some of the prevention tests will be ordered by your primary care physician and others may be ordered by your oncologist. Share this form with all your physicians.

Health Maintenance form reviewed and copy given to patient

☐ Yes ☐ No (If no, explain why not): _____

Recommendations from your oncologist

Healthy living is important now that you are through treatment. This may include smoking cessation, diet modification, sunscreen use, weight-bearing exercise, stress reduction, or other behaviors that would enhance your well-being.

☐ Smoking cessation ☐ Diet modification ☐ Sunscreen use ☐ Stress reduction/psychosocial support

☐ Exercise program ☐ Financial counseling ☐ Weight loss ☐ Other: _____

Other ongoing chronic conditions that need follow-up with your primary care physician:

_____

_____

If you have not done so, please make an appointment with your primary care physician.

Resources are available:

As you continue your life as a survivor, you may have more questions or concerns. There is help for you! Here are a few suggested resources:

- *Your physicians and other members of your healthcare team.*
- *The Cancer Survivorship Center, 1999 Dempster Street, Park Ridge, IL 60068, (phone) 847.723.5650*
- *The American Cancer Society, www.cancer.org, (phone) 800.782.7716.*
- [List other resources, as applicable.] _____

Five-Year Follow-Up Plan. This section contains a disease-specific follow-up plan detailing the frequency of planned doctor visits, and scheduled laboratory and imaging tests, as applicable, in their frequency and duration (i.e., how often, for how many years). Additionally, reference is made to the need for continued follow-up with other physicians and healthcare providers involved in the individual's cancer treatment. These plans were developed following ASCO and NCCN guidelines for appropriate post-treatment cancer patient surveillance and are disease-specific. Where no such guideline exists (less-common cancer conditions), the treating oncologist develops a surveillance plan based on his or her experience and expertise.

Our SCP Generation Process

As treatment nears completion, the chemotherapy RN who has been thus far responsible for the patient's therapy delivery generates a draft of the SCP. This process was intuitive in our practice as we have a primary nurse model, where all chemotherapy nurses are assigned to their patient at the start of therapy and will follow that patient through the entire trajectory of treatment. At the start of SCP creation, auto-populated and generic content is automatically transferred into the plan. Thereafter, the RN, who is the clinician with the most familiarity and experience with the patient's treatment course, records information on treatment timings, toxicities, dose reductions, delays, etc., into the SCP. Upon completion of therapy, the RN forwards the document to the treating oncologist who is then responsible for finalizing all of the information. In addition, the physician is also responsible for generating the detailed five-year surveillance plan.

Our SCP Delivery

A dedicated clinic visit for delivery of the SCP and supporting documents is scheduled within three to eight weeks after the last treatment cycle. The patient first spends 20 minutes of this visit with the treating oncologist who presents and explains the major components and structure of the SCP, including the five-year surveillance plan.

Immediately after the MD visit, the patient then meets with the primary chemotherapy RN who reviews the entire care plan in detail. This step is vital as it provides an opportunity for patients to clarify any questions about the documents with a clinician with whom they are comfortable and familiar.

The finalized survivorship care plan and its supporting documents are then printed and given to the patient, as well as uploaded to the electronic patient portal. A copy is also sent to the physicians associated with the patient's care (PCP, radiation oncologist, surgeon, and others, as applicable).

Our Results

The composite of the SCP, health maintenance form, and five-year surveillance plan is a comprehensive treatment summary and care plan. Using our EMR, all documents are easily customized to each individual patient, diagnosis, and treatment. The language used throughout all documents is carefully selected to be easily understood and highly-informative for all involved parties—from providers to patients and their families. The documents, coupled with a dedicated care plan delivery meeting, provide a detailed summary of the care provided and contain a personalized road map for each patient for the next five years and beyond. Finally, by sharing these documents with the patient's other providers, all care partners are involved in the patient's survivorship.

Cancer Survivorship Care Plan development team at Oncology Specialists, SC. (L to R) Anna Shew, RN, OCN, BA; Sigrun Hallmeyer, MD; Abigail Dillon, RN, BSN, OCN; Susie Sultan, RN, BSN, OCN; Susan Kelby, RN, OCN, MSN; and Marybeth Mardjedko, RN, MN (practice manager).

Our Process within the Context of SCPs Today

We hope that some of the deficiencies surrounding SCPs in use throughout the U.S. cancer care community have been addressed in our effort, including variation in content and variation in delivery timing, which we sought to standardize. Our SCP has been modeled on the IOM framework and remains consistent with its requirements. Addressing the barriers to SCPs regarding their use of time and straining of limited resources reported in literature, our EMR-driven process allows for efficient generation of the care plan in terms of both time and effort.

In our experience thus far, the estimated RN time and oncologist time required for generation of the SCP are 15 to 30 minutes and 15 minutes respectively. The delivery meeting involving the treating oncologist and RN whom the patient has grown familiar with, serves as a reinforcing step to ensure any ambiguous parts of the documents are sufficiently explained to and understood by the patient.

The feedback we have received since implementation of this process has been overwhelmingly positive. Patients appreciate the opportunity to understand and reflect on their diagnosis and treatment course. The implementation of the survivorship care plan provides patients a measure of reassurance about what lies ahead. We have learned that the opportunity to ask questions about the disease, treatment, and the upcoming survivorship

Patient-centered discussion and review of the Cancer Survivorship Care Plan.

surveillance schedule is important to patients, especially at the end of treatment when the initial stress and anxiety surrounding a cancer diagnosis is no longer strongly preventing the patient from comprehending and absorbing complex information.

Future Direction

Through our survivorship care plan generation and delivery process, we have created a resourceful tool that provides description of care and continuation of support. Our employment of the SCP is a significant tool in providing holistic and patient-centered care to our cancer survivors rather than abandoning them to an unregulated environment once they leave the highly-ordered realm of cancer treatment. We have been able to demonstrate that the IOM guidelines and updated CoC standards for SCPs are attainable in a busy community oncology practice. We hope that our EMR-driven process is one that can be replicated by other oncology practices in the community.

We have noted to our own surprise that there is great variation within our group of physicians regarding the recommendation and implementation of our five-year surveillance plans. As a result, we aim to standardize these plans (based on national or expert consensus guidelines, when available) and are in the process of developing standardized disease- (and if applicable stage-) and treatment-specific surveillance plans for all diagnoses encountered in our institution.

Now that the need for SCPs has been made clear by some of the literature cited previously (see pages 44-50), and these plans are slowly gaining more traction in terms of use, we recognize further steps are needed to improve their utility. In line with this finding, we hope to study the effectiveness of our SCP and quantify patient feedback so that necessary changes can be made. Currently, patients provide feedback at the time of the survivorship care plan discussion meeting. In the future we plan to contact a sample size of patients post-meeting and ask that they fill out a specific questionnaire. While our SCP is being fully implemented, studied, and modified for patients in the adjuvant and curative treatment setting, we hope to develop survivorship care plans for patients with advanced disease moving onto their next therapy, including all stage IV patients completing a first course of therapy. We strongly believe that this group of patients (and their associated healthcare providers) will also greatly benefit from the information provided. OI

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