Cancer Quality Alliance Proceedings

Passport for Care: Implementing the Survivorship Care Plan

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The Need

In their report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,¹ the Institute of Medicine and National Research Council recommend that a patient completing primary treatment for cancer be given a summary of treatment and a comprehensive plan for follow-up. In addition, it is suggested that this survivorship care plan be provided to the patient's primary care provider. Such a plan would inform the patient (and health care provider) of the long-term effects of cancer and its treatment, identify psychosocial support resources in the community, and provide guidance on follow-up care, prevention, and health maintenance.² This recommendation emanates from the recognition that as a consequence of success in cancer therapy, there are approximately 12 million survivors of cancer in the United States. Many of these survivors suffer long-term health sequelae of their illness and its treatment.

The Passport for Care (PFC) was developed to be the childhood cancer survivor's signpost, guiding the survivor and health care provider through this challenging and ever-changing world. The need for survivorship care plans is particularly relevant in the population of survivors of childhood cancer. Each year, approximately 12,000 children in the United States are diagnosed with cancer. As a result of recent research advances, approximately 75% of these patients become long-term survivors. In fact, experts estimate that by the year 2010, one in every 250 adults will be a survivor of childhood cancer. However, survivorship is not without risk. The Childhood Cancer Survivor Study of 10,397 survivors found that 62.3% had at least one chronic medical condition, and 25.7% had a severe or life-threatening condition.³ The report of the 2003 and 2004 President's Cancer Panel states that "for the nearly 10 million Americans now living with a cancer history, life after cancer means finding a new balance—one that celebrates the triumph and relief of completing treatment, recognizes changes or losses the disease has wrought, and assimilates revised perspectives, newfound strengths, and lingering uncertainties. Typically, few signposts exist to guide these highly personal journeys into a familiar but forever changed world."⁴

PFC Features

The PFC is an Internet-based tool developed to provide survivors of childhood cancer and their health care providers with

the individualized, accurate, and timely health care information necessary to maximize their health potential. Figure 1 offers a glimpse of the design and resources of the PFC. The PFC provides long-term survivors and their health care providers with summaries of the survivors' cancer history and treatment, displayed in a user-friendly format.

This information drives algorithms to produce individualized monitoring and management recommendations derived from the Children's Oncology Group (COG) long-term follow-up guidelines (www.survivorshipguidelines.org). These guidelines represent expert consensus regarding the evidence for screening recommendations for all of the 146 known potential late effects of childhood cancer and its treatment formulated by more than 20 expert task forces of the COG. The PFC displays these recommendations in user-friendly outputs. For example, the health care provider is provided with all of the information necessary to evaluate the survivor, including the appropriate questions to ask when taking the history, the specific findings to search for in physical examination, and the appropriate laboratory and diagnostic tests to order. These outputs are individualized for each survivor on the basis of his or her unique treatment history. Another view of the information gives the health care provider a quick summary of all of the recommended tests. The levels of expert consensus for each recommendation as well as the pertinent medical references are made available through links and rollovers.

The initial PFC version is specifically designed for use by the survivor's health care provider. A survivor Web portal under development will give each survivor the ability to control the sharing of his or her information as well as access to social networking features including disease-specific survivor chat rooms and survivor stories. Additional features under development include information resources for the survivor individualized on the basis of his or her zip code and specific needs, such as health insurance information, prosthetic shops, and support groups. The confidentiality and privacy of information in the PFC is protected using security methodologies compatible with the requirements of the Health Insurance Portability and Accountability Act and the highest levels of Internet security procedures.

Figure 1. Selection of Passport for Care resources.

Passport for Care Admin (logged in: [username])
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 Provided for: Testing Clinic

Care Summaries | Security List | Clinic List | Consent Management | User Administration | System Notifications | Help Desk/FAQ

List of Donors

Care Summaries | Guideline Administration | Guideline Screening Administration

Peter Smith (CONSENT VIEW & UPDATE)

Summary of Treatment | Additional Information | Cumulative Summary | Follow-Up Guidelines | Revision History

Abbreviated Summary of Treatment

SECTION ONE

DEMOGRAPHIC INFORMATION

Prefix: Peter MI: Last Name: Smith Sex: M Date of Birth: 06-03-1994 (mm-dd-yyyy)

Medical Record Number: [blank]

CANCER DIAGNOSIS

Diagnosis: Leukemia Date of Diagnosis: 07-10-2000 (mm-dd-yyyy) Date Therapy Completed: 01-24-2003 (mm-dd-yyyy)

Acute lymphoblastic leukemia

Update Section One

SECTION TWO

SECTION THREE

Please enter all treatment agents for every cancer experience.

SURGERIES

PROCEDURE: 1 Central venous catheter LATERALITY (IF APPLICABLE): [blank]

CHEMOTHERAPIES

Drug Name: 1 Dexamethasone Additional Information: 904 mg/m2

2 Asparaginase 60000 units/m2

3 Methotrexate (low dose IV) 5000 mg/m2

RADIATION

Note: To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)

SITE/FIELD: 1 Spine: Spine (lumbar) TOTAL DOSE/W BOOST (Gy): 45.00 Gy

2 Head/Brain: Cranial (whole brain) 24.00 Gy

HEMATOPOIETIC CELL TRANSPLANT

OTHER THERAPEUTIC MODALITY

COMPLETE EVALUATIONS

NAME: Peter Smith
 DIAGNOSIS DATE: 07-10-2000
 SEX: Male
 AGE DIAGNOSED: 6-1/2 Years
 DOB: 06-03-1994
 DIAGNOSIS: Leukemia Acute lymphoblastic leukemia

HISTORY

EVALUATION

POTENTIAL LATE EFFECT

General

Assessment of nutritional status: Every six months until growth is completed, then yearly Growth hormone deficiency

Skin/Head

Skin lesions: Changing moles (asymmetry, bleeding, increasing size, indistinct borders) Dysplastic nevus; Skin cancer

Tenderness or swelling at previous catheter site Thrombotic; Vascular insufficiency; Infection of retained out of the tract

Eyes/Ears/Nose/Mouth/Throat/Head

Rhinorrhea, postnasal discharge Chronic sinusitis

Visual changes (decreased acuity, halos, diplopia) Cataracts

Xerostomia Xerostomia; Salivary gland dysfunction

Cardiovascular

Vasospasms of hands, feet, nose, lips, cheeks, or earlobes related to stress or cold temperatures Vasospastic attacks (Raynaud's phenomenon)

Musculoskeletal

Bone pain (especially in irradiated field) Bone metastases

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Care Summaries | Security List | Clinic List | Consent Management | User Administration | System Notifications | Help Desk/FAQ

List of Donors

Care Summaries | Guideline Administration | Guideline Screening Administration

Peter Smith (CONSENT VIEW & UPDATE)

Demographics | Primary Diagnosis | Relapses | SMH | Additional Information | Cumulative Summary | Follow-Up Guidelines

Periodic Evaluations

History

EVALUATION POTENTIAL LATE EFFECT FREQUENCY

General

Assessment of nutritional status

SCORE 1: There is uniform consensus of the panel that: (1) there is high-level evidence linking the late effect with the therapeutic exposure and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

1 Growth hormone deficiency (90) Guideline | References | Health Links YEARLY Every six months until growth is completed, then yearly

1 Dysplastic nevus; SK Guideline | References | Health Links

1 Thrombotic; Vasc Guideline | References | Health Links

Tenderness or swelling at previous catheter site

This is a summary. Please see complete guidelines on the website.

REFERENCES

1. American Society of Clinical Oncology. Survivorship care plan: a guideline for the effective use of survivorship care plans. J Clin Oncol. 2006;24:2811-2819.

2. American Society of Clinical Oncology. Survivorship care plan: a guideline for the effective use of survivorship care plans. J Clin Oncol. 2006;24:2811-2819.

3. American Society of Clinical Oncology. Survivorship care plan: a guideline for the effective use of survivorship care plans. J Clin Oncol. 2006;24:2811-2819.

PFC Testing and Implementation

Baylor College of Medicine and the COG—a consortium of approximately 230 children's cancer programs throughout North America and Europe—plan to use the PFC to distribute individualized COG long-term follow-up guidelines via the Internet. The COG will continue to update the guidelines in the PFC, which now serves as the central repository for its survivorship guidelines. The PFC has been in use at Texas Children's Cancer Center in Houston, Texas, for the past year and

is currently being implemented in three additional COG clinics for beta testing. Over the next 18 to 24 months, we plan to make the PFC available to all COG clinics.

PFC and Outcomes

The hypothesis behind the development of the PFC is that physician behavior in the care of long-term survivors, the quality of the care, and the health outcomes of these patients may be

enhanced by access to guidelines that are customized to a patient's medical history. However, the value of the PFC in improving health care behaviors and outcomes will need to be demonstrated rigorously using randomized, controlled trial methodologies. Clinical trials must be designed to demonstrate the fundamental premise that use of the PFC alters health care provider behavior to increase compliance with COG guidelines and improve survivor knowledge of and adherence to self- and provider screening recommendations and healthy behavior. In addition, clinical trials are needed to assess whether the adoption of these guidelines will, in fact, alter the health outcomes of this patient population.

PFC for Survivors of Adult Cancer

The PFC provides a model for care of pediatric cancer survivors that will, in the future, be extended to survivors of adult cancers. However, this process must await the development of comparable guidelines for the care of survivors of adult cancers.

References

1. Institute of Medicine, National Research Council: From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC, National Academies Press, 2005
2. National Coalition for Cancer Survivorship and Institute of Medicine National Cancer Policy Forum Workshop: Implementing Cancer Survivorship Care Planning: Workshop Summary. Washington, DC, National Academies Press, 2007

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Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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