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Survivorship care planning holds numerous potential benefits to patients, but more research is needed to inform its integration into standard oncology practice.

Improving Survivorship Care for Patients With Colorectal Cancer

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Background: The consequences of cancer and its treatment are substantial. The aging population and recent advances in detection and treatment of cancer are expected to augment the burgeoning cohort of cancer survivors. During the transition to off-treatment status, patients may experience heightened needs coupled with significant decrements, if not dissolution, in quality of care during this critical period of re-entry. A basic source of this problem is the lack of communication and coordination of care during this transition. Treatment summaries and survivorship care plans have been proposed as potential solutions to improve quality of care for cancer survivors. Patients with colorectal cancer provide an ideal population within which to begin to empirically examine their clinical utility.

Methods: Potential benefits and promising research methodology are proposed, including adoption of a treatment summary (brief synopsis of cancer care received) and a survivorship care plan (recommendations for follow-up care). The status of the evidence base is reviewed.

Results: To date, treatment summaries and survivorship care plans remain largely untried and untested in adult oncology despite their promise to improve patient outcomes and quality of life.

Conclusions: The implementation of treatment summaries and survivorship care plans rests on the provision of strong evidence of efficacy and feasibility in the context of follow-up care for cancer survivors. Qualitative, observational, and interventional research should be initiated in order to identify benefits to patients and survivors by the enhancement of survivorship care planning.

Introduction

Advances in the detection and treatment of cancer have created a burgeoning population of cancer survivors, now numbering 11 million Americans.^{1,2} Over the next 20 years, widespread cancer screening, improved detec-

tion and treatment success, and the aging of the population will collectively augment the incidence of cancer, resulting in an even larger cohort of cancer survivors.³⁻⁵ The consequences of cancer and its treatment are substantial, even among patients who successfully complete their initial treatment. For example, survivors of non-metastatic colorectal cancer face a 40% chance of recurrence post-treatment in addition to residual physical issues including bowel dysfunction (eg, diarrhea, incontinence, or pain) and sexual functioning. Within the cancer trajectory, the transition from on-treatment to off-treatment status is a critical period. Unfortunately, many cancer survivors are unaware of the exact treatment they received, much less their heightened health risks, leaving them ill-equipped to manage future health care needs.⁶

In this paper, we highlight important problems that have been identified in the quality of care currently pro-

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vided to cancer survivors. In addition, we describe recommended changes in clinical practice designed to improve the quality of care following completion of initial treatment. Finally, we identify research that is needed to advance these proposed changes in clinical practice. The focus is on colorectal cancer survivors, since they represent one of the largest groups of survivors and because strong evidence exists for making survivorship care recommendations.

Lost in Transition: Issues in Survivorship Care

A recent Institute of Medicine (IOM) report titled *From Cancer Patient to Cancer Survivor: Lost in Transition*³ highlighted gaps between the needs of survivors following completion of initial treatment and current oncology practice. Broadly, these gaps are largely due to the lack of evidence-based guidelines for survivorship care, the lack of integration of survivorship care into cancer treatment planning, and the multifaceted nature of cancer treatment itself. Evidence-based clinical practice guidelines and consensus standards of care are foundations of assuring quality care. A consensus on surveillance practices has been reached to monitor recurrence for certain cancers (eg, American Society of Clinical Oncology [ASCO] surveillance guidelines for colon/rectal cancer).^{7,8} Surveillance practices for colorectal cancer include a colonoscopy in the first year post-treatment, carcinoembryonic antigen (CEA) testing every 3 months within the initial 3 years post-treatment, and routine medical visits (every 3 to 6 months in the first 3 years post-treatment).⁷ However, surveillance for disease recurrence represents but a single component of the requisite comprehensive approach to the care of cancer survivors.

The IOM report identified four components as being essential to comprehensive survivorship care: prevention, surveillance, intervention, and coordination of care.³ Preventive efforts comprise the use of methods that are efficacious in preventing the recurrence of the original cancer, the occurrence of new cancers, and the occurrence of late effects. Surveillance efforts comprise the use of methods that are efficacious in monitoring for cancer spread, recurrence, or second cancers as well as assessments to detect medical and psychosocial late effects. Intervention efforts comprise the use of methods that are efficacious in addressing the consequences of cancer and its treatment. These issues may include medical problems or symptoms such as pain, neuropathy, radiation injury (proctitis, cystitis, vaginitis), sexual function, compromised bowel function, ostomy-related issues, fatigue and psychological distress, and concerns related to employment, insurance, and disability. Coordination of care includes the arrangement and integration of necessary follow-up care between specialists and primary care providers to ensure that the survivor's health needs are met.

Coordinating follow-up care is crucial. During the transition from active treatment to off-treatment status

(survivorship), quality of care often suffers. Many cancer survivors are lost to systematic follow-up within the health care system, resulting in fragmented, uncoordinated care.⁹ Managing the mobile survivor population presents a unique challenge to providers.^{10,11} Part of the issue is that cancer treatment is inherently more complex than treatment of many other diseases. For example, the management of diabetes may require providers from two medical specialties, a primary care physician and an endocrinologist. In contrast, cancer care is delivered by numerous oncology specialists across different settings (inpatient surgery, outpatient infusion, or radiotherapy clinics) over extended periods of time and through cycles of illness. Among oncology specialties, there are distinct documentation standards and formats. A patient with colorectal cancer may have a medical team consisting of cancer care providers from three or four specialties (eg, surgical oncology, radiation oncology, medical oncology, and gastroenterology), all of whom have different documentation and services. However, primary care physicians will increasingly provide the bulk of follow-up care for the growing cohort of cancer survivors. Thus, the absence of a synopsis of cancer history (diagnostic status, prognosis, treatment received, and treatment response) makes the synthesis of post-treatment risks and requisite care challenging. Additionally, the current method of disjointed, inconsistent communication between oncology specialists and primary care physicians presents a significant challenge in providing quality care for survivors.³ The delinking of cancer treatment from routine medical care has established a chasm between oncology specialty providers and primary care physicians. The current mode of communication and information exchange (infrequent and indeterminate) between providers widens this gap.

In 2001 a report titled *Crossing the Quality Chasm* from the IOM's Committee on Health Care Quality in America¹² encouraged improved coordination of care for patients via an increase in collaboration and communication between clinicians and institutions to ensure the appropriate, timely exchange of information. The IOM report also endorsed the proactive anticipation of patients' needs, rather than impromptu or improvised response/reaction to emergent events. Given the complex and ongoing nature of cancer care, anticipation of needs and coordination of care for patients and survivors appear to be reasonable approaches. For no population is this more crucial than cancer patients ending active treatment and beginning re-entry — the transition from patient to survivor.

Treatment Summaries and Survivorship Care Plans

The IOM report identified the provision of treatment summaries and survivorship care plans to cancer patients and their health care providers upon completion of active treatment as an important means of promoting coordination of care and aiding the transition from cancer patient to cancer survivor.^{3,4} The ASCO

Cancer Survivorship Expert Panel has created templates of a treatment summary and a survivorship care plan for colon cancer.¹³ ASCO's development effort was informed by the National Initiative for Cancer Care Quality study¹⁴ and the 2005 Update of ASCO Practice Guideline for Colorectal Cancer Surveillance.¹³ Via literature reviews and a consensus among a panel of experts, ASCO's colorectal cancer treatment summary and survivorship care plan templates incorporate guidelines regarding appropriate follow-up care, primarily recommendations for surveillance.⁷

A treatment summary is intended to be a comprehensive cancer care record that synthesizes information spanning diagnosis and staging, diagnostic imaging results, and treatments received. The ASCO Colon Cancer Adjuvant Treatment Plan and Summary template is a two-page fillable document. When completed, it provides details regarding cancer diagnosis (how cancer was detected, site in colon, predisposing conditions, and family history) and stage. It also provides details regarding type of surgery (primary colon operation, emergent or elective), CEA levels (pre- and post-operative), nodal status, and major comorbid conditions. The ASCO Colon Cancer Adjuvant Treatment Plan and Summary also has a section detailing any adjuvant treatment received. This section includes information on the patient's height and weight (pre- and post-adjuvant treatment), pretreatment body surface area (BSA), type of chemotherapeutic agent used, clinical trial status, start and end dates of chemotherapy, route, dosage, schedule, and total cycles. The plan also denotes whether a dose reduction was needed or not, and a count of the cycles that contained oxaliplatin. Side effects of chemotherapy regimen, serious toxicities, hospitalization for on-treatment toxicity status, and reason for stopping adjuvant treatment are also noted along with treatment response (disease status post-treatment), end of treatment grade of neuropathy, ECOG performance status, and nutritional status (Fig 1).

A survivorship care plan should include specific information outlining recommended tests and their frequency to monitor for recurrence, second malignancies, ongoing toxicities, and late effects, along with designation of the responsible physician(s).^{3,4,10,15,16} The ASCO Colon Cancer Survivorship Care Plan (Fig 2) is a one-page document that outlines components of follow-up care. There are four follow-up care recommendations (physician's visit, CEA test, CT scan, and colonoscopy) with a table detailing the recommended timing of follow-up care and a tracking chart for the first 5 years post-treatment, complete with target dates of the physician visits (eg, every 3 months during the first year) and blank spaces to record results of recommended surveillance tests (eg, CEA tests, date, value ng/mL).

Posited Benefits of Treatment Summaries and Survivorship Care Plans

Potential long-term and short-term benefits of treatment summaries and survivorship care plans have been noted

in the IOM report and by others.^{3,10,13,16} Treatment summaries and survivorship care plans are posited to improve communication among specialty health care providers, which will, in turn, facilitate coordination of follow-up care.⁶ Broadly, the long-term benefits may include prevention/reduction of late effects, better adherence to surveillance recommendations, and longer survival via enhanced communication and coordination of care.³ One potential short-term benefit of providing treatment summaries and survivorship care plans is increased patient knowledge of their cancer diagnosis, treatment, and ongoing cancer-related risk factors. In addition to increased patient knowledge, the provision of care plans is expected to increase patient satisfaction, which together influence patients' perception of coordination of care and consequently, result in improved patient adherence/compliance.³ Another potential short-term benefit is increased patient awareness of appropriate follow-up care, including recommendations for detection of late effects, and surveillance for recurrence of primary cancer and development of secondary cancers. Increased knowledge and awareness are also likely to produce greater patient confidence in carrying out recommended follow-up care, enhanced communication with health care providers, and greater satisfaction with care during the transition from active treatment to follow-up and post-treatment care.³

Survivorship Care Planning: Status of the Evidence Base

To improve quality of care for cancer survivors, current standard practice in oncology will require marked alterations. For such a change to occur, strong scientific evidence is needed demonstrating that provision of treatment summaries and survivorship care plans is feasible, efficacious, and cost-effective. The IOM report advocated for the concurrent implementation and investigation of treatment summaries and survivorship care plans.⁴ Treatment summaries and survivorship care plans have yet to be widely adopted despite these foreseeable benefits.¹⁵ Even when adopted, their impact has not been subjected to rigorous empirical investigation. The IOM report endorses empirical investigation of treatment summaries and survivorship care plans to cancer survivors, especially benefits to key stakeholders.^{4,17,18} To date, research on outcomes and posited benefits has not been conducted.

Building the Evidence Base for Survivorship Care Planning: The Case for Colorectal Cancer

Although it is desirable to evaluate the impact of treatment summaries and survivorship care plans for all cancer types, methodological and practical considerations suggest initiating this line of research through the focus on a single form of cancer. Colorectal cancer patients represent an ideal population in which to initially pilot-test the provision of treatment summaries and survivorship care plans. First, colorectal cancer is the third most prevalent type of cancer, accounting for 11% of all survivors.^{1,2} Colorectal cancer survivors comprise the third

largest group of survivors.³ Second, 80% of people diagnosed with colorectal cancer have local or locally advanced cancer, which offers a greater chance for treatment success and survival compared to other cancers.

Third, many colorectal cancer survivors experience an extended period of time post-treatment during which frequent surveillance (ie, CEA testing) is recommended and survivorship needs can be evaluated and addressed.¹³

Colon Cancer Adjuvant Treatment Plan and Summary v 2.0 09/07 1

The Treatment Plan and Summary provide a brief record of major aspects of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.

Provider name: _____

Patient name: _____ **Patient ID:** _____

Patient DOB: (/ /) **Age at diagnosis:** _____ **Patient phone:** _____

Support contact name: _____

Support contact relationship: _____ **Support contact phone:** _____

BACKGROUND INFORMATION

Cancer detection: Screening Symptoms Incidental

Site in colon: Right Transverse Left Sigmoid

Predisposing conditions: None Inflammatory bowel disease FAP HNPCC

Family history: None 2nd degree relative 1st degree relative Multiple relatives

Pre-op colonoscopy to cecum: Yes No **Other lesions:** None Low risk polyps High risk polyps

Primary colon operation: _____ **Date of surgery:** (/ /)

Surgery type: Elective Emergent **CEA pre-op:** _____ **CEA post-op:** _____

Stage: IIA IIB IIIA IIIB IIIC **T stage:** T1 T2 T3 T4 **N stage:** N0 N1 N2

Number of lymph nodes removed: _____ **Number of lymph nodes positive:** _____

Notable pathology findings: _____

Notable surgical findings/complications: _____ **Ostomy:** Yes No

Major comorbid conditions: _____

ADJUVANT TREATMENT PLAN **ADJUVANT TREATMENT SUMMARY**

White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy

Height: _____ in/cm **Pre-treatment weight:** _____ lb/kg **Post-treatment weight:** _____ lb/kg

Pre-treatment BSA: _____

Name of regimen: _____

Treatment on clinical trial: Yes No

Start Date: (/ /) **End Date:** (/ /)

Bio/Chemotherapy Drug Name	Route	Dose	Schedule	Dose reduction needed	Number of cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	

Possible side effects of this regimen:

Hair loss

Neuropathy

Low blood count

Fatigue

Diarrhea

Dehydration

Nausea/Vomiting

Other: _____

Number of cycles containing oxaliplatin: _____

Serious toxicities during treatment (list all): _____

Hospitalization for toxicity during treatment: Yes No

Reason for stopping adjuvant treatment: _____

Disease status at end of treatment: No evidence of disease

Possible recurrence Recurrence

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 Important caution: this is a summary document whose purpose is to review the highlights of the colon cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

Fig 1. — The American Society of Clinical Oncology (ASCO) Colon Cancer Adjuvant Treatment Plan and Summary provides a cancer care record that synthesizes information spanning diagnosis and staging, diagnostic imaging results, and treatments received. Available at <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries>. Reprinted with permission. © 2009 American Society of Clinical Oncology. All rights reserved.

Colorectal cancer patients have specific identifiable and measurable survivorship issues such as neuropathy, sexual functioning, bowel dysfunction, and ostomy issues.³ Fourth, ASCO has developed evidence-based guidelines for appropriate follow-up care of colorectal cancer unlike many other types of cancer.^{7,13} Finally, as mentioned pre-

viously, ASCO has developed a template of a treatment summary and survivorship care plan that is ready for adaptation and adoption.⁷ These factors provide an ideal platform for the investigation of the ostensible yet unmeasured benefits of implementation of treatment summaries and survivorship care plans.

Colon Cancer Adjuvant Treatment Plan and Summary v 2.0 09/07		2
ADJUVANT TREATMENT PLAN	ADJUVANT TREATMENT SUMMARY	
Central venous catheter placement needed: <input type="checkbox"/> Yes <input type="checkbox"/> No	Neuropathy at end of treatment (Grade): <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4	
ECOG performance status at start of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4	ECOG performance status at end of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4	
Nutritional status at start of treatment: <input type="checkbox"/> Excellent <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor	Nutritional status at end of treatment: <input type="checkbox"/> Excellent <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor	
Special circumstances:		
ONCOLOGY TEAM MEMBER CONTACTS		SURVIVORSHIP CARE PROVIDER CONTACTS
Provider:		Provider:
Name:		Name:
Contact Info:		Contact Info:
Provider:		Provider:
Name:		Name:
Contact Info:		Contact Info:
Provider:		Provider:
Name:		Name:
Contact Info:		Contact Info:
Provider:		Provider:
Name:		Name:
Contact Info:		Contact Info:
Pre-treatment comments		Post-treatment comments
<p>© 2007 American Society of Clinical Oncology. All rights reserved. Important caution: this is a <u>summary</u> document whose purpose is to review the <u>highlights</u> of the colon cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with colon cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for colon cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.</p>		

Fig 1. — The American Society of Clinical Oncology (ASCO) Colon Cancer Adjuvant Treatment Plan and Summary, page 2. Continued from page 38.

Survivorship Care Planning: Research Agenda

The IOM report endorsed both qualitative and quantitative research methodology to assess outcomes associated with the use of treatment summaries and sur-

ivorship care plans.^{3,4,6,9,10,16} Several types of research are necessary to expand the evidence base, including studies using qualitative, observational, and interventional study designs.^{6,19}

Colon Cancer Survivorship Care Plan v2.0 09/07

Patient Name:		Medical Oncologist Name:		
FOLLOW-UP CARE RECOMMENDATION	YEAR 1	YEAR 2	YEAR 3	YEARS 4 AND 5*
Doctor's Visit	Every 3 to 6 months	Every 3 to 6 months	Every 3 to 6 months	Every 6 months
CEA Test	Every 3 months	Every 3 months	Every 3 months	As determined by your doctor
CT Scan (chest and abdomen)	Every year, if recommended by your doctor	Every year, if recommended by your doctor	Every year, if recommended by your doctor	As determined by your doctor
Colonoscopy	Once†		At 3 years	

* After 5 years, the need for future tests and visits are decided by the patient and doctor.
 † A colonoscopy should be done around the time of surgery. If the examination shows no signs of a recurrent tumor or polyps, a colonoscopy should be done at 3 years, and if normal, every 5 years thereafter.

The following tests are *not* currently recommended by ASCO for regular follow-up care because there is not enough scientific evidence to support a recommendation:

- A complete blood count (CBC) test or liver function tests
- A fecal occult blood test, which is a test that looks for blood in the stool

COLON CANCER FOLLOW – UP SHEET

To begin the chart, fill in the date of diagnosis. Add the years/months in the first column to the date of diagnosis to obtain target dates. Record visits, test dates, and CEA values in the rows corresponding to each target date as they are completed. Darkened rows indicate that a particular procedure is not required at that time.

Date of Diagnosis (DOD): ____/____/____

ESTIMATED TARGET DATES		DATES COMPLETED			
DOD plus	Target Dates	CEA ¹ (Date/Value ng/mL)	Counseling Visit ²	CT Scan ³	Colonoscopy ⁴
+ 0y/3m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 0y/6m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 0y/9m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 1y/0m →	____/____/____	____/____/____	____/____/____		
+ 1y/3m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 1y/6m →	____/____/____	____/____/____	____/____/____		
+ 1y/9m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 2y/0m →	____/____/____	____/____/____	____/____/____		
+ 2y/3m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 2y/6m →	____/____/____	____/____/____	____/____/____		
+ 2y/9m →	____/____/____	____/____/____	(opt) ____/____/____		
+ 3y/0m →	____/____/____	____/____/____	____/____/____		
+ 3y/6m →	____/____/____		____/____/____		
+ 4y/0m →	____/____/____		____/____/____		
+ 4y/6m →	____/____/____		____/____/____		
+ 5y/0m →	____/____/____		____/____/____		

¹ Carcinoembryonic antigen (CEA) testing is not recommended *during* the administration of adjuvant chemotherapy.
² As guidelines suggest 3 to 6 months for counseling visits, optional dates are marked with (opt)
³ Recommended for high-risk patients.
⁴ Acceptable to wait 3 years for follow-up if the pre-or perioperative colonoscopy examined the *entire colon*.

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 The Survivorship Care Plan recommendations are derived from the 2005 Update of the American Society of Clinical Oncology Practice Guideline. This plan is a practice tool based on ASCO® practice guidelines and is not intended to substitute for the independent professional judgment of the treating physician. Practice guidelines do not account for individual variation among patients. This tool does not purport to suggest any particular course of medical treatment. Use of the practice guidelines and this plan is voluntary. The practice guidelines and additional information are available at <http://www.asco.org/guidelines/crcfollowup>.

Fig 2. — The American Society of Clinical Oncology (ASCO) Colon Cancer Survivorship Care Plan outlines components of follow-up care, including recommended tests to monitor for recurrence, second malignancies, toxicities, and late effects. Available at <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries>. Reprinted with permission. © 2009 American Society of Clinical Oncology. All rights reserved.

Qualitative studies using focus groups or individual interviews with diverse stakeholders can be helpful in pinpointing unmet needs of cancer survivors, detecting problematic issues in coordination of care, and identifying barriers to the implementation of treatment summaries and survivorship care plans. To date, two qualitative studies have been conducted exploring patient and provider reactions to treatment summaries and survivorship care plans. In the first study, Hewitt et al¹⁸ conducted a qualitative study with cancer survivors, nurses, primary care physicians, and oncologists. Participants were asked about survivorship care and then shown a survivorship care plan while their reactions were recorded and later transcribed. In general, survivors and primary care physicians endorsed the future use of survivorship care plans. Survivors also reported many unmet needs (eg, being overwhelmed with verbal information from providers and psychosocial needs not being addressed). Nurses expressed interest in creating and implementing the plans. Oncology specialists indicated that survivorship care plans seemed valuable, but expressed concerns about their actual implementation. For example, oncologists viewed the plans as time-consuming and noted that they currently were neither required nor reimbursed by insurers. In the second study, Miller¹⁷ conducted interviews with breast cancer survivors who had been given a survivorship care plan and their primary care providers. As in the previous study, overall reactions to treatment summaries and survivorship care plans were favorable. The cancer survivors reported that the plan was helpful, clear, and potentially effective for the transition from patient to survivor. The primary care physicians of these patients viewed the plan as a concise summary of treatment and believed that it was helpful in identifying what to monitor.

Future qualitative studies should focus on obtaining patient and other key stakeholder (primary care or specialty health care providers, family members) information on specific benefits conferred by the implementation of treatment summaries and survivorship care plans. A reasonable initial strategy would be to ask patients and providers about the incremental improvement in patient knowledge, patient satisfaction with care (coordination of care), and patient awareness of necessary follow-up care as well as intentions to adhere to recommendations from oncology specialists regarding follow-up care and monitoring.

Observational research, spanning such designs as cohort studies, case-control studies, and cross-sectional studies, can be utilized in the investigation of the practical/pragmatic elements of survivorship care planning. Earle¹⁹ has suggested that observational research be conducted to quantify and prioritize specific areas of need in cancer survivorship. Such studies, designed to answer Gordon Paul's²⁰ question — what (treatment), how, and by whom? — are necessary. The potential benefits of treatment summaries and survivorship care plans span patients and health care providers (from oncology specialists and primary care physicians). Studies comparing

separate components (surveillance schedule only vs a survivorship care plan plus cancer care record) and formats (electronic, written) are needed. For example, a study could be conducted that compares patient knowledge of recommended follow-up care before and after their transition consultation visit among cancer survivors who received a treatment summary compared with similar patients who had received both a treatment summary and surveillance plan. Similarly, satisfaction with care could be compared among cancer survivors who received an electronic vs paper copy of their survivorship care plan. Additionally, details regarding the setting in which the survivorship care plan was provided (by an oncology specialist or an advanced registered practice nurse) should also be conducted.¹⁹

Observational research designs can also be used to assess unmet needs and gaps in awareness of available resources and possible cancer-related late effects among survivors. Such designs could include assessing a large cohort of survivors across multiple treatment sites, perhaps identified using cancer registries.⁶ Follow-up observational studies of the same patients could further examine whether provision of a survivorship care plan enhances patient knowledge via information to meet these specific (unaddressed) needs, such as available resources or identification of which physician to contact for additional medical management. Additionally, quality of life, and daily functioning at work and at home could be assessed among survivors and compared to information from collateral/auxiliary sources (eg, family members who are primary caregivers).

A critical aim of written survivorship care plans is to improve coordination of care among patients, cancer specialists, and primary care physicians.⁶ Using an observational design, the ease and effectiveness of current communication with oncology specialists could be assessed via collection of survey data from primary care providers for their patients who are cancer survivors (who did or did not receive a survivorship care plan). Similarly, medical claims data and medical record review of survivors (number of hospitalizations, and emergency room visits) could be examined to identify the potential benefits of managing cancer-related symptoms (eg, pain and fatigue).¹⁹ Given the current status of ever-dwindling resources in the face of increasing demand for services for survivors, data such as these could also delineate resource availability and utilization, and guide studies of the cost-effectiveness of survivorship care planning.

Interventional research, such as randomized controlled trials (RCTs), comprises the third type of research needed in survivorship care. Knowledge, satisfaction, and confidence are factors that are known to influence patients' current and future health behaviors, such as adherence to medical recommendations.²¹⁻²³ Although the IOM report posited these as short-term benefits of providing treatment summaries and survivorship care plans, they have yet to be demonstrated in controlled studies. One reason is the lack of methodology to measure many of these outcomes, which require the use of

self-report methods.⁴ Thus, the development and validation of appropriate outcome measures represents a critical first step in the evaluation and implementation of treatment summaries and survivorship care plans.

Toward this end, we are currently conducting research using both qualitative and quantitative methods to produce outcome measures that could be used to examine the potential short-term benefits of providing treatment summaries and survivorship care plans to colorectal cancer survivors. Qualitative interviews with stakeholders (health care providers and colorectal cancer survivors) are being conducted in which each group is questioned regarding potential benefits of implementing a treatment summary and survivorship care plan to survivors. These data will be used to adapt existing measures of patient knowledge, satisfaction with care, and patient intentions and self-efficacy in obtaining follow-up care for use with cancer survivors or create new measures if additional potential benefits are identified.

In the second phase of our study, an RCT will be conducted comparing colorectal cancer patients completing treatment assigned to receive standard transition consultation care (routine end-of-treatment visit with oncologist) to patients assigned to receive a written copy of their individualized treatment summary and survivorship care plan. Outcome measures such as patient knowledge, patient satisfaction with care, and patient self-efficacy and other outcomes (identified in phase one of the study) will be administered immediately prior to randomization and receipt of the assigned form of care. The same outcome measures will be completed several weeks later to determine the short-term effects of provision of treatment summaries and survivorship care plans on patient knowledge, satisfaction with care, and confidence/self-efficacy in obtaining follow-up care.

Intervention studies with longer follow-up periods are also needed to build the evidence base for this proposed change in current oncology practice. ASCO recommends that colorectal cancer survivors receive frequent monitoring during the first 5 years of survivorship (5 years post-treatment). An RCT conducted with assessment of outcomes across greater periods of time would allow for determination of the potential long-term benefits of the provision of treatment summaries and survivorship care plans. These might include greater adherence to recommendations regarding surveillance and engaging in health promotion behaviors. Possible endpoints in appropriately designed (ie, empirically rigorous) studies could also include quality of life and survival.

Conclusions

Advances in detection and treatment as well as the aging baby-boomer population will result in an ever-increasing population of cancer survivors.^{3,9,19,24,25} The transition from active treatment to off-treatment status is pivotal to the long-term health of cancer survivors. It is a period when loss to follow-up and breakdown in the quality of care are common. Provision of a treatment summary

and survivorship care plan was recommended in an IOM report to aid the transition to survivorship, though these forms have not been widely adopted.^{3,10,16} Suggested components of treatment summaries and survivorship care plans include the patient's diagnosis, cancer treatment history, current side effects and potential late effects, recommended surveillance, and identification of medical team members responsible for providing follow-up care.^{10,11,16} Implementation of treatment summaries and survivorship care plans was proffered by the recent IOM report to improve the efficiency and coordination of care for cancer survivors.³ However, these forms have yet to be put into widespread use. To do so will require a significant change in standard oncologic care practices and documentation. Moreover, their use has not been subjected to empirical investigation, nor has methodology been developed to assess potential benefits of treatment summaries and survivorship care plans. As suggested by the IOM report, short-term benefits of implementation of treatment summaries and survivorship care plans are posited to include increased patient knowledge of their cancer care, and increased satisfaction with care and confidence in obtaining follow-up care.³ Research on these proximal and other more distal outcomes is necessary to address this issue. Colorectal cancer survivors represent an ideal population in which to conduct such studies given the prevalence of colorectal cancer, the high survival rates post-treatment experienced by patients with early-stage disease, and the frequency of recommended follow-up care, which cumulatively allow an opportunity to examine factors influencing outcomes and survivorship needs. The IOM report suggested that research be conducted concurrent with implementation of treatment summaries and survivorship care plans.³ At present, these plans are not widely adopted. Even when adopted, the projected benefits of their provision have not been empirically examined. Qualitative, observational, and interventional studies should be initiated in order to examine how outcomes for cancer survivors may be improved by enhancing survivorship care planning.

References

1. National Cancer Institute Office of Cancer Survivorship. Estimated US Cancer Prevalence Counts: Who Are Our Cancer Survivors in the U.S.? <http://cancercontrol.cancer.gov/ocs/prevalence/index.html>. Accessed July 30, 2009.
2. Jemal A, Siegel R, Ward E, et al. Cancer statistics, 2008. *CA Cancer J Clin*. 2008;58(2):71-96.
3. Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Institute of Medicine of the National Academies. Washington, DC: The National Academies Press; 2005.
4. Hewitt M, Ganz PA, eds. Implementing Cancer Survivorship Care Planning: Workshop Summary. Institute of Medicine of the National Academies. Washington, DC: The National Academies Press; 2007.
5. Ayanian JZ, Chrischilles EA, Fletcher RH, et al. Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol*. 2004;22(15):2992-2996.
6. Ayanian JZ, Jacobsen PB. Enhancing research on cancer survivors. *J Clin Oncol*. 2006;24(32):5149-5153.
7. American Society of Clinical Oncology. Colorectal Cancer Treatment Plan and Summary Resources. <http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Quality+Care/Quality+Measurement+%26+Improvement/Chemo+therapy+Treatment+Plan+and+Summary/Colon+Cancer+Treatment+Plan+and+Summary+Resources>. Accessed July 31, 2009.
8. American Society of Clinical Oncology. Breast Cancer Treatment Plan and Summary Resources. <http://www.asco.org/ASCOv2/Practice+%26>

+Guidelines/Quality+Care/Quality+Measurement+%26+Improvement/Chemo therapy+Treatment+Plan+and+Summary/Breast+Cancer+Treatment+Plan and+Summary+Resources. Accessed July 31, 2009.

9. Earle CC. Cancer survivorship research and guidelines: maybe the cart should be beside the horse. *J Clin Oncol*. 2007;25(25):3800-3801.
10. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol*. 2006;24(32):5112-5116.
11. Grunfeld E. Looking beyond survival: how are we looking at survivorship? *J Clin Oncol*. 2006;24(32):5166-5169.
12. Crossing the Quality Chasm: A New Health System for the 21st Century. Committee on Quality of Health Care in America. Institute of Medicine. Washington, DC: National Academies Press; 2001.
13. Desch C, Benson A, Somerfield M, et al. Colorectal cancer surveillance: 2005 update of the ASCO practice guideline. *J Clin Oncol*. 2005;23(33):8512-8519.
14. Malin JL, Schneider EC, Epstein AM, et al. Results of the National Initiative for Cancer Care Quality: how can we improve the quality of cancer care in the United States? *J Clin Oncol*. 2006;24(4):626-634.
15. Ganz PA. Monitoring the physical health of cancer survivors: a survivorship-focused medical history. *J Clin Oncol*. 2006;24(32):5105-5111.
16. Ganz PA, Hahn EE. Implementing a survivorship care plan for patients with breast cancer. *J Clin Oncol*. 2008;26(5):759-767.
17. Miller R. Implementing a survivorship care plan for patients with breast cancer. *Clin J Oncol Nurs*. 2008;12(3):479-487.
18. Hewitt ME, Bamundo A, Day R, et al. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. 2007;25(16):2270-2273.
19. Earle CC. Long term care planning for cancer survivors: a health services research agenda. *J Cancer Surviv*. 2007;1(1):64-74.
20. Paul GL. Behavior modification research: design and tactics. In: Franks CM, ed. *Behavior Therapy: Appraisal and Status*. New York, NY: McGraw-Hill; 1969.
21. Fishbein M, Ajzen I, eds. *Belief, Attitude, Intention, and Behavior: An Introduction to Theory and Research*. Reading, MA: Addison-Wesley; 1975.
22. Ajzen I, Fishbein M, eds. *Understanding Attitudes and Predicting Social Behavior*. Englewood Hills, NJ: Prentice-Hall; 1980.
23. Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process*. 1991;50:179-211.
24. Ganz PA. Why and how to study the fate of cancer survivors: observations from the clinic and the research laboratory. *Eur J Cancer*. 2003;39(15):2136-2141.
25. Erikson C, Salsberg E, Forte G, et al. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3(3):79-86.