

**The Cancer Treatment Summary**

*Changing the Culture of Documentation to Facilitate High Quality Cancer Care*

Deborah Schrag, M.D. M.P.H.  
Memorial Sloan-Kettering Cancer Center  
1275 York Ave New York, NY 10021  
Phone: 212-639-7472  
e-mail: [schragd@mskcc.org](mailto:schragd@mskcc.org)  
Fax: 646-735-0011

**Abstract:**

Impediments to communication between health systems, physicians, and patients as they traverse the spectrum of cancer care interfere with efficient, high quality treatment delivery. In contrast to surgery, cancer chemotherapy is typically administered over many days, and often across settings. It is notoriously difficult, and often impossible, to re-create cancer treatment histories from medical records. Traditionally, medical record keeping in oncology does not include preparation of synoptic overviews at key transition points. For these reasons, it can be difficult for patients and physicians to assemble an accurate understanding of individual chemotherapy treatments as well as the overall trajectory of a patient's cancer care. In response to problems with coordination of care between oncologists and other health care providers—especially at critical junctures such as the completion of primary or adjuvant therapy—ASCO is developing templates to help medical oncologists to prepare synopses that provide an overview of care at key transition points. This commentary outlines the rationale for preparation of treatment summaries and describes early efforts to facilitate this undertaking.

Cancer care in the 21<sup>st</sup> century is exceedingly complex. As cancer patients live longer and the range of chemotherapy treatment options expands, patients are ever more likely to receive care from multiple physicians, across diverse delivery systems, and over multi-year periods. In this context, it can be challenging for both oncologists and other health care providers to assemble all the information that is necessary to understand a patient's cancer treatment history. It is not just that obtaining the actual physical records is problematic—although it can be and indeed often is—rather, the more common challenge is extracting a coherent summation of myriad events from a series of chronologically organized records. Without a summary available to them, patients who have experienced a series of complex treatments are ill equipped to become partners in their own care.

Cancer quality-of-care research has highlighted the importance of care coordination. One strategy for improving coordination is to change the culture of medical records documentation so that preparation of synoptic treatment summaries at key transition points becomes routine. The goals of this commentary are to: 1) describe the rationale for a treatment summary in oncology; 2) address challenges for implementation; and; 3) identify key components of these summaries with illustration of a draft template.

### *Insights from quality of care research*

Over the past 5 years, ASCO, the NCI and numerous investigators have conducted large-scale studies to understand barriers to delivery of high quality care.<sup>1-4</sup>

ASCO sponsored the National Initiative on Cancer Care Quality (NICCCQ), a survey and review of medical records of breast and colorectal cancer patients in 5 cities. While the NICCCQ study found that patients usually received the key components of care, it also demonstrated how difficult it was for highly trained researchers to extract from medical records such basic information as what adjuvant chemotherapy regimen was delivered.<sup>4</sup> Even though many oncologists use flow sheets to record chemotherapy administration, the organization and style of these documents varies considerably, and

they are difficult for other clinicians to understand. The NICCCQ researchers had difficulty ascertaining from charts whether patients had completed prescribed courses of treatment, the reasons for treatment discontinuation, and the planned next steps. The analogy to a child's educational file is apt. Reviewing cancer records was similar to sifting through reams of paper only to find numerous spelling quizzes but not end of term report cards.

When the NICCCQ researchers presented their work to an advisory group of ASCO members and advocates from the Susan G. Komen Breast Cancer Foundation and the National Coalition for Cancer Survivorship (NCCS), the chemotherapy treatment summary emerged as a logical response to the study findings. The rationale for a treatment summary responds to deficiencies in care delivery perceived by the patient advocate community and also stems from research conducted by NCI's Cancer Care Outcomes Research and Surveillance Consortium (CanCORS),<sup>2</sup> the Cancer Research Network,<sup>3</sup> and other researchers.<sup>56</sup> Recent impetus comes from an Institute of Medicine panel that has endorsed preparation of treatment summaries as part of its comprehensive efforts to optimize care for cancer survivors.<sup>7</sup> While the value of such synopses is clear for patients who are transitioning back to non-oncology providers, they are also likely to be useful for patients with chronic malignancy undergoing complex multi-modality therapy over extended periods.

The development of a treatment summary is proposed as a strategy to help achieve three objectives related to improving the quality of cancer care:<sup>1</sup> 1) coordination of care as patients transition among various health care providers; 2) communication between patients and physicians; and 3) efficiency of cancer care delivery by streamlining the burden of document preparation and management for clinicians and their support staffs.

### *The Culture of Medical Records Keeping*

Beyond the legal requirements, medical records keeping helps physicians recall their own thoughts from one visit to the next and provides key information to other providers. Although some new electronic systems are changing the *status quo*, medical records are almost always organized

chronologically. When care evolves over time, these records become progressively denser and more difficult to review, and key information may get buried.

Although hospitalizations are encapsulated with discharge summaries, re-creating the trajectory of the cancer care requires review of medical oncology records to determine the drugs given and the context of treatment. This information is typically dispersed across multiple visit notes, flow sheets, and treatment administration records. It can be sufficiently difficult to reconstruct a cancer history from a medical record that a physician in the ER evaluating a dehydrated patient with longstanding metastatic breast cancer may avoid the chart altogether and instead try to obtain this history directly from the patient. When patients are careful historians, this strategy works well. However, when patients are too ill to provide their history, are not accompanied by informed caregivers, or have language barriers, important information may not be conveyed.

Medical records are replete with detail that responds to reimbursement requirements rather than the need to communicate clinically relevant information. For example, Medicare's billing rules, developed in the early 1990s, specified the number of items in the physical exam and the number of body systems that need to be included in a systems review in order to bill for complex "evaluation and management" visits. Physicians developed standardized templates as workarounds to circumvent the repetitive and onerous task of documentation necessary to justify reimbursement for complex visits. As a result, charts became thicker, but not necessarily more informative.

Some medical events are straightforward to describe because they involve a particular date or procedure. When physicians want to know about surgery, they know to ask for the operative and the pathology reports. Radiation oncologists routinely prepare summaries describing the reason for radiation, the area radiated, the treatment planned, and the treatment actually delivered. While radiation oncologists may use somewhat different templates for this summary and may provide more or less accompanying narrative detail, preparation of these synopses is deeply entrenched in their culture.

In contrast to radiation and surgery, which constitute discrete episodes of care, the boundaries of a chemotherapy regimen may be less clear. Nevertheless, there are often obvious time points for summation such as the completion of a course of primary therapy as recommended by both the President's Cancer Panel and the IOM Committee on Cancer Survivorship. The necessary first steps are to develop consensus within the community of cancer care providers about the core elements these documents should contain. ASCO can marshal the vast expertise of its membership and its organizational resources to help achieve this goal. Some preliminary proposals for consideration are:

### *What are the Key Elements in a Chemotherapy Treatment Plan and Treatment Summary?*

#### *Chemotherapy Treatment Plan*

A chemotherapy treatment plan is a synoptic document prepared at the initiation of a course of chemotherapy treatment. Preparation of a plan at the start of treatment simplifies preparation of a treatment summary at the end. Its key elements include specification of the:

- Diagnosis: cancer site, histology and stage
- Goals of therapy, anticipated benefits
- Name of the regimen, the component drugs in the regimen, and the starting dosages
- Duration of treatment and number of planned cycles
- Strategy for assessing response
- Major side effects and precautions
- Assessment of major risks, benefits; and reasonable alternatives

Ideally, the document should be reviewed with the patient and his or her family member when treatment is started. Because patients are often overwhelmed at the time of diagnosis, having a document that can be referred to later is valuable. The treatment plan is not designed to review all side effects since widely available educational materials already fill this role.

## *Chemotherapy Treatment Summary*

A chemotherapy treatment summary is a succinct document prepared at the end of a course of chemotherapy treatment. If a treatment plan has been prepared, the summary information can be appended. If not prepared, then the background information in the plan constitutes the first section of the summary. Essential elements the summary should contain are:

- What treatment was planned, and what was delivered?
- How was treatment tolerated? What were any major toxicities and hospitalizations resulting from treatment complications such as febrile neutropenia?
- What happened? What was the patient's treatment response based on radiographic, biochemical, or clinical criteria?
- Why was treatment stopped?
- Where to go next? Planned next steps (e.g. an alternative regimen, expectant management, post-treatment surveillance etc.)
- Who will assume responsibility for what? Which provider is responsible for performing which aspects of follow-up? Is any other special monitoring indicated as a consequence of the cancer or its treatment?

Figure 2. illustrates a draft treatment summary for a patient with stage III colon cancer who has completed adjuvant therapy. It is critical to note that this document is a synopsis; it does not include all details about the care provided and does not supplant the medical record. The first page illustrates a sample plan and the second page is the summary.

## *Challenges for Implementation of Cancer Treatment Plans and Summaries*

Changing the professional culture of medical oncology to include preparation of treatment summaries will be extremely challenging. Feedback from ASCO committees and volunteer physician practices indicates that although physicians think that treatment summaries are valuable, the main

obstacle to implementation is physicians' limited time. As a consequence, demonstrating that such documentation is not overly burdensome and developing tools to make it less time consuming will be necessary if this activity is to become common practice. Overall, a profound cultural shift will be required to change well-established practice patterns. Systematic evaluation will be necessary to demonstrate that this activity is indeed valuable and fulfills its intended purpose of improve communication and coordination of care.

Some of the most frequent questions and concerns about treatment summaries are:

*Who is the primary target audience?*

The target audience for treatment summaries includes both patients and health care providers; however, it is a challenge to address both audiences effectively with the same document. It is neither feasible nor practical to have separate versions geared towards distinct audiences because of the time and workload required for preparation. Presently, the goal is to develop a version that is relatively free of oncology-specific jargon and therefore suitable for non-oncology physicians.

The early version of the summary shown in Figure 2 is geared more towards health care providers than towards patients. Technical, rather than lay language is used to convey material succinctly in a format most familiar to physicians. The goal is for oncologists to use these documents as a springboard for discussion with patients, and to have a document that patients can share with their other physicians and family. Experience with other documents such as radiology reports that patients obtain suggests that patients view these as valuable even if they do not understand some of the terms. As shown in Figure 2, a "resource page" with useful referrals and community resources is one strategy that may enhance the value of the summary for patients.

*When should a summary be prepared?*

Preparation of a summary logically occurs at the end of a course of adjuvant or primary curative therapy. For patients with a chronic malignancy such as low-grade lymphoma the appropriate time points for these synopses may be less clear-cut. The guiding principle is that completion of a regimen or any substantial change in the direction, goals, or nature of treatment should trigger preparation of a summary. Guidelines such as those developed by the National Comprehensive Cancer Network, might include specification of logical time points for summation.<sup>9</sup> Inevitably, these determinations will involve physician judgment and discretion.

### *What is the right platform—paper or computer?*

Because many oncology practices still rely on paper record keeping or digital environments that use “scanned” documents, development will need to proceed on several fronts. Once consensus about the key elements is achieved, paper versions that can be completed by pen, templates for telephone dictation, and electronic versions can all be customized to particular environments. Eventually, the optimal strategy is to integrate treatment summaries as components of electronic health record systems. If these documents are three-dimensional with branching logic, drop down menus, and features that automatically populate fields in summary documents with pharmacy and pathology data, they will be able to capture important detail succinctly and efficiently and are therefore more likely to be adopted.

### *Static or living document?*

Treatment summaries will need to be updated as screening recommendations change, as recurrences that warrant additional testing arise, and as new evidence on late effects emerge. For patients who have completed therapy, recommendations for screening or follow-up may later change. However, because the goal is not to replace the medical record which provides a longitudinal comprehensive record of care, even a static summary may still be valuable.

### *What about physician liability?*

Some physicians are concerned about their liability exposure if for example, a screening recommendation changes, but a treatment summary is not updated. Similarly, summary documents may omit details only later recognized as important. Dating the documents and appending disclaimers that make it clear that treatment summaries do not replace a complete medical record should largely obviate these concerns.

### *Can this activity be reimbursed?*

Preparing a treatment summary and reviewing the material with a patient is considered complex coordination of care and can be submitted for payment using level-four or level-five codes for evaluation and management. There is no reason to expect that insurers would not reimburse providers for this service; however, it is not clear that preparation of the summary can be reimbursed if it does not include face-to-face interaction with the patient. Pilot work will need to determine the amount of time required to prepare these documents and to specify mechanisms for reimbursement with input from the payor community.

### *Should there be one or several versions of the treatment plan/summary?*

Developing a template that works for all situations in oncology is an insurmountable challenge. Pilot experience suggests that the summary information that is needed for patients with metastatic disease who transition from one treatment to the next is quite different from that needed for patients who have completed primary curative therapy. Additionally, these synopses will be most useful if they are tailored to specific tumor sites. ASCO members could collaborate to develop templates tailored to specific common clinical scenarios available in modifiable format, oncologists could then customize and adapt these documents to suit their own practices. ASCO can support this endeavor by creating a forum for sharing these documents as different versions are developed. The goal should be a source for open-access, non-proprietary templates that include core elements and standard

vocabularies for recording them. It would make sense to start with summary templates geared towards patients with early stage breast, colorectal, and lung cancer who have completed primary systemic therapy. Collaboration with radiation oncologists might permit development of an integrated document that reflects multidisciplinary cancer care for diseases like prostate and head and neck cancer.

*How can implementation be encouraged?*

Few patients currently receive either a treatment plan or summary. Changing deeply embedded practice and documentation patterns, however, will not be easy. To be successful, implementation will need to proceed along several fronts. ASCO can help by encouraging development of template versions that oncologists can tailor to their individual needs. Patient advocacy groups like NCCS can encourage patients to ask for these documents. Electronic medical record vendors can embed treatment plan and summary templates in their systems. Payors can facilitate help by explicitly reimbursing providers for preparation of these documents and for reviewing them with patients.

*Might non-oncology professionals prepare these summaries?*

Some hospitals rely on non-oncology professionals to prepare discharge summaries. Similarly, other members of the cancer care team such as nurses might assist with preparation of oncology treatment summaries. However, because the goal of this effort is to foster dialogue between oncologists and their patients, oncologists should engage directly in the process of reviewing the treatment summary with their patients even if some aspects are completed by support staff or even automatically populated by sophisticated electronic medical records systems.

*Conclusion*

Problems relating to coordination and communication have been recognized as hampering the delivery of high quality cancer care. Changing the culture of documentation is one strategy to address these shortcomings. Consensus among practicing oncologists about common data elements to be included in a treatment summary is a necessary first step. Subsequent work developing, piloting and evaluating templates and if these steps are successful, taking this initiative to the next level by developing electronic formats that integrate with medical records systems will be needed to achieve maximum impact. Preparation of summaries for patients making the transition to survivorship after completion of primary curative therapy or is the logical place to start this initiative and has already been endorsed by an Institute of Medicine Panel.<sup>7</sup> If a critical mass of providers engages in this effort, a “tipping point” may be reached such that this summation becomes part of standard oncology practice. Professional organizations like ASCO, in partnership with NCCS and other patient organizations, can facilitate this process by engaging its large membership in efforts to develop consensus regarding what key elements these documents should include as well as a clearinghouse of template versions to help practitioners achieve this goal. Because preparation of treatment summaries involves real work, it will also need to be adequately reimbursed if it is to become standard practice. Changing the professional culture and accepted practices of documentation and aligning incentives to support this effort should promote better communication and coordination. Careful evaluation will be necessary to see if these efforts result in meaningful improvement in the quality of cancer care.

**FIGURE**

1. How Treatment Summaries might improve cancer treatment delivery

## Figure 1. Goals of the Oncology Treatment Summary

Adoption of a Treatment Summary could improve 3 interrelated aspects of cancer care delivery:

- 1) **Care Coordination:** between providers
- 2) **Communication:** between patients and providers
- 3) **Efficiency:** document tracking, record keeping for patients, providers, systems, and research

**Care Coordination** is important because:

- Better survival means more patients transition back to non-oncology health care providers
- Treatment is increasingly complex and teams often include many sub-specialty members
- Society is increasingly mobile and patients transition across practice sites.

**Communication** is important because:

- It is a pre-requisite for shared decision-making.
- More complex treatments and preference-sensitive options are now commonplace.
- Patients desire it.

**Efficiency** is important because:

- It limits time spent reviewing/obtaining/providing medical records.
- It facilitates tracking of processes and outcomes of care for quality improvement initiatives.
- It facilitates document storage, retrieval, copying, and transmission.
- It facilitates tracking of care for public health and research data collection.



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