

Survivorship Care Plans for Patients With Head and Neck Cancer

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Objective: To determine the perceived value of survivorship care plans (SCPs) (cancer treatment summaries and follow-up recommendations).

Design: Survey of patients and their physicians between 3 and 4 years after receipt of the SCP.

Setting: Ambulatory, tertiary care medical center.

Patients: A convenience sample of head and neck cancer survivors living 3 years after each had been mailed a personal SCP shortly after completion of cancer treatment. Twenty survivors were contacted, and all agreed to participate.

Interventions: Institutional review board–approved, scripted telephone survey to determine whether pa-

tients and their primary care physicians still had their SCPs and found them useful.

Main Outcome Measures: Survey responses.

Results: Only 2 of 20 survivors and 11 of 21 physicians or dentists were able to locate or remember having received the SCPs 3 years later. Eighteen of 20 survivors were unsure of the value of SCPs.

Conclusions: Despite a widely held belief that patients benefit from receiving SCPs, our initial attempt found little awareness of these documents by either the head and neck cancer survivors or their primary care physicians.

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THE TRANSITION FROM CANCER patient to cancer survivor can be a difficult and mysterious process. One widely endorsed effort to ease the passage has been the creation and use of a written survivorship care plan (SCP) for each person completing cancer treatment. As first articulated by the Institute of Medicine (IOM) in *From Cancer Patient to Cancer Survivor: Lost in Transition*,¹ the SCP would be a robust and vital document created to inform patients, physicians, and the rest of the survivorship care team of the long-term effects of cancer and its treatment, to identify psychosocial support resources in their communities, and to provide guidance on follow-up care, prevention, and health maintenance.²

In 2005, the Medical College of Wisconsin Head and Neck Cancer Program embraced the development of SCPs and implemented a plan to create documents using the IOM criteria for a sample of recently treated patients. During the following months, a series of patients and their physicians were sent treatment summaries and SCPs. The plans were time-consuming and

challenging to prepare, and the SCP program was discontinued when there was no longer a trained, motivated person available to create the documents. Three years later, we contacted the initial SCP recipients and their physicians to determine whether the treatment summaries and SCPs had been useful.

METHODS

From May 1, 2005, through April 30, 2006, a convenience group of 30 recently treated head and neck cancer survivors, their primary care physicians, their referring physicians or dentists, and community-based treating oncologists were mailed a 2-page SCP. The document consisted of a cancer treatment summary and a cover letter. The reports were sent as a part of clinical care and not as part of a research study.

The treatment summaries included many of the data elements recommended in the IOM report,¹ including date of diagnosis, type of cancer, stage and site of cancer, summary of treatment course (biopsy date, initial visit date, and treatment modalities, including surgical summary, radiation dosage, and chemotherapy drugs and dosages), research protocol numbers (if any), names and full contact information for all treating physicians, and estimated follow-up

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Table 1. Demographic Characteristics of the Cancer Survivors^a

Characteristic	Survivors Receiving the SCP	Survivors Still Alive at the 3-Year Study	Survivors Who Died Before the Study
Total population	30	20	10
Male sex	19	12	7
Female sex	11	8	3
Age, median (range), y	57 (33-90)	52 (33-82)	66 (45-90)
Race			
African American	3	2	1
Hispanic white	1	0	1
Non-Hispanic white	25	18	7
Asian	1	0	1
Insurance			
Medicaid	3	1	2
Medicare	15	9	6
Self-pay	2	2	0
Commercial	10	8	2
AJCC stage			
1	7	6	1
2	3	1	2
3	5	4	1
4	15	9	6
Site			
Oral cavity	14	10	4
Oropharynx	7	5	2
Larynx	3	0	3
Sinus	1	0	1
Parotid	1	1	0
Thyroid	2	2	0
Unknown primary site	2	2	0

Abbreviations: AJCC, American Joint Commission on Cancer; SCP, survivorship care plan.

^aData are presented as number of cancer survivors unless otherwise indicated.

schedule. The cover letter included a note of congratulations, a table explaining the goals for the cancer-related follow-up visits (surveillance, adverse effect identification and management, support and education, and health behavior monitoring), and the signature of one of the treating physicians. The documents were mailed to each survivor as soon as feasible after completion of treatment, usually within 2 months.

The cover letter suggested that the survivor keep the summary document for future reference. Identical copies of the treatment summary and the cover letter were mailed to each survivor's primary care physician, to the referring physician or dentist, and to each community-treating oncologist (if managed outside our institution).

No SCP-specific follow-through was performed after the SCP was mailed. There were no protocols in place to determine whether the survivor had received the SCP, and the documents were not specifically discussed during follow-up visits. Each survivor had routine follow-up until death or the time of the study.

After 1 year of SCP use, departmental infrastructure support changed, and there was no longer a qualified person available to routinely gather the data and prepare the SCPs. Therefore, no additional SCPs were prepared or mailed.

Three years later, institutional review board approval was obtained to contact each living survivor who had received the SCP, as well as the primary care physician, the referring physician or dentist, and any outside treating oncologists. A standardized telephone questionnaire was developed to determine

Table 2. Survivor Survey Responses

Response	No. of Survivors
Do you remember receiving the SCP?	
Yes	2
No	17
Unsure	1
Do you still have the SCP?	
Yes	1
No	18
Unsure	1
Have you ever used the SCP?	
Yes	1
No	16
Unsure	3
How important do you think survivorship information is for cancer patients?	
Very important	1
Moderately important	1
Unsure	18

Abbreviation: SCP, survivorship care plan.

whether the survivors remembered receiving the SCP, whether they still had the document, whether they had ever used the SCP, whether the documents were helpful, how important they believed survivorship information was to them, and whether their primary care physician had received the document.

The community physicians and dentists who had received one of the SCPs and who were still in practice were contacted directly and asked whether they still possessed or remembered having received the document and whether they found the information useful. Medical college-based health care professionals were not surveyed because each had electronic access to all of the information contained in the SCPs.

RESULTS

Of the 30 patients to whom the SCPs were mailed, 20 were still alive at the time of the study 3 years later. The SCPs had been mailed to survivors between 0 and 8 months after completion of treatment (median, 2 months). Characteristics of the entire group and the 20 who were still alive are given in **Table 1**. A variety of racial heritages, payer types, stages, and cancer sites were represented.

SURVIVOR SURVEY

All 20 of the survivors who were contacted by telephone agreed to participate and were included in the study (**Table 2**). Of the 20 survivors, only 2 (10%) remembered receiving the SCPs; 1 of these 2 found the document useful, had referred to it, and still had it available. The other who recalled having receiving the SCP no longer possessed it. One survivor was unsure whether he had received the SCP. None of the rest of the survivors recalled having ever received the SCP. Three survivors thought they might have used the SCP at some point even though 2 of them did not recall having received it in the first place.

When asked, "How important do you think survivorship information is for cancer patients?," the one survivor who still had her SCP replied, "very important." Almost all the other survivors responded that they were "unsure."

Table 3. Community Physician and Dentist Survey Responses

Health Care Professional	Was Able to Locate or Recall Receiving the SCP	Could Neither Locate Nor Recall Receiving the SCP	Total
Primary care physicians	4	12	16
Otolaryngologists	4	3	7
Dentists	1	4	5
Community oncologists	2	2	4
Total	11	21	32

Abbreviation: SCP, survivorship care plan.

Because so few of the survivors recalled receiving the SCP, little useful information was gleaned from scripted questions, such as “Do you think that this follow-up plan and treatment summary letter is useful?” and “Do you know whether your primary care physician ever received this letter?”

PHYSICIAN SURVEY

Among the 20 survivors, there were 28 medical college and 32 community physicians and dentists still in practice at the time of the survey (**Table 3**). Of the 32 community physicians and dentists, 34% could either locate the SCP document or recalled having received it. At least 1 professional from each of the categories recalled receiving the SCP.

COMMENT

The IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,¹ focused attention on the development of clinical practice guidelines for the care provided to each of the more than 11 million cancer survivors in the United States and the millions more around the world. Within the report’s 10 recommendations, the IOM proposed that every cancer survivor be provided with a written SCP, including a “comprehensive care summary and follow-up plan that is clearly and effectively explained.”^{1(p4)} Content areas to be included in every SCP were adapted from the 2004 National Cancer Institute President’s Cancer Panel report *Living Beyond Cancer: Finding a New Balance*,³ which resulted from 2 years of testimony and town hall–style meetings soliciting views of cancer survivors, caregivers, advocates, health care professionals, insurers, federal and state government employees, media representatives, and support organization representatives. Despite oncologists’ concerns regarding pragmatic and logistical problems of preparing the plans,^{4,5} the SCP process has since been embraced by influential organizations around the world, including the Lance Armstrong Foundation, The Oncology Nursing Society, the American Cancer Society, the National Coalition for Cancer Survivorship, and the American Society of Clinical Oncology.

Recent studies⁶ have reported that full adherence to the IOM recommendations is rare, even in organizations with dedicated support personnel. The reasons for

this are not yet clear. Because the IOM recommendations are broad, the effect of SCP deployment will take years to measure. Advocates hope that wide acceptance will improve survivorship care for both individuals and the wider population by improved adherence to screening guidelines, enhanced communication, wider use of multidisciplinary care, and improved physical and psychological health.⁵ From the outset, the IOM report encouraged research into the effectiveness of SCPs, noting that “[d]espite the lack of evidence to support the use of survivorship care plans, the committee concluded that some elements of care simply make sense—that is, they have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary.”^{1(p5)}

In 2012, the American College of Surgeons Commission on Cancer released new program standards mandating that each Commission on Cancer–accredited cancer program “develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. . .” and lays out data elements to be included that overlap with the IOM recommendations.^{7(p78)} The plan must contain a record of care, disease characteristics, and an evidence-based follow-up care plan. To maintain Commission on Cancer accreditation, cancer programs must be in compliance with the standard by 2015.

Although there is robust literature describing the benefits and logistics of implementing SCPs,⁸ clinical trials measuring their effectiveness are rare. In a prospective trial, Grunfeld et al⁹ examined the use of SCPs in breast cancer survivors being transitioned from specialty oncology care back to their primary care physician. The trial randomized 408 breast cancer survivors in 6 Canadian tertiary cancer centers into an intervention group (SCP, a 30-minute personal educational session, and a copy of the SCP and user-friendly follow-up guidelines sent to each primary care physician) and an observation group (routine final oncology clinic visit with no specific interventions). They identified no measurable differences between the 2 groups in cancer-related distress, psychological distress, health-related quality of life, survivor satisfaction, or continuity of care at 12 months. The intervention group was more likely to be able to identify their primary care physician as being responsible for follow-up (99% vs 89%). The authors question whether this lone association is worth the significant resource allocation needed to prepare and disseminate the SCPs. An accompanying editorial¹⁰ points out that the study by Grunfeld et al might be limited in its general applicability because of the disease site (breast) and its patient care setting (a country with universal access and a focus on primary care).

Our results surprised us. We were disappointed that our group of cancer survivors almost universally failed to remember the SCPs and that few community partners found the SCPs potentially useful. Problems with the current study include the small sample size, the lack of planned follow-through after the SCPs were mailed, and the lack of prospective data collection.

A potential barrier to successful SCP implementation in our population includes the insensitivity of tem-

plate SCPs to individual survivors' levels of health literacy. According to a subset analysis of the National Assessment of Adult Literacy,¹¹ 36% of Americans have either basic or below basic levels of health literacy, consistent with being able to read and comprehend only the simplest of documents. Blacks, Hispanics, Native Americans, people of low educational attainment, elderly people, and poor people are disproportionately represented in the lowest health literacy categories. By necessity, SCPs include significant blocks of medical jargon and terms unfamiliar to most laypersons. As an exercise, we informally subjected SCP end-of-treatment sample summary notes found in the IOM report¹ to the Flesch-Kincaid reading grade level calculator (Microsoft Word 2007; Microsoft Inc). The SCPs ranged from a 10.9 grade level for the colorectal cancer sample to a 14.5 grade level for the Hodgkin lymphoma sample. Similarly, the American Society of Clinical Oncology SCP template, even with no clinical data included, scored at the 12.3 grade level. All of these are well above the mean US reading level of approximately the eighth grade.

Another barrier to useful SCPs in our population might have been the timing of the information. The SCPs were mailed shortly after completion of cancer care, just when survivors were beginning to recover and were receiving a deluge of mail from the hospital, the physician practice, and their insurance companies. Without specifically highlighting the importance of the information, expecting the survivor to remember a single piece of mail received at that time was probably unreasonable.

A final barrier might have been the volume of data generated during cancer care; a single document, even an important summary, becomes a needle in a haystack for other health care professionals who use differing electronic medical record systems or paper charts. Even if the document was received and scanned into the record system of the community health care professional, it might be all but irretrievable.

Survivorship care plans might be qualitatively less vital for our population than for some cancer survivor groups. Although SCPs are potentially critical for cancer survivors who are being completely transitioned from cancer specialists back to their primary care physicians, the variety and quantity of information included might need to be tailored for survivors of head and neck cancer and others who are routinely offered long-term specialty follow-up.

We continue to work on how best to share important survivorship information with survivors and their primary care physicians. Laminated pocket summary cards or password-protected electronic vaults might be more useful than one-time paper documents. The information might be more accessible if included routinely in a printed after-visit summaries report in the clinic. Whatever format is used, SCPs must include instruction tailored to an appropriate reading level for each survivor.

Despite focus group survivors reporting a "strong patient demand for a written follow-up plan,"^{2(p35)} our initial attempt found little interest in these documents by either the survivors of head and neck cancer or their primary care physicians. Although we continue to believe that sharing treatment summary information is valuable to both cancer survivors and their primary physicians, the currently recommended SCP format was not effective for either audience.

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