Journey Forward: The New Face of Cancer Survivorship Care

By Jennifer Hausman, MPH, Patricia A. Ganz, MD, Thomas P. Sellers, MPA, and Joel Rosenquist, MPA

Identifying the Need

In light of new and more effective medical advancements, many cancers are now being recognized and treated as chronic conditions, with real and ongoing long-term physical and psychosocial health consequences.¹ The 2005 report from the Institute of Medicine (IOM)¹ identified the need for ongoing late- and long-term effects monitoring, yet the report found that survivors are often lost in transition after active treatment because of both lack of awareness about survivorship needs and poor coordination of care between oncologists and primary care physicians (PCPs). Care is often fragmented and poorly coordinated because most patients are cared for by community clinicians and are not seen within an integrated health care delivery system.

Many of the 12 million survivors of cancer² in the United States are unaware of their changed health care needs. Those who are aware often have difficulty navigating a system that was not designed to address their needs.¹ Fortunately, patient needs and concerns are becoming more integral to cancer care. Studies have shown that patient-centered care has the potential to rectify the barriers outlined by the IOM, improve patient satisfaction and the quality of care and health outcomes, and decrease health care costs.³

This new focus on patient-centered care has begun addressing many of the issues that survivors of cancer face, and it represents a significantly different approach to the delivery of survivorship care through the introduction of facilitated dialogue between the patient and providers. Changing the culture of oncology by involving the patient in shared decision making requires a combination of efforts across key areas: informed and involved patients, receptive and responsive health professionals, and a supportive health care environment.⁴

One specific strategy to change practice and facilitate post-treatment communication and coordination is the development of survivorship care plans, which include comprehensive treatment summaries and follow-up care plans that are clearly and effectively explained.¹ Along with detailing the disease and its treatment regimen, a plan promotes patient-centered care by providing an assessment of the survivor's psychosocial needs and recommending resources, preventive behaviors, and interventions.

Yet, although there is general consensus that survivorship care plans hold promise in addressing post-treatment care, a preliminary market research focus group indicated that plans have not seen widespread use, largely because many patients and PCPs are simply not aware of them and oncology professionals have considered them too time-consuming and burdensome because of their complexity and paper-based format.^{5,6}

A New Model for Change

Among its several recommendations, the 2005 IOM report called for a joint effort by health care providers, patient advocates, payers and health plans, employers, and sponsors of research to raise awareness of the needs of survivors of cancer, to establish survivorship as a distinct phase of cancer care, and to ensure the delivery of appropriate care.¹ In response, the American Society of Clinical Oncology (ASCO) began developing survivorship care plan templates. Other tools were subsequently developed, such as the LIVESTRONG Care Plan (powered by Penn Medicine's OncoLink [Philadelphia, PA]), NursingCenter.com's Prescription for Living (Lippincott, Williams & Wilkins, Ambler, PA), and homegrown solutions to respond to the need for greater survivorship care planning.

In early 2007, the pooled knowledge, relationships, and resources of WellPoint, the University of California, Los Angeles (UCLA) Jonsson Comprehensive Cancer Center, the National Coalition for Cancer Survivorship, and Genentech formed the Journey Forward program, which seeks to:

- change the way survivorship care is delivered;
- establish a new standard of care for survivors of cancer;
- enhance patient and physician understanding of late- and long-term effects of cancer treatment and survivorship; and
- improve the continuity and coordination of care.

With multiple perspectives and differing abilities, the four organizations lend their strengths and create synergy to address the needs of all members of the oncology community—providers and patients—and policymakers.

WellPoint brings to the collaboration its ability to reach out to broad networks of providers; to use provider satisfaction surveys to gauge reactions to the implementation of survivorship care plans and assess preparedness to treat long-term survivors of cancer; and to use patient surveys to assess satisfaction with the Journey Forward toolkit and the intention to request a survivorship care plan from providers. The National Coalition for Cancer Survivorship represents the voice of survivorship and maintains key relationships with policy makers, which are essential to improving the quality of survivorship care. The UCLA Jonsson Comprehensive Cancer Center contributes a considerable history and body of survivorship care planning research through the involvement of Patricia Ganz, who is widely known as a pioneer in the post-treatment movement. Genentech provides a strong track record of oncology support programs that address issues faced by patients and providers.

Finally, reflecting the critical role of nursing professionals in the delivery of survivorship care, the Oncology Nursing Society—representing more than 35,000 registered nurses and other health care providers—is planning to join the collaborative, thereby extending its reach.

Evidence-Based Initiative

The collaborating organizations have developed Journey Forward to enable health care providers to quickly and easily create customized treatment summaries and follow-up care plans to enhance communication and coordination, improve post-treatment care, and empower patients to be more involved in their survivorship experiences.

On the basis of the IOM’s recommendations and the availability of the ASCO surveillance guidelines and treatment plan and summary templates, the collaborative developed the Survivorship Care Plan Builder (SCPB), a software tool used to create treatment summaries and care plans, the Journey Forward Patient and Provider Toolkits used to disseminate the tool, and other resources. The SCPB runs on Windows platforms, including Windows XP, Windows Vista, and Windows 7. Care plans produced by the SCPB can be exported to Microsoft Word, to Microsoft Excel, and to PDF format. Patient data—which can be stored on the user’s local hard drive or on a secured, internal network drive designated by the user—are saved as an XML file.

The goal of the Journey Forward program is to provide efficient ways to facilitate and simplify communication between doctors, clinicians, and survivors. The sharing of the Journey Forward plan for follow-up care presents an opportunity for open, honest discussions between providers and survivors and allows the latter to voice needs and concerns, thus empowering survivors to be more involved in their care. When given to other health care providers, the plan facilitates a handoff and provides adequate resources so other providers feel more knowledgeable and better able to deliver appropriate survivorship care. In addition to addressing the need for more patient-centered post-treatment care, Journey Forward survivorship care plans have the potential to impact cost as well as quality of care by reducing duplicate, excess, and inappropriate testing by supporting screenings rather than more costly interventions. Journey Forward collaborators anticipate that outcome research will be conducted to explore these hypotheses. Specifically, Journey Forward aims to:

- summarize and communicate what transpired during cancer treatment;
- describe known and potential late- and long-term effects of cancer treatments with expected time course to enable monitoring;
- convey to the survivor and other providers what needs to be done to promote a healthy lifestyle; and
- help prevent disease recurrence, decrease the risk of other comorbid conditions, and ensure higher-quality cancer care.

Journey Forward resources include the SCPB software tool for providers as a centerpiece that empowers oncology professionals to generate custom care plans in a fraction of the time it would take to do so longhand. The SCPB captures information essential to post-active treatment, presents it in a manner easily assimilated by patients and their PCPs, and assists oncologists and PCPs in delivering follow-up care (Appendix Fig A1).

The Journey Forward SCPB—adapted in part from the ASCO Chemotherapy Treatment Plan and Summary templates and the ASCO Survivorship Care Plan Surveillance Guidelines for patients with breast and colon cancers—provides electronic templates with drop-down menus that can be personalized for individual patients (Appendix Fig A2). Current versions of the Journey Forward SCPB include breast and colon cancer templates and a generic version. Additional tumor-specific templates are planned using templates that have been vetted by ASCO.

Finally, to empower the survivor of cancer, Journey Forward resources include a patient toolkit with materials such as “Tips on Talking With Your Doctor,” which encourages patients to ask oncologists for a survivorship care plan (Table 1; Appendix Fig A3).

The collaborative convenes regularly to ensure that Journey Forward resources remain current, targeted, and highly relevant to each stakeholder in the oncology community and to continue driving the adoption of survivorship care planning. The Journey Forward program is, and will, be provided free of charge to individuals and institutions.

Evidence Based

Leveraging WellPoint’s affiliated health plans’ provider networks and access to plan members, the Journey Forward program was developed and continues to evolve on the basis of survey results, focus group findings, and ongoing feedback about the program. Notably, WellPoint’s affiliated health plans’ annual internal provider satisfaction surveys since 2006 continue to demonstrate that PCPs feel better prepared to handle the transition and any late cancer effects when they receive timely end-of-treatment summaries and survivorship care plans.⁷ In 2007, four patient focus groups were conducted, including male and female survivors of colon and breast cancers treated with various modalities.⁶ During this same time period, in-depth interviews were conducted with California and Colo-

Table 1. Journey Forward Program Resources

Resource
Provider toolkit
Open letter to oncology providers
Overview and benefits of survivorship care plans (with sample templates)
ASCO survivorship care plan surveillance guidelines
Survivorship Care Plan Builder overview and CD-ROM
Resource directory
Patient toolkit
Overview and benefits of survivorship care plans (with sample templates)
Tips on talking with your doctor
Medical history builder overview and CD-ROM
Patient guidelines for follow-up care
Resource directory
JourneyForward.org
Resource for all program materials, electronic tools, and updates
Survivorship library

rado health care providers, including oncologists, oncology nurse practitioners, PCPs, and obstetrician/gynecologists.⁵ To provide strategic direction and vital feedback on program materials, a Journey Forward advisory board meeting was held in October 2007 with key opinion leaders from national organizations and cancer centers, community oncology and primary care providers, survivors of cancer, and representatives from the Journey Forward collaborative.

Evidence of Change

Providers and survivors of cancer are implementing Journey Forward, given its public availability since 2009, promotion through conferences, and mailings to targeted adopters. As of August 2010, the Journey Forward collaborative metrics indicate that more than 4,000 health care professionals are actively using the SCPB. The number of users continues to increase as more providers and survivors are made aware of its availability. In 2010, WellPoint conducted a quantitative research study⁸ among survivors of breast and colon cancers who were members of its affiliated health plans to assess satisfaction with the Journey Forward program and materials. Study conclusions led the collaborative to promote survivorship care planning earlier in treatment cycles or just at the conclusion of active treatment.

Challenges Ahead

The Journey Forward program is not without its challenges. Notably, additional scientific evaluation is needed to validate outcomes and demonstrate the impact and value of receipt of a treatment summary and care plan. Additionally, evidence-based surveillance guideline research and survivorship data for many cancer types are lacking and are necessary to enhance the value and benefit of survivorship care plan implementation.

In 2010, the Centers for Disease Control has funded two institutions (the University of North Carolina at Chapel Hill [Chapel Hill, NC] and a partnership between Dartmouth College [Hanover, NH] and the University of Vermont [Burlington, VT]) for special interest project grants to advance the understanding of best practices in survivorship care planning by examining the feasibility of completing and delivering an end-of-treatment consultation note in accordance with IOM guidance, specifically using the Journey Forward tool. The objectives of the special interest project grants are to:

- implement a survivorship care plan using Journey Forward material that includes the essential care plan components outlined in the 2005 IOM report;
- define how the information in the survivorship care plan will be obtained, who will be responsible for completing the plan, and who will communicate the plan to the survivor;
- pilot the survivorship care plan in a clinical setting, evaluate the process of plan completion from the provider's perspective, and gauge the utility and comprehensibility of the plan from a survivor's viewpoint; and
- disseminate knowledge gained from this intervention and suggest future outcome measures and studies.

Future challenges include the incorporation of the SCPB into existing electronic medical records (EMRs). As EMRs become the standard in practice and case management, addressing this need will be critical to widespread adoption of Journey Forward tools. The collaborative continues to explore ways to overcome this potential barrier with current efforts working with EMR vendors and the National Cancer Institute and its EMR initiative.

Finally, there is the challenge of adequate reimbursement for oncology providers to prepare survivorship care plans for patients; time spent delivering the survivorship care plan is reimbursable. However, there are two efforts underway to incentivize survivorship care planning including revised accreditation standards by the Commission on Cancer to add new survivorship care planning requirements in 2012 and a reintroduction of the Comprehensive Cancer Care Improvement Act legislation that will provide Medicare reimbursement for completing survivorship care plans.

Changing the Practice of Survivorship Care: An Innovative Collaboration

The Journey Forward collaboration is unique in its member diversity and mission, because it is focused on the improved coordination of post-treatment care through the use of survivorship care plans. Few, if any, models of this scope exist within the cancer community. Although the value of collaboration is recognized, this model of working together with such diverse but essential stakeholders to impact practice behavior represents a unique approach to improving the quality of survivorship care. As with any health care innovation, it may take 10 to 20 years for the acceptance and institutionalization of this approach. Given the increasing emphasis on patient-centered care, the tools and strategies that are made available through Journey Forward will facilitate this approach for patients who have recently completed cancer treatment and to ameliorate concerns about their being lost in transition.

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Authors' Disclosures of Potential Conflicts of Interest

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Author Contributions

Conception and design: Jennifer Hausman, Patricia A. Ganz, Thomas P. Sellers, Joel Rosenquist

Manuscript writing: Jennifer Hausman, Patricia A. Ganz, Thomas P. Sellers, Joel Rosenquist

Final approval of manuscript: Jennifer Hausman, Patricia A. Ganz, Thomas P. Sellers, Joel Rosenquist

Jennifer Hausman, MPH, is Clinical Research Manager, WellPoint. Patricia A. Ganz, MD, is Professor, University of California, Los Angeles, Schools of Medicine and Public Health, Division of Cancer Prevention & Control Research, Jonsson Comprehensive Cancer Center. Thomas P. Sellers, MPA, is President and Chief Executive Officer, the National Coalition for Cancer Survivorship. Joel Rosenquist, MPA, is Senior Manager, Genentech.

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Appendix

Figure A1. Completed survivorship care plan.

File Edit Tools Help

Cancer Survivorship Care Plan Builder

Breast Cancer Survivorship Care Plan for Jane Doe

General Information | Background Information | Treatment plan | Treatment summary | Follow-up care

Care plan prepared by:
 Care plan prepared on:
 Practice site:
 Patient name:
 Medical record number:
 Patient phone (home):
 Patient phone (cell):
 Patient email:
 Age at diagnosis:
 Date of birth:

Care Team:

	Name	Phone	Email
Support contact	John Doe	707-555-1200	JohnDoe@gmail.com
Hematologist/oncologist	Dr. Pam Gatto	707-555-1001	Gatto@gmail.com
General/breast surgeon	Dr. Jake McDermott	707-555-1212	McDermott@gmail.com
Radiation oncologist	Dr. Tanner Vausekukas	707-555-1213	Vausekukas@gmail.com
Plastic surgeon	Dr. James Romano	707-555-1214	Romano@gmail.com
Primary care physician	Dr. Stephanie Vargas	707-555-1215	Vargas@gmail.com
OB-GYN	Dr. Beth Krantz	707-555-1216	Krantz@gmail.com
Nurse/nurse practitioner	Dr. Jane McDermott	707-555-1217	Smith@gmail.com
Mental health/social worker	Dr. Jane McDermott	707-555-1218	Krantz@gmail.com
Coordination of care	Dr. Stephanie Vargas	707-555-1219	Deutch@gmail.com
Nurse navigator	Dr. Jane McDermott	707-555-1219	Deutch@gmail.com

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File Edit Tools Help

Cancer Survivorship Care Plan Builder

Breast Cancer Survivorship Care Plan

General Information | Background Information | Treatment plan | Treatment summary | Follow-up care

Chemotherapy start date:
 Height: in Pre-treatment BSA: 1.77 m²
 Pre-treatment weight: lb Pre-treatment BMI: 25.6
 Last pre-treatment menstruation:
 Pre-operative chemo administered: ☐ Yes ☐ No
 Regimen:
 Treatment on clinical trial:
 Possible side effects of regimen:
 Radiation therapy planned:
 Reconstruction planned:
 Endocrine therapy planned:
 Biologic therapy planned:
 Pre-treatment comments:

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File Edit Tools Help

Cancer Survivorship Care Plan Builder

Breast Cancer Survivorship Care Plan

General Information | Background Information | Treatment plan | Treatment summary | Follow-up care

Chemotherapy end date:
 Post-treatment weight: lb Post-treatment BSA: 1.85 m²
 Post-treatment BMI: 27.3
 Post-treatment menstruation:
 Grade 3 or higher toxicity:
 Hospitalization for toxicity: ☐ Yes ☐ No
 Neurotoxicity that impairs activities: ☐ Yes ☐ No
 Reason for stopping chemotherapy:
 Disease status at end of treatment:
 Progression of disease on treatment:
 Toxicity of treatment:
 Radiation completed:
 Reconstruction completed: ☐ Yes ☐ No
 Endocrine therapy start date:
 Biologic therapy prescribed: ☐ Yes ☐ No
 Post-treatment comments:

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Figure A2. Sample pages from Journey Forward Survivorship Care Plan Builder software.

Guiding survivors as they move ahead

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